Center for Public Policy Solutions

When test results outpace care:

How immediate test result release laws leave patients alone with life-changing diagnoses and the policy framework to reduce harm

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Introduction

Minnie Hughes never imagined her test would come back positive. When it did, the Charlotte, North Carolina, resident was left with more questions than answers.

Minnie learned about her stage 3 breast cancer diagnosis not directly from her doctor, but through her online patient portal. At first, the information was confusing. The reference ranges, indicators, and other technical terminology included in the report were meant to be interpreted by a clinician with years of medical education and clinical expertise, not by a patient alone on her computer.

Minnie only realized the results indicated a positive cancer diagnosis after reaching out to a relative with a nursing background to interpret the results. The single word she uses to describe the experience? "Devastating."

Federal policy has made cases like Minnie's far too common. Test results are required by law to be electronically released to patients immediately, even before a clinician has had a chance to review and discuss them with the patient.

When patients receive results, particularly those containing life-threatening or life-altering diagnoses, the natural reaction is to become overwhelmed with questions: What does this mean? What do I have? What comes next? How do I treat this? How much will this cost?

Without their clinician to calmly and expertly interpret the results, a patient's search for answers usually leads them to the internet. Search engine results can return incorrect information and depict worst-case scenarios, causing unnecessary fear, anxiety, and stress.

Immediate test result release requirements were a well-intentioned policy decision enacted by the 21st Century Cures Act[i], as part of a broader push to establish important patient rights and protocols involving access to their own electronic health information (EHI). Unfortunately, it also created unintended patient harm and undermined the crucial clinician-patient relationship due to the emotional and psychological distress created by delivering test results without clinical support.

This report explores how this law was designed, its function since taking effect, patient impact, and our proposed solutions to ensure sensitive information is delivered to patients in a timely manner with the humanity and understanding of trusted clinicians.

'Fear and trying to stay positive'

The staff at her radiologist's office explained to Minnie how the results of her breast biopsy would arrive. "They told me that I would probably get it on my portal first and then get a phone call, and they told me that it was going to be up to me to open up the portal or wait for the phone call," Minnie said.

She didn't expect the results to arrive on a Saturday during a family vacation with her siblings and parents, but when they did, she decided to open them.

Test results are required by law to be electronically released to patients immediately, even before a clinician has had a chance to review and discuss them with the patient.

"I texted my niece the results and she called me immediately. My niece asked, 'Who's biopsy is this?' I said, 'It's mine.' She said, 'You have cancer.'"

– Minnie Hughes

"I'm thinking, 'I don't have cancer,'" Minnie said. "Everyone is reassuring me saying, 'You're fine, you're in great health and there's no cancer in your family.'"

At the time of her biopsy in 2023, Minnie was an active 56-year-old, running marathons and teaching fitness classes at the YMCA. "I was worried, but not really," Minnie said about receiving her results.

When she opened the results, which looked like they were written in code, she couldn't make sense of them. A family member suggested Minnie reach out to her niece, a nurse, to help interpret the results.

"I texted my niece the results and she called me immediately," Minnie said. "My niece asked, 'Whose biopsy is this?' I said, 'It's mine.' She said, 'You have cancer."

A flood of emotions followed. "What's going through my head at that moment is fear. Fear and trying to stay positive at the same time. A lot of mixed emotions," Minnie said. Later that night through tears, Minnie told her siblings one by one about her diagnosis and realized how little she knew about her situation.

"All my siblings asked 'What stage? What are you going to do?' And I couldn't answer any of their questions," Minnie said. "I don't know how I got it, I don't know what stage I'm in, I don't know if I have to have a mastectomy, I don't know if it's spread."

If a clinician had delivered the test results to Minnie, these questions could have been addressed immediately. That's what she would have preferred. "I think if the patient got some devastating news like that from a doctor, it's not going to change the emotions, but at least there's somebody to talk to."

In 2026, following extensive treatment at Novant Health, Minnie is cancer-free, back to distance running and teaching fitness classes, but her routine follow-up tests can still be emotionally challenging. "I still get MRIs to make sure the cancer hasn't come back and the results are coming through my portal," Minnie said. Receiving those test results before getting a complete explanation about what they mean creates more moments of worry and uncertainty. "I'm looking for something like 'your MRI is clear,' but the initial test result is not written like that."

Cases like Minnie's are widespread across the country, however the exact scope of the problem is difficult to pinpoint because of differences in individual hospitals, health systems, and other clinician policies. Each year, the U.S. healthcare system administers over 14 billion[ii] diagnostic tests. Even if only a small fraction of those is misunderstood by patients, this translates into millions of moments of confusion, tens of millions of unanswered questions, and a whole lot of unnecessary emotional and psychological harm.

Why this is happening

Today, patients receive their test results immediately because of provisions in the 21st Century Cures Act which require patients be able to obtain their EHI in a timely manner, including laboratory, radiology, pathology, and other test results. This requirement is enforced through federal interoperability requirements[iii] and information blocking regulations[iv]. "Information blocking"[v] is a practice "likely to interfere with, prevent, or materially discourage access, exchange, or use of electronic health information."

"I think if the patient got some devastating news like that from a doctor, it's not going to change the emotions, but at least there's somebody to talk to."

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- *The 21st Century Cures Act requires patients to be able to obtain their EHI in a timely manner, enforced through information blocking regulations.*
- *Information blocking is any practice "likely to interfere with, prevent, or materially discourage access, exchange, or use of EHI."*
- *Penalties can reach $1 million per violation of information blocking regulations.*

Individuals or entities that violate the information blocking provision face severe penalties of up to $1 million per violation.

In the years since it passed, the 21st Century Cures Act has created a broader shift in healthcare policy toward enhanced transparency, real-time patient access to their health information, and streamlined information exchange between entities in the healthcare system.

That shift seemed like common sense. No patient wants to wait for results any longer than is necessary, particularly when the results either confirm a suspected diagnosis or provide a clean bill of health. However, immediate access can create unintended challenges.

Take, for example, a finding of a lipoma on a test. For most patients, just hearing the suffix "-oma" might immediately turn their minds to cancer. After all, most of us know someone diagnosed with melanoma, lymphoma, carcinoma, sarcoma, or blastoma. However, lipomas are common, benign soft tissue tumors made up of fat cells that are cause for concern only in the rarest of circumstances. A quick conversation with their clinician could keep patients from assuming the worst and causing themselves significant stress and anxiety.

There are narrow exceptions[vi] created by the 21st Century Cures Act that allow clinicians to delay the delivery of test results if it might result in patient harm. However, this "Preventing Harm Exception" defines patient harm as solely physical harm in alignment with the definition of "harm" under the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule and does not include emotional and psychological harm and distress.

Clinicians take an oath to "first, do no harm." That oath does not stop with physical harm and must also include emotional or psychological harm, as is clearly reflected in the section of the American Medical Association's Code of Medical Ethics[vii] relevant to the reporting of clinical test results:

> *"To ensure that test results are communicated appropriately to patients, physicians should adopt, or advocate for, policies and procedures to ensure that … test results are conveyed sensitively, in a way that is understandable to the patient/surrogate, and the patient/surrogate receives information needed to make well-considered decisions about medical treatment and give informed consent to future treatment."*

The best way to satisfy this standard is for test results release to be accompanied by a conversation, particularly in the case of life-altering results.

The current opt-out provision of the policy does not offer enough protection for patients. Patients can choose to opt out of immediate test result notifications. However, in practice, this presents its own challenges. David Rizzieri, MD, physician-in-chief of the Novant Health Cancer Institute, emphasized that patients may not fully appreciate the potential negative effects of receiving test results without context. "Test results can sometimes contain pain and grief that no one can prepare for," he said.

Patients should not learn of a cancer diagnosis while checking out at the supermarket, nor should they learn they have a life-threatening genetic condition while waiting to board a flight. We can and we must do better.

The 21st Century Cures Act does have a 'Preventing Harm Exception' but it defines patient harm as solely physical harm and does not include emotional and psychological harm and distress.

"Test results can sometimes contain pain and grief that no one can prepare for."

– Dr. David Rizzieri, physician-in-chief, Novant Health Cancer Institute

The impact on patients and others

The relationship between patients and their doctor must be considered the foundation of healthcare. The rapid release of test results places unnecessary strain on that relationship[viii] by introducing confusion, fear, and misinformation at a vulnerable moment in a patient's care journey. If patients believe their doctor or health system is responsible for the distress caused by the immediate release of test results, trust and communication erode, putting patients' health at risk and leaving clinicians with additional administrative and emotional burdens. This creates additional downstream effects such as increased utilization[ix], rising costs, workflow disruption, and added strain on an already overburdened workforce.

When test results are delivered through a portal and patients receive a serious diagnosis they weren't expecting, the reflex in that moment is to reach out for answers. Novant Health clinicians consistently cite instances of patients calling their office and sending multiple online portal messages to understand the impact of their test results. In some cases, distraught patients physically show up at clinician offices in person in search of reassurance or clarification.

These events are not isolated, nor limited to a single specialty, care setting, or diagnostic test.

According to Jason Connelly, MD, chief health informatics officer (CHIO) at Novant Health, patients with a cancer diagnosis may receive test results indicating a small reduction in the size of a tumor. While patients may see this as a positive sign of improvement in their outlook, the reduction may not be clinically significant. When clinicians add appropriate context to the results, patients who are already navigating a difficult cancer journey may be left disappointed and dejected.

Similar patterns appear in acute care settings. Pamela Oliver, MD, executive vice president and chief medical officer at Novant Health, noted that patients in the emergency department (ED) often receive results through their patient portal before the clinician can reach them during their rounds. When a test result is negative, some patients may decide to simply leave the ED without additional conversation with their doctor. This has the potential to delay care for a serious underlying condition that could be discovered with further testing.

Conversations with clinicians in obstetrics, gynecology and other specialties highlighted similar troubling situations. Patients have learned they've suffered a miscarriage through a portal alert. Others see that something about their Pap test is irregular, there's a suspicious finding on a mammogram, or they've contracted a sexually transmitted infection (STI). But those are the only details they can decipher from the complex technical jargon in the results. They are then left with only that initial diagnosis until they can connect with their clinician for more information.

Patient impact is magnified by the sheer volume of all tests performed across each specialty. In 2025 alone, Novant Health performed 860,144 computed tomography (CT) and magnetic resonance imaging (MRI) scans across its system. Including annual PET scans and ultrasounds, the total number of imaging tests performed climbs to over 1.3 million.

The relationship between patients and their doctor must be considered the foundation of healthcare.

14 billion

diagnostic tests administered in the U.S. healthcare system every year

1.3 million

imaging tests performed in 2025 by Novant Health

Even when specialists order these scans, primary care providers (PCPs) are often the first call a patient makes to help interpret the results. That's not the way it should work, as the "ordering physician or APP [advanced practice provider] is responsible for result management, not the patient's PCP," according to the American Medical Association (AMA). However, because patients have a unique, established, and often close relationship with PCPs, patients feel comfortable turning to them for answers. While specialists typically order the most advanced and invasive tests tailored to specific diseases, PCPs order the highest volume of routine and preventive tests. This places a significant burden on PCPs to respond to test results they both ordered and didn't order.

A conversation with Catherine Ohmstede, MD, a Novant Health pediatrician, revealed how often even the most routine tests can create uncertainty for patients, as well as their families and caregivers. In one example raised by Dr. Ohmstede, three components on a cholesterol panel from a child's well check flagged "abnormal" because they were healthier than the typical range. A parent reviewing the results could easily suspect something is wrong with their child. But the clinician's note, added after results were delivered to the patient, explains the results were excellent and why some components measured out of range.

Well Child on 04/14/2026

Component	Date	Value	Ref Rance	Status
• HGB	04/14/2026	14.0 (A)	11.5 - 13.5 g/dL	Final
• Cholesterol	04/14/2026	186 (A)	100 - 169 mg/dL	Final
• HDL	04/14/2026	73 (A)	40 - 59 g/dl	Final
• Triglycerides	04/14/2026	45	0 - 89 g/dl	Final
• LDL	04/14/2026	0	0 - 99 g/dl	Final

Assessment & Plan

Cholesterol panel is excellent. Total cholesterol appears high because HDL "good" cholesterol is so high. Hemoglobin is also excellent. Keep up the great work with healthy eating and exercise!

The pressure of instant access

As part of empowering patients as consumers[x], providing them with immediate access to imaging, lab, pathology and other test results was intended to increase patient engagement in, and ownership of, their own care. However, where test results can be delivered in an instant, answers can be found online just as fast and those answers aren't always accurate.

AI has advanced rapidly in recent years and a variety of powerful chatbots are readily available for anyone to use. Some healthcare specific AI tools are clinically trained on medical resources and provide medically sound guidance to questions. In some cases, healthcare specialty chatbots even consider a patient's health record when sharing answers, but not every AI platform does this.

General-purpose AI chatbots do not provide answers that are tailored to each patient's unique circumstances such as their family history, their preexisting conditions and comorbidities, and care preferences like a healthcare specific AI can. Researchers have found[xi] general-purpose AI provides a high volume of inaccurate, even dangerous responses when asked health questions.

Three components on a cholesterol panel from a child's well check flagged "abnormal" because they were healthier than the typical range. The clinician's note, added after results were delivered to the patient, explains the results were excellent and why some components measured out of range.

General-purpose artificial intelligence does not provide medical answers that are tailored to each patient's unique circumstances. Researchers have also found general-purpose AI provides a high volume of inaccurate, even dangerous responses when asked health questions.

Patients today also have greater access to their clinician than ever before due in part to the ability to send direct messages, known as inbox messaging. Clinicians strive to respond to these messages from patients as quickly as possible, but it's impossible to be as fast as a search engine when the patient and clinician are not face-to-face.

When a clinician can't respond instantly to inbox questions about test results, patients often turn to general-purpose AI despite its shortcomings. Those chatbot answers then frame patient expectations and if a clinician's assessment of results is different, there is often additional time spent by the clinician explaining the differences and debunking inaccurate information the patient has received from other sources.

Specifically, oncology clinicians have shared difficulties with patients uploading verbose online search engine explanations to their patient portal, leaving clinicians with thousands of words' worth of information to decipher and limited time to craft a rapid response.

While crafted with the intent to improve a patient's access to their medical information, the 21st Century Cures Act reveals core tensions between transparency and interpretation: the desire for transparent access to results quickly for patients, the ability for doctors to interpret results in a timely manner and patient anxiety, and standardization versus specialty-specific nuance. While a problem across all medical specialties, these tensions are especially visible in high-risk and emotionally sensitive areas such as oncology, prenatal testing, pathology, and other specialties.

Policy solution/Recommendations for policymakers

The Novant Health Center for Public Policy Solutions believes that a simple adjustment to existing federal policy will improve or remedy most of the immediate test result issues highlighted in this report while also preserving the transparency principles inherent to the 21st Century Cures Act. There is also policy action that states can take individually that accomplishes the same reform while remaining compliant with federal law. Our proposed solutions at the federal and state level balance patient access to their health information with a person-centered framework for how and when test results are delivered.

Our solution: Expand the definition of preventing harm and establish a 72-hour release window

Our solution is a federal regulatory update that expands the Office of the National Coordinator for Health Information Technology's (ONC) existing 21st Century Cures Act framework for the Preventing Harm Exception to information blocking rules. The expanded exception would explicitly include psychological, mental and emotional harm as valid grounds for delaying the release of test results. Broadening the existing exception would provide health systems with clearer operational guidance and a more practical basis for delays based on clinician discretion.

Additionally, clinicians and health systems should be able to delay the immediate electronic delivery of test results for up to 72 hours. This would create a structured window for clinicians to review, assess and proactively respond to results. For policymakers, making the change would require an update to federal guidance by replacing "immediate" with "within 72 hours of result availability."

Our policy solution

- Expand the federal definition of preventing harm to include psychological, mental and emotional harm.
- Allow clinicians and health systems to delay the electronic delivery of test results for up to 72 hours.
- Preserve patient's ability to opt out of the 72-hour release window and immediately receive test results.

State-level solutions already in place


Texas


Kentucky


California

Several states have already enacted legislation creating similar exceptions in compliance with federal law which allows state laws[xii] to require preconditions for EHI release. For example, Texas passed legislation[xiii] in 2025 allowing for a 72-hour delay in the electronic release of certain "sensitive" test results. In this case, a sensitive test result is considered: (1) A pathology or radiology report that has a reasonable likelihood of showing a finding of malignancy; or (2) A test result that may reveal a genetic marker.

Kentucky[xiv] and California[xv] have both acted as well, and the AMA has drafted model legislation[xvi] that other states can use as a starting point in drafting similar laws. While a consistent federal standard is preferable and possible through ONC regulatory action, the Center also supports state-level policy changes in North Carolina and South Carolina to ensure patient harm is prevented as much as possible.

Implementing this change on the health system side would require a single configuration change within the electronic health record system. EPIC, the leading EHR platform in the United States, already supports delayed release in its technical infrastructure for the previously mentioned "Preventing Harm Exception" that currently relates to privacy and physical harm.

Preserving patient choice

Our solution would ensure patients maintain complete control over the delivery of their test results. Novant Health clinical leaders interviewed for this white paper noted that for certain patients, especially those on prolonged oncological journeys or managing chronic conditions, receiving results immediately is necessary. Therefore, our solution includes the ability for patients to opt out of the 72-hour release window and have their test results delivered electronically immediately as they become available.

Summary

Our proposed solution is designed to align healthcare policy with the realities of patient care. A federal regulatory update expanding the ways clinicians can prevent patient harm and establishing a 72-hour window for releasing test results would meaningfully reduce much of the patient harm outlined in this white paper.

Modifying the current process would protect clinicians using personal discretion to deliver test results compassionately and eliminate many communication friction points between patients and clinicians.

The tools and technology to support this solution already exist and clinical consensus is continuing to grow. What is now required is policy which recognizes the difference between timely and immediate access. This distinction ensures when difficult news must be delivered to patients, we keep humanity in healthcare and support patients the right way.

Our proposed solution is designed to align healthcare policy with the realities of patient care. It would:

- Prevent psychological and emotional patient harm.
- Protect clinicians using personal discretion to deliver test results compassionately.
- Eliminate many communication friction points between patients and clinicians.

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About Novant Health

Novant Health is an integrated network of more than 900 locations, including 21 hospitals, nearly 800 physician clinics and urgent care centers, outpatient facilities, and imaging and pharmacy services. This network supports a seamless and personalized healthcare experience for communities in North Carolina and South Carolina. Novant Health is nationally recognized for our unwavering commitment to safety and the highest quality care, and we serve as a catalyst for healthcare transformation through clinical trials, leading-edge research, innovative care delivery models and robust virtual care networks. The expertise and empathy of our nearly 44,000 team members along with more than 9,100 independent and employed clinicians are at the heart of Our Cause as industry leaders caring for communities across the Carolinas. In 2025, Novant Health provided more than $2.1 billion in community benefit, including financial assistance and services.

About the Novant Health Center for Public Policy Solutions

The Novant Health Center for Public Policy Solutions shapes and advances public policies to address the issues that matter most to clinicians and patients. We move beyond theory and drive action on public policies that combat clinician burnout, address access and affordability challenges, and enable innovation. Our approach utilizes the latest research, direct expertise from frontline clinicians, and our collective experience as a leading not-for-profit health system to enable human-centric solutions at all levels of government. For more information, visit NovantHealth.org/PolicySolutions

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