HEALTH DATA
surgery 0
clinical test
medications
blood pressure
lab test 52%
vaccination 82%
BMI normal

DNA

10-may-14

patient #08001 / John Adams

gender ♂
age 23

HR 95 bpm
120/60
ECHO D
CD PWR<500
Frq 2.0 MHz
1800 mm
AO 100%

$

What Does It Mean to Be an Empowered Patient?

PROVIDED BY

healthcare innovation
PEOPLE. PROCESS. TECHNOLOGY TRANSFORMATION.

IN COLLABORATION WITH

formstack

A few years ago, patient advocate Bray Patrick-Lake posted a picture on Twitter of a pile of computer disks and two binders full of paper, which she titled "My 100 percent worthless longitudinal health record."

"I don't even have a place where I can put a disk in a computer, so even this disk they mailed to me, I don't know what to do with it," said Patrick-Lake, who was speaking at the 2016 Health Datapalooza conference in Washington, D.C. The annual conference's rallying cry of patient empowerment is "Nothing about me without me." But what does it mean to be an empowered patient? How can digital technology create meaningful change in the way individuals interact with healthcare systems?

Patrick-Lake serves on the National Advisory Panel for the nationwide All of Us precision medicine initiative, and she has said that one goal is to help create a complete picture of patients, not just clinical health data from an electronic health record, but also bringing in sensor data, environmental data, behavioral and lifestyle data as well as genetic information. "The key to all this is frictionless participation," Patrick-Lake said. "We should be able to direct how our data gets shared for research very easily rather than this backward construct of trying to get data back that should be ours."

As healthcare organizations prioritize digitized processes to share data for care coordination, research, and payment, patients are demanding access to their own records. Patients want the opportunity to track their health, consult easily with other providers, and contribute data to research studies. But in the past, incompatible data formats, consent policies, misconceptions about HIPAA regulations, privacy and security concerns, and business process transformation have all been barriers to the type of data liquidity e-patient advocates are seeking. But a lot has changed in the four years since Patrick-Lake spoke at the Datapalooza conference.

For one thing, the federal government has expanded its regulatory framework to push for greater data interoperability using a relatively new data standard called FHIR (Fast Healthcare Interoperability Resources) and standard application programming interfaces (APIs), with the idea that healthcare entities should use modern internet technologies commonly used by other consumer-facing businesses such as Amazon. (Think how easy it is to go on Amazon's website and order something. Could interacting with your physician office or hospital become that frictionless?)

In March 2020, the Office of the National Coordinator for Health IT (ONC) and the Centers for Medicare & Medicaid Services (CMS) released final rules related to interoperability of health data. The ONC rule implements the clinical interoperability aspects of the 21st Century Cures Act and adds guidelines around pricing transparency and information blocking.

In a press briefing, National Coordinator for Health IT Don Rucker, M.D., said the regulation aims to "allow for the safe and secure access of health information [going] back to patients," adding that finalizing these policies will "enable Americans to have electronic access to their health data on their smartphones, if they choose."

The ONC rule, he continued, requires hospitals and doctors to provide software access points, or endpoints, to their electronic health record (EHR) databases so that patients can download these records to their smartphones. Ultimately, what the government is striving toward, Rucker said, is to give patients the ability to manage their healthcare the same way they manage their travel or other parts of their lives.

"By giving patients computable control of their health information, we will see a growth in patient-facing health IT markets from an entirely new app ecosystem that will be fueled by transparency about both product and price," Rucker explained. "We think this health app economy will have new services, and we see the smartphone as a tool to connect other devices to it, [such as] glucometers, blood pressure cuffs, digital scales, peak flow meters and heart rate monitors. The technology we are unleashing here will democratize healthcare in powerful ways."

Now it falls to health systems, physician practices and the large and small health IT companies they work with to put these new rules into action. While some EHR vendors have expressed concerns about patient privacy and the timelines for compliance, others are eager to get to work with customers on implementation.

Check out this updated timeline outlining compliance for the new ONC interoperability guidelines.

In a March 11, 2020 article, Formstack's Head of Marketing and Product Strategy Rob Wiley gave some context for these changes, noting that "these final interoperability rules call for healthcare organizations to give patients better access to their personal health data and clearer information about cost, empowering them to make informed decisions about what care they receive and where. It's clear that in the coming years, the U.S. healthcare system will continue to incorporate more technology that promotes interoperability and patient empowerment."

Focusing Care on Patient Goals

In a Feb. 24, 2020, blog post, Anne Snowdon, BScN, MSc, PhD, director of clinical research at HIMSS, gave some specific examples of what she calls "consumer-enabled care." Snowdon described a few scenarios: a family who lives in a rural community without specialist care but needs help managing their chronic conditions like diabetes and heart disease, or a woman unable to attend obstetric care appointments due to her full-time job and the demands of caring for her children.

"The hallmark of consumer-enabled care is offering choices and options to address a person's unique needs and life circumstances—ensuring care is available when and where it is needed. In a consumer-enabled system, provider teams partner with consumers who define their personal health goals and preferences, providers then tailor care delivery to personal health goals and provide the tools and support needed to make informed health decisions on how they wish to manage their health," Snowdon wrote. "These tools could include managing health conditions and tracking progress digitally, or virtual care visits with a provider team, to support patients in actively managing their personal healthcare journey. Care is focused on achieving the consumer's personal health outcomes and goals." [1]

The growth in use of digital health tools such as Fitbits and other wearable devices by consumers has opened up opportunities for healthcare providers to integrate patient-generated health data (PGHD) into their records.

As a 2018 ONC white paper notes, "PGHD can provide a more holistic view of a patient's health and quality of life over time, increase visibility into a patient's adherence to a treatment plan or study protocol, and enable timely intervention before a costly care episode. Clinicians can strengthen their relationships with, and improve the experiences of, their patients by using PGHD to develop a personalized care plan and to engage in shared decision-making to foster better outcomes." [2]

Patient Engagement Evolution

In the realm of shared decision-making, one disruption that involves using technology to build a deeper partnership between patients and doctors has sprung up from within health systems. OpenNotes is an international movement that's making healthcare more transparent. It urges doctors, nurses, therapists, and others to use the patient portal to invite patients to read the notes they write to describe a visit. The movement has spread like wildfire. Today more than 40 million U.S. patients have access to their notes. OpenNotes has been shown to have a positive impact on patient engagement. Research indicates that 78% of patients reported that OpenNotes helped them take their medications as prescribed, while 25% of patients who contact their doctor as a result of reading their note report a possible error, according to the OpenNotes website. In another study, 77% to 87% of patients said that accessing their notes made them feel more in control of their healthcare.

The healthcare system also is being disrupted from the outside by technology advancements and consumerization. The advent of direct-to-consumer genetic testing (DTC-GT) from companies such as Ancestry and 23andMe has forced health systems to respond with training on genetics for primary care providers on how to discuss the results with patients and refer them to genetic specialists for counseling, when appropriate. A paper recently published in SAGE Open Medicine notes that "consumers can download and share their genomic information and reports directly with their healthcare providers and families and other interested third parties (e.g. researchers and health product developers). The study also found that the "growing levels of DTC-GT consumer engagement

combined with the rapid growth of genomic medicine suggest that consumers are either motivated or inspired to generate, use, and share their raw genomic information when the information can be leveraged in ways that serve consumers' health needs and goals, values, curiosity, and/or beliefs (e.g. determine genetic health risks, whether or not based on geographic ancestry, or identifying biological family members)." [3]

The Impact of COVID-19

During the COVID-19 pandemic, providers have had to adopt new technologies faster than usual. Many are using telehealth platforms for the first time, or having providers work remotely or in new settings.

Learn how frontline healthcare workers are using Formstack's mobile-ready forms, automated document generation, and fast eSignature collection to combat the COVID-19 pandemic.

The coronavirus emergency highlights the increasing importance of the digitization of the healthcare experience, with the rapid creation of mobile screening questionnaires and moving from requiring physical signatures to digital signatures or reviewing documents in an asynchronous way.

Health systems are finding that eSignatures are a critical component of business – for uses ranging from patient consent to participating in a health information exchange to information requests and releases. Many patient care organizations still struggle with mailing, faxing, or scanning forms to collect signatures, despite the fact that the technology exists to allow users to complete their forms using a computer, tablet or mobile phone.

The pandemic also offers a great example of how patients with control of their own health data can contribute to clinical research studies. A group of clinical informatics experts from across the country has come together to stand up a platform for what they call "participant-centered, rapidly deployed, digitally enabled research." The INSPIRE (Innovative Support for Patients with SARS-COV-2 Infections Registry) project has a goal of working in near real time to generate knowledge to combat the global pandemic.

The researchers are using a platform called Hugo Health to enable patients to access their EHR data via API and synchronize it with the research database. Within only a few weeks of the project's conception, Rush University Medical Center in Chicago began enrolling COVID-19 patients in its registry and other academic medical centers are getting on board.

Besides just getting their EHR data, the project will prompt patients after hospital discharge to add data from other sources and describe their current state with patient-reported outcome measures.

Re-Inventing Health System Workflows to Empower Patients

Besides sharing clinical data, there are other ways that healthcare organizations can empower their patients by removing friction from data gathering and insurance transactions to save patients time and to allow them to get the most out of interactions with clinicians.

One of the most frustrating things for consumers in healthcare is going from office to office and not having coordination of care, said Rob Wiley, Formstack's Head of Marketing and Product Sstrategy. "You can demonstrate coordination of care and instill confidence not just in how the healthcare providers speak to one another, but also in how the information flows," he said. "Creating a consistent experience says we know who you are in a variety of contexts and we are going to protect your information."

Formstack offers digital tools that allow healthcare providers to quickly gather data, generate documents, and collect eSignatures. With the Formstack platform, providers can create and embed mobile-friendly, HIPAA-compliant forms on their website, such as record releases, patient registrations, medical history forms, and satisfaction surveys. Data gathered with these forms can then be sent to an EHR or other patient management system, such as Salesforce, and used to generate documents and schedule appointments.

Indiana Health Group (IHG) turned to Formstack first and foremost for efficient, HIPAA compliant patient onboarding. The IHG multidisciplinary mental health facility sees between 6,000 and 8,000 new patients per year, and each is required to complete a detailed patient history questionnaire that covers general medical history as well as mental health history. Patients are empowered to quickly and securely share health information that is critical to their care.

But the behavioral health facility didn't stop there. IHG also uses Formstack as its primary route of communication between patients and clinicians. Using a link on Indiana Health Group "Contact Us" page, patients can reach out to a specific healthcare provider with any questions or concerns. This provides a quick and easy way for the practice to manage patient communication, with the added benefit of providing an audit trail in case of any miscommunication.

Additionally, IHG uses Formstack to gauge patients' mental health status through rating scales, such as a depressive symptom rating scale, as well as to gather information related to disability or medical leaves from work. "I think patients like the experience of filling out the forms online. There's even some data to suggest that people are willing to be a little bit more honest or forthright in the information they provide if they can do so from the perceived anonymity of the screen," said Dr. Chris Bojrab, a board-certified psychiatrist with Indiana Health Group. "In our case, I think it often makes for a more comfortable experience since patients can be sharing some things that might be a little uncomfortable to talk about or that they might feel some degree of guilt or embarrassment about."

IHG's online patient onboarding process with Formstack keeps the practice running smoothly by automatically scheduling appointments, improving communications between providers and patients, and giving the right people access to the information they need.

More Important Than Ever

In the wake of the coronavirus emergency, the federal government announced it would relax enforcement of some of the provisions of the new interoperability rules by a few months. That is welcome news to many provider groups, especially smaller and rural ones, but some organizations stress that actually the pandemic makes putting the rules in place more urgent, not less. The nonprofit Pew Charitable Trusts, a research and policy organization, noted in a letter to HHS Secretary Alex Azar that "the COVID-19 pandemic gripping the nation underscores the importance of these regulations in enabling greater data exchange and providing patients with their information." [4]

Pew added that with mandatory stay-at-home orders and social distancing guidelines, patients may lack the ability to go into a hospital or doctor's office to pick up their records. "Additionally, patients may be seeing new clinicians via telehealth for the very first time due to restrictions on in-person office hours or because of their symptoms. What these patients share is a greater need to have remote access and exchange of their health data to make more informed healthcare decisions," the letter stated.

The organization further noted, "HHS's new rules are essential in facilitating this connection through greater use of APIs, which help obviate the need for patients to get their records in person because they will be able to more easily get and share their records from a personal device."

At least one prominent health IT leader agrees with Pew. In a recent interview with Healthcare Innovation, John Halamka, M.D., president of Mayo Clinic Platform, said that people have brought up the burden of working on compliance issues in the world of COVID-19.

"But in the world of COVID-19, patients having access to their data is even more important," Halamka said. "So, yes, you could relax those deadlines, but maybe you should speed them up, to be honest."

Footnotes:

1. https://www.himss.org/resources/consumer-enabled-healthcare-delivery-focuses-keeping-people-well

2. https://www.healthit.gov/sites/default/files/onc_pghd_final_white_paper.pdf

3. What motivates the sharing of consumer-generated genomic information?
   https://journals.sagepub.com/doi/full/10.1177/2050312120915400

4. https://www.pewtrusts.org/-/media/assets/2020/04/pew_letter_to_sec_azar.pdf

healthcare innovation
PEOPLE. PROCESS. TECHNOLOGY TRANSFORMATION.

formstack