

Patients Can Read Your Clinical Notes Starting Nov 2

"Open Notes" Mandates Access to Writings, Test Results

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Starting November 2, all patients in the United States will have immediate access to clinical notes and thus will be able to read their doctors' writings, as well as test results and reports from pathology and imaging.

The [21st Century Cures Act](#) mandates that patients have fast, electronic access to the following types of notes: consultations, discharge summaries, history, physical examination findings, imaging narratives, laboratory and pathology report narratives, and procedure and progress notes.

But this federal mandate, called "open notes" by many, is potentially confusing and frightening for patients, say some physicians. Others worry that the change will increase workload as clinicians tailor notes for patients and answer related questions.

The law means that inpatient and outpatient notes will be released immediately and that patients will have immediate access to testing and imaging results, including results from sexually transmitted disease tests, Pap tests, cancer biopsies, CT and PET scans, fetal ultrasounds, pneumonia cultures, and mammograms.

Such notes could contain sensitive information, and there is concern that patients could be shocked, confused, or annoyed by what they read, even with more run-of-the-mill notes.

Champions of open notes say that the benefits, including better provider-patient communication, greatly outweigh such risks.



Dr Charlotte Blease

"This is about convenience — a bit like online banking," comments [Charlotte Blease, PhD](#), resident scholar at OpenNotes, an advocacy nonprofit organization headquartered at the Beth Israel–Deaconess Medical Center in Boston, Massachusetts. "But it's a culture shift for doctors," she tells *Medscape Medical News*.

"It turns physician paternalism on its head," says [C. T. Lin, MD](#), chief medical information officer, UCHealth, Denver, Colorado. The change requires "some letting go of old traditions" in medicine, he writes in an August [blog post](#), referring to the fact that a computer screen — and not a physician — may tell patients about a new health problem.

Lin summarizes the experience at the University of Colorado Cancer Center, which has allowed patients to have access to oncology notes for the past 5 years: "No issues and highly appreciated by patients. We have nothing to fear but fear itself."

A New Audience

Other institutions have also been voluntarily implementing open notes.

UC Davis Health in Sacramento, California, has run an optional program for the past year. However, only about two dozen of approximately 1000 staff physicians opted in to the program.



Dr Scott MacDonald

"This illustrates the point that it's a new thing that physicians aren't used to doing. They've traditionally written notes for the benefit of their colleagues, for billing, for their own reference," says [Scott MacDonald, MD](#), an internist and electronic health record medical director at UC Davis Health, tells *Medscape Medical News*.

"They've never — until recently — had the patient as one of the audiences for a note," he says.

Liam Keating, MD, an otolaryngologist in Martinez, California, recalls that he once wrote "globus hystericus," and the patient wanted to sue him for saying that the patient was hysterical. "I now just code 'Globus' (if I don't jump straight to LPD [lateral pharyngeal diverticulum])," he commented in response to a [Medscape commentary](#) on open notes.

Sensitive information occurs more often in certain specialties, for example, psychiatry, genetics, adolescent medicine, and oncology, say experts.

"Cancer is an area that is highly charged for patients and doctors alike," MacDonald points out. When reading pathology or imaging notes, patients may learn that they have been diagnosed with cancer or that they have a recurrence "without the physician being able to contextualize it and explain things — that's just new and scary," he says.

California law dictates that providers cannot post cancer test results without talking with the patient first, says MacDonald, but not all states have such laws.

Adjustments Needed, or Not, With Open Notes

At UCHealth in Anschutz, Colorado, [Robert Breeze, MD](#), vice-chair of neurosurgery, says he has adjusted his practice to accommodate open notes and to anticipate trouble spots.

"When I order imaging or send pathology specimens, I have already discussed with the patient the possibilities, including cancer, and what we will do next. Patients deeply appreciate these discussions, before they see the results," he comments in an institutional [white paper](#) issued in anticipation of the changes on November 2.

This is called precounseling, says [Trent Rosenbloom, MD, MPH](#), director of patient portals at Vanderbilt University Medical Center, Nashville, Tennessee, which has been a pioneer in information sharing with patients. Their system does delay the release of information in the case of "complicated" results, such as from cancer biopsies, he tells *Medscape Medical News*.

However, [Christiaan Hoff, MD, PhD](#), a surgeon at the Medical Center Leeuwarden, the Netherlands, wonders how important it is for the physician to be present when the patient receives bad news, including news about cancer. "We may overestimate our added value in these situations," he suggests.

"Our empathy may not outweigh" the disadvantages of the situation, and the "finer points of our explanation will often go unnoticed" by the stressed patient, he comments. Hoff was also responding to the [Medscape commentary](#) about open notes.

In that commentary, [Jack West, MD](#), a medical oncologist at City of Hope Cancer Center, Duarte, California, was concerned about misunderstandings. Oncology is complex, and patients can struggle to understand their prognosis and planned treatment efficacy, especially in cases of metastatic disease, he wrote.

This concern is somewhat refuted by a study [published October 5](#) in *Cancer Cell*. Responses to two surveys involving 96 oncology clinicians at three US centers found that almost half (44%) believed that their patients "would be confused" by open notes.

However, only 4% of the 3418 cancer patients from the same surveys reported being confused by open notes. (A majority of participants had more than a high school education, and English was their primary language.)

"Patient and clinician views about open notes in oncology are not aligned, with patients expressing considerably more enthusiasm," write the authors, led by [Liz Salmi](#), senior strategist at OpenNotes, who has been treated for [brain cancer](#).

"All clinicians are anxious at first," Salmi tells *Medscape Medical News*. "Those patients who have more serious or chronic conditions...are more likely to read their notes."

The survey results echo the early experience reported from Sweden, where open notes was launched in 2012. "Patients have loved it from the beginning," says [Maria Haggland, PhD](#), of Uppsala MedTech Science Innovation Center.

However, when the scheme first launched, it was considered to be "very controversial," and "there were a lot of complaints, from health care professionals, especially," she adds.

Over time, clinicians have embraced open notes, and the program has 7.2 million patient accounts in a country of 10 million people, she observed during an October 5 [webinar](#) on open notes.

More Work for Already Overworked Clinicians?

An outstanding concern about open notes is that it will cause more work for healthcare professionals.

Traditionally, doctors have written notes using medical lexicon, including a lot of abbreviations and jargon for efficiency's sake. Now that patients will read the notes, will clinicians have to spell out things in lay terms, alter their writing so as not to offend, and generally do more work?

[William Harvey, MD](#), chief medical information officer, Tufts Medical Center, Boston, acknowledged that that may be the case.

In a forthcoming note to staff about the November 2 start of open notes, Harvey will include a reminder to accommodate the patient as a reader. But that may or may not mean an increase in work volume, depending on the provider. "Clinical note writing is highly personal. There's an art to it," he tells *Medscape Medical News*. "So it's hard to give standard advice."

[Steven Reidbord, MD](#), a psychiatrist in private practice in San Francisco and a lecturer at California Pacific Medical Center, is particularly concerned about the impact of open notes on progress notes, which he calls a tool to develop strategies and make observations while working with a patient.

By watering down the language for patients, "you are trading away the technical precision and other advantages of having a professional language," he tells *Medscape Medical News*.

"These notes serve many masters already," he says, referring to purposes such as utilization review and billing. "The more masters they serve, the less useful they are to get medical work done."

Medical information officer MacDonald says the new law doesn't mandate a change in writing style.

In [a study](#) published last year, researchers analyzed notes written by oncologists before and after adoption of open notes. They found that on average, clinicians did not change their note writing. The investigators analyzed more than 100,000 clinical notes written by 35 oncologists at a single center.

Advocates for open notes emphasize that there are benefits for clinicians.

"Doctors are overworked. They're overburdened. But empowered patients can help the doctor," says OpenNotes' Blease. She cites survey data that show that patients better understand their treatment plan and medication, which can cut down on physician workload.

Open notes are "what you make of it," says [Marlene Millen, MD](#), an internist at UC San Diego Health, which has had a pilot program for 3 years. Each day, Millen discusses a shared note with two or three patients. "I actually end all of my appointments with, 'Don't forget to read your note later,'" she tells *Medscape Medical News*.

"I was a little afraid of this initially," she says, but within the first 3 months of the pilot, about 15 patients gave her direct feedback on how much they appreciated her notes. "It seemed to really reassure them that they were getting good care."

The persons quoted in this article have disclosed no relevant financial relationships.

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