Mastering the Inbox Information Era: Patient-Generated Data and Mobile Health are Changing the Management of Health Information

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By Mary Butler

When Melissa Ziller's daughter was diagnosed with type 1 diabetes three months before her third birthday, Ziller grappled with all the usual worries that come with the diagnosis. Chief among them was pricking her toddler's fingers multiple times per day to test her glucose levels. Shortly after her daughter was outfitted with an insulin pump, however, her endocrinologist recommended a smartphone application that monitored her daughter's glucose levels with a Bluetooth device linked with a sensor on the insulin pump.

The application allows Ziller, her husband, and her parents—frequent babysitters—to view the child's blood sugar levels in real time. If her blood sugar dips too low, everyone is alerted and Ziller can give her daughter grapes or fruit juice right away—all while avoiding frequent finger sticks.

"Right now because it is so early, I'm still getting used to it and I kind of obsess about it because I'm constantly watching the app," Ziller says. "But I think as her numbers become more stable, this will be a lifesaver and it'll help me to see what different things trigger her highs and lows and plan accordingly."

Ziller can share the glucose meter readings with her endocrinologist via the app by either uploading the data through a shared website or bringing her smartphone in to the doctor's office.

Fortunately for Ziller, her physician is tech savvy in ways that will empower her and her daughter for years to come. The quick and easy data sharing will allow Ziller peace of mind as well as help prevent the high financial and physiological consequences of being noncompliant with diabetes treatments in the long term.

As some patient advocates suggest, it's an exciting time to be a healthcare consumer. Electronic health record (EHR) incentive programs are giving patients access to portals that allow them to get test results and communicate securely with physicians. And mobile devices and applications like the one the Zillers use are giving patients and their family members more control over their health. Engaged patients can be healthier patients, lowering costs for themselves as well as for the healthcare system.

At the same time, however, providers and health information management (HIM) professionals are rushing to meet patient and consumer expectations of this new "inbox information era," where tech companies like Apple are launching mobile health apps that can be integrated with major EHR vendors. The proliferation of apps and EHRs has meant that providers and HIM departments are being inundated with patient-generated data that can be both extremely valuable to physicians and a liability if it's not protected, interpreted, and analyzed properly.

In the midst of all this change, patients are beginning to wake up to the idea that they are entitled to timely access to their own information. However, some are finding new barriers. Some providers are charging fees or inappropriately citing HIPAA as the reason for being unable to release records. Also, the Centers for Medicare and Medicaid Services (CMS) announced that they are considering relaxing the criteria for the "meaningful use" EHR Incentive Program—a program that helped jumpstart patient-centeredness in health IT. For example, the current program requires providers to prove that five percent of their patients are using their patient portals. But a new proposal would require that providers prove only one patient used the portal, which has started a backlash in the patient advocate community.

As patients start taking charge of their health, HIM professionals will be on call to help both patients and clinicians, ever mindful of the risks and benefits of this new era of healthcare.

New Technology, Old Problem

The cliché that "the more things change, the more they stay the same" is true for HIM professionals who manage patient data in the print world and the electronic world. One of the big concerns about patient-generated data, whether it's being sent and received in patient portals or from smartphones, is that providers and HIM professionals could be awash in data that's time consuming to manage or triage.

But David Muntz, CHCIO, FCHIME, LCHIME, FHIMSS, senior vice president and CIO at the GetWellNetwork, and advisor to AHIMA's board of directors, says there's nothing new about this.

"HIM professionals are constantly advising the medical facilities where they work about what data should be part of the medical record, and what shouldn't be," Muntz says. "Not so much what should be in an EHR, but what's supposed to be part of the official, legal medical record… You have to remember how many places from which data gets collected and what may or may not make it to the official legal medical record."

Muntz points out that the digital dilemma of sorting the good information from the superfluous information is one that perpetually plagued paper health record systems. He says we're seeing proliferation of the same problem now, but at a faster rate because data are generated in so many other places and there isn't always one central place where it is kept.

Patient-generated data, or patient-reported data, is as old as the medical profession. Patients have been telling their caregivers their symptoms and concerns long before there were records to document them. What's changed is how patient information is being captured—and that's where HIM excels.

Bill Van Doornik, MS, RHIA, manager of advisory services at KPMG, works with major providers to help them, among other things, engage with patients through portals, smartphone apps, and secure instant messaging or texting platforms. He advocates for HIM playing a major role in engagement efforts in hospitals. "HIM needs to be at the table for those discussions," Van Doornik says.

He adds that portal access gave patients "a taste" of what's possible in terms of communicating with physicians thanks to meaningful use, which is driving portal use, he says. He also says some healthcare systems are experimenting with sending out secure text messages for things like appointment reminders. He anticipates a sea change in the way patients communicate with providers in coming years.

"The ability to do text messaging is something that's very familiar to patients. Even if it's not immediate, it feels more immediate than a phone call might be. I think that many patients see portals as something less immediate," Van Doornik adds. "I think the idea of secure text massaging with providers is very appealing."

HIM's role in this will be to determine how these communications impact workflow, and to think through how information sent through portals and messaging apps is stored in the EHR.

"Then we also need to work with our IT department about things like data provenance to ensure we're not losing info that's valuable in tracking the process. Are we capturing dates that data came into the system, the source of the data, the metadata that comes in?" Van Doornik says.

Putting Patients in Charge

Since health information exchange is in its early stages and consumers want the ability to have their health records travel with them, private companies have tried to fill the demand.

One of those companies, PatientsLikeMe, is part social network and part personal health record (PHR) platform —or, as Sally Okun, MMHS, RN, PatientsLikeMe's vice president of advocacy, policy, and patient safety describes it, "a patient-powered research network."

PatientsLikeMe has 350,000 members, representing 2,500 health conditions. Members can use the website's tools to create health profiles using structured data survey tools. The data survey tools ask specific questions about the user's treatments and symptoms. Those symptoms, treatments, side effects, and diagnosis conditions are then coded against standard terminologies such as SNOMED CT, CPT, and ICD-10, which makes it possible to integrate them with some EHRs.

People who use PatientsLikeMe can create PDFs of their profiles and physically give them to their physicians to provide historical data captured between office visits.

Okun says chronic conditions such as epilepsy and diabetes are particularly well suited to PatientsLikeMe since conditions that require self-management work well with this type of data collection.

"The one concern I have about multiplicity of apps is that some can end up with three types trying to collect condition specific measures that don't necessarily come together in a meaningful way," Okun says. "Using apps are great because they're handy. Pulling that in to somewhere meaningful is where the challenge can be."

Proceed With Caution

The advantages of patients becoming more engaged with their care are innumerable, but IT and HIM professionals have plenty of reasons to tread carefully. Many EHRs aren't set up to easily integrate data from smartphone apps, so if a physician makes a decision based on information a patient brings into an office visit without properly documenting it, that opens the door to risk.

Van Doornik says that setting policies and protocols around mobile device data is right in an HIM professional's wheelhouse. HIM can help physicians make a determination about whether they want to acknowledge when patient-generated data is meaningful or helpful, as well as assess how that information can be captured in the record. It's no different from, for example, if a physician has an ultrasound machine in his exam room and makes a diagnosis based on what he or she sees on a screen.

"HIM would say, 'You have to make sure you have that image in the EHR so we can reference that against your interpretation,'" Van Doornik says. "I think that's the role HIM will continue to play when we look at patient data they're bringing in."

He also urges caution to providers recommending mobile apps to patients. Since apps aren't regulated and might very well have viruses, physicians and HIM need to do due diligence before advising a patient on a given app. "The point is that you've got to be careful in vetting through what the application has been scrutinized against—the risk of using this application. I think that's a role we [HIM] play as well," Van Doornik explains.

Muntz says patients, too, should be vigilant about the security of their information and how they—and their physicians—use and store it. "The interesting thing is, when a patient becomes the custodian of data, it does minimize some of the concerns about privacy and security and confidentiality, because if you're the custodian of the information and you are able to collect the information in a device that is secured, then you're going to control all of those aspects," he notes.

The Engagement Leap of Faith

Patient advocates as well as survey data report that patient engagement is a trend that is here to stay. A recent Accenture survey found that 49 percent of patients globally are using or would be willing to use wearable technologies to measure and track fitness and vital signs.[1] Additionally, 73 percent of physicians surveyed revealed they have seen positive return on investment with such personalized health devices.

That said, there is still room for the acceptance of this trend to grow. A recent study published in the *Journal of General Internal Medicine* noted that while patient-physician communication frequently occurs outside the clinical setting, "many institutions discourage electronic communication outside of established electronic health record systems."[2]

Sally Okun, MMHS, RN, vice president of advocacy, policy, and patient safety at PatientsLikeMe, says that although she understands why some providers may discourage patients from bringing in their own information—they feel overwhelmed by the data they do have, and their vendors don't support it—providers must recognize that what patients have to offer is valuable.

"I think providers need to open their minds to that. Anything we can do to help support that patient's ability to be able to bring meaningful data to the point of care is something we're committed to doing," Okun says.

Still, opportunities for patients to be involved in their care are growing, and it's leading to better outcomes. "But at this point it's not clear that the technology is available or that providers are set up to receive the information in a useful way for them and for consumers," says Dena Mendelsohn, JD, MPH, a staff attorney at Consumers Union, the policy and advocacy arm of *Consumer Reports*.

Mendelsohn is also vigilant about reports from consumers who are being stymied when they do try to get their data from their providers. Some patients have reported instances where they've requested records they are legally entitled to, but are told that HIPAA doesn't allow it, which is a problem the Office of the National Coordinator for Health IT (ONC) addressed this spring in a report to Congress.[3] Additionally, some providers are instituting fees for portal access.

Mendelsohn says she understands that while implementing EHRs isn't free, "at the end of the day we believe that using portals will make offices more efficient and engage consumers," she says. "Charging for information that's easily accessible, that is not taking anyone's time, it's not even using paper or ink, so we don't think there should be fees in that area."

Lygeia Ricciardi, EdM, president of Clear Voice Consulting, says that charging beyond a reasonable fee for medical records "doesn't promote a sense of trust."

"It makes you feel nickeled and dimed, and as if someone doesn't care about you in the big picture," Ricciardi says.

One of the struggles of getting patients to use portals is that they are unlikely to use them unless they're in the middle of a health crisis or have chronic conditions and where, like Ziller and her daughter, communicating with a physician and providing updates is a critical part of health maintenance.

Ricciardi says that it can be hard to motivate patients by asking the question "Would you like access to your electronic health record?" If HIM, physicians, or front desk staff do a little extra education, however, they can make that question less abstract and more concrete. For example, if patients are asked "Do you want to be able to access your child's immunization records online from home, instead of trying to track them down before school starts?" patients and caregivers will tend to be more enthusiastic.

"The key thing isn't more engagement, it's better and more effective engagement," Ricciardi says. "In some cases it may be more too. But in many cases, success isn't 'every American logs in and checks every day.' You still need people to access it when it's really relevant to them. Potentially for prevention and also just in cases where if you do have an accident and you get a new diagnosis, and it's critical, you need that health information."

Notes

1. Accenture. "Healthcare IT: Top 5 eHealth Trends Reshaping the Industry in 2015." June 2015. http://techtrends.accenture.com/us-en/healthcare/healthcare-technology-vision-2015.html.
2. Lee, Joy L. et al. "Patient Use of Email, Facebook, and Physician Websites to Communicate with Physicians: A National Online Survey of Retail Pharmacy Users." Journal of General Internal Medicine. June 24, 2015. http://link.springer.com/article/10.1007%2Fs11606-015-3374-7.
3. Office of the National Coordinator for Health IT. "Report on Health Information Blocking." April 2015. http://healthit.gov/sites/default/files/reports/info_blocking_040915.pdf.

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