

Preventing patient harm

Sixty-five percent of patients want to speak with their physician first before getting life-changing test results.

The 21st Century Cures Act directs the U.S. Department of Health and Human Services (HHS) to improve patients' access to their medical records. The American Medical Association strongly supports this and efforts like [OpenNotes](#). However, HHS' implementation of the Cures Act is causing patients emotional and mental harm.

HHS is directing physicians to immediately release information to patients—in many cases, prior to the physician reviewing the information and without regard to whether a release could be mentally or emotionally distressing to the patient. Health systems and electronic health record (EHR) vendors are implementing HHS' guidance in a way that pushes all information to patients often before the physician knows the report or lab test is available.

Patients are experiencing mental or emotional harm due to these new policies. For example, we know of parents who have worried all weekend about a report stating "possible malignancy" on their newborn's imaging study. Without proper context or the ability to speak to a physician, parents are left in agony after discovering this information in a patient portal or as an alert on their smartphones.

The AMA and dozens of state societies and medical specialties continue to hear from patients and physicians about the harm being caused when critical or abnormal lab results and reports are sent to patients without context. We have collected hundreds of stories from patients and physicians about serious emotional distress and ethical concerns caused by the implementation of HHS' regulations.

"Sometimes we order 12 labs to clear a patient for a certain treatment—the results come in piece meal, and we need all 12 labs to develop a plan — our patients get barraged with lab results with no explanation."

—Dermatologists in an academic medical center

"I had a patient whose brother is on dialysis for nephrotic syndrome. My patient, who was quite healthy, saw the term "chronic kidney disease, Stage 3" on one of his medical forms for what I would consider mild renal insufficiency. Shortly thereafter [my] patient died by suicide. The family said he was distraught that he would soon need dialysis like his brother. No note left, but one wonders if his misinterpretation of the transparent medical information contributed to his hopeless state and terminal action."

—Cardiologist

"My sister-in-law received a recent diagnosis of breast cancer in April 2021. She underwent lumpectomy and lymph node sampling. The results of her pathology were posted to her patient accessible chart late Friday after her surgeon's office had closed. Her pathology report included retained cancer at her breast margin and three positive lymph nodes. She was unable to reach anyone involved with her care due to office closure for the weekend. That left her frightened and anxious about her future."

—Patient caregiver

"This policy of sharing notes immediately has caused patient confusion, anger and sadness—including patients who have found out they had cancer or a miscarriage without first being able to discuss their diagnosis with a physician."

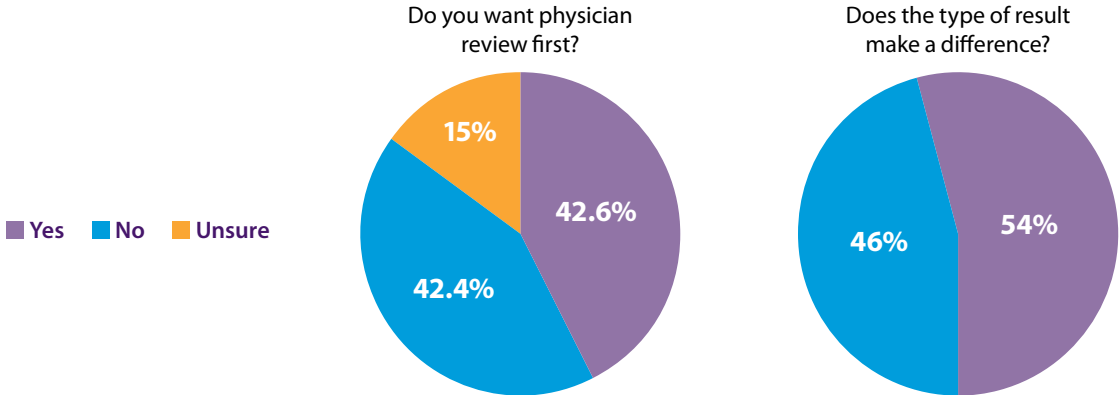
—Emergency medicine physician

While most of the information released to a patient is beneficial, there are certain tests, reports, or notes that require physician review and patient/clinician discussion. When asked how current regulations account for this, policymakers state it is the physician’s responsibility to coordinate the release of reports for each patient and for every lab or test ordered—even if their EHR doesn’t support that capability. Federal policy ignores the complexities of the patient-physician relationship and limitations of current technology. For example, in emergency departments, patients often are unconscious and cannot be “asked for their OK” to withhold test results and certified EHRs often don’t support this feature. Clearly, the policy is flawed, too blunt, and needs to be changed.

While these are powerful examples of patient harm, they are anecdotal. The AMA seeks to understand the patient perspective and has compiled evidence based on survey findings. In early 2022, the AMA partnered with Savvy Cooperative, a patient-owned source of health care insights, to conduct a survey of 1,000 patients across the country.

- Participants were asked if they prefer their health care provider to contact them about results of lab tests or diagnostic studies **before** the results show up in a patient portal. Nearly 43% said “No.” **Less than half of patients want their information immediately with or without physician review.**
- For those who said “No,” participants were then asked if it made a difference if the results showed them (or someone in their family) as having a debilitating, life-limiting, or terminal illness. More than 50% of people said, “Yes,” it would make a difference. **More than 50% of patients who do want their information immediately first want a physician to review and contact them in cases of debilitating, life-limiting or terminal illness.**

Prefer contact from their provider



The data is clear, patients want their information but, in certain cases, they want to speak to their physician first.

HHS’ information-blocking exceptions set the bar too high and are not sufficient to address these cases and are causing emotional and mental harm. Lack of guidance and clarity is causing confusion across health systems and EHR vendors.

In no way is the AMA suggesting that patients should not have access to their information. But a temporary hold on a limited amount of information until physician review is often what’s best for the patient, is part of standard medical practice, and research has shown is what patients want.

We call on HHS to review its guidance and ensure patients with chronic or life-limiting disease are not hurt by federal policy. Misinterpreting reports and tests, which too frequently and easily can occur, does not help, but harms individuals.

HHS must update its guidance to explicitly allow physicians, using their professional judgment, to withhold some information if immediate or proactive release could cause a patient mental or emotional harm.