

ePatient Dave: VOICE OF THE PATIENT

What happens when patients get involved? Better outcomes

BY DIANA MANOS, Senior Editor

HE CALLS HIMSELF ePatient Dave – a universal name, and intended to be so, for he would like to represent the “voice of patient engagement.”

The name is also a very personal one. His name is Dave, yes, and he’s also been a patient. He battled cancer and won, making him keenly aware of what’s personally at stake.

ePatient Dave is the founder of a “movement,” one that goes on past the current federal and consumer push for patient engagement; a movement that dares to break mores that have existed for as long as there have been physicians and patients.

It’s a collection of cultural rules that have ensured a gap between patients’ and physicians’ knowledge about the patient’s care – contributing, at times, to patients’ fears of going to the doctor. It’s a fear that also keeps a patient from seeking care, sometimes, and does not encourage a wellness-based focus, most of the time.

ePatient Dave, whose real name is Dave deBronkart, is co-founder and board member of the Society for Participatory Medicine. He helped to launch his fast-growing popularity as the face of this movement with a tale of his own. In deBronkart’s first book about cancer, *Laugh, Sing, and Eat Like a Pig*, he described how he became an empowered patient, how that helped him beat Stage IV cancer and what healthcare can learn from it.

deBronkart was diagnosed in January 2007 with Stage IV, Grade 4 renal cell carcinoma that had metastasized. His median survival time at diagnosis was just 24 weeks; with tumors in lungs, several bones and muscle tissue, his prognosis was not good. *Laugh, Sing, and Eat Like a Pig* is extracted from the real-time journal he kept on CaringBridge.org – unedited – combined with later insights from his discovery of the

“ePatient” movement.

According to deBronkart, he received “great treatment” at Boston’s Beth Israel Deaconess Medical Center: His surgeon removed his tumors laparoscopically, and the Biologic Therapy program helped him participate in a clinical trial for the powerful but severe High Dosage Interleukin-2, or HDIL-2. His last treatment was July 23,

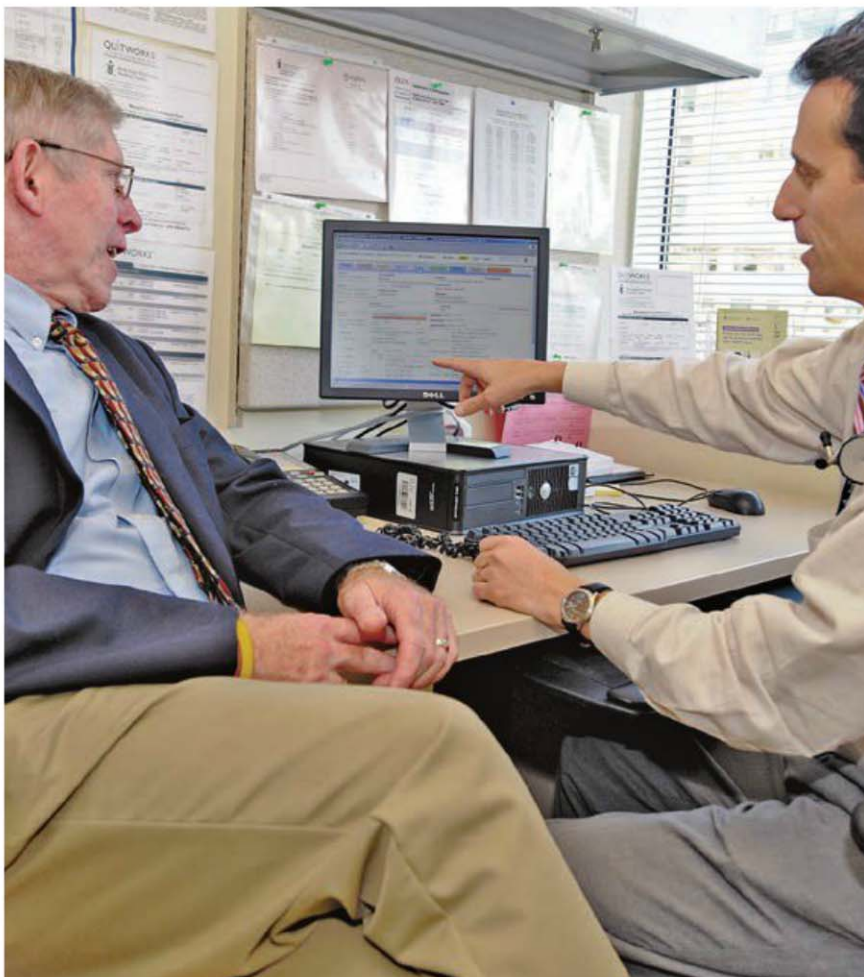
2007, and by September it was clear he’d beaten the disease. His remaining lesions have continued to shrink.

A year after the diagnosis, deBronkart was invited by his primary physician, Danny Sands, MD, to join the annual retreat of the e-Patient Scholars Working Group, founded by the late Tom Ferguson, MD, who deBronkart describes as “a true visionary.”

“The group consisted of pioneers, both medical and lay, who have been quietly – and not so quietly – altering the balance of power in healthcare, demonstrating that as the Internet brings patients together with information and with each other, a new world of participatory medicine is evolving in which patients become potent agents in creating and managing their own health, in partner-

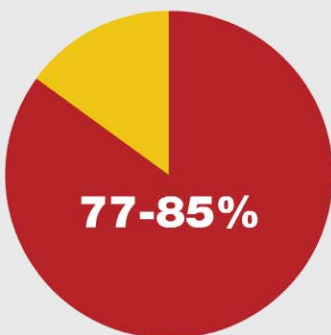


Danny Sands, MD

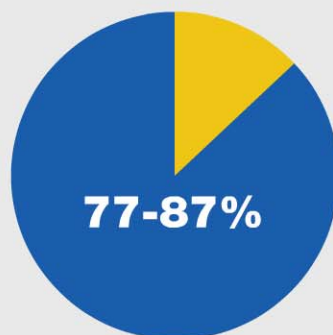


Dave deBronkart, aka ePatient Dave, consults with his physician, Danny Sands, MD.

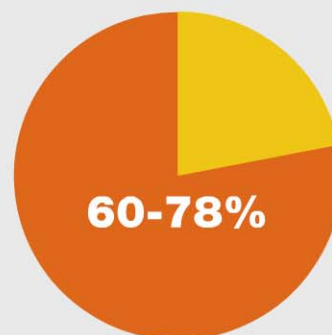
Participants in the OpenNotes study reported important benefits



77-85% reported better understanding of their health and medical conditions.



77-87% felt more in control of their care.
70-72% said they took better care of themselves.



60-78% reported doing better with taking their medications.

ship with physicians," his book read.

Ferguson believed that ePatients are "empowered, engaged, equipped and enabled. deBronkart immediately saw himself in those terms. He became an active blogger on ePatients.net and took on educating himself as much as he could. He went part time in his day job in 2009 and left the industry entirely in 2010 to devote full time to healthcare.

deBronkart has testified in Washington, appeared in *TIME*, *US News & World Report*, *The Boston Globe*, and was named to the HealthLeaders "20 People Who Make Healthcare Better" list.

"This is the first time in my life I've felt I have a calling," deBronkart wrote in his book, "something I can't get away from. It's what I need to do. I've had plenty of fulfilling jobs in a great career but not a calling. This is it."

According to deBronkart the core issue behind it all is, "people perform better when they're informed better."

ANOTHER SET OF EYES

Before deBronkart became a patient and advocate of better use of health IT, he was "a marketing guy and a



"OpenNotes set out to answer a simple, but revolutionary, question: What happens when we give patients access to the notes their doctors write about them?"

Tom Delbanco, MD

data guy," he says. "I see things from the patient's perspective, but I'm also good at expressing high-tech ideas. It's really, really important to me that people understand that this is not an anti-clinician issue. To me it's a tragedy when a well-trained clinician looks in the chart and gets the wrong information. The best-trained person will do exactly as they're supposed to based on the data they have, and possibly cause harm."

This is why deBronkart is so adamant about patient involvement. It allows another set of eyes to ensure that patient data is correct.

"Everybody knows you can't proofread your own work," he says. In the world today with some data

on paper and some electronic, often data must be typed into a chart. There can easily be typos – and dangerous ones, at that. Such a situation arose with deBronkart's mother, who after a hip injury was discharged to a rehabilitation center. Notes were typed in at the rehab center from the hospital charts, and, luckily for deBronkart's mother, some members of the family who were proofreading the chart discovered a big error. The correction was made before any harm could be done.

"This is a real-life simple example," deBronkart says. "Other situations could be much more complicated. With the family knowing the information, it makes all the sense in the world for them to

check the record. The second piece in this story is that the provider welcomed the family engagement. That's how simple it is.

"Nobody has more at stake with the accuracy, completeness and availability of the data than the patient does," he says. "It doesn't make sense to try and solve data quality by pounding on providers. How would they know if the data is wrong? All we need to do is welcome patient family engagement with the chart. Doctors don't have proofreaders."

In deBronkart's case of cancer, having access to his electronic charts and a portal with which to communicate with his doctors made all the difference. He says the portal allowed him to make follow-up appointments, be reminded of instructions and follow-up on his care. There are heated debates going on about whether or not patients should see their lab results without discussing it with their physician first. deBronkart finds this ridiculous and another example of old ways of thinking holding back the growth of the patient-doctor team.

A PHYSICIAN'S POINT OF VIEW

Danny Sands, an assistant clinical professor of medicine at Harvard Medical School, says he helped deBronkart take charge of his own care by advising him to get involved in cancer patient social media groups and by becoming active in viewing his own charts.

"Our story is about transparency," Sands says, admitting that he and deBronkart hope their story serves to inspire. Sands agrees that health portals are critical for patient involvement. Though they are a fairly recent phenomenon in many parts of the country, Sands' practice has provided portals for 14 years.

Sands is a former president of the Society for Participatory Medicine, which he co-founded with deBronkart and other advocates. The not-for-profit organization is devoted to promoting the concept of participatory medicine, a movement in which networked patients

shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners.

Sands says the biggest change needed is a change in doctors' attitudes. The federal meaningful use incentive program to help financially incentivize physicians to adopt electronic health records is good, he says. But that's just the letter of the law. "It's the spirit of the law

that is more important for sustained transformation in healthcare. The spirit of the law involves an attitude of transparency, a partnership with patient." "We need to be more humble," he tells his physician colleagues.

Sands runs across doctors every day who disagree with this line of thinking, he says. "I explain to them this is where it's going. This is the way you'd want to be treated if you were a patient. You have to ask yourself why you went into medicine," he said.

"Most people didn't go into medicine because they wanted to know everything and regurgitate information and speak down to people. Most people went into medicine because they wanted to be kind and help the patient with the expertise they could bring to the table. So what I'm offering is a path for them to go back and be that kind of a doctor," he says.

'A LONG TIME COMING'

One of the more promising aspects of this movement is OpenNotes, an initiative that invites patients to review visit notes written by their doctors, nurses or other clinicians.

Patients with access to notes written by their doctors feel more in control of their care, and report a better understanding of their medical issues, improved recall of their care plan and say they're more likely to take their medications as prescribed, a 2012 Beth Israel Deaconess Medical Center-led study found.

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that most of their fears about an additional time burden and offending or worrying patients did not materialize. Many reported enhanced trust, transparency, and communication with their patients. The findings were published in the Oct. 2 issue of the *Annals of Internal Medicine*.

“Patients are enthusiastic about open access to their primary care doctors’ notes,” said Tom Delbanco, MD, co-author, a primary care doctor at BIDMC and the Koplow-Tullis professor of general medicine and primary care at Harvard Medical School, in an Oct. 2 news release announcing study findings. “More than 85 percent read them, and 99 percent of those completing surveys recommended that this transparency continue. OpenNotes may both engage patients far more actively in their care and enhance safety when the patient reviews their records with a second set of eyes.”

It’s been a long time coming. “I’ve only wanted to do this for about 30 years,” Delbanco says of promoting the open sharing of notes with patients. “It’s simple to invite them into the doctor’s black box and see what we write about.”

The notes are important because they are the narrative part of the care story, he says. “Sharing the notes is a good way of leveling the playing field between us and them.”

“Perhaps most important clinically, a remarkable number of patients reported becoming more likely to take medications as prescribed,” adds Janice Walker, RN, co-author and a principal associate in medicine in the division of general medicine and primary care at BIDMC and Harvard Medical School, in the news release.

Patients become more engaged in their care just by “seeing (the notes) in black and white,” Walker says. To drive home the point, she shares a personal story. “My doctor had been telling me for years to lose weight, but when I saw that he called me ‘mildly obese’ in his note, and how he’s really worried about my weight, it finally sank in and I decided to do something about it.”

PATIENT BENEFITS VS. IMPACT ON DOCS

The Geisinger-led study – funded primarily by the Robert Wood Johnson Foundation, with additional support from the Drane Family Fund, the Richard and Florence Koplow Charitable Foundation and the National Cancer Institute – involved 105 primary care physicians and 13,564 of their patients. A yearlong voluntary program provided those patients – some at an urban academic medical center, some at a predominantly rural network of physicians, and some at an urban safety-net hospital – with electronic links to their doctors’ notes.

Of 5,391 patients who opened at least

one note and returned surveys, between 77 percent and 87 percent reported that open notes made them feel more in control of their care, with 60 percent to 78 percent reporting increased adherence to medications. Only 1 percent to 8 percent of patients reported worry, confusion or offense; three out of five felt they should be able to add comments to their doctors’ notes, and 86 percent agreed that availability of notes would influence their choice of providers in the future.

Among doctors, a maximum of 5 percent reported longer visits, and no more than 8 percent said they spent extra time addressing patients’ questions outside of visits. A maximum of 21 percent reported taking more time to write notes, while between 3 percent and 36 percent reported changing documentation content.

No doctor elected to stop providing access to notes after the experimental period ended.

“The benefits were achieved with far less impact on the work life of doctors and their staffs than anticipated,” said Delbanco, in a news release. “While a sizeable minority reported changing the way their notes addressed substance abuse, mental health issues, malignancies and obesity, a smaller minority spent more time preparing their notes, and some commented that they were improved.”

LEGAL ASPECTS

The growing trend for physicians to share their written notes with patients is not such a bad idea, says David Harlow, principal at The Harlow Group, a healthcare attorney and consultant. Legally, he says, doctors should have no concerns with showing their notes to patients.

“The patient has a right to access their record,” Harlow says. “There are certain types of notes not releasable to patients, but those are few and far between. You should assume that something you are putting in a record is something that can be read by a patient.”

Harlow says sharing of notes shouldn’t affect care one way or another. The sharing of patient records is something that has long been the case and is not being reinforced. It’s

much easier now that records can be offered in an electronic format.

In the most recent update to the HIPAA rules, patients can ask for their entire record in the format of their choosing. “Patients are slowly being more recognized,” Harlow says of current laws.

Programs such as OpenNotes are helping to get patients more involved in their own care, Harlow says.

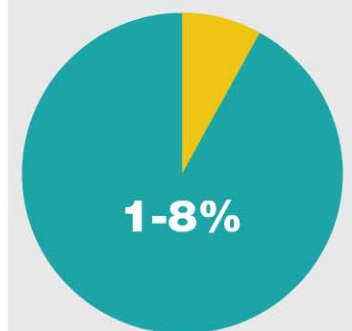
“OpenNotes is a more involved and a better approach than shipping a copy of the record to the patient,” he adds. “OpenNotes is going broader; it really creates more of an ongoing dialogue.”

Harlow says he can understand that some doctors may feel a sense of discomfort in sharing notes, but in essence, patients have always had the right to access their notes.

Some clinicians think the record belongs to them. “There is this tension that exists, but it doesn’t necessarily have to be seen as a negative,” he says. “I think the shift to electronic records is part of what creates this discomfort on the part of doctors because now it’s so much easier to share the record.”

The use of patient portals, required for meaningful use incentives, has also contributed to patient access to records. In Stage 1, providers were required to have portals, but they didn’t necessarily have to get patients to use them. Stage 2 has bumped that up to requiring 10 percent of patients to use the portal.

Very few patients (1-8%) in the OpenNotes study reported being confused, worried, or offended by what they read in their doctors’ notes.



1-8%

This broader access is a patient’s right, Harlow says. Access through a portal can be conducive to better care and care management, as payment systems change to encourage fewer office visits, as long as it doesn’t affect care negatively, he says.

As far as sharing notes, beyond the strictly legal aspect of it, “at some level, folks can understand it’s the right thing to do,” Harlow says. More communication between patients and their doctors can lead to better clinical outcomes. ■



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