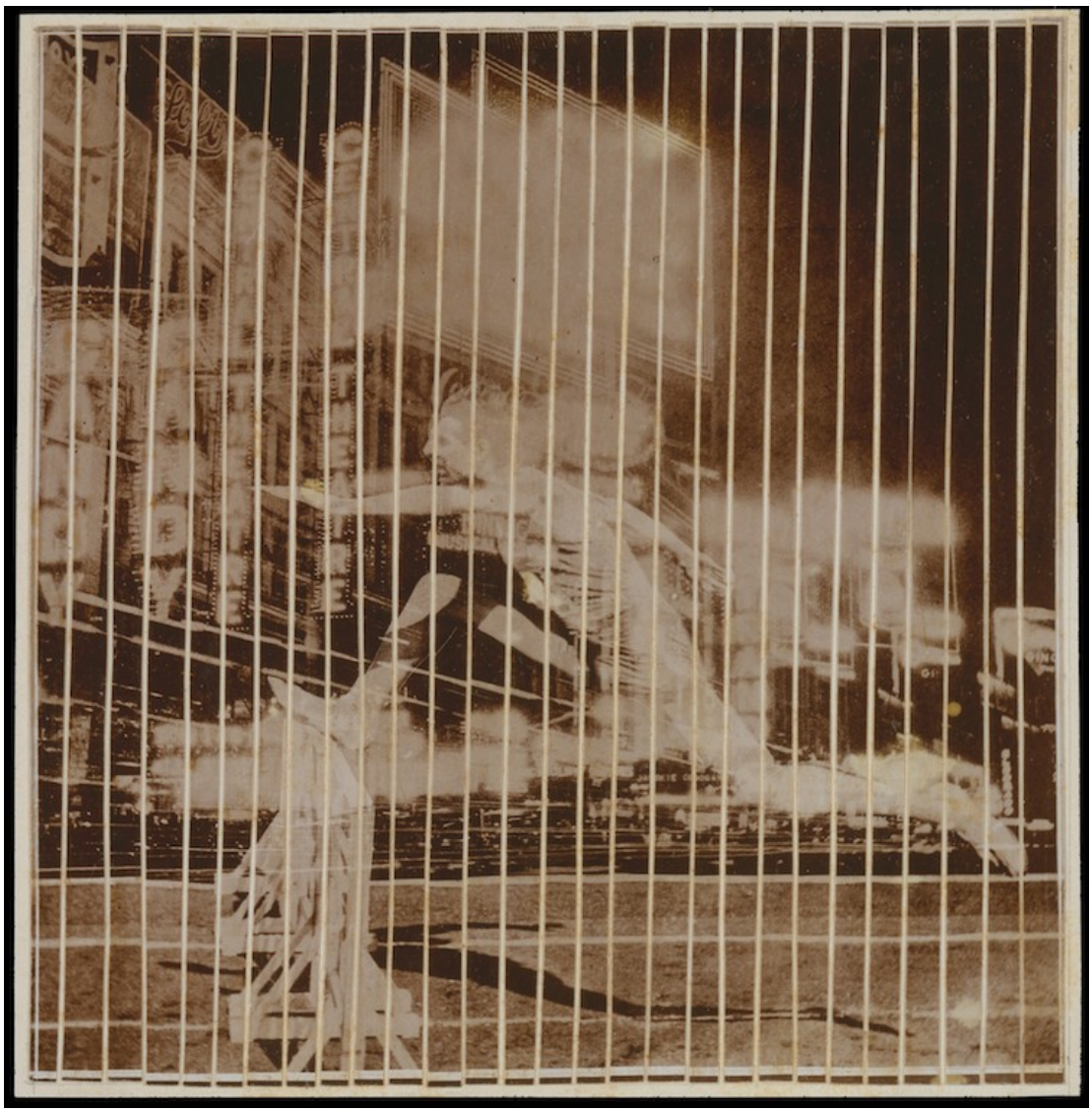
Fast Forward: Why Patients Should Own Their Medical Records

written by Theresa Hush | March 15, 2017



Up to now, who owns patient medical records hasn’t been a big issue. In fact, the “who owns” question has been largely confined to provider purchasing discussions regarding health care data analytics or other sharing of patient records, when providers want to assert their ownership of the data. Patients have had no voice in this conversation.

Few people question the provider’s ownership of a patient’s record, which is supported by state statutes (only one state grants ownership to patients) as well as the rare case of litigation.

All that changes going forward. Why? Because big revisions in health insurance will make it necessary for patients to control their own data so that they can also control their costs. Patients will need data history to navigate the health care system, discuss options with providers, and make informed choices based on benefits and cost. The technology is already available to do so without disrupting providers' clinical systems.

This is the new reality: Health care consumers not only *will* own their medical records, but they *should*.

Assault on Consumer Health Care Costs Is Just Beginning

By any measure, the cost of health care coverage and expenses are rising for consumers, at a faster rate than their ability to pay. Employers, too, are scrambling to manage the increasing costs of health care, but their solutions are to adopt benefit plans that share these costs with their employees, through more employee premium sharing, deductibles and coinsurance. As a result, more consumers are finding it difficult to pay for their health care.

These are retrospective trends; bigger problems lie ahead, and not just for people who may lose coverage under the ACA Repeal. Tom Price, Secretary of Health and Human Services, is supporting legislation that would allow providers to bill patients for the balance of provider charges above the Medicare payment.

Providers' willingness to accept "assignment"—payment in full from Medicare for covered services—has been the backbone of

Medicare for its beneficiaries. Rollback of these protections would create a huge increase in costs to consumers, since provider charges are set voluntarily. They conform to no "rational" pricing model because almost all prices are negotiated with insurance carriers. Physicians set their charges arbitrarily high—3 to 4 times the Medicare fee—and then discount those fees for patients who cannot pay.

The result of a rollback: on top of other cost shifts to consumers and loss of coverage, patients may also end up paying for a big pay hike for providers. While we can expect health care consumerism to take hold gradually as part of broader social and economic trends, these federal cost-cutting proposals, if adopted, may well turbocharge a powerful grassroots political movement for fundamental change in health care.

Consumer-driven Medicine and Patient Loyalty

Health care providers frequently move in and out of insurance networks, causing problems for consumers. Those consumers may have chosen the coverage out of a list of their employer's offerings because of provider preference, only to discover later that their providers exited the network. This common fallout from price negotiations between insurance companies and providers leaves consumers angry and continually at risk of finding new providers.

Providers can't blame patients for lack of loyalty when they are willing to cancel their agreements with insurers, or when consolidation among providers cause changes in the patient's plan coverage.

Medical Records Are Hidden and Don’t Travel Well to Patients

Even when patients finally restart care with accepted network providers, they frequently face disruptions in continuity of care that are not their fault, because they are forced to deal with the cost, hassle and inevitable delays of transferring their medical records from previous providers.

Despite the fact that providers have adopted EMRs that could trade data broadly, this almost never happens, even between systems on the same EMR. Patients are left to manage the situation on their own. In fact, even in 2017, it can take months for patients to get real data from one provider to another in the same city, using the same electronic medical record. To make matters worse, patients receive no verification or information about what was sent from one provider to another.

Even for patients who are not changing providers, but just want to seek second opinions or research on their conditions and alternative treatments, the need to compile their information and original records makes it difficult to proceed. It’s no surprise that patients justifiably feel trapped when their records are held in systems they cannot control.

Access to Medical Records Via Provider Portals Doesn’t Cut It

Providers have made a huge investment in clinical systems and patient portals that give their patients access to test results, payment records and so on. So why is this not enough?

First, test and lab results, as well as all other records such as inpatient clinical data, are under the control of providers who release some (but not all) of the information. Patients almost always see lab results only after their physicians do. However, there is a growing minority of patients who want to get their data immediately and don't care to have it filtered by a physician. As rising costs engage consumers who are used to controlling their information in other spheres of their lives, that group is likely to become the majority.

Providers have long held the belief that they are responsible for using their expertise to appropriately convey complicated clinical results to patients. But some of these concerns may be unfounded, as case studies reveal. In fact, the sharing of data appears to contribute to better communication and partnership between patient and provider.

Second, records accessed through patient portals are incomplete. They do not contain images, or tumor samples, or other physical and digital specimens. So even if patients could download the reports, they could not independently direct them to another provider, because the reports don't always contain sufficient data for that provider to assess clinical status.

Third, in order for patients to transmit the relevant data to a provider, they must create a medical records request, specify the data requested, and direct that data to another provider. And then wait as many as four to six weeks for the records transfer to take place (if ever).

Why is Medical Record Ownership Important for Patients?

The words “empowerment” and “freedom to choose” are given new political meaning in the current health care debate. They also signal a transition away from “patient engagement” and “patient adherence,” common phrases among providers that mean patients should follow their providers’ plan of care.

The problem for patients is that they cannot necessarily afford the plan of care outlined by the provider, and that there are real informed choices to be made. Much of medicine is still not well researched, and irrefutable answers are not common. Unfortunately, the body of evidence is often lacking on “evidence-based” research, because outcomes are rarely studied adequately. In addition, it is far from universal practice among physicians to read medical research, as several medical journals have revealed. Physicians are too busy to read, have trouble with the language, or don’t have time or inclination to evaluate the strength of the research.

There is not only room for patients in the medical decision process; this is essential. Only by being able to review and manage their own data can consumers have the medical literacy they need to participate in those decisions.

Finally, we must address the whole American idea of “ownership.” When records were paper, it was perfectly logical that they be kept by the provider for reference and management. But now we are in a different world. It is common for people to own data, and the idea that something as essential to your life as clinical data is “owned” by providers and “granted” to consumers will not be well accepted in the future. As the

younger population and digital natives enter into the health care system for the first time, they will expect to have their own records to manage their own costs and direct their own care.

Companies and Technology are Creating Alternatives for Consumers

The big tech companies all recognize the prospective possibilities of creating centralized consumer health records, the failure of Google and Microsoft notwithstanding. They all know now, as we are beginning to see, the possibilities of housing the patient's record via a CDA standard transfer. Further, we are seeing startups that may work as storage houses for these records, as well as data platforms that can share communications and progress notes, as well as clinical data.

As consumers become more independent and organized, they will undoubtedly begin choosing providers based on their adoption of consumer-friendly practices and technology. One organization that is worth watching in this space, with experience in a retail consumer market and eager for health care prowess: Walmart.

Providers, Start Here

Most providers have a strong patient vision but are struggling to manage competing technology efforts. Adoption of EMRs, analytics, revenue cycle software and, perhaps, population health and marketing has left them breathless. They want a break. But that time is *not* now.

Providers without a patient portal should consider it as a top

priority. However, for the reasons mentioned above, understand that this alone is not enough. Reflect on and evaluate these options as you develop a stronger consumer-focused strategy:

Help Providers Move Toward Shared Decision-making

Build physician support and understanding for changes in the physician-patient relationship. If you can help physicians appreciate the culture change in their role as well as that of the patient, you can help them be more effective coaches and communicators.

Begin a formal shared decision-making process, including mentoring of physicians, as a performance improvement initiative. While doing so, you should measure the results of changes in attitude for both providers and patients, as well as changes in outcomes.

Examine and revise your policies and operations for the review and release of patient results. While this includes educating and working with physicians on changes to the timing or communication about results, it may also make sense to evaluate technology for full sharing of records and notes, getting physicians on board in the process.

Increase Your Patient Centeredness

Insist on consistency and longevity as part of your health plan strategy so that patients are not forced to leave by changes in coverage. This means evaluating your managed care contracting and decisions to prioritize patient tenure along with fees;

Discover your out-of-network flow of patients. If you don’t have the data from your insurance carriers and Medicare, you

can obtain this for analysis. This data will also be essential to track your relative per patient cost compared to other providers in the market, which is calculated by Medicare for you.

Find out why patients go elsewhere. There may be preferred providers elsewhere, but don't discount the possibility that patients are not getting the support or communication they need to achieve their goals. They will vote with their feet.

Create consumer advisory committees to inform your strategies. You have business experts on your boards to develop the business, and physician leadership to guide your clinical directions. You should also ask your customers.

Develop your price transparency plan. In addition to clinical data, patients will demand information on how your prices compare, and what their episodic costs will be if they get care from you. This will no doubt force you to evaluate your entire price strategy that was once geared exclusively to insurance coverage. It should now be redirected to patients.

Start Now to Get Data to Patients

Push your EMR to develop fast mechanisms for expanding your current portal. If you don't have one, fix that.

Evaluate your options for getting patients a feed of their data to go into a portable record. You may partner with an entity that already has a product, or take a developmental track.

Expand your data outreach to patients with features that will enhance your shared goals, such as sharing quality measures applicable to the patient, so that your patients are aware of how you—and they—are being measured.

- Share episodic pricing as appropriate for your organization: for procedures, management of common conditions, and inpatient/outpatient stays by condition.

As the environment pivots to adjust to the new driving force of health care consumers, health care providers will need to be ready. We have been in a regulatory and insurance driven market for a long time, and that has tended to slow the pace of change. Be prepared for time to speed up. Consumers act fast.

Founded as ICLOPS in 2002, Roji Health Intelligence guides health care systems, providers and patients on the path to better health through Solutions that help providers improve their value and succeed in Risk. Roji Health Intelligence is a CMS Qualified Clinical Data Registry.

Image Credit: *Runner in the City,* Metropolitan Museum of Art, El Lissitzky (Russian, Pochinok 1890-1941 Moscow) ca. 1926, Ford Motor Company Collection, Gift of Ford Motor Company and John C. Waddell, 1987.