

OpenNotes: *Putting Medical Record Transparency to the Test*

By Irene M. Wielawski

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Ellen Godfrey was crestfallen when her doctor of 30 years retired. She had invested a great deal in the relationship and the prospect of finding a replacement was daunting. How could she, at age 72, establish the bond of trust that had taken so many years to build with her old doctor?

With trepidation, Godfrey phoned the doctor referral service at Beth Israel Deaconess Medical Center, the Boston hospital where she received most of her care. Presented with a

roster of doctors who were accepting new patients, she chose the first name on the list. As it turned out, the doctor she selected was participating in a national experiment to give patients electronic access to their medical records—including the notes doctors write about them after an office visit or hospitalization.

Godfrey's previous doctor had vigorously opposed the idea of patients seeing their medical records, objecting even to sharing results of routine matters such as blood cholesterol tests. Godfrey had never quite understood why. A retired schoolteacher who still worked as a reading

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tutor, she liked knowing the details of things, including what was going on in her body. “I love being involved and that means staying healthy, so I want to understand my part in that.”

So, when Godfrey received an email offering her online access to her new doctor’s notes, as well as to test results and prescriptions, she eagerly signed up. “I thought it was a great idea,” she says. “You can’t possibly remember everything a doctor tells you in an office visit. At the very least, I thought it would be a good way to document what was going on with my health, and remind me of medication instructions and things to do before the next visit.”

Even so, Godfrey was a little nervous when she opened her new doctor’s first note about her. “I was wondering what she thought of me,” Godfrey recalls. “She’s very young and I’m not—I was hoping that wouldn’t get in the way of our understanding one another. The note was very long and detailed, and my first reaction was, ‘Wow, this really took her a lot of time.’ As I read it, I think it was a revelation to me that she had really listened because everything was there in the note, just exactly as we discussed it. I was so relieved. The accuracy of the note, and the ease with which we were able to discuss things, gave me confidence that I had found the right doctor.”



Ellen Godfrey’s experience with the national experiment known as OpenNotes illuminates the potential of including patients in clinical communications about their own diagnosis and treatment, thereby engaging them as partners in achieving and sustaining health. Proponents of such transparency say this is increasingly important for health care quality as patients shift from relying on a personal doctor to interacting with members of a clinical team, each of whom will

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have unique patient-care duties. Being able to read all these clinicians' notes could help patients better understand their medical conditions and reinforce the doctors' follow-up instructions. In return, are potential benefits to the health care system.

Most of the illnesses that send people into the system today are chronic ones—cardiovascular disease, for example, or metabolic disorders such as diabetes—and they can be very expensive to treat. Although long-term studies are lacking, informed patients are widely believed to manage their conditions better, resulting in fewer crises and better treatment outcomes. At the very least, having access to their medical records would enable patients to monitor accuracy and fill in clinically relevant gaps in information.

Patients, moreover, are legally entitled to these medical records. The federal Health Insurance Portability and Accountability Act (HIPAA) of 1996 addressed a previously patchwork situation in which patients' rights to their records varied from state to state—and even where permitted, access was devilishly difficult and costly. HIPAA also set the stage for electronic sharing of these records with clinicians, health care organizations, insurance companies, researchers, and various government agencies.

But including patients in such streamlined point and click access has been slow—and intentionally limited. While some health care organizations have created electronic portals through which patients can schedule appointments, email their health care providers, and see lab and other test results, doctors' narrative notes have remained largely off limits. The reluctance to

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share them with patients reflects a long-held professional view that these observational and interpretive findings are for clinicians' eyes only.

The OpenNotes experiment, which ran for 12 months in 2010 and 2011, challenged this insider culture, sparking debate about what constitutes appropriate communication with patients. In the end, most of the doctors who agreed to participate in the OpenNotes experiment were won over, and patients responded with striking enthusiasm. Several large health care systems have since added the option to their patient portals, fueling momentum for broader adoption and attracting new champions to help work out the bugs.

Like all true experiments, OpenNotes raised more questions than it could answer. Among them were concerns about the quality and communicative value of doctors' narrative notes. Simply put, they are all over the map in terms of clarity, accuracy and completeness. If the idea behind sharing these records with patients is to engage them in sustaining health, how helpful is a file of poorly organized information replete with insider jargon and content gaps?

"We debate these questions endlessly," says Tom Delbanco, co-principal investigator of OpenNotes and professor of general medicine and primary care at Harvard Medical School.

"The beauty of what we're doing is that it's simple—and yet exceedingly complex at the same time. We're just at the Model T stage."

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A Timely Idea

Comparing OpenNotes to the early days of the automobile is apt for the revolutionary change that OpenNotes' co-principal investigators—Delbanco and Jan Walker, a health services researcher and assistant professor of medicine at Harvard Medical School—set out to bring to the culture of medical practice. It was fitting, therefore, that after a nearly 10-year search for funding, Delbanco and Walker found a home for OpenNotes in the Robert Wood Johnson Foundation's Pioneer Portfolio, which specializes in novel ideas with the potential to be health system game changers.

On first review in early 2008, however, the Pioneer Program staff was unimpressed. “Our initial reaction was, ‘What’s the big deal here—just that you can get a record online?’” recalls Paul Tarini, an early reader of the grant application and, later, the head of the pioneer team. “But as we talked about it, we realized that OpenNotes could potentially lead to an attitudinal shift in doctors towards their patients and improve the dialogue.”

To refine the idea, Delbanco and Walker worked closely with Stephen Downs, a member (and later the leader) of the Pioneer team. Downs' background is in physics, which leads him to favor projects that are “simple and elegant” in design even as they tackle complex problems. He saw those elements in OpenNotes. Says Downs: “The knowledge that the note is being written not just for colleagues, but also for patients, we thought had the potential to change the way the doctors think about their patients.”

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In October 2008, the Foundation awarded Delbanco and Walker a 14-month planning grant of \$118,000 to design a test of OpenNotes involving primary care doctors at three sites. The sites were selected to reflect the diversity of health care settings in the United States. In addition to Beth Israel Deaconess, which was the institutional recipient of the grant, the researchers recruited Geisinger Health System in rural Danville, Pennsylvania, and Harborview Medical Center, a public hospital in Seattle, Washington. In May 2009, the Foundation awarded Delbanco and Walker an additional \$1,397,000 to implement OpenNotes at the test sites and evaluate the experience of participants. This was followed in 2011, 2012 and 2013 by awards of \$647,000, \$450,000, and \$2,100,000, respectively, to expand adoption of OpenNotes at the experimental sites and develop tool kits for other institutions seeking to adopt the idea. OpenNotes also received financial support from the Drane Family Fund, the Florence and Richard Koplow Charitable Foundation, and the National Cancer Institute.

To Share or Not to Share

In theory, transparency sounds like a wonderful thing. If we all had the same information, there would be a common basis on which to jointly identify problems, share ideas and arrive at solutions.

But the degree to which anyone, in any realm, can truly lay it all on the table has long been a matter of debate. Politicians, scientists, merchants, soldiers, even families—all find reasons to hold back information or at least control the timing of its release both within and outside the group. Considered in this context, the fact that doctors selectively inform patients and make private judgments about when and how to convey certain details of diagnosis and prognosis

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should come as no surprise. Indeed, this has been the popularly accepted norm for centuries, and not just in the United States.

In part, this served historically to shield patients from how little medical science had to offer them in the face of infection, cancers and most other ills. Keeping the truth from dying patients was seen as a kindness—as it sometimes still is. Even when the prognosis isn't so dire, the range of patients' personalities and competencies continues to influence what doctors say and how they say it—and contributes to their unease at the prospect of letting all of their patients automatically see raw, unmediated medical notes.

Patients' candor also ranges widely. Many are like Ellen Godfrey, eager to understand their conditions and to do the work necessary to sustain health. They are courteous and forthright in responding to questions about symptoms, medical history, and lifestyle that inform the diagnosis. But other patients lie about things like alcohol and drug abuse, diet, or how they became injured. They exaggerate or minimize symptoms, and fail to follow medication or other instructions. Some demand prescriptions when none are warranted—and can become combative if they don't get their way.

Other patients are anxious and easily frightened, even by relatively minor findings. A few have psychiatric or neurological disorders that lead them to misinterpret or distort even basic communication. These patients are time consuming, difficult to manage, and sometimes frightening to have in the office. Why complicate matters by giving them access to blunt clinical communications containing their doctors' suspicions of, say, a cocaine habit, mental illness, or

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unsafe sex practice? Or, in the case of nervous patients, why heighten their distress with scary differential diagnoses—cancer? heart disease? brain tumor?—that pending tests could rule out?

Finally, not everyone wants to know the details of his or her illness or prognosis, or is in a condition to absorb the information. Compassion, sometimes demanded by family members, may lead to a softened or incomplete version of the truth. Indeed, it has long been considered part of the art of medicine for doctors to view the questions patients ask as indicators of how much information they want or feel prepared to handle.

Proponents of greater transparency in health care, however, say that medicine has lagged other professions, clinging to tradition and unwarranted paternalism even as patients turn to the Internet to research their diagnoses and treatment options. Old habits may die hard, but there's more to it than that. Transparency changes power dynamics, and that can be very disruptive in hierarchical cultures such as health care. The result has been little change, despite nearly five decades of discussion among medical leaders about the potential benefits of allowing patients to read and contribute to their medical records.

The OpenNotes research team knew this history well and, in pre-experiment surveys, corroborated these mixed feelings among doctors at the prospective test sites. Respondents wondered: Would patients be able to understand clinical notes since their main purpose is to communicate efficiently with other health care professionals? Did adding patients as readers mean the doctors would have to write their notes differently—or maybe dumb them down? Would the doctors subsequently be inundated with phone calls and emails from confused and

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possibly frightened patients? “Our doctors worried further about inappropriate reactions to what patients read,” the research team reported in a 2010 article published in *Annals of Internal Medicine*. “They feared that some might become ‘cardiac cripples’ after reading descriptions of inconsequential arrhythmias, others might be devastated by an observation about mental illness, or speculations about cancer might trigger panic.”¹

Another complicating element was the clinicians’ personalities. Doctors, too, vary in temperament and communicative skills. Through the surveys, the research team identified many areas of anxiety about sharing clinical notes with patients, ranging from the mundane—worries about awkward phrasing, poor spelling, and typos that might be off-putting to patients—to perceived violation of the medical profession’s core principle: “First, do no harm.” Clinical shorthand such as “SOB,” referring to shortness of breath, could easily be misinterpreted, as could the use of “obese” to describe a patient who simply exceeds a recommended body/mass index. The standard professional phrasing “patient denies...” as a means of systematically ruling out diagnostically relevant symptoms or behaviors might offend some readers. Collectively, the doctors were concerned that their notes might inadvertently cause “fear, frustration, guilt, anger, depression, confusion, or hopelessness,” the researchers reported.²

Mostly, though, the doctors worried about extra demands on their time due to phone calls, letters, and emails from patients wanting to discuss or dispute the notes, and a consequent pressure to make notes less precise or complete in order to avoid patient blowback. “I was very uneasy,” says Diane Brockmeyer, an internist with a specialty in domestic abuse cases who was among those surveyed. In addition to responsibility for about 750 patients at Beth Israel

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Deaconess, Brockmeyer wears a number of hats in the hospital's Healthcare Associates medical group, including directing quality initiatives in anticoagulation therapy. "I'm extremely busy, and although I'm a big fan of patient engagement, I just didn't want the hassle of dealing with a large amount of noise from patients that had no clinical benefit."

Surveys of patients also revealed misgivings. Some patients said they did not trust computers to deliver their medical records privately. Others shared the doctors' concerns about misunderstanding medical terminology, and a few said they would rather not know what their doctors wrote for fear of becoming anxious or reading critical comments. Several worried about the notes being a substitute communication that would lead their doctors to spend less time talking to them in person.

The surveys collected positive comments, too. Doctors perceived advantages in efficiency and clinical quality by, for example, giving patients lab test results in the same report as their doctors' interpretations and recommendations. Doctors also saw benefits for chronically ill patients and their families who might learn how to manage things better at home if they had notes to refer to for guidance. Patients, meanwhile, saw electronic access to their medical records as a "logical next step" in doctor-patient communication, and they were not daunted by the prospect of having to decipher medical terms.

"Many expected to search for explanations of technical language on the Internet," the researchers reported. "Some believed their doctor's notes would prove educational simply by reminding them of what happened during the visit. They expected some notes to reassure them and to calm

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their fears; other notes might be ‘truth tellers’ and push them to face the reality of a health issue, such as obesity and mental illness, and perhaps break down defenses. Many liked the idea of sharing notes with family, friends, partners, and informal consultants, anticipating that this would help build a personal care system at home.”³

Launching the Experiment

Collectively, 113 primary care doctors and 22,703 of their patients at Beth Israel Deaconess, Geisinger, and Harborview signed up to participate in a trial of OpenNotes. The dissimilarity of the test sites gave the experiment extra heft; not only were they located in different parts of the country, they also varied in institutional culture and resources available to support OpenNotes.

Boston’s Beth Israel Deaconess is one of a cluster of internationally renowned academic medical centers affiliated with Harvard Medical School that attract patients, faculty, and students from around the globe. The hospital has been a national leader in deployment of new technology; its in-house electronic medical record system was the first in the United States to achieve the federal standard of “meaningful use.” Beth Israel Deaconess was also an early adopter of the idea of Internet portals through which patients can make appointments and have access to their medical records—mostly test results until OpenNotes debuted.

Geisinger, an integrated health system with its own insurance plan, serves a mostly rural population in central Pennsylvania. It is the dominant health care provider in the region, with a tertiary-level hospital, community-based primary care practices, nursing homes, rehabilitation facilities, and home health agencies. Geisinger is often cited as a national model for team-based

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patient care and innovation in reducing health care costs without sacrificing quality. Like Beth Israel Deaconess, it has a widely used patient Internet portal.

Harborview is a public hospital caring primarily for poor and underserved patients, including prisoners, people with HIV and AIDS, victims of domestic violence, and substance abusers. Located at the top of what Seattle locals call “Pill Hill,” the majestic ‘30s-era Art Deco-style facility is one of the few public hospitals in the United States that runs in the black. This is partly due to its designation as a level 1 trauma center for the Pacific Northwest; the hospital also has several clinical areas of excellence that attract privately insured patients. Although county-owned, Harborview is managed by the University of Washington, whose medical school uses the hospital as a site for teaching and research. Unlike Beth Israel Deaconess and Geisinger, Harborview and its network of outpatient clinics had no patient Internet portal before OpenNotes.

Each of these test sites had dedicated champions. At Beth Israel Deaconess, it was Delbanco and Walker. Although faculty of Harvard Medical School, both are based at the hospital. Walker has a nursing background and a master’s degree in business administration, and has long had a research interest in patients’ experiences with health care. Delbanco, an internist, has been on the forefront of the movement to engage patients more actively in their care. Indeed, he was part of the research team in the 1980s that popularized the phrase “patient-centered care,” now a fundamental principle of U.S. health reform.

At Geisinger, the champion was Jonathan D. Darer, the health system’s chief innovation officer. An internist with a master’s degree in public health, Darer had previously worked at Kaiser

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Permanente in Baltimore, where he had become interested in finding ways to leverage the existing health care infrastructure to achieve better population health. OpenNotes struck him as a useful tool in that pursuit, and he agreed to join Delbanco and Walker on the research team. “If you look at the success rates of people trying to quit smoking, it’s about 3 percent overall,” Darer says. “But if you can get the message to someone right after they’ve had a heart attack, you can get to 40 percent. So, timely communication can make a big difference both in the patient’s response to medical advice and in their motivation. When the communication is also transparent, which is what OpenNotes promises, you can demonstrate to patients that you’re working on their behalf—and that they should, too.”

At Harborview, the OpenNotes champion was Joann G. Elmore, a professor of medicine at the University of Washington who at the time of the study was Harborview’s chief of general internal medicine. Elmore brought to the research team a particular interest in improving the quality of doctors’ notes. “There’s too much abbreviation, jargon, mistyping, errors caused by cutting and pasting previous notes, and poor organization of information,” she says. “OpenNotes is a useful teaching tool; our medical students need to learn to write clear, educational, and professional notes with the patient in mind as a reader.”

In all three locations, the plan was to offer OpenNotes in outpatient primary care settings only, and to make participation by doctors and patients purely voluntary. To introduce the experiment and recruit doctors who would, in turn, make OpenNotes available to their patients, the researchers made presentations at medical staff meetings and also buttonholed individual doctors. Delbanco was particularly adept at the latter—with 40 years on the Harvard faculty, he’d been a

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teacher to many doctors at Beth Israel Deaconess, and he used that leverage unabashedly. Darer was able to build on an already well-established Internet portal called MyGeisinger through which patients can schedule appointments, email their doctors, and view lab test results. Some 225,000 people—40 percent of Geisinger’s patients—have MyGeisinger accounts. Adding doctors’ notes to the information they can access through this portal wasn’t difficult, nor did it strike many patients as a big deal.

Elmore did not have the same technological advantages. Harborview had a homegrown electronic medical record system that solely served the communication needs of clinicians. To accommodate OpenNotes, the hospital’s technical staff had to build one from scratch atop the existing system. This greatly limited the number of doctors and patients eligible for the experiment. But what Elmore did have was enthusiastic support for the OpenNotes concept from Harborview’s executive director, Eileen Whalen. “I thought it was a no brainer,” says Whalen. “We’re a public hospital with a challenging patient population, some of whom have behavioral health issues, addictions, lives on the streets. So transparency is a big deal for us. We want to teach our patients to own their problems and be part of our wellness programs and stay out of the hospital. OpenNotes fits right in with that.”

The researchers also went out of their way to accommodate concerns raised by doctors and patients in the pre-experiment surveys and to underscore the voluntary nature of the OpenNotes experiment. At all three sites, doctors were assured that no extra writing would be required. They also were allowed to choose which of their patients would be invited to participate in the experiment. At Beth Israel Deaconess, the doctors were given the additional authority to

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withhold certain notes from patients. To address privacy concerns, participating patients received instruction in setting up password-protected Internet accounts through which they would receive their doctors' notes. Finally, all participants were told they could drop out of the experiment at any time.

What Happened

Among other results, Diane Brockmeyer, the initially skeptical Beth Israel Deaconess internist, had a complete turnaround. "My expectations were completely off base," she says. "It turned out to be a lovely experience, and it was almost completely value-added. I've had dozens and dozens of experiences in which patients have said they were reminded to do something or were able to see how far they've come in the last year. It's been much less fuss than I anticipated."

Brockmeyer says she excluded a handful of patients because they were "overtly psychotic." At first, she also wrote her notes differently than she had when the expected readership was solely fellow clinicians. "I was conscious of using more partnering language in order to emphasize the shared decision-making," she says. But after the first 20 to 30 notes, she stopped trying so hard, although she believes her notes today are more patient-friendly. "In the beginning I was worried that there would be vocabulary and other comprehension issues, but that did not play out in my experience," she says. "I've had only two people call to correct information. Another patient expressed concern about personal information in a note and was very satisfied by my offer to put that note on monitoring (meaning it would not be routinely visible in the medical record)."

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At the end of the experiment, 99 percent of participating patients wanted OpenNotes to continue, and none of the doctors who completed the experiment—105 out of 113, or 93 percent across the three test sites—chose to stop using OpenNotes. The data is stronger for doctors, almost all of whom filled out post-experiment surveys. Of 22,703 patients who initially signed up, 19,371, or 85 percent, completed the experiment. But only 13,654 actually got a note to open (the others did not have a doctor’s visit during the trial period) and of these patients, 41 percent completed surveys.⁴

The data revealed a significant gap between doctors’ and patients’ perceptions of the value of open medical records. More than twice the percentage of patients as doctors “agreed” or “somewhat agreed” with post-experiment survey questions that timely access to clinical notes could help patients understand their medical problems, take better care of themselves, prepare for office visits, and comply with medication regimens.⁵ Even more telling was the divergence in responses to questions about potential risks to patients of reading their medical records. At the end of the experiment, 13 percent of the OpenNotes doctors at Beth Israel Deaconess still thought the notes would be “more confusing than helpful” to patients. By contrast, only two percent of their participating patients thought so. Results at Harborview and Geisinger were similar, as was the gap between doctors and patients in their perceived risk of clinical notes’ offending patients or making them anxious.⁶

These results tantalized the research team, which saw in the responses a need for more focused research on patients’ wishes. “We know very little about how to actually engage patients,” says Geisinger’s Darer. “There are no outcomes data and everyone is trying to figure out what kind of

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information really matters and is helpful to patients. OpenNotes is a first step but there is so much more to do.”

Interviews of patients who participated in OpenNotes illuminate the variety of ways in which they applied the knowledge gained from having access to their doctors’ notes. Take, for example, the experience of Amanda Bengier: Bengier was already familiar with OpenNotes when she got her invitation to participate because she happens to work in Darer’s innovation unit at Geisinger and had a hand in rolling out the experiment to clinicians. Still, she was amazed by how helpful doctors’ written notes turned out to be in managing the health of her only child, Jack, 6, who was born with spherocytosis, a hereditary form of anemia in which the body produces misshapen red blood cells that the spleen identifies as damaged and therefore works to destroy.

At the time of Jack’s diagnosis, his serviceman father (the parents are now divorced) was deployed in Afghanistan. “I was pretty much on my own, and it took a good year or two for me to learn all the signs and symptoms to watch for—jaundice, pallor, fatigue, dark pee—that meant Jack was in trouble,” says Bengier. “I’d take him to his doctor and try to absorb everything I needed to know to take care of him, but Jack would be running around, playing with the toys, and I’d be trying to manage him while also listening to the doctor and trying to memorize what he said.”

OpenNotes brought order to this chaos, says Bengier. Reading doctors’ notes on her home computer in the quiet of the evening, after she’d put Jack to bed, provided her with both ongoing education about the illness and a searchable record of her son’s progress. She uses the notes like

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an online course, routinely looking up unfamiliar terms, even practicing their pronunciation in case someone asks her to explain a symptom. Bengier believes this has made her a better advocate for Jack, especially when she has to take him to the emergency room. “Spherocytosis is pretty rare—a lot of doctors have never heard of it,” she says. “Because I’m up on the notes and the terminology, I’m able to let the emergency room people know why we’re there and get Jack what he needs.”

For Geisinger patient Robert Harter, 62, a supervisor at the Wise potato chip factory in Berwick, Pennsylvania, OpenNotes is a practical solution to hearing problems that make it difficult for him to catch everything said in an office visit. Harter is deaf in one ear and has severe hearing loss in the other. “It helps to be able to read about what happened because when my doctor talks to me I might be catching only every third word,” Harter says. “Also, I like seeing my test results before an appointment because it gives me something better to talk about when I go to see my doctor.”

Eileen Hughes, 52, of Jamaica Plain, Massachusetts, a community benefits program manager for Beth Israel Deaconess, has several chronic medical conditions, including type 1 diabetes and an autoimmune disorder, which require careful self-management. She uses OpenNotes for record keeping and to inform the dialogue during office visits, much as a clinician would. “When I arrive at my appointments, I’ve already reviewed my test results and notes from the last appointment so I can free up time to focus on more current issues with my doctor,” she says. “I feel like my appointments are more satisfying as a result.”

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Timothy Kelley, 56, of Auburn, Washington, came into the experiment already well educated about his primary illness, AIDS, having kept up on the latest science and treatments through Seattle's close-knit gay community. But keeping track of dosages and schedules for more than 20 prescription drugs is an ongoing challenge. "A lot of my medical appointments are related to drug side effects, and OpenNotes helps me monitor dosage changes, things like that," says Kelley, whose HIV infection dates back to 1994. "It also lets me correct errors in my medical record. For example, some of my meds weren't on the medication list and it's important for everyone to know what I'm taking. So we got that corrected."

Before OpenNotes, Kelley relied on a cheat sheet in his wallet. He would update it after every visit to Harborview's Madison Clinic, a dedicated HIV/AIDS facility that is part of a network of outpatient doctors' offices at the public hospital. But as Kelley developed new HIV-related conditions and other diagnoses—heart problems, allergies, type 2 diabetes—his neatly typed, single-spaced wallet list grew to three pages. OpenNotes makes it easier for him to review this complicated history and his doctor's advice; it also serves to reassure him that his views were "heard" during the office visit, even if his doctor didn't agree. "Sometimes, if I'm arguing about something I feel strongly about—like using herbal supplements on top of the medicines my doctor wants me to take—I don't always listen very well to the other point of view," says Kelley. "When I read the note later, sometimes I have to say, 'Yeah, I understand his point now and he's right.'"

Doctors who were interviewed also had a wide range of comments, both about their OpenNotes experience and about what may lie ahead as OpenNotes expands from primary care settings to

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outpatient specialty practices and clinics and, eventually, to the complex records of patients hospitalized for serious illness. The types of patients that these doctors see were often influential in their assessments.

Diane Brockmeyer, for example, the Beth Israel Deaconess internist who became an OpenNotes fan over the course of the experiment, has lingering concerns about privacy safeguards, particularly for patients who are victims of domestic violence and might come to further harm if private medical conversations are revealed. For this reason, Brockmeyer is grateful for the option at her hospital to put certain notes on “monitoring” so they’re not easily accessible, even to medical personnel.

William E. Greenberg, chief of psychiatry at Beth Israel Deaconess, also has reservations, not so much for psychiatric outpatients as for those hospitalized with psychosis and other dangerous exacerbations of mental illness. “Our inpatient unit is a locked unit with a solid percent of patients who are there against their will,” says Greenberg. “So these are not collaborative relationships of the sort one might have in an outpatient primary care setting. Yet other clinicians certainly need to know our patients’ diagnoses and medications or if there’s an eating disorder or some other influential condition. These are some of the discussions in our department about how to work with OpenNotes.”

On the other hand, Geisinger’s chief of rheumatology, Eric D. Newman, has not only embraced medical record transparency but has gone way beyond OpenNotes in using online communication tools with his patients. He credits his specialty for being unusually attuned to the

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benefits of doctor-patient collaboration, because virtually all of the patients seen in a rheumatology practice have incurable conditions that require a high degree of self-management and monitoring. Newman has his patients come early for appointments so they can sit at one of several computer terminals in the waiting area and type in answers to questions about what they have experienced since the last appointment. The responses hit Newman's computer screen before the patient walks through his door. "It lets us start the visit at thirty miles per hour," he says, and provides clinically important information that might not otherwise come up in an office visit.

Robert D. Harrington, medical director of Harborview's Madison HIV clinic, initially worried that OpenNotes would cause more harm than good due to the complexity of treatment of HIV-related illness, even in an outpatient setting. But he says he's only seen benefits in the small group of HIV patients handpicked to participate in the experiment (unlike at Beth Israel Deaconess and Geisinger where doctors excluded only a few of their patients, many were excluded at Harborview for such things as mental illness and substance abuse as well as practical considerations such as whether they had access to a computer). Overall, according to Harrington, the patients who participated in OpenNotes seemed to have a better grasp of their medical problems, the reasoning behind various treatments, and the importance of compliance with medication regimens. "In HIV, adherence to treatment is the driver of good health," Harrington says, adding that public health is also served when HIV patients understand how the infection spreads and what they should do to prevent that.

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Still, Harrington thinks the idea needs refining. “OpenNotes is a fire hose of information pouring into the patient,” he says. “This, by itself, is not communication, although the information can facilitate communication and prompt important discussion that helps to engage patients in their care, which is very important. But I think we still have a way to go in understanding what kind of information patients actually find useful.”

Harrington’s colleague in the HIV clinic, Shireesha Dhanireddy, shares this view, wondering if there might be a middle ground between the paternalistic status quo and total transparency that takes into account the wide range of doctor-patient relationships. Many of these relationships are cut and dried—professional and cordial but not especially warm. But others are quite personal, for reasons that range from simply good chemistry to the emotional intimacy that develops when two people share a difficult journey. Dhanireddy recalls a favorite patient of longstanding whom she enthusiastically recommended for OpenNotes only to be dismayed by his reaction to reading her notes.

After the first note, the patient told her he did not want to read any more because the way they were written made him feel like just another sick person, rather than someone she cared about. “He felt completely objectified by my writing style which is very formal because my goal is to communicate with other clinicians as efficiently as possible,” Dhanireddy says. “The note is not always reflective of the personal relationship.”

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Aftermath

How doctors express themselves in encounter notes was one of dozens of new areas of inquiry sparked by the OpenNotes experiment. Another was the inadequacy of current electronic medical records platforms, which tend to load billing information at the front end while burying doctors' notes, discharge summaries, medication instructions, and other information useful to clinicians and patients behind several screens. Still another concern was how to facilitate electronic access for people without computers. And throughout these post-experiment discussions rang the question: what do patients want?

Of the three OpenNotes test sites, Beth Israel Deaconess emerged as the most institutionally proactive. Indeed, executives there saw the 99 percent approval rating by patients in the experiment as a call to mandate medical staff participation.⁷ By early 2014, all outpatient primary care and specialist departments at Beth Israel Deaconess are expected to offer OpenNotes to an estimated 225,000 adult patients 18 and older; inpatient notes are projected to be available later in 2014.⁸

The speed of the rollout from a small primary care-based experiment to system-wide adoption reflects management's conviction that OpenNotes will give Beth Israel Deaconess a competitive edge in the crowded Boston hospital market. Behind the push is Kevin Tabb, the hospital's president and chief executive officer, who sees ramifications in OpenNotes beyond its popularity with patients. "OpenNotes is one step along the spectrum of transforming the relationship with patients into one of engagement and active participation," says Tabb. "For too long, hospitals have sat around waiting for very sick people to show up, thinking of themselves as being in the

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‘heads in beds’ business. We looked, we diagnosed, we documented, and we didn’t tell you anything. Today, we have to think differently about our patients—because we’re in the health care business.’

At Geisinger, the OpenNotes experiment was rapidly expanded in 2013 to all primary care practices, as well as to outpatient specialists—a total of some 550 doctors and advanced-practice nurses serving more than 120,000 patients. According to Jonathan Darer, another 300 clinical fellows and residents, as well as their supervising doctors, are expected to participate in 2014. But unlike Beth Israel Deaconess, Geisinger has chosen not to require participation. Rather, each medical department will be able to decide how and when to adopt OpenNotes, including whether to mandate it among department members or allow participation to be voluntary. The belief is that in the give and take within each clinical department, Geisinger’s doctors will come up with ways to refine OpenNotes that might not surface were the medical staff simply ordered to participate. Darer and others point to the variability of concerns among specialists, especially those dealing with psychiatric or neurologically-impaired patients, and the dearth of research data on patients’ wishes. Studies of electronic communication tools in medical settings have focused almost exclusively on the information needs of clinicians and health care organizations.

Geisinger is also trying to improve the accuracy and utility of the notes. John B. Bulger, the health system’s chief quality officer, has a growing list of expressions now banned from patient records due to their potential to cause error or misinterpretation. He has leaned on guidelines from The Joint Commission, an accreditation organization for hospitals, to compile it. For example, “MgSO4” and “MagSO4” as abbreviations for magnesium sulfate are barred because

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they can be dangerously misread as morphine sulfate. Everyone must now type out “magnesium sulfate.” Also out are fractional dose measures rendered as, for example, “.5” rather than the newly mandated “0.5.” This is because decimal points are easily overlooked on a shiny computer screen or handheld device, leading to “.5” being read as “5”—a tenfold increase in dosage.

Bulger is also working to address generational communication styles newly mucking up the medical record. Texting and social media shorthand like “c u” for “see you,” have lately cropped up as doctors speed type their medical notes. This is not a great way to communicate with a broad-based patient population, says Bulger, nor with health care workers in the many settings that a patient may be cared for: hospital, nursing facility, outpatient office, or home. “It used to be that the hospital staff rolled the patient out to the sidewalk for their ride home, thinking, ‘That’s it, I’m done,’” says Bulger. “But today we’re dealing with a continuum of care, whether patients are in the hospital or being followed up by their own doctor. The notes have to provide reliable information for all of these providers. OpenNotes has the potential to increase this reliability because there’s another set of eyes on the information and that’s the person who really knows—the patient.”

Finally, at Harborview, OpenNotes is being expanded from use by a select group of doctors and their patients to a standard offering of the outpatient adult medicine and ophthalmology departments. The hospital also plans to use OpenNotes in its residency training programs to teach new doctors better communication skills. Internist Jared Klein, a former chief resident and now a mentor to internal medicine trainees, is leading the initiative. “Residency is a key time for

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them to reflect on their interactions with patients, and to think about how to take the information they communicate face to face with patients and present it in a note that these same patients will read later,” says Klein. “Right now, the notes are being driven by electronic templates primarily designed to elicit a billable minimum of services.”

Klein believes this will be less of a problem if doctors learn early in their careers that patients, too, will be reading what they write. “I tell my trainees all the time: 60 percent of a doctor’s job is communication, 30 percent is medical judgment, and 10 percent is medical knowledge. So skill both in verbal and written communication is key. I think OpenNotes can help me make that point.”

Even as Beth Israel Deaconess, Geisinger, and Harborview work to refine and expand OpenNotes, the idea of giving patients electronic access to doctors’ notes is spreading. At The University of Texas MD Anderson Cancer Center, 84 percent of active patients have electronic access to their full medical records, and the cancer center has looped in referring doctors as well.⁹ A half million Cleveland Clinic patients are expected to be able to see doctors’ notes by the end of 2013, via the clinic’s online portal, MyChart.¹⁰ And by early 2014, an estimated two million patients in the United States will be able to read their full medical records online. About a million of these are veterans using the Blue Button link on their My HealtheVet electronic portal. Launched by the U.S. Department of Veterans Affairs in 2010, Blue Button gives patients electronic access to test results and medications so they can self-report medical histories, insurance status, and vital information such as weight and blood pressure. In January 2013, Blue Button opened patients’ entire medical record, including doctors’ notes.¹¹

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Conclusion

So convinced was Timothy Kelley of the benefits of reading his doctors' comments that he set out to gather his medical records going back to when he was first diagnosed with HIV in 1994: "I wanted to see what I was doing when my health deteriorated and what I was doing when I was getting better so I could continue those things and keep my health."

Kelley had to request paper copies, because OpenNotes provided computer access only to records from 2010, when the experiment began. This is where Kelley's legal right to these records foundered amid the small print of HIPAA that permits health care providers to charge a fee for photocopying. At Harborview, the rate is currently twenty-six cents a page. "I was only able to get the records back to 2006 before I had to stop due to finances," says Kelley, who lives on Social Security disability stipends. "It cost me over \$150 so I have to wait until I save some money to go back further."

It turns out that Harborview's rate is a bargain. Although federal law requires health care organizations to provide patients with their medical records, state laws define the process of obtaining them, including setting copying fees. These fees vary from state to state. Colorado, for example, allows fees up to \$14 for the first 10 pages, 50 cents a page for pages 11 to 40, and 33 cents a page for the rest.¹² Florida permits fees of up to \$1 a page for the first 25 pages and 25 cents per page after that.¹³ New York allows charges of up to 75 cents per page.¹⁴

The culture that OpenNotes sought to change is manifest in these laws and business practices which, besides creating cost barriers for patients like Kelley, dictate an elaborate process for them

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to follow, including: written requests on approved forms, separate applications for each record, notarized signatures in some jurisdictions, and waiting periods of up to 30 days. As if to underscore the double standard, many states explicitly exempt doctors and health care organizations from these fees and process requirements when they request patient records. In the context of current thinking about the importance of patients working collaboratively with health care personnel, such fees and procedural hoops are at best counterproductive. They call to mind the discouraging 1-800 customer phone services that keep people on hold for so long that they simply hang up. “We have to find a better way of connecting the many parts of our health care life,” says Risa Lavizzo-Mourey, president and CEO of the Robert Wood Johnson Foundation, who sees OpenNotes as a tool to that end. “Part of that is redesigning the health care delivery system in a way that puts the patient in the center and population health as a priority.”

With regard to the inadequacies of current electronic medical record design, in which billing codes and other non-clinical data obscure the display of doctors’ notes and other information useful to patients, there is nothing preventing health care organizations and vendors from collaborating on improvements. These electronic platforms began as billing systems with the medical information included as back-up documentation for claims. It seems a simple thing to pursue redesigns on behalf of patients and clinicians, especially given the billions of dollars in federal subsidies for health care providers to encourage meaningful use. In fact, OpenNotes leaders Delbanco and Walker, have discussed the issue with a leading electronic medical record vendor, and Geisinger is pursuing an in-house fix by adapting its existing electronic medical record platform to support OpenNotes.

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Less obvious is how to deliver medical records in a way that supports *patients'* meaningful use.

The questions raised by Harborview's Harrington and others about the value of spraying a “fire hose” of technical information at patients are not so easily answered (see the samples of medical record notes reprinted in the appendix). And new questions will surely arise as OpenNotes moves from the primary care setting into specialties that treat patients with more medically complex problems, including cognitive and psychiatric disorders.

Such discussions are perhaps the richest legacy of the OpenNotes experiment—an idea whose impact is likely to extend well beyond what even those who conceived of the project could have envisioned. Among doctors and patients who field-tested OpenNotes, the tool has clearly helped to break down the us/them mentality that historically colored their relationship. The challenge for those moving swiftly to replicate and expand OpenNotes is to keep patients in the research loop. Geisinger's Darer notes the dearth of information on patients' wishes. How they use OpenNotes and deploy its benefits in daily life are critically important questions to answer if the health care system is to realize the theoretical promise of patient engagement: better population health at lower cost.

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APPENDIX

Sample Medical Records

(The following are actual records redacted to protect the privacy of the patients.)

OpenNotes: *Putting Medical Record Transparency to the Test*

By Irene M. Wielawski

SAMPLE NOTE #1

Note Date:

Signed by . , MD on at pm Affiliation:

VS: Wt. 160 lbs BMI 22.3 Kg/m2 P 56 BP 144/90

Active Medication list as of . :

Medications - Prescription

AMLODIPINE - 10 mg Tablet - 1 Tablet(s) by mouth once a day
HYDROCHLOROTHIAZIDE - 25 mg Tablet - 1 Tablet(s) by mouth once a day
LISINAPRIL - 30 mg Tablet - 1 Tablet(s) by mouth once a day
METOPROLOL TARTRATE [LOPRESSOR] - 100 mg Tablet - 1 Tablet(s) by mouth twice a day

Medications - OTC

ASPIRIN [ASPIRIN CHILDRENS] - 81 mg Tablet, Chewable - 1 Tablet(s) by mouth daily

HISTORY OF PRESENT ILLNESS: is here after an overnight admission to hospital, where he was seen with, syncope, hypokalemia and paroxysmal atrial fibrillation. He has subsequently been seen there by a cardiologist who called me and wondered if he might have amyloid, without realizing that he had a long history of hypertension.

He left there on new dosages of medicines, but the same medicines, and he will call me later today with the exact dosages of what he is taking. He does not have them with him. While at the hospital, he had numerous evaluations, but he was felt safe to leave, and is tired of being seen out there and wants to return to care here. I am delighted to have him back.

He feels fine now. He does not get the same monitoring at work that he used to because his nurse left, but right now he feels pretty much back to normal. He is back to work.

They told him apparently that he was on "too much medicine," and I assume they meant by that the hydrochlorothiazide, given his hypokalemia, but he is not sure which medicines have been changed.

Of note is the fact that his stress test here in March was basically fine. He has not had an x-ray here in seven years and I will repeat that today (unchanged and not particularly remarkable). We will also take a look at his cardiogram and of course check his electrolytes (K+ on the low side, bicarbonate on the high side).

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PHYSICAL EXAMINATION:

GENERAL: On evaluation today, he looks well.

VITAL SIGNS: His blood pressure is 144/88 by me, sitting, and the same supine. His pulse is 60 and entirely regular over 2 minutes. His weight is stable.

LUNGS: Clear.

HEART: I do not hear adventitious cardiac sounds. There is no sign of cardiac decompensation.

ABDOMEN: His liver is not enlarged.

NECK: His veins are not distended.

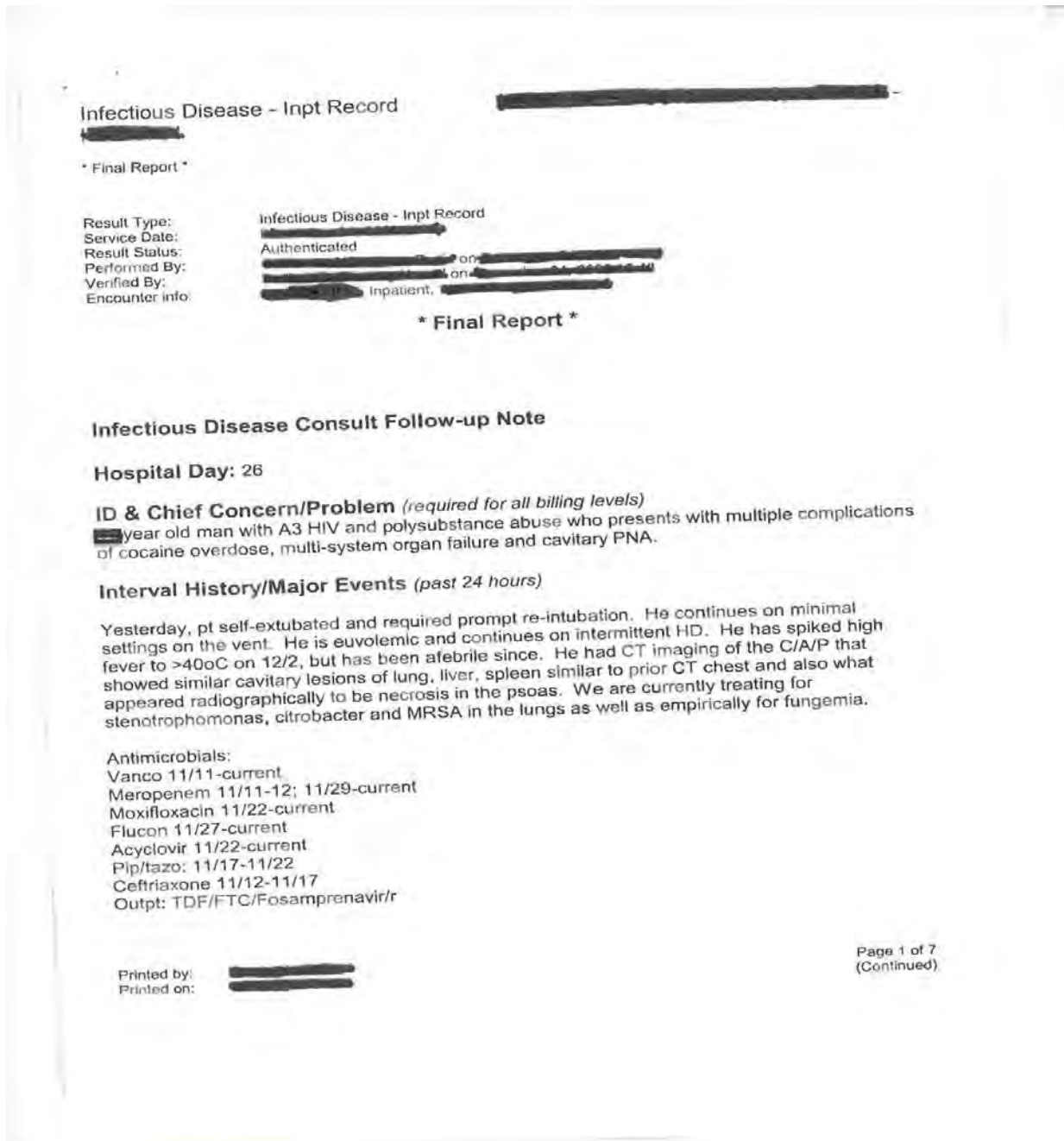
EXTREMITIES: His ankles are fine.

ASSESSMENT AND PLAN: It sounds to me as if much of this was induced by hyperkalemia, and we shall have to indeed check that out over time and likely change his regimen. I have urged him for now to eat lots of bananas, and drink lots of orange juice

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SAMPLE NOTE #2



OpenNotes: *Putting Medical Record Transparency to the Test*

By Irene M. Wielawski

Infectious Disease - Inpt Record

* Final Report *

Review of Systems Unable to Obtain due to Patient Condition

CONSTITUTIONAL Negative _ EYES Negative _ ENMT Negative _
CARDIOVASCULAR Negative _ RESPIRATORY Negative _ GI Negative _
GENITOURINARY Negative _ NEURO Negative _ MUSCULOSKELETAL
Negative _
SKIN Negative _ ENDOCRINE Negative _ ALLERGY/IMMUNOLOGY Negative _
HEME/LYMPH Negative _ PSYCHIATRIC Negative _

Allergies

NKA

Scheduled Medications

Acyclovir susp (conc 40mg/mL) Dose: 200 mg = 5 mL Feeding Tube QDay
Calcium carb 1250mg(elem 500mg)/5mL susp Dose: 1,250 mg = 5 mL Feeding Tube Q8
Hours
Chlorhexidine gluconate 2% topical cloth Dose: 1 application Topical QHS
CONCENTRATE IV MEDS IN NORMAL SALINE Dose: 1 each MISC QDay
Heparin 5,000units/mL inj Dose: 5,000 units = 1 mL Subcutaneous Q8 Hours
Lansoprazole 30mg soluble tab Dose: 30 mg = 1 tab Feeding Tube QDay
Lidocaine/Diphenhydramine/Al-Mg hydroxid Dose: 15 mL PO BID
Meropenem Dose: 1 g IVPB Q24 Hours
Moxifloxacin/0.8% NaCl Dose: 400 mg = 250 mL IVPB Q24 Hours
Phenytoin 300mg/12mL susp Dose: 300 mg = 12 mL Feeding Tube Q12 Hours
Sedation Vacation Dose: 1 each MISC QAM
Sodium chloride 0.9% inj 10mL (syringe) Dose: 10 mL IV Push Q8 Hours
Vitamin multiple, with mineral 15mL soln Dose: 15 mL Feeding Tube QOther Day

Infusions

Dextrose 5% in Water 850 mL + Sodium bicarbonate 150 mEq Dose: 850 mL IV Infusion
Fentanyl 5,000 mcg + Diluent 100 mL Dose: 100 mL IV Infusion
Lorazepam 40 mg + Dextrose 5% in Water 20 mL Dose: 20 mL IV Infusion
Sodium Chloride 0.9% 1,000 mL Dose: 1,000 mL IV Infusion

PRN Medications *(Please, see the medication profile)*

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Infectious Disease - Inpt Record

* Final Report *

Vitals (Most recent and 24 hour range.)

Date	Result	Last	MIN	-	MAX
12/04/09 08:05	Temp C:	37.4	36.7	-	37.4
12/04/09 11:01	HR:	104	100	-	110
12/04/09 11:01	RR:	17	16	-	42
12/04/09 11:01	SBP Non-Inv:	97	87	-	117
12/04/09 11:01	DBP Non-Inv:	59	52	-	75
12/04/09 11:01	MAP Non-Inv:	70	61	-	86

Neurophysiology Data (Most recent, lowest and highest for 24 hour range)

Date	Result	Last	MIN	-	MAX
12/04/09 08:09	GCS Total	10	10	-	14

I&O Data

Height: 173.0 (cm) 5' 8" (ft / in) (11/08/2009)
Admit Wt: 79.30 (kg) 174 (lbs) (11/08/2009)
Last Daily Wt: 68.4 (kg) 150 (lbs) (12/03/09 05:00)
Previous Daily Wt: 68.7 (kg) 151 (lbs) (12/02/09 04:00)

(24 Hour IO Total = from 06:00 the prior day to 05:59 listed day)

Result	12/01/2009	12/02/2009	12/03/2009	12/04/2009	12/05/2009	Total
Intake Total (0600)	1817	1931	1742	1721	431	7642
Output Total (0600)	0	837	45	750	320	1952
Net I&O Total (0600)	1817	1094	1697	971	111	5590
Daily weight	67.6	69	68.7	68.4		N/A

Respiratory Data (Most recent and 24 hour range.)

Date: 12/04/09 08:40
Ventilator Mode: AMV
O2 Sat: 100
O2 Percent Administered: 30
O2 Delivery Device: Ventilator

PHYSICAL EXAM

Gen: intubated/sedated
Neuro: lightly sedated, responsive to voice, follows commands in spanish

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Infectious Disease - Inpt Record

* Final Report *

HEENT: PERRL, anicteric, purulent ulcer on the right upper lip.
CV: RRR no murmur, no edema
Pulm: course mechanical BS anterolaterally
GI: NABS, soft, NT
Skin: opened bullae over patella b/l are healing

Laboratory Studies (Most recent results in 24 hour range)

RESULTS FROM TODAY
12/04/09 03:45

134 97 74
4.2 25 6.5 < 120

- ICa ---
- Ca 9.2
- Mg 2.6
- Phos 7.6

RESULTS FROM YESTERDAY
12/03/09 03:20

130 94 50
3.5 27 4.7 < 97

- ICa ---
- Ca 8.5
- Mg 2.1
- Phos 5.1

RESULTS FROM TODAY
12/04/09 03:45

8.2
10.88 25 533

- PT 13.7
- INR 1.1
- PTT 32

RESULTS FROM YESTERDAY
12/03/09 03:10

7.9
8.94 24 468

- PT 13.8
- INR 1.1
- PTT 34

Last 6 Hematocrits in Preceding 24 Hours

(NOTE: Comments/notes for Labs are viewable on Flowsheet)

12/04/09 12/03/09
03:45 03:10
25 24

ABG Results

(NOTE: Comments/notes for Labs are viewable on Flowsheet)

7.40 / 40 / 131 / 24 / Calculated O2 SAT not reported. / 40 / Information not provided

Other Results

Radiological Studies

CT Chest/Abd/Pelv (12/2)

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Infectious Disease - Inpt Record

* Final Report *

IMPRESSION:

1. Fluid collections within the lung parenchyma are suspicious for abscesses. Surrounding consolidation is compatible with pneumonia, with small bilateral parapneumonic effusions.
2. Bilateral psoas muscle enlargement with areas of necrosis is likely rhabdomyolysis in patient with this clinical diagnosis. Alternatively it could represent hemorrhage or infection.
3. Peripheral irregular hypodensities in segment 7 of the liver again most likely are small infarcts. These are not significantly changed since prior exam.
4. Wedge-shaped low-density regions in the spleen are not significantly changed since prior exam again likely reflect infarcts.

Microbiology

- 11/30: BAL- LLL GPCs & GNRs: see cultures 11/28 (>30,000col/mL of non-LF GNRs)
11/28: ET sputum: 2+ stenotrophomonas, 2+ MRSA
11/24: Pleural fluid: NGTD
11/24 & 26: ETT: 2+ stenotrophomonas, 2+ citrobacter
11/22: penile: pending HSV. negative GC/CT, RPR
11/20: lip: HSV-1
11/19: ETT: 2+ stenotrophomonas, 2+ citrobacter
11/15 (BAL): MSSA, Citrobacter #1,2, neg: flu, viral, AFB, aspergillosis
11/14 arthrocentesis (b/l knees): NGTD
11/12 NP swab: Neg: flu
11/11 Sputum (ET): 4+ citrobacter braakii #1, 4+ S. pneumo, 3+ MSSA, 3+ C. braakii #2
11/10-11 Blood (periph & HD cath): S. pneumo
11/8 Sputum (ET): 3+ H. influenzae, 1+ MSSA, 3+ S. pneumo, 2+ yeast

Problems / Assessment / Plan

■ year old man with A3 HIV and polysubstance abuse who presents with multiple complications of cocaine overdose, multi-system organ failure and cavitary PNA. Pt seems to be making very mild clinical improvement based on the afebrile since almost 48 hours. However, the psoas abscesses are concerning for necrosis vs. infection, especially in the setting of initial S. pneumo bacteremia and we would recommend sampling these to determine sterility. Also, the stenotrophomonas should probably be covered by a second active agent and micro plate rounds today determined that the MICs for moxifloxacin are borderline; the lab will be running sensitivities on the stenotrophomonas from the BAL on 11/30. Active agents against his bug are

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* Final Report *

TMP-SMX and minocycline with TMP-SMX having better activity.

Recommendations

- consider IR sampling of psoas fluid collection
- agree with current ABx regimen
- recommend adding TMP-SMX (tmp component 7.5mg/kg) IV qday

Thank you for the opportunity to participate in the patient's care. We will follow closely with you. Please call with any questions.

Attending Statement:

I did not see the patient, but have reviewed the findings above.

Signature Line

Electronically Reviewed/Signed On: 12/04/09 at 16:21

Resident, Department of Medicine

Electronically Co-Signed On: 12/04/09 at 16:43

Attending, *[redacted]*, Dept. of Medicine
Division of Allergy and Infectious Diseases, *[redacted]*

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Infectious Disease - Inpt Record

* Final Report *

JDG
DD:12/04/09

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SAMPLE NOTE #3

*** Final Report ***
Surgery Admit/Consult Note

Dept Surgery: Initial Hospital Admission Consult

Date: 07/04/08 **Time:** 1500 **Pt Location:** ED

Consult requested by: ED **Reason:** concern for bowel obstruction
Consult request template viewed in requesting service progress note:

Completed by: Resident Fellow Attending
Surgery Attending:
Service: 1 2 Thor Vasc A B S

ID/CC:
fever, abdominal pain

HPI:
The pt. is a XX y/o gentleman with a PMHx significant for Crohn's disease complicated by entero-enteric fistula, chronic abdominal pain for a few months resulting in decreased PO intake and weight loss of 20 pounds over the last several months. The pt was seen in surgery clinic (Dr. XXXX) on 5/29/08 and CT revealed significant inflammation of the distal ileum, ileocecal valve and cecum. The pt was scheduled for surgery in early August for removal of the effected areas.

Today the pt present with a few day history of abdominal pain, distention, with decreased stool and flatus. Pt reports some fevers. Positive bilious vomiting prior to presentation to the ER. He reports that his abdomen did not feel distended to him.

ROS:
 Unable to obtain history due to patient intubation, sedation, other incapacity, unable to obtain from alt source.

Const: negative Comments: as in HPI

Eyes: negative Comments: _

ENMT: negative Comments: _

CV: negative Comments: _

Resp: negative Comments: _

GI: negative Comments: _

GU: negative Comments: as in HPI

MSK: negative Comments: _

Skin: negative Comments: _

Psych: negative Comments: _

Endo: negative Comments: _

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Lymph: negative Comments: _

Allergy: negative Comments: _

Past, Family, Social History:

PAST MEDICAL HISTORY:

1. As in HPI.
2. GERD.

PAST SURGICAL HISTORY:

Wisdom teeth removal.

ALLERGIES:

NO KNOWN DRUG ALLERGIES. HOWEVER, HE STATES THAT MORPHINE GIVES HIM HALLUCINATIONS.

CURRENT MEDICATIONS:

1. Humira 40-mL injection every 2 weeks.
2. Hydrocodone 5/325 1 to 2 pills q4-6h as needed for pain.
3. Ciprofloxacin 500 mg PO twice daily.
4. Metronidazole 250 mg PO twice daily.)

SOCIAL HISTORY:

The patient lives in XXX with his XXX and X children. He is a manager at XXXX. He denies drug, tobacco, or alcohol use.

FAMILY HISTORY:

1. The patient states that he has a family history first-line brother 34 Crohn disease.
2. Father died of MI at age 48.

Exam:

VITAL SIGNS: Temp: 36 BP: 121/70 Pulse: 96 Resp: 20 Weight: _kg SaO2: 98% on RA
Vital Sign Assessment Normal other: borderline tachycardia

GENERAL: _

HENT: perri, eomi, oropharynx clear icterus other: _

HEAD/NECK: supple, no thyromegaly, no bruits other: _

LYMPH: no lymphadenopathy

lymphadenopathy: neck supraclavicular axilla groin other: _

CVS: rrr, s1s2, no m/r/g other: _

Extremities: no c/c/e edema B 1+/2+/3+/4+ other: _

Pulses	<u>Right</u>	<u>Left</u>	<u>Right</u>	<u>Left</u>
	Fem _	Fem _	Pop _	Pop _
	Dp _	Dp _	Pt _	Pt _

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Carotid: _
Other CVS: _
RESP: CTA bilaterally crackles expiratory wheezes other: _
SKIN: warm, dry, no jaundice/sig lesions/rashes jaundiced other: _
BREAST: normal other: _
GI: decreased BS, soft, +TTP in supra-pubic region and RLQ. No round tenderness,
no gaurding.
Hernia: no hernias ventral/inguinal/femoral incarcerated other: _

KEY PHYSICAL EXAM FINDINGS: TTP in RLQ and supr-pubic regions

Labs:
WBC 26
Alb 3.2
UA: WNL's

Studies/Records Reviewed:

Acute abd series: dilated loops of small bowel with air/fluid levels, no free air under diaphragm

CT abd/pelvis: Small bowel is diffusely distended up to the terminal ileum, where there is short segment of diffuse circumferential wall thickening, luminal narrowing, and mesenteric fat stranding. The colon is unremarkable. No abscess or fistula is identified.

Resident Assessment & Plan:

The pt. is a XX y/o gentleman with a PMHx significant for Crohn's disease complicated by entero-enteric fistula, chronic abdominal pain for a few months resulting in decreased PO intake and weight loss of 20 pounds over the last several months. Pt. now with fever, vomiting and elevated WBC. Abd series suggestive of small bowel obstruction, CT abd/pelvis reveals no identifiable fluid collections, but an area of thickened bowel wall in the terminal ileum. The pt has a bowel obstruction secondary to a Crohn's flare and known terminal ileal stricture disease scheduled for elective surgery by Dr. XXXX in late August.

-recommendations:

-admit to medicine

-obtain GI consult for medical management of Crohn's flare

-cont. NPO, NG-tube, bowel rest

-IV antibiotics

-TPN

-Surgery will continue to follow and if pt worsens or does not improve will consider taking the pt to the OR for surgical intervention, however ideally the pt. will improve so that the procedure may be down electively.

Resident pager Number:

XXX-XXXX

ATTENDING STATEMENT:

I personally saw and evaluated the patient. I discussed the patient with Dr. XXXX. I agree with the findings and plan as documented in his/her note.

Whether this patient needs surgery in the near future or electively in Aug as planned, it is very important that he doesn't lose any more nutritional decline. Strongly recommend TPN asap.

OpenNotes: *Putting Medical Record Transparency to the Test*

By Irene M. Wielawski

Date of Service: 7408 _

Today's Date is: 07/06/2008

Signature Line

Electronically Reviewed/Signed On: 07/05/08 at 01:45

XXXXX

Resident, Dept of Surgery

REDACTED

REDACTED

Electronically Co-Signed On: 07/06/08 at 14:40

XXXXXXXX

Attending Physician

Department of Surgery REDACTED

REDACTED

AGH

DD:07/04/08

OpenNotes: *Putting Medical Record Transparency to the Test*

By Irene M. Wielawski

SAMPLE NOTE #4

Breast Care - Outpt Record

* Preliminary Report *

Result Type: Breast Care - Outpt Record
Service Date: [REDACTED]
Result Status: Transcribed
Result Title: [REDACTED]
Performed By: [REDACTED] ARNP, [REDACTED]
Encounter Info: [REDACTED], Outpatient, [REDACTED]

* Preliminary Report *

ROOSEVELT BREAST CLINIC NOTE

IDENTIFICATION

[REDACTED] is a [REDACTED]-year-old Hispanic female who is referred this date by [REDACTED] R for evaluation in regard to a left breast abscess.

CURRENT BREAST PROBLEM

The patient apparently developed swelling, erythema and a raised area in the left breast approximately 3 months ago. She was subsequently seen and evaluated and treated with clindamycin, which improved her pain and swelling somewhat. However, the pain, erythema and swelling subsequently returned. She was then seen again in December in a local ER and treated with vancomycin. She developed a rash on vancomycin and this was discontinued. She was then seen in the [REDACTED] on January 11, 2010 and started on Keflex 500 mg 4 times a day. Her symptoms did not improve and she was subsequently seen in the [REDACTED] on January 11, 2010. At that time, she was noted to have diffuse erythema in the area of fluctuance at the 7 o'clock position in the left breast. An ultrasound was completed and revealed a superficial abscess at the 7 o'clock position measuring 4 x 8 x 2.5 x 3.8 cm. This was noted to be immediately inferior and medial to the nipple and extending deeply into the breast in the medial and superior directions.

The decision was made to proceed with I&D, which was completed on January 11, 2010. The patient was then discharged on Bactrim DS and instructed to take 2 tabs twice daily. She was also provided with oxycodone, Tylenol and ibuprofen for pain. She was referred to the Breast Health Center for followup and presents for same. She reports that since being seen at [REDACTED], her husband has been changing the dressings on her left breast. There has been a minimal amount of drainage noted. The dressing was most recently changed last p.m. She reports that her pain at the time of her I&D was 10 on a scale of 1-10. The pain has decreased since that time. She reports some decrease in the extent of the redness noted. She denies any nipple discharge, pulling, tugging, or dimpling.

Printed by: [REDACTED]
Printed on: [REDACTED]

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(Continued)

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By Irene M. Wielawski

Breast Care - Outpt Record

* Preliminary Report *

PAST BREAST HISTORY

She does report a history of a previous mastitis while nursing approximately 3 years ago, however, denies abscess formation.

MAMMOGRAM HISTORY

She reports she did have a mammogram at [REDACTED] in [REDACTED] in November, which was reportedly within normal limits and ultrasound as noted above.

GYNECOLOGICAL HISTORY

The patient is P4, G4, however, 1 of her children died in the neonatal period. She is not currently using a form of contraception, however, reports LMP January 3, 2010, with normal amount and duration of flow.

FAMILY HISTORY

Negative for breast, ovarian, colon, or prostate cancer.

CURRENT MEDICATIONS

1. Bactrim DS 2 tabs twice daily.
2. Ibuprofen 200 mg every 4-6 hours as needed for pain.
3. Oxycodone 5 mg, 1-2 tablets every 8 hours as needed for pain.
4. Tylenol 500 mg every 6 hours as needed for pain.

PAST MEDICAL HISTORY

The patient does report an allergy to vancomycin. She denies other antibiotic allergies. She does report a history of anxiety and depression and a history of gallstones as well as hypertension. She additionally has had gestational diabetes. She denies other chronic or acute disease.

PAST SURGICAL HISTORY

C-section times 2 in 2001 and 2006 as well as an umbilical hernia repair.

REVIEW OF SYSTEMS

A 14-system review of systems was completed. Please refer to the Breast Health Center Patient Intake Form.

GASTROINTESTINAL: The patient does report some cramping and constipation secondary to current pain medications. She denies other acute complaints at this time, other than those associated with the current breast problem.

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(Continued)

OpenNotes: *Putting Medical Record Transparency to the Test*

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Breast Care - Outpt Record

* Preliminary Report *

SOCIAL HISTORY

The patient does not work. She is married. Her husband accompanies her today. She denies exposure to chemicals or radiation. She is a nonsmoker. She drinks 1 to 2 caffeinated beverages per day, 2 servings of high-fat food. She does not drink alcohol. She exercises with caring for her children and cleaning house.

PHYSICAL EXAMINATION

VITAL SIGNS: Weight is 166. Blood pressure 110/66, pulse 84 and regular, temp is 36.6.

GENERAL: Extremely pleasant, cooperative, however, somewhat anxious Hispanic female in no acute distress who is communicating through an interpreter this date. Her husband also accompanies her today and he does understand English.

HEENT: Normocephalic. Sclerae anicteric. Conjunctivae clear.

NECK: Supple, no nodes.

LUNGS: Completely clear throughout.

HEART: Regular rate and rhythm without audible murmur.

BREASTS: Asymmetric in appearance, the left larger than the right. There is a large, approximately 7-cm area of a circumareolar erythema and I&D site with packing. There is no erythema in the right breast. The packing from the left breast wound was removed revealing an approximate 2-cm wound with no visible exudate at this time. There is a minimal amount of exudate on the dressing. There is an area of thickness in the left breast measuring 7 x 5 cm, extending from the 7 o'clock position in the medial area of the breast to the 3 o'clock position in the lateral aspect of the breast. There is thickening in the subareolar area.

The left breast was prepped with Betadine and the wound repacked with half-inch gauze. Although this was a somewhat painful procedure, the patient tolerated the procedure well. The wound was then covered with 4x4s and secured in place.

DIAGNOSTIC STUDIES

Ultrasound results as noted above. The previous mammogram is unavailable on today's exam.

ASSESSMENT

■-year-old female with a long-standing history of an abscess in the left breast with I&D completed on January 11, 2010.

PLAN

1. I have discussed ■■■■■ with ■■■■■, who will plan on seeing her tomorrow at the

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(Continued)

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Breast Care - Outpt Record

[REDACTED]

* Preliminary Report *

[REDACTED] Cancer Care Alliance at 4:30.

2. [REDACTED] will continue on her Bactrim. I have added in Augmentin 875,1 twice daily for 10 days. I have asked her to take at least 2 doses of her Augmentin today. We have discussed the use of her pain medications and using the Oxycodone judiciously.

1. We have discussed that GI upset is a common side effect with Augmentin, however, if she develops a rash, she should discontinue the medication and continue with her Bactrim as previously noted.

Signature Line

[REDACTED]
[REDACTED] Surgery Dept
[REDACTED]
[REDACTED]

[REDACTED]
[REDACTED] 0
[REDACTED]

2406150

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Printed on: [REDACTED]

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By Irene M. Wielawski

Notes:

¹ Delbanco, T et al. “OpenNotes: Doctors and Patients Signing On,” *Ann Intern Med*, 2010;153:121-125.

² Delbanco, T et al., *Ibid*, pg. 123

³ *Ibid*, pg. 123

⁴ Delbanco, T et al., “Inviting Patients to Read their Doctors’ Notes: A Quasi-experimental Study and a Look Ahead,” *Ann intern Med*, 2012;157:461-470, pg. 464

⁵ *Ibid*, pg. 465

⁶ *Ibid*, pg. 465

⁷ Delbanco, T et al., *Ann intern Med*, 2012

⁸ <http://www.bidmc.org/News/Around-BIDMC/2013/August/OpenNotes.aspx>

⁹ Feeley, TW, and Shine, KI, editorial: “Access to the Medical record for Patients and Involved Providers: Transparency Through Electronic Tools,” *Ann Intern Med*. 2011;155:853-854

¹⁰ <http://www.healthcareitnews.com/news/cleveland-clinic-opens-emr-patients?topic=08,18>

¹¹ https://www.myhealth.va.gov/mhv-portal-web/anonymous.portal?_nfpb=true&_nfto=false&_pageLabel=faqsHome#MHVFeatures

¹² <http://www.cobar.org/index.cfm/ID/226/subID/1348/CITP/Medical-Records/>

¹³ http://www.fhima.org/NewsAndHotTopics_Homepage/Press%20Release%20-%20New%20Physician%20Medical%20Record%20Copy%20Fees%20Now%20In%20Effect.pdf

¹⁴ <http://www.health.ny.gov/publications/1443/>