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# Portal Authority

BY MARC SILVER

*Patients log on to access medical records and talk with doctors.*

**Note to self:** Are blood test results back yet? Second note to self: How do they compare with the last round? Third note to self: Call oncologist's office to report that anti-nausea meds aren't working. Fourth note to self: Return call to doctor who returned my earlier call but missed me and left a message on voice mail. Fifth note to self: Buy more notepads.

If there were a job description for cancer patients, it would call for the persistence of a presidential candidate, the organizational skills of a wedding planner, and the memory capacity of a computer chip.

But in fact, the Internet is now lending patients a hand. At a small but growing number of hospitals and clinics, patient portals shoulder some of the burden.

### What's a Portal

If you don't know what a portal is, you've got plenty of company. No, it's not the latest name for a chemo port. A portal is a specialized website with a heap of helpful features. Businesses have portals for employees (you can look at everything from insurance plans to the in-house cafeteria special). Colleges have them for students. And medical facilities are introducing them for patients.

All patient portals aren't alike, but they typically include some of these options: review medical records, check test results, review doctor and nurse instructions, renew prescriptions, schedule appointments, update a home address or other personal information, and exchange e-mails with doctors.

Any patient can benefit, but portals are especially helpful for those dealing with a chronic illness like diabetes or a disease like cancer, with months of active treatment and years of follow-up. But portals aren't a panacea for the inefficiencies of the health care system. Both medical professionals and patients worry about possible risks, from security of data to the insecurity of a patient who comes across seemingly bad news online without a doctor to provide context and a plan for action.

Not many medical facilities have portals, and there's no central directory of patient portals, either. But there are some significant early adapters: Kaiser Permanente, for example, has close to two million members who log on to KP HealthConnect. Boston is a hotbed of portal activity. Some 30,000 patients are

enrolled in Patient Gateway, which serves Brigham and Women's Hospital, Massachusetts General Hospital and Dana-Farber Cancer Institute. PatientSite at Beth Israel Deaconess Medical Center launched in 2000. More than 200 physicians and 40,000 patients use it.

But portals don't always welcome patients. Some clinics and hospitals have a portal that serves its medical staff, who can review and share information and look at a patient's progress over the years; they just haven't yet developed the means to bring patients into the fold.

☒ I thought, 'Wow, this is amazing.' When in my lifetime have I ever been able to get access to my blood tests, or any of my tests, before I hear from my doctor? ☒

—Libby Levinson

## Dubious Doctors

The medical community is putting up a bit of resistance. "Many doctors aren't comfortable in a world where the patient has access to information," says Daniel Sands, MD, assistant professor of medicine at Harvard Medical School and senior medical informatics director for Cisco Systems. "The world is changing. We have to get used to the fact that patients do have information"—and eventually, every patient will have access to his or her medical record.

Physicians aren't exactly Internet geeks, either. A study published last year in the *Journal of Medical Internet Research* reported that overall, physicians show "only modest advances in the adoption of e-mail communication" with patients. Of 4,203 physicians in Florida who responded to a survey, a mere 16.6 percent had exchanged e-mails with a patient. That's no surprise to Philip McCarthy, MD, chief of the division of Blood and Marrow Transplantation at Roswell Park Cancer Institute, which has its own patient portal. "We have to wait for physicians who are computer savvy to become the critical mass before this is more accepted."

Doctors also worry the burden of e-mail will make their 25-hour day last even longer. In reality, the opposite may be true. Saul Weingart, MD, PhD, an internist at Dana-Farber who researches patient portals in his role as vice president of the Center for Patient Safety, suggests responding to e-mails in a batch, which is far more efficient than the never-ending game of telephone tag. "My main advice to doctors is, 'Don't be afraid.'" Doctors may worry about fielding 15-page e-mails. "I tell people that it's much better to get that than to be on the phone for an hour," says Dr. Weingart. Besides, he says, the three most common responses to the e-mails doctors receive from patients are "yes, no, and see me!"

For cancer patients, the portal can demystify the disease and its treatment. "A lot of patients feel scared and isolated and alone," says Dr. Sands. "They feel there's stuff going on that they're not involved in—they can't see the blood test, the CT scan results." He believes patients take health issues more seriously when they

can see their record on a computer monitor.

Portals also have the potential to improve patient-doctor communication about side effects. “People might feel really icky two or three days after treatment,” says Michael Hassett, MD, a breast oncologist at Dana-Farber. But they might not tell the doctor until the next visit. With quick feedback from a portal, “maybe we could try to help them at the time rather than waiting three weeks.”

To assess the usefulness of PatientSite, Dr. Weingart sent out alerts to 5,000 patients after they received a prescription from the doctor: Have you filled it, and if so, have you had any problems? About 80 percent of them opened (and presumably read) the message. Of those who read it, 17 percent reported they did have a problem. What’s more, all this e-mail communication becomes a part of the patient’s record, as opposed to phone calls, which may or may not make it onto paper.

### Consumer Confidence

Patients tend to be pro-portal for exactly the reasons you’d expect. “I registered and clicked around PatientSite and I thought, ‘Wow, this is amazing,’ ” says Libby Levinson, 62, of Framingham, Massachusetts, who was diagnosed with breast cancer nine years ago. “When in my lifetime have I ever been able to get access to my blood tests, or any of my tests, before I hear from my doctor?”

The convenience is a boon. She sets up appointments and renews prescriptions via PatientSite. If she isn’t sure of a future appointment date, PatientSite will tell her.

Talking to a portal can be easier than talking to a doctor. “Sometimes you don’t want to talk, especially when you don’t feel good,” says Carole Mietzsch, 39, of Boston, who was diagnosed with cervical cancer last year and is being treated at Beth Israel Deaconess. “I can log in, go to e-mail and say, ‘I don’t feel good, I’m in pain, what should I do about this?’ ” She calls the portal a “great communication tool between you and your doctor.” She’s even programmed her Blackberry to ring when she gets an e-mail. So her Caribbean ring tone could mean her doctor has sent her a message.

Getting records into the right hands is infinitely easier. “[A portal] allows medical records to be shared between clinics and services without delay and without error,” says Jay Anders, MD, chief medical officer for InteGreat Concepts in Scottsdale, Arizona, a company that specializes in designing portals for group practices. As any patient who has schlepped records from office to office knows, that’s a huge advantage.

### Log On, Freak Out

Patient portals have a potential dark side. “The thing people worry about the most is that patients will see something in their record that alarms them,” Dr. Sands says. “It doesn’t happen all that often, but it does occasionally happen.”

“The complaint I’ve heard,” says Hester Hill Schnipper, chief of oncology social work at Beth Israel Deaconess, “is that someone had a test or scan, went online, got the results, and read bad news. Say someone reads an MRI report that says something like, ‘multiple liver nodules.’ Obviously, they’re going to be terrified. What is multiple—100 or four? It is likely that the doctor presenting the results wouldn’t say ‘multiple’ but perhaps, ‘We only see a little cancer in your liver.’”

At the Cleveland Clinic, where patients can use a portal called My Chart, the oncology department hasn’t yet signed on. Mikkael Sekeres, MD, an oncologist in the Department of Hematologic Oncology and Blood Disorders, likes the idea of the portal but urges caution when it comes to sharing test results without a doctor present. “I have to stress that it’s not paternalistic. It’s more that cancer is so contextual.”

A patient’s response to a report of an abnormality may be quite different from the doctor’s response. Even a primary care doctor’s response may differ from a cancer expert. “God forbid a patient get results and the doctor is out of town, and the patient has to stew with that for a few days,” says Dr. Sekeres, who would prefer a system that puts test results on hold until the appropriate doctor releases the information.

Levinson knows what he’s talking about. She logs into PatientSite to check blood tests. “Occasionally they’re elevated and I freak out,” she says. That’s when she gets on the phone. The test is usually repeated and the results are fine.

Patients may misread information and panic. Kristel Dahlstedt, 55, a breast cancer survivor, was looking at her pathology report on PatientSite and was upset to see “stage 3” since her doctor had told her she was stage 1B. It turned out she had confused the tumor stage with grade—how abnormal the cancerous tissue appears when viewed under the microscope. The tumor was grade 3, which meant her breast cancer cells were fast-growing, the doctor explained. But in general, Dahlstedt is a portal proponent.

In any kind of system, a conversation with the doctor can set the ground rules. “I tell patients, ‘I will tell you good or bad news however you want it—in person, over the telephone, or via the portal. You let me know,’ ” says Roswell Park’s Dr. McCarthy.

## Fear of Hackers

A concern on both sides of the doctor-patient relationship is keeping a patient’s medical information safe from prying eyes, like a potential employer or an unauthorized insurance company. The info is encrypted—tech talk for applying a secret code to a file to make it appear as a scrambled mess. At some hospitals, patients are sent a password via snail mail to further protect their record.

To adhere to HIPAA rules about patient privacy, e-mail communication occurs within the confines of the portal. Whether it’s the doctor or the patient who sends the message, it’s not sent via regular e-mail. Rather, the doctor or patient receives an ordinary e-mail noting that a message awaits them within the portal. That may be a little cumbersome, but it helps protect the patient’s medical history.

Asked about the risk of records falling into the wrong hands, Dr. Anders says, "It's possible, but highly improbable." Security practices are comparable to those that protect your financial information during online banking, he says. That's good because the stakes are high. A record thief could send out many copies of an electronic file with ease, which isn't the case with paper records.

Then again, a portal doesn't always keep blood tests, X-rays, and other bits of information sitting in one neat electronic file. They could be housed in different parts of the portal, just as in the non-digital world, where mammogram films may be in the radiologist's office and surgical reports may sit in the surgeon's filing cabinet. When you log on, you can assemble them on one screen.

Security matters, but a more pressing question for the typically overwhelmed cancer patient may be: How do I find out if my doctor is part of a portal? A hospital or clinic website will typically promote the portal on the homepage. If not, it's time to write one more note to yourself: Bug doctor to join the portal revolution.