Healthcare DIY: Empowering Consumers to Optimize their Healthcare through Health Information

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By Mary Butler (Illustration [in print version] by Marla Campbell)

There's no doubt that consumers of a certain age take comfort in going to the doctor, agreeing with their diagnosis, and following his or her treatment plan to the letter without doubts or hesitation. But this paternalistic approach to healthcare is starting to erode as younger generations of patients are beginning to handle the provision of care as they do any other major purchase.

These new engaged patients frequently take a list of questions to the doctor with them—perhaps after first performing an Internet search on the physician's background and their symptoms—check their lab and imaging reports through their online patient portal, and compare treatments on disease-specific message boards. The Internet's democratizing effect has given consumers more access to healthcare information than ever before, and the results have been as diverse as consumers themselves.

Online patient portals give patients an opportunity to spot mistakes in their health records and can prompt patients with chronic conditions to schedule needed tests and checkups. Image-enabled health information exchanges (HIEs) are helping to reduce redundant diagnostic procedures such as CT scans and X-rays, and interoperable electronic health records (EHRs) are saving patients and providers valuable time and effort by digitizing personal health information.

But there are downfalls of having a wealth of unfiltered medical information. Giving patients access to all of their health data—lab values, procedure notes, tests—without context can induce anxiety and confusion when wrongly interpreted by a layperson. For example, myths about vaccinations are rampant on the Internet, leading parents to ignore what used to be routine inoculations against measles, polio, and other infectious diseases. Subsequently, outbreaks of once-rare diseases are popping up at an alarming rate.

Health IT is outpacing health literacy in some, but not all, cases. So many new tools are available to consumers who don't know how to use them. Health information management (HIM) professionals, however, can help bridge the information gap for healthcare consumers and practitioners. Their understanding of both the clinical and reimbursement sides of healthcare makes them ideal ambassadors to serve providers and consumers, and there is no shortage of ways to do it.

The Rise of the Engaged Patient

As healthcare reform efforts increasingly shift consumers away from employer-paid insurance plans, and more Americans become self-employed, many consumers have been forced to shop for services and health plans on their own for the first time. This is especially true for young people. And just like any other service, such as streaming and downloading movies and books, buying groceries, and even tracking biking and running mileage, these consumers want their healthcare and health information available on demand. Providers are responding to these calls with help from the "meaningful use" EHR Incentive Program and HIPAA modifications—which both incentivize providers to give patients better, and more electronic, access to health information.

Providers and consultants refer to this provider-patient interaction as "consumer engagement" or "patient engagement." Kimberly Hume, MSN, RN, patient engagement coordinator at Wolters Kluwer Clinical Drug Information, says patient engagement is just a new buzzword for the way healthcare always should have been done, and how it is delivered today. It needs to be two-way communication that "should take place in whatever format the patient wants: verbal, written, e-mail, through looking at a chart, an online portal, whatever format works best for the patient," Hume says.

Hume and Elizabeth Tomsik, PharmD, RPh, senior director of content at Wolters Kluwer Clinical Drug Information, says that it's only been within the last 10 to 15 years that patients have started coming in to see their doctors armed with information and questions. But because a lot of the information patients are finding comes from websites with flimsy evidence and research, consumers are also more likely to make poor decisions based on poor information.

HIM professionals can help combat this by providing educational information to patients before an office visit or procedure, potentially by pushing educational materials through patient portals when an appointment is scheduled.

"I think the characteristics of the newly engaged patient are they want to know more, get results in a timely fashion. These people are busy. They want to schedule things at their own convenience, whether at 10 o'clock at night, they want to do that. They want to ask their doctor questions," Hume says. "In a world of instant gratification, we expect the same thing from our healthcare."

Even aside from providing patients with their records and more interactive office visits, Tomsik says hospitals are trying very hard to take a more humanized approach to their interactions with patients. "So it's not just about empowering patients, but I think patients are also looking for nicer facilities when they're in the hospital," Tomsik says. "You can see hospitals addressing this by improving their environment and the services they provide to patients in an inpatient setting and an outpatient setting. You'll see cooking classes for people with heart disease. Focus groups for people with a specific disease."

Participation in payment reform initiatives, such as accountable care organizations (ACOs), bundled payments, and patient-centered medical homes, demand a high degree of patient education. An increase in tying payment to quality measures has also improved patient engagement. Hospitals face penalties for readmitting patients within 30 days of a discharge, so it pays to make sure that patients and their caregivers understand the importance of medication compliance and preventive care. The Centers for Medicare and Medicaid Services in 2012 launched a program to fine hospitals with high rates of patient readmissions. The upper levels of this penalty could be up to a 2 percent cut in Medicare reimbursements.

"These are things that can be managed with thorough patient education, combined with the teach-back process," Hume explains. "Evaluate what they do know. By doing that, you're able to ensure they really do know what to do in an emergency, know how to take care of their loved one. I think [due to] the Affordable Care Act, ACOs are really going to be driving better patient education."

Lygeia Riccardi, EdM, who recently stepped down from her position as director of consumer eHealth in the Office of the National Coordinator for Health IT (ONC), says she can relate to the old model of healthcare, to an extent.

"My grandmother was very strongly in the camp of 'the doctor knows what he's doing,'" Riccardi says, adding that there was a certain appeal "in really seeing this doctor almost as like a medicine man, someone who's imbued with this ability to heal that's superhuman in some way."

According to Riccardi, consumer engagement also includes activities that occur outside the bounds of the traditional patient-physician relationship or the health system. "So it could be things like using an app on your smartphone to track your calories or fitness, or participating in an online community to talk with other individuals who have a shared interest in a particular condition. I define it pretty broadly," Riccardi says.

A recent article in the *New Yorker* titled "How to Tell Someone that She is Dying" also notes the drift from physician-directed care to an era of empowered patients.[1] "As recently as the nineteen-seventies, medical decision-making in the United States was largely a doctor-knows-best endeavor. Physicians dictated clinical care without feeling compelled to tell patients about their treatment alternatives. Frequently, in fact, they did not even inform patients of their diagnoses," author Peter Ubel notes. "Medical practice has since undergone a paradigm shift. Physicians now recognize that patients not only have a right to information but also have the right to refuse medical care."

HIM's Role in Consumer Engagement

While HIM professionals are well positioned to work on patient or consumer engagement projects and strategies, they often get shut out of the planning phase. Kim Murphy-Abdouch, MPH, RHIA, FACHE, clinical assistant professor and clinical coordinator of HIM at Texas State University, and member of AHIMA's Consumer Engagement Practice Council, says that often HIM department representatives too frequently are an afterthought when it comes to implementing consumer-facing EHRs and patient portals.

“The HIM department in many cases is [brought in] after the fact,” when a portal has already been implemented, Murphy-Abdouch says. “My opinion about why this happens is that in many facilities, EHR and portal implementation is an IT project. That the knowledge of the actual contents of the record, and how it can be used and how to be more helpful to patients, isn’t necessarily thought of.”

When consumers have questions about using the portal, they’re sometimes referred to the patient registration specialist, and they aren’t necessarily the best people to inform and advise patients about portals in the hospital setting. In the physician office, it’s often front desk personnel to whom consumers direct their questions. And again, front desk staff may not be trained to address these questions, Murphy-Abdouch says.

While Murphy-Abdouch favors giving patients full access to their EHRs, she notes that much of the contents of an individual’s EHR are viewed and used by other healthcare professionals caring for the patient and is information the patient doesn’t necessarily need.

“I’m a proponent that HIM should thoughtfully develop a standardized list of the pertinent information that’s in a patient’s record, whether paper or electronic,” Murphy-Abdouch says. “[HIM] should help them [patients] understand what those important pieces mean, such as lab results, radiology reports, consultations, operative reports—things that can help inform them about what’s taken place and also the important measures of their own health.”

Studies have shown that when providers make patients’ records available to them, it benefits the patient and the provider. A year-long study funded by the Robert Wood Johnson Foundation tracked three major health systems, encompassing 105 physicians and 19,000 patients, and found that when patients had complete access to their records they felt more in control and satisfied with their care. The program, known as the OpenNotes Project, reached three conclusions, according to research published in *Annals of Internal Medicine*. Patients involved in the study:

- Reported improved understanding of their care
- Were better able to remember and follow their care plans
- Were more compliant with their medications

“Patients accessed visit notes frequently, a large majority reported clinically relevant benefits and minimal concerns, and virtually all patients wanted the practice to continue,” concluded the study authors.[2] “With doctors experiencing no more than a modest effect on their work lives, open notes seem worthy of widespread adoption.”

Riccardi acknowledges that the lack of health literacy among consumers can make physicians anxious about complying with ROI requests. For example, a patient might see the acronym S.O.B. in a progress note and take offense. But physicians and HIM professionals know the acronym means “shortness of breath.”

“But I actually see greater risks in not giving people access to their information... the risks of not engaging people are incredibly high,” Riccardi adds.

For instance, when patients can view their own records, they might find drug allergies and potential interactions that aren’t noted. HIM and physicians can then correct these errors.

The Hustle and Flow of Health Information

One of the driving forces of patient engagement initiatives is making health information available where and when patients need or want it. That desire and demand is what’s helping to make HIEs work. But many HIEs are only able to exchange part of a patient’s record, and are incapable of exchanging video or images. However, this gap in information exchange is starting to be filled at some HIEs and provider networks who have turned to cloud computing to help with large file transfers like images.

Provider and individual state participation in HIEs have the potential to significantly improve how patients and physicians share health information and lower costs for all involved—especially if they can share images, video, and other lab results. Colorado has two HIEs: the Colorado Regional Health Information Organization (CORHIO) and the Quality Health Network (QHN). Both are working with vendor GNAX Health, and the Colorado Telehealth Network (CTN)—a statewide broadband network—to image-enable their physician portals so that images and diagnostic reports will be available through the HIEs. George Robbie, general manager and vice president of sales for GNAX Health, says the primary way that hospitals and physicians currently share imaging reports is by giving the patient a compact disc (CD) with the reports burned onto it. While Robbie rates the effectiveness of the CD method as “pretty good,” there’s still a chance that multiple providers won’t be able to read the images from the CD. Image quality can also often be poor.

To combat this, GNAX has developed a system that renders images and videos into a normalized vendor-neutral format called a DICOM (Digital Imaging and Communications in Medicine)—similar to the standardization for documents such as PDFs—that can be stored securely in a cloud archive. It supports all the major imaging types including radiology, cardiology, ultrasound, and nuclear medicine. GNAX writes the images into two places for safekeeping and disaster recovery purposes. A unique aspect of Colorado’s HIEs and GNAX’s services is that they have brought together health systems that would typically view other systems as competitors but instead collaborate to make this information exchange possible, Robbie says. For example, if a patient is injured in a skiing accident in Aspen and needs an X-ray or CT scan, their home physician could easily access the scan when they follow up with an office visit in Denver through one of Colorado’s HIEs.

Robbie says HIM professionals need to have an awareness of these technologies because of the release of information component. When it comes to moving a patient’s information from one provider to another provider, or to an HIE in another state, which could very well have different regulations, HIM needs to track whether the appropriate consent has been signed and obtained. “The direction we’re starting on right now, the topic is how do we share information? What is the value of that information across hospital settings? How does that benefit the patients so they don’t have duplicate studies so they aren’t exposed to more radiation than they need to be, and in which they can see information readily,” Robbie says.

Image-enabled HIEs will also provide the flow of information that is needed to make ACOs—who depend on sharing all types of data in order to lower costs—work. “Look at Boulder, and look at the flow patterns from the payers. And how they’re moving inside the Boulder community,” Robbie says. “Very few times do they go outside that area for care. They stay inside that hold pattern, inside that ACO environment where people are sharing information and patients aren’t moving as broadly.”

He suspects that ACOs will encourage rural community access hospitals and clinics to exchange information more freely. “We’re not seeing that as being a major adoption just yet, but I’m sure that it may happen soon.”

Closing the Information Gap

Sherri Loeb, BSN, RN, patient engagement strategist at Emmi Solutions, has worked as a nurse in multiple types of healthcare settings for over 30 years. Loeb felt that, given her background, she was as healthcare literate as an individual could be. Yet when her husband was diagnosed with Stage IV metastatic prostate cancer in August 2011, Loeb was struck by how frustrating and confusing it was to navigate the healthcare system from the patient’s side. Many of the difficulties Loeb and her husband faced could have been eased by more responsive patient engagement programs and a reliable health IT infrastructure.

For example, the experience of waiting for crucial lab results with a disease as grave as cancer provoked almost as much anxiety as the diagnosis itself, Loeb says. As a seasoned nurse, Loeb knows approximately how long it takes for a lab to process and analyze blood tests, so waiting, sometimes days or even weeks for a result was excruciating.

“When you have labs and imaging, they’re usually done and in the electronic record in hours, but consumers have to wait days or weeks to receive them,” Loeb says. “The way most are set up is that results have to go through the doctor and the doctor has to release them. Some have automatic releases, where if the physician hasn't released them after seven days [the system releases it]. This makes it easier for consumers to access their own info."

She adds that EHRs and patient portals need to be integrated so that as soon as a test result is available the patient can log in and read it. It's also important for providers to find out each patient's preferred method of communication. If the patient prefers to be called with the results, that's how clinical staff should relay new information. If a patient prefers portal access or even an e-mail, the provider should account for that as well.

Loeb also encountered frequent care coordination roadblocks because she took her husband out of state for certain treatments and became frustrated when multiple providers couldn't sync her husband's medications and medical history. This is a common complaint about the interoperability of EHR platforms, but Loeb says that even when different care teams were using the same health IT vendor the problem persisted.

"While it's really nice to have physicians pick up the phone and really talk to each other, that's pretty difficult," Loeb says. "To get a physician to be available at the same time as another physician is like pulling teeth. And it really impacts the continuity of care and it ultimately affects your experience."

Like other patient advocates, Loeb believes patient engagement begins even before an office visit or prior to a procedure to ensure shared decision-making between a provider, the patient, and a caregiver. "They need to educate their patients across the whole continuum of care, creating multi-modal programs to help educate people," Loeb says. "We're not in a world anymore where nobody wants to know about their illnesses. If you have no idea about what you're going into, you can't even ask the right questions."

Patient education also includes explaining the reason behind patient safety checks. For example, Loeb was alarmed that during many of her husband's hospitalizations, a nurse would come into the room to check vital signs or administer medications without verifying her husband's name. As a nurse, Loeb knows that asking a patient to verify information like their name and age is a safety measure to prevent medication errors and allergic reactions. But a less savvy hospital patient might find multiple requests to verify identifiers rude if it's not explained to them as a safety measure.

"I hate to keep bringing up 'shared decisions' but you need to bring up different options because not everybody's the same. What's good for patient A isn't good for patient B," Loeb says.

Federal Patient Engagement Efforts Advancing

While at ONC, Riccardi oversaw several health IT initiatives aimed at providing consumers and providers with tools that simultaneously lower costs and improve patient safety. Chief among these projects is the Blue Button Initiative, which aims to help consumers download their health information from participating insurance companies, pharmacies, and health systems—including the Veterans Administration and other Medicare providers. Healthcare organizations participating in Blue Button include an icon on their websites alerting consumers to the availability of their secured personal health information.

The Blue Button Initiative is aiming to overcome the lack of interoperability among EHRs by suggesting a subset of national standards, developed by the Standards & Interoperability Framework, to support the sharing of information in a structured way. Ideally Blue Button will make it possible for patients to take their smartphone to the doctor's office and share medication lists, lab and imaging results, and other components of their health history in a format any physician can access. In essence, Blue Button turns consumers into their own personal HIE, Riccardi notes.

Riccardi also worked on patient engagement aspects of meaningful use and HIPAA. Stage 2 of the meaningful use program requires that patients be able to view, download, and transmit their data through an online portal—a requirement with which both providers and vendors are still struggling to comply. Riccardi maintains that it's too early to tell if meaningful use's patient portal requirement is meeting its intended patient engagement targets.

"I will say it's a challenge for them, trying to figure out how to navigate and do it, not just technically but for some of them it is a workflow change, it's potentially a cultural change," Riccardi says.

She also points to provider compliance with updates to the HITECH Omnibus Final Rule, which went into effect in September 2013 and was a major step forward in patient engagement. The rule's updates make it easier and cheaper for patients to obtain copies of their health records, request changes, and give consent as to how their health information is used by a provider. While older HIPAA rules gave providers anywhere from 30 to 60 days to respond to a patient's release of information request, HITECH's updates to HIPAA attempt to streamline the process.

"HITECH says give the patient their health record within 72 hours. That's a lot tighter and consistent with consumer expectations in a digital age," Riccardi says.

These changes directly impact HIM professionals' workflow and processes, but are necessary, experts say, to steer healthcare away from the days of doctor-knows-best and toward a more patient-centered healthcare system where patients play a role in their health—and use their health information to improve their care.

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Patient Engagement Initiatives and the Future of HIE
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Marc Perlman, global vice president for healthcare, life sciences, and education and research industries at Oracle, discusses his work on the Patient Engagement Framework and the future of HIE.

Notes

1. Ubel, Peter. "How to Tell Someone that She is Dying." *New Yorker*, July 7, 2014. http://www.newyorker.com/online/blogs/elements/2014/07/cancer-chats.html?utm_source=tny.
2. Delbanco, Tom. "Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and Look Ahead." *Annals of Internal Medicine* 157, no. 7 (2012):461-470.

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