



# Getting patients involved by sharing the screen

By Jerry Berger | August 10, 2016

Eileen Hughes has a long list of ailments that include Type 1 diabetes and a rare autoimmune disorder that has sent her to five different specialists. But she feels confident about her health, for one simple reason: She can read and study the notes her clinicians write after each visit.

Hughes is a program manager at Beth Israel Deaconess Medical Center, one of the early adopters of OpenNotes — a pioneering patient engagement program, based on the concept that patients should see precisely what their doctors write during each visit.

OpenNotes was launched in 2010, as a pilot project among 105 primary care physicians and 13,564 patients at Beth Israel Deaconess in Boston, Geisinger Health Systems in Pennsylvania, and Harborview Medical Center in Seattle. Now, it's available to approximately 7 million patients at more than 25 healthcare systems, many of which have expanded the program to specialists and behavioral health providers.

And as more health systems embrace population health — and the notion that patients need to be active participants in their own care — the once-controversial program is gaining new adherents.

## OpenNotes for a health system

The communication demands on a large healthcare system, serving 43 hospitals and 250 clinics in nine states, was part of the reason South Dakota-based Sanford Health joined OpenNotes upon the launch of an upgraded patient portal.

Because patients in the system often travel six hours to see a specialist, Sanford Health already had a tradition of sharing. Some cardiologists have been dictating notes in front of their patients since the 1970s, to avoid confusion when patients spoke with their primary care physicians, says Heidi Twedt, M.D., Sanford's chief medical information officer.

Last fall, Sanford piloted OpenNotes in primary care, neurosurgery, and infectious disease clinics among approximately 30 physicians and 8,000 patients. Half of the patients used Sanford's patient portal and about half of them opened their notes, she says. Providers were told they could use medical terms, but should be conscious that patients were reading.

While some physicians had initial concerns about the time it would take to deal with patient questions, there were zero requests to change the program —

even in neurosurgery, which was selected for the pilot because the notes are so complex, Twedt says.

As a result, Sanford plans to roll out notes across many areas, including inpatient, which went live at the end of July.

## Growing support

Sanford joins a committed roster of OpenNotes supporters that embraced the program after trying it out. After the initial experiment, a 2012 study published in the *Annals of Internal Medicine* found that 99 percent of patients who participated in the original trail at BIDMC, Geisinger and Harborview wanted to continue to share notes – and, after some initial concern about added workload, no physicians asked to turn off notes.

Still, OpenNotes has its skeptics, who say patients could become confused or upset over medical abbreviations like SOB (short-of-breath) or that it will increase their workload.

Peter Elias M.D., a primary care physician in Maine, is not one of them. He independently began sharing notes on paper with patients several years ago, with the goal of working collaboratively on treatment plans.

But more importantly, Elias wrote in the Health Care Blog, “what I have experienced is a variation on the advice I got many years ago regarding relationships: if it’s important, then it’s important enough to be open about and deal with. If you aren’t willing to deal

with it openly, you are not allowed to save it up and spring it on your partner (patient) later.”

OpenNotes founders say the key to the program is transparency – and trust.

“This is about saying to your doctor or nurse or social worker, ‘let me read what you wrote about me,’” says Tom Delbanco M.D., the program’s co-director. “The basic notion is fully transparent communication with patients who can participate in the health care. The note is already sitting on the record. All we are doing is unblinding it.”

The growth of OpenNotes makes perfect sense to Hughes, who embraced the program after an endocrinologist told her that “his job was to help me learn more about diabetes, but ultimately it was my disease to manage.” The BIDMC patient portal allowed her to stay on top of her prescriptions, even identifying a case where a pharmacist prescribed a wrong dosage.

“Having access to notes, include those from the specialists, helped me to completely understand the disease and the complications if it was not managed correctly,” she says. “I believe having OpenNotes and all my information has changed my relationship with all my providers in a very positive way.”

*Jerry Berger is a freelance writer in Boston. He can be reached at [jerryberger@gmail.com](mailto:jerryberger@gmail.com).*



A daily news hub reporting from the heart of the health care internet, with access to a comprehensive data set of health care transactions from athenahealth’s nationwide network. We equip leaders with actionable insight and inspiration for making health care work as it should.

## Stay in the know

Sign up for weekly data and news:  
[insight.athenahealth.com/newsletter](https://insight.athenahealth.com/newsletter)