For most patients, the details of their medical care have long been buried in records and unearthed only with persistence. But University of Colorado Hospital is among a growing number of institutions that are helping patients shine a brighter light into once dark corners of care.

"More and more patients have done their homework and are ready for a more advanced conversation with their physicians," he said. "They are asking for and demanding more access to information about themselves. We believe that transparency will increase patient engagement and participation in their care."

The OpenNotes concept was pioneered in 2012 among 105 primary care physicians at Beth Israel Deaconess Hospital in Boston; Geisinger Health System, headquartered in Danville, Pa.; and Harborview Medical Center in Seattle. Some 13,500 patients gained access to their progress notes; 87 percent of them opened at least one note.

In a post-intervention survey, large percentages of patients said having access to the notes helped them feel more in control of their care and improved their medication compliance. Nearly all wanted access to the notes to continue and no physicians decided to stop – despite initial worries from some about the notes disrupting their workflow and creating confusion for patients. The authors summarized the research results in an October 2012 article published in the Annals of Internal Medicine.

Today, OpenNotes has gone systemwide in the three pilot organizations. The concept is now in place at a total of 18 institutions, UCH being the latest.

Open-door policy. Lin pioneered "My Doctor's Office" and "My Medical Record," UCH-based precursors to My Health Connection, and has long championed widening patients' access to their providers and their own medical information. He isn't surprised it's catching on.

"We found in opening online communication with physicians and releasing test results that the world doesn't come to an end," he said. Still, he heard many of the same questions from physicians.
prior to the roll-out of OpenNotes, and two primary care practices opted out.

"Some of them asked, ‘What’s the point?’ and said opening the progress notes to patients adds no value,” Lin said.

The concept is “not without controversy,” Steve Hess, chief information officer for UCHealth, acknowledged. Until relatively recently, the notion that providers should exercise stringent control over patients’ access to their own records was widely accepted.

“But in my opinion, the patient owns the information. We are only the custodians of it,” Hess said. “Patients today are more involved in their care and are less willing to be simply blind recipients of their medical information.”

Cracking the code. Making the progress notes available to patients at the selected practices required embedding logic into the after-visit summary that is already available to My Health Connection patients, said Matt Mimnall, associate systems analyst with the Epic Ambulatory Services team at UCH. The notes become visible only after the provider signs the note and closes the encounter, Mimnall said.

The logic ensures that progress notes are available only to patient visits at the seven participating practices, Mimnall said. Notes from psychologists and psychiatric notes are also excluded unless they are part of a shared clinical note with a medical provider, as can be the case at AF Williams Family Medicine Clinic, for example.

After he built the structure for the progress notes in My Health Connection, Mimnall invested time in testing it to make sure the notes displayed properly and that excluded information didn’t appear. One week after the Aug. 19 launch, he said he’d received “no feedback at all” from providers about the feature.

Prepping providers. For Lin, laying the OpenNotes groundwork centered on communicating with providers. One key message: Consider the long-term benefits, not the potential short-term pain. Every physician has encountered a difficult patient who eats up time with dozens of questions and corrections about minute details of their care, Lin said. But that should not be the standard used to decide whether or not to implement OpenNotes, he maintained.

“Rather than saying we’re not going to sign up for OpenNotes until the system can handle that patient, I believe we should consider the 99 percent who will be grateful to be trusted with the information,” Lin said. “We know that for them, the transparency is a huge satisfier.”

Corey Lyon, DO, medical director for AF Williams, said Lin approached him about a year ago about participating in the OpenNotes project. After Lin presented the concept and the evidence behind its effectiveness, the providers at AF Williams agreed to participate, Lyon said.

“There were some concerns among physicians about not knowing how patients would react,” he said. “But in my opinion, OpenNotes is very patient-centered. The evidence has shown that patients enjoy seeing what their progress notes are saying and that it helps them further understand their treatment plan and what is working — and it can potentially help with compliance.”
Lyon said OpenNotes can help providers clarify for patients the often confusing world of medical care. “A lot of information is given them in a 15- or 20-minute visit,” Lyon said. “This is the next step in helping communication with patients.”

Lin and the Epic team provided AF Williams and the other participating practices with support materials prior to the launch, including FAQs for providers and patients. But Lyon stressed the practice took a business-as-usual approach.

“The main message I gave providers was, ‘Don’t do anything different. The progress note is still a medical form of communication, and that is how we’re going to use it,’” he said.

There was no additional training required, Lyon said. After one week, there had been no increase in workload or requests from patients to change anything in the notes. “The staff has handled it with ease,” he said.

Hess said the hospital will monitor feedback about OpenNotes from providers and patients in the months ahead, but emphasized that it’s here to stay. The next steps will involve adding practices, not only at UCH, but across the UCHealth system. OpenNotes is just one piece of a larger movement toward opening the previously sheltered world of health information to consumers, Hess said.

“We believe we are being patient advocates,” he said. “Knowledge is power, and we need to involve patients in the health care process. The walls are being knocked down.”

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OpenNotes Pioneers
Seven primary care practices agreed to participate in phase one of the OpenNotes project at UCH:

» Lowry Specialty Practice
» Seniors Clinic
» Lone Tree Health Center
» AF Williams Family Medicine
» Family Medicine-Boulder
» Family Medicine-Park Meadows
» Family Medicine-Westminster

The WISH (Women’s Integrated Services in Health) and University Medicine-Anschutz clinics declined to participate at this time.