

ConsumerReports®



Better Health Care:

Your Medical Data What You Need to Know *Now*



WHY THIS TOPIC?



When Consumer Reports was founded in 1936, we were driven by the principle that consumers deserved a fighting chance at a fair exchange in the marketplace. So when they bought a product, it would in fact work as advertised. Or when they used a service, like a health-care provider, their expectations were met, and they were treated fairly and honestly.

While the marketplace has changed a lot over the past eight decades, what has not changed is consumers' need for an independent voice like Consumer Reports to help them discern fact from fiction and translate complicated data into actionable advice.

There are few areas more complex than health-care data, and Consumer Reports is very grateful to Atlantic Philanthropies and AcademyHealth for their support in allowing us to bring this guide to life. Our goal is to help you understand how health care is being improved through the use of data analysis. Specifically, the guide highlights concrete examples of how large amounts of data and new technologies are being used to improve health care and health outcomes for patients.

We do, of course, look at this research through the lens of consumer privacy and the need for—and rights of—patients to have control over their data. Many of the examples we highlight show how patients are contributing data and actively participating in the creation of meaningful systemic change. We believe this reflects the best form of engagement, but we emphasize that the patient should always be informed about how their data are being used.

You can find and download this guide and the previous publications for free at ConsumerHealthChoices.org/GettingHealthCareRight. For print copies, contact us at HealthImpact@cr.consumer.org.

Note: If you're reading a print copy of this guide, the PDF has links to the resources we cite.

We hope you find this publication helpful. If so, please share it.

Marta L. Tellado
President & CEO
Consumer Reports



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Introduction: Big Data & Health Care

In 2009, a team of engineers from Google and the Centers for Disease Control and Prevention (CDC) published a landmark research paper claiming that the flu could be tracked based solely on people's Google searches. Around the same time, millions of consumers started downloading health-care apps, buying wearable data-generating devices, and participating in online communities that enabled them to track and/or share what they ate, how much they exercised, and the results of their medical care.

Those were the initial stirrings of what has become a powerful new movement in health care: using large amounts of digital data to help people stay healthy and improve the delivery and quality of care.

Google Flu Trends now helps health officials worldwide deploy flu vaccine and medicines, and alert hospitals and doctors to outbreaks. And those fitness apps and devices? They're all over the place.

Big data is the term of art for this new movement, and it has revolutionized the way many industries do business. Using increasingly powerful computers and software, companies can collect and analyze billions of bits of data at relatively low cost.

In health care, the data from medical bills, electronic health records (EHRs), e-devices, and Internet and social-media

interactions can be mined to uncover useful trends and patterns. Indeed, many health-care companies have started using the tricks of the trade employed so successfully by the likes of Amazon.com, Facebook, Google, LinkedIn, Pinterest, Twitter, and Yahoo.

You may have noticed efforts to use big data on a personal level: an e-mail from your pharmacy, a pop-up ad for a health-care product, a call from your health-care plan asking if you want to take part in a program to reduce your risk of stroke or heart attack.

Meanwhile, the data from apps and wearable devices are generating interesting—if not yet profound—findings. For example, using data on 130 million nights of sleep from people who have downloaded its sleep app, the company Jawbone found that people in New York City get quite a bit less sleep during the workweek than on weekends. By contrast, people in Orlando, Fla., average about the same amount of sleep per night all week long.

The big-data revolution comes with risks. With the volume of data sloshing around today's electronic systems and digital devices, some of it is being used in ways that people may not want or that compromises their privacy.

In the pages that follow, you'll find profiles of cutting-edge data initiatives. In some, consumers contribute data to improve their own care and health, and for science and the public good. In others, data are gathered and mobilized by third parties to improve care. You'll find what you need to know now both to participate in this revolution *and* to protect your information.

Your Data Go to Work

Mayo Clinic Takes a Leap of Faith

The renowned Mayo Clinic in Rochester, Minn. joined forces in 2013 with a subsidiary of health-insurance giant UnitedHealthcare to launch one of the largest health-data projects in the country. The joint project is Optum Labs.

Courtesy of UnitedHealthcare, Optum Labs now has data on the treatment of about 100 million people spanning a period of 20 years. Most of that information is in the form of health-insurance *claims*—that is, the detailed bills hospitals and doctors submit to insurers. When compiled for a single patient, claims can tell a medical story. They show, for example, when and why a patient visited doctors, whether the patient filled a prescription, had surgery, underwent tests, went to an emergency room, or was admitted to a hospital. Claims, when analyzed carefully, can also reveal whether treatment went well or poorly.

Researchers have long used claims analysis to investigate the effectiveness of treatments, and the value treatments provide for the money.

Optum Labs is scaling up such analyses by many magnitudes, drawing from millions of electronic claims and using software to search for patterns and trends.

Although valuable, medical bills tell only part of the story. The medical records providers keep—formerly on paper and increasingly in electronic format using EHRs—can offer even greater insight into whether and how well treatments work.

Optum Labs says it has access to the “de-identified” contents of about 30 million records—that is, the information about patients’ treatments and their demographics such as age and gender, without their identities. Optum Labs is packaging all this information into a searchable database that permits researchers to probe the links between treatments and results. Dozens of such studies are underway. A few have already yielded useful findings. For example, one study looked at blood-sugar control, life span, and quality of life among 37,501 people with diabetes. It strongly confirmed earlier findings that older, less-expensive generic medicines worked just as well as newer, more-expensive ones to keep people healthy and out of the hospital.

“What we’re trying to find out is what really adds value to a patient’s outcome over time, especially with these high-impact diseases,” Mayo Clinic CEO John Noseworthy, M.D., told the *Minneapolis Star Tribune*. “Ultimately, we as a country have to figure this out, so people can have access to high-quality care and it doesn’t bankrupt them or the country.”



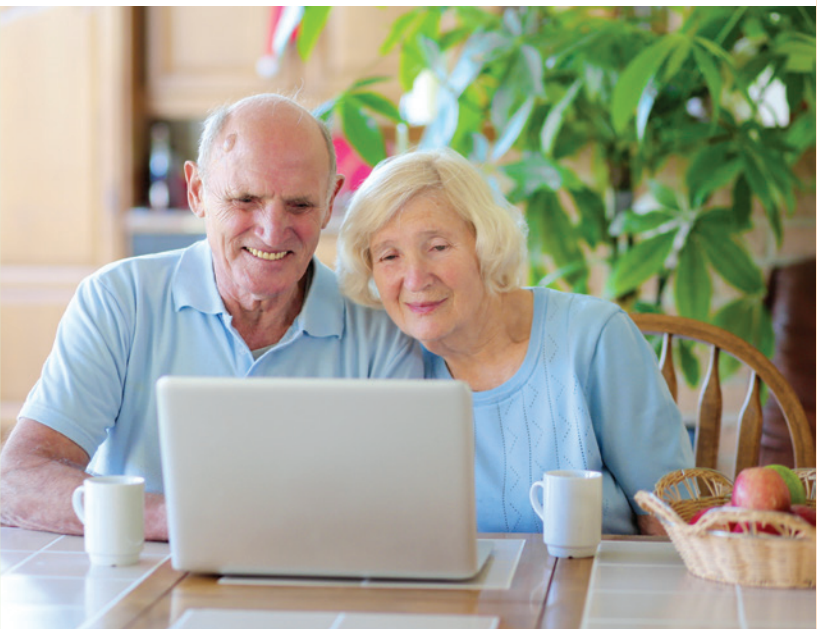
Getting You Involved

Consumers are becoming active contributors of health data by taking part in social, online, and disease support networks that both generate and spread new medical knowledge. One of the largest initiatives to engage patients began in 2013 under the auspices of the Patient-Centered Outcomes Research Institute, or PCORI, a new organization created by the Affordable Care Act.

PCORI's job is to fund research that directly compares treatments and health-care services. Congress mandated that PCORI get input from patients and families as it does that job. One upshot: PCORI has funded the launch of 18 "patient-powered research networks." National patient groups are organizing the networks, which cover a wide range of common conditions including depression, colitis, chronic obstructive pulmonary disease (COPD), and epilepsy.

The focus is on enabling patients to share their experiences, treatments, and results. But the networks also encourage patients to participate in developing research questions—a novel step in the world of medical research. And as it turns out, patients have different priorities and unique insights about their treatments.

Across all 18 patient networks, an estimated 500,000 to 1 million people are expected to enroll and share their medical experiences and data. The COPD Foundation Network, for example—one of the 18—hopes to enroll 75,000 to 100,000 patients by the end of 2015, drawn from its existing network of 240,000 people with COPD nationwide, says foundation president John Walsh.



CHRISTOPHER CASLER



IMPROVING COPD CARE

Karen Deitemeyer looked forward to retiring in 2008 so that she could become more actively involved in volunteer work. Now 69, she is channeling her energy into helping others with the disease she was diagnosed with in 2001—chronic obstructive pulmonary disease, or COPD. Deitemeyer, who lives in Melbourne, Florida, is an advocacy captain for the Miami-based COPD Foundation. She regularly speaks about the disease to local groups throughout Florida.

"The problem with COPD is there's not enough awareness of it, and even when people are aware they may be reluctant to seek help or support because of the stigma of the disease," Deitemeyer says. "Most people, like me, got it from smoking and many are ashamed of that."

COPD, which includes emphysema and chronic bronchitis, affects some 25 million people in the U.S.; half don't know they have it. Most who get it are age 55 or over.

Deitemeyer's newest effort to improve COPD care is to participate in a research network created by the COPD Foundation. The network is one of 18 being set up nationwide using funds from PCORI (See *Getting You Involved*, this page). Deitemeyer says she'll be contributing her experiences and treatment data to the network over the next few years.

"What they want to know is how the disease is affecting my life as I get older, and what treatments and behaviors ease my symptoms," Deitemeyer says. She has agreed to make all of her medical records accessible to researchers.

She'll also be in a position to learn about clinical trials of new treatments—and help design those trials, something she says was important to her. "We know as patients what we need and what's important to us. It's very exciting ... this is testing the future of how people can improve their own care while they also help researchers and doctors understand the disease and treatments better," Deitemeyer says.



MAKING A CONTRIBUTION

Amy Fees' life took a dramatic turn in 2011 when at 38 she was diagnosed with a rare genetic condition called Fabry disease. Fabry can cause a range of symptoms including nerve and joint pain. But the larger problem is that it's associated with an elevated risk of heart disease, stroke, and kidney failure.

Fees, who lives in Austin, Texas, was determined to learn all she could about the condition and to take a proactive approach to treatment. "I had just started taking medical classes to become a medical illustrator," she says. "So the timing was good from that perspective."

But Fees became even more involved than she expected after she stumbled across the PatientsLikeMe website (See *Patients Like You*, this page). There, she found an online community of Fabry disease patients. It also quickly became clear to her that much was still unknown about how the disease progressed and which treatments were working best.

In Fabry, a genetic mutation disrupts the proper functioning of a critical enzyme that breaks down fats in the body. Most people with Fabry have elevated risk of problems with their hearts, blood vessels, and kidneys. But some Fabry patients have a variant of the mutation that makes them more vulnerable to heart- and blood-system complications, and others have a variant that makes them predominantly vulnerable to kidney complications. One big question is whether the various groups of patients respond differently to treatment.

Working with PatientsLikeMe and doctors, Fees is helping to set up a research protocol to get at that question. She also contributes to the Fabry disease group on the site and serves on PatientsLikeMe's 12-member team of patient advisors. But she says her biggest contribution is recording her own condition and treatment on the site. That includes detailed reports on her responses to treatment, her mental state, and a range of physical measurements.

"It's very engaging," Fees says. "It makes you feel good about yourself, and like you are helping others, and contributing to science and the public good." And, she says, she has learned from others how to take better care of herself.

"Our patients are increasingly interested in taking a bigger role in their care, and technology now enables active participation," Walsh says.

People who enroll must consent to share their experiences, report their health outcomes, and provide access to their medical records. They'll also be able to interact with and learn from each other on the group's website.

One early goal is to track which COPD drug treatment regimens work best for which patients. "The point is to let patients report their treatment results," Walsh says. "Doctors will be assessing their status, too. But what we really want to do is expand the nature of research to include the patient-reported outcomes; that's what's been missing."

ImproveCareNow is similar to the PCORI initiative. It launched in 2007 as an online resource for families with children who have Crohn's disease and ulcerative colitis—chronic immune conditions often referred to collectively as inflammatory bowel disease. With funding from government and the private sector, ImproveCareNow in 2015 encompasses 73 pediatric gastroenterology centers in 34 states and about 21,000 children—one-third of the children in the U.S. with inflammatory bowel disease.

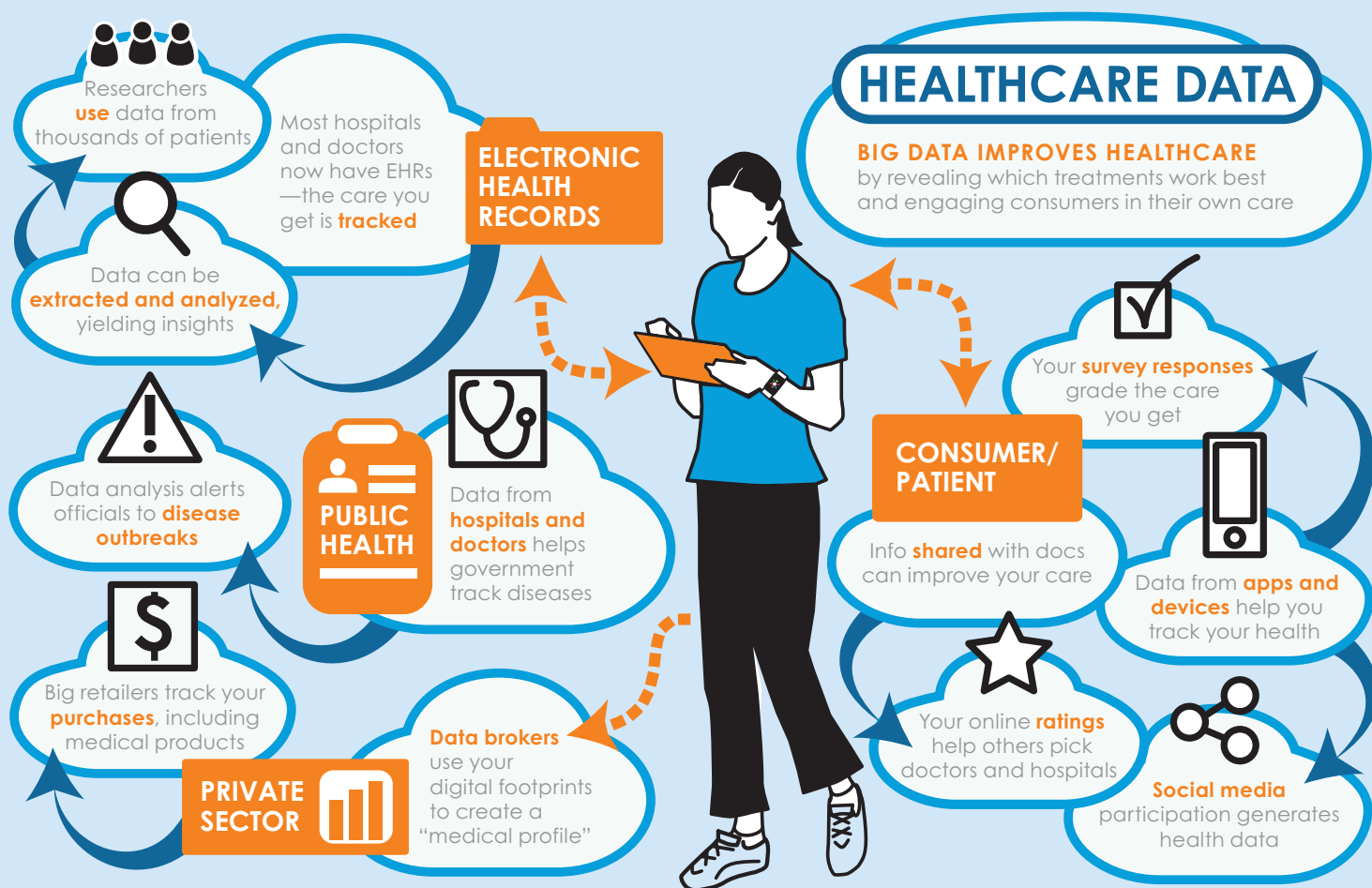
Partly attributable to the rapid spread of knowledge the network has facilitated over the past eight years, almost 80 percent of children with those conditions are now free of active disease, up from 55 percent in the early 2000s.

"We want the doctors and patients to do experiments together," says Michael Seid, Ph.D., who, with Peter Margolis, M.D., Ph.D., heads up the project. Children and their parents are chronicling their experiences through blogs, social media, and EHRs. Doctors then analyze that information to see which medications and treatments are working best, and to detect how habits of daily living (primarily what and when kids eat) affect health and well-being.

Patients Like You

When Ben and Jamie Heywood's brother Stephen was diagnosed with Lou Gehrig's disease (amyotrophic lateral sclerosis, or ALS) in 1999, at age 29, they scrambled to find every scrap of information they could about the disease, connect with people who had it, and search for ways to improve and prolong their brother's life.

Along the way they had an idea: Why not create an online community for people with ALS and other such dire diseases or chronic conditions? The result was PatientsLikeMe



DESIGN BY LAURA KINNEBERG

(patientslikeme.com), launched in 2004 and now one of the most prominent sites on the Web helping people track their illnesses, compare treatments, report their experiences, contribute data for research, and support one another.

As of early 2015, PatientsLikeMe has 325,000 members who have reported their experiences with more than 2,400 conditions and diseases. People with fibromyalgia, multiple sclerosis, diabetes, depression, and Parkinson's disease are most active on the site. About 27 million data points have been collected and organized, and made accessible to members.

Company cofounder Ben Heywood says the company is all about openness. "We believe sharing your health-care experiences and outcomes is a good thing," he says. "When people do this, collaboration on a global scale becomes possible and it speeds up the pace of research."

Part of the company's openness, says Heywood, is acknowledging its work with industry. A significant portion of PatientsLikeMe's revenue comes from allowing pharmaceutical, medical-device, and other health-care

companies access to de-identified and aggregated patient data on its members' experiences and treatment histories.

The site connects people through online forums, and members have full access to all the data and information on their conditions. Participants can track their symptoms on the site, as well as treatment outcomes such as pain levels, sleep, functions, mood, appetite, and quality of life. Many are also helping the site figure out new ways to gather and use data. (See *Making a Contribution*, page 6.)

PatientsLikeMe has a detailed privacy policy. Heywood emphasizes that the site keeps information that might identify members strictly secure and does not share it with client companies. Unlike Facebook, however, PatientsLikeMe does not require its members to use their real names; they can join and use the site under an invented name. Although Heywood says the company makes no attempt to identify people using false personas, it does use sophisticated tools to ferret out suspicious data and information that users post, and to identify people who might be using the site to advocate products or sketchy treatment ideas.

WHERE THE DATA COME FROM

Claims. This is the term-of-art for the medical bills that hospitals, doctors, labs, pharmacies, and other health-care providers send to insurers, the government, and you. Because bills contain medical information—such as diagnoses, services provided, and fees—they are useful for probing patterns of care and costs. Bills are not designed to give detailed and nuanced data on actual treatment or the outcomes of treatment, however, and are thus limited in the information they convey.

Clinical. These are the data contained in medical records kept by doctors, hospitals, and insurers, including Medicare. Medical records are increasingly digital, in the form of EHRs. When appropriately used, EHRs are immensely more useful than paper records for quality improvement and research because electronic data can be manipulated by software instead of laboriously extracted by hand.

Public health. Doctors and hospitals submit data to government agencies on reportable diseases (such as influenza) to track trends and outbreaks. The federal government also gathers extensive statistics on hospitals, doctors, nursing homes, and other providers. Increasingly, researchers are matching up that data with data from other sources to probe patterns of care and gaps in health-care services. Information from public health surveillance is being made directly available to consumers. For example, check out healthmap.org, which tracks infectious diseases around the world.

Patient-generated. Patients generate data on their own experiences in several ways. Surveys from hospitals, insurers, and government agencies ask people about their experience with health-care providers; those assessments factor into provider ratings and payment. Consumers may choose on their own to rate hospitals and doctors online, just as they do other services and products. At the same time, wearable devices and smart-phone apps enable consumers to record their own health data such as blood pressure, heart rate, or mood. They can share those data with doctors to inform care, and feed them into larger pools of data for public-health and research purposes.

Private companies. Companies such as Amazon.com, Target, Walgreens, and Wal-Mart are now tracking consumers' purchases and online behavior and habits. Such data can provide important signals relevant to health. For example, if pharmacy chains see an unexpected spike in local prescriptions for asthma and allergy medicines beyond seasonal variation, that could be a sign of air-quality degradation.

Your Rx Drug Experiences

The Food and Drug Administration (FDA) tests prescription drugs before approving them for sale, a process that can take several years. But once a new drug hits the market and hundreds of thousands or even millions of people take it, serious problems can turn up.

Remember Vioxx, the much-touted pain-relief drug? It was approved in 1999, but not long after its release studies found that Vioxx increased heart-attack risk. As a result, the FDA and the medical community forced Merck, the drug's maker, to withdraw Vioxx from the market in 2004—but not before 20 million people had taken it and an estimated 88,000 had suffered a heart attack attributable in part to the drug. An estimated 38,000 died, and in 2007 Merck agreed to pay \$4.8 billion to victims.

That same year, in the wake of Vioxx and several other high-profile drug-safety failures, Congress mandated that the FDA develop a computer-based system to track and analyze the safety of drugs and medical devices *after* they hit the market.

The result is the FDA Sentinel Initiative. Started in 2008, Sentinel has become another powerful example of big data at work. Eighteen organizations—including many of the nation's largest health-insurance companies, plus nearly 100 hospitals and inpatient facilities—make a large body of data available through Sentinel. To date, that encompasses 178 million people, 4 billion prescriptions, and 42 million hospital stays.

In large part to protect patient privacy, Sentinel's data trove is not kept in a centralized database; rather, participating institutions are part of what is called a *distributed network*. The insurers and health systems that work with Sentinel own and retain full control of the information but make it available in a format that enables researchers to query it through a software program.

The breakthrough? The FDA can potentially get information about possible problems with a drug in a matter of weeks, as compared with months or years using traditional research methods.

As of February 2015, queries have led to assessments of 137 drugs. Of those, the FDA has probed 18 more closely (several probes are ongoing) and issued a drug-safety communication in four cases. Sentinel research findings are available to the public on the FDA's website (fda.gov).

Checking Up on Your Doctor

Consumers routinely check online reviews before booking a restaurant or trip, or making a major purchase. They're beginning to do the same with doctors and hospitals. A 2012 survey of 2,137 adults, published in The Journal of the American Medical Association, found that one in four people had consulted a physician-rating site when picking a primary care doctor that year, and 5 percent had rated a doctor online.

Healthgrades, the largest private-sector hospital- and physician-rating site, says about 1 million people visit its site every day and have access to 4 million consumer reviews.

Although consumer reviews of doctors and hospitals are useful, they reflect only a part of the actual quality of care a doctor or hospital delivers. Many initiatives now aim to



WHAT'S AN ALGORITHM?

The concept of *algorithms* is central to understanding how large amounts of data are analyzed to yield insights. An algorithm is basically a step-by-step approach to solving a problem or completing a task. For example, a recipe is a simple kind of algorithm.

Algorithms are ubiquitous in computer programming. They are the instructions, in code, telling the computer what to do. You can use simple algorithms to sort and analyze small amounts of data by hand. Large volumes of data, however, based on the experiences of tens of thousands or even millions of people, require algorithms that only powerful computers can handle.





Today, algorithms are used to perform myriad functions all around us every day. Dating sites like eHarmony and OkCupid use algorithms to suggest who we might like to date, and retail stores use algorithms to decide which coupons might interest you based on other items you purchased. Algorithms run a significant portion of large-investor trading on stock markets. And algorithms are how Amazon.com and Netflix scan and sort your page views, purchases, and preferences to direct ads or advice to you.

In health care, algorithms are used to analyze large sets of data on diseases and health systems. They help track outbreaks, characterize the genetic basis of disease, and weigh treatment results and costs. Algorithms are also used to determine which patients are more likely to end up in the hospital and predict which patients will—or will not—respond to particular treatments.

In a technique called *predictive modeling*, for example, an algorithm might scour insurance claims to identify people who have been diagnosed with one or more chronic illnesses (such as diabetes and high blood pressure), visited an emergency room frequently in recent months, and filled (or didn't fill) multiple prescriptions. Insurers and doctors can then target those patients for preventive and ongoing care to try and keep them healthy and avoid hospitalizations.

Predictive modeling and similar approaches are becoming more sophisticated as the volume and quality of data increase, and as scientists get better at mining and acting on data. That has raised concerns about privacy, especially as researchers combine various sources of data about individuals—say, from their online and social-media lives with data from their electronic medical records—to develop health or medical profiles. See our advice on page 15 about protecting your medical identity.

CONSUMERS AND DOCTORS ON DIGITAL HEATH

	Consumers		Doctors	
Agree that mobile devices can help clinicians coordinate care more effectively	47%	 CARE COORDINATION	79%	Say mobile devices help them more effectively coordinate care
Would be likely to use devices attached to phone for health-care evaluations (ear infection, strep, ECG)	50%	 DO-IT-YOURSELF SERVICES	42%	Would be comfortable relying on results of patient do-it-yourself tests to prescribe medication
Would be comfortable having their health data shared among health-care organizations if it meant improved care coordination	56%	 DATA SHARING	30%	Are electronically sharing data with physicians outside of their practice
Have one or more health apps on their phones or tablets and use them at least once each week	65%	 MOBILE APP USAGE	68%	Would be willing to prescribe a mobile health app to help a patient manage a chronic disease

Adapted from *Healthcare Delivery of the Future: How Digital Technology Can Bridge Time and Distance Between Clinicians and Consumers*; PWC Health Research Institute; Nov. 2014, Page 10.
pwc.com/en_US/us/health-industries/top-health-industry-issues/assets/pwc-healthcare-delivery-of-the-future.pdf.

rectify this, and gathering detailed information on the quality and results of care is among the largest data enterprises in health care today. For examples, check out Medicare's Hospital Compare site (medicare.gov), Consumer Reports' hospital ratings (ConsumerReports.org), or Healthgrades (healthgrades.com) to compare hospitals.

It's harder to assess physician care, for a host of reasons. Despite the challenge, about 50 initiatives are underway to assess and publicly report on physician performance. A handful are private-sector initiatives that are national in scope, such as the Society of Thoracic Surgeons' initiative (sts.org/national-database) to provide performance information on the outcomes of coronary bypass surgery; the Health Care Incentives Improvement Institute's searchable database of doctors who have agreed to have their quality of care monitored (inquirehealthcare.org); and

the National Committee for Quality Assurance's recognized clinician directory (recognition.ncqa.org).

Medicare, however, is the biggest potential player in this sphere. It covers 52 million elderly and disabled people and collects data on all physician bills and payments. A recent court decision ordered Medicare to make the data available to the public. As a start, Medicare in 2014 released data on 2012 payments to individual doctors: Go to nytimes.com.

As mandated by Congress in the Affordable Care Act, Medicare also launched the website Physician Compare (medicare.gov/physiciancompare/search.html). That site is just beginning to come together. Among the data posted so far: performance scores for treatment of people with diabetes for 66 of the nation's largest physician group practices, and lists of doctors who participate in several Medicare quality-improvement initiatives.

Apple Plunges Into Health Data

It's possible, even probable at this point, that over the next decade smart-phone and tablet applications will produce the same kind of changes in health care as we have seen over the past decade in music, news, banking, weather tracking, social networking, photo sharing, and game playing. There are already more than 40,000 health-care-related apps.

Hundreds of start-up companies are producing novel innovations. But it's perhaps not surprising that Apple's efforts garnered the most attention. In 2014 and 2015 the company launched two software platforms. One is called HealthKit and the other ResearchKit. HealthKit lets you aggregate and store on your device data from Apple-approved health and fitness apps. For example, if you have a fitness app, a sleep app, and a glucose-monitoring app, you can integrate data from all of them into HealthKit, as long as they are HealthKit compatible. ResearchKit is a platform that helps medical researchers create iPhone apps to recruit people for research studies. Once recruited, study participants can upload their data into the app, and into HealthKit, and specify with whom they want to share the data.

Apple's strategy is to compel app developers to create apps that are compatible with HealthKit. But Apple is also partnering with companies that make EHRs, and with the health-care providers that use them, to create an electronic ecosphere of data sharing for doctors and patients.

For example, Apple is partnering with Epic, one of the largest EHR vendors. Epic systems are in thousands of hospitals and doctors' offices. In turn, Apple is testing integration of HealthKit with Epic EHRs at several large health centers. One of them is Ochsner Health System, which operates 13 hospitals in Louisiana. The initial pilot test was simple: Ochsner gave 100 patients with heart failure wireless scales to transmit their weight every day to Ochsner's My Chart EHR. Rapid weight gain in such patients can signal dangerous fluid retention due to heart failure. If doctors saw a patient's weight shoot up, they could adjust medications quickly, sparing patients unnecessary complications and hospitalizations.

The test worked, according to Ochsner, and made a difference in patient care, with medications usually being adjusted within hours. As a result, Ochsner plans to link Apple's HealthKit with its EHR in 2015.



"In the past, we relied on patients to log information, bring it to us, and then we would input the data and decide a course of action," said Robert Bober, M.D., director of cardiac molecular imaging at Ochsner, in an October 2014 press statement. "Now we can share information seamlessly between patient and physician to allow real-time, accurate analysis of a patient's health status."

Doctors at Stanford University's School of Medicine and the Duke University Medical School are also testing HealthKit. Stanford doctors are using it in a pilot study to monitor blood-sugar levels for pediatric patients with diabetes. In those cases, the patients' iPhones are equipped with an app that can receive data from children's

glucose-monitoring devices. If the pilot study improves patient care, Stanford—like Ochsner—plans to integrate HealthKit with its Epic EHR.

At Duke, HealthKit will track vital signs, such as blood pressure and weight, for patients with cancer and heart disease who are living at home.

ResearchKit has also exploded out of the box. In the weeks after it was launched, in March 2015, some 60,000 people enrolled in five studies through Apple iTunes Store apps. For example, a team of Stanford University researchers built an app to recruit consumers into a study of ways to encourage people to modify their behavior to

PRICE DATA CAN HELP YOU CHOOSE

Discovering how much medical services cost has long been problematic, obscured by complex insurance coverage and billing systems. That's changing, albeit slowly, and just in time as employers and insurers shift more and more costs to consumers through higher deductibles and co-payments.

Government and insurers now recognize the importance of making the data they have on medical bills more transparent to the public, even when that information is still a bit confusing and not yet conducive to easy price shopping.

For example, in 2013, Medicare started releasing detailed data on hospital costs. The information covers some 3,000 hospitals, and it lists the average fees billed to the government for 100 common inpatient visits and 30 types of outpatient visits. You can find the data at medicare.gov or at the Centers for Medicare & Medicaid Services website (cms.gov). Although you can't use it to find out what you'll pay a Medicare provider, it provides a rough gauge of the price ranges of hospital services—even if you are not enrolled in Medicare.

The government took another step toward price transparency in 2014, when it released data on Medicare payments to physicians (cms.gov). The first batch is for payments made to doctors in 2012, covering about 5,000 kinds of procedures. Data for 2013 payments will be released this year, and annual releases will follow after that.

Although Medicare has a website with the data files on doctor payments, as cited above, it's not consumer-friendly.

Searches for payment data pertaining to a particular doctor are best done at a site set up by *The New York Times* (nytimes.com).

Private insurers have joined the push. Most now offer their enrollees data on average prices for medical services. In February 2015, a nonprofit organization called the Health Care Cost Institute launched a free consumer-focused website (guroo.com) with pooled data from 40 million enrollees in four of the nation's largest health-insurance companies (UnitedHealthcare, Humana, Aetna, and Assurant Health).

In its initial phase, the site has cost data on about 70 common conditions or tests, with an emphasis on services consumers commonly shop for in advance, such as knee surgery. Searches yield average national prices as well as average prices in your state, when available (so far, 41 states and Washington, D.C.) and the nearest big city (300 to date). But, notably, the site doesn't give the price a particular hospital or doctor has charged.

Similar price data for a range of medical services are also available at two other websites, healthcarebluebook.com and fairhealthconsumer.org.

It's still difficult to know what an individual provider will charge you (after factoring in insurance coverage), or to understand all of the factors (and thus costs) that might go into a specific surgical procedure or course of treatment. Comparing doctors and hospitals on the quality of care they deliver is also still in its infancy. For now, the available online tools can serve as benchmarks to help you assess what you will be charged by your own providers, which is especially important when you have to pay the bulk of the bill.

improve heart health. Within 24 hours 11,000 people had signed up.

“To get 10,000 people enrolled in a medical study normally, it would take a year and 50 medical centers around the country,” Alan Yeung, M.D., medical director of Stanford Cardiovascular Health, told *Bloomberg News*. “That’s the power of the phone.”

Apple has sought to address privacy and ethical concerns up front. It bars developers from selling any HealthKit data to third parties for any purpose. And data generated at hospital systems such as Ochsner, Stanford, and Duke are protected by a federal law (HIPAA, see page 15). that

makes the sharing of personal medical data other than for direct patient care a crime.

Still, other concerns have been raised. Some researchers caution that the accuracy of mass data gathering from consumers is not yet confirmed. In addition, iPhone users choosing to participate in such studies aren’t necessarily typical of the general population, a point that could render results less-widely applicable. On the other hand, in medical studies conducted without the use of phones and apps, participants are often lost to follow-up. With the app, in theory, it should be easier to participate and report data. Apple plans to make ResearchKit available soon as open-source software.

HOW YOU CAN PARTICIPATE

Here are ways to contribute or use data to improve your own health and the health of others. See “Your Data, Your Privacy” on page 14 to learn about the precautions you need to take.

- **Ask your insurer, health system, and doctor** if they use an EHR system or have a patient Web portal that lets you view and/or contribute your own data. Those systems give you an opportunity to play a larger role in your care, sharing your needs and preferences as well as monitoring your responses to treatments and medications.

- **Try a fitness device or mobile phone app** that tracks your workouts, sleep cycles, or other aspects of your life and health. By recording observations of daily living you can learn a lot about yourself, your health habits, and how they relate to your health.

- **Participate in an online patient community**—there are thousands of them. Most are specific to a single condition or disease but some are broad-based. As the profiles on the previous pages indicate, a growing number of websites specialize in gathering information from you—and sharing information with you. Caution: Some patient and disease support sites are heavily subsidized by pharmaceutical or medical-device companies and may have a bias in favor of prescription drugs or products made by those companies. You may not be comfortable with that. The best way to find a site that meets your needs is to search online. You can find quite a few starting points at online.supportgroups.com and dailystrength.org/support-groups. You can also search online for the name of a disease or condition followed by the words “patient support groups” or “patient community.”

- **Consider participating in a clinical trial.** Trials are critical to advancing knowledge about which treatments work best. Participating in one is not right for everyone, but doing so has been made easier recently by social media and new apps, as well as changes in the ways trials are conducted. For example, there are now online lists of clinical trials (clinicaltrials.gov). If you’re offered access to one, discuss with your doctor whether the option is right for you.

- **Monitor your experiences.** You can start by tracking your treatments and experience of care in a more formal way. That is, keep a record—a medical diary—of how you feel and what physical and psychological and emotional responses you have to a treatment. That record may be especially useful if you have a chronic condition. Ask your doctor what would be most useful for her to know over time. Look for apps that can help you with the task.

- **Rate your doctors** at a review site online. You can choose from several (healthgrades.com, ratemds.com, vitals.com, yelp.com, zocdoc.com). The more people providing honest, balanced reviews, the more reliable and accurate the ratings will be. And check out reviews and ratings when choosing a doctor or hospital: At ConsumerReports.org, click on “Health” and then “Doctors and Hospitals.” Also see informedpatientinstitute.org for a list of doctor- and hospital-ratings initiatives nationwide, with assessments of each. Caution: Some sites use weak methodologies to rate providers, and ratings often vary from site to site for the same providers.

- **Crowdsource your treatment experiences** by rating your treatment online. For example, check out curetogether.com and the Cochrane Collaboration’s site (community.cochrane.org/cochrane-reviews). Beware of sites that are just fronts for a specific doctor, group practice, or clinic.

Your Data, Your Privacy

Electronic data can help you manage your health and improve the care you get, but there are risks. Medical identity theft and the unwanted disclosure of personal health information are growing problems. And there's simply more electronic information about your behaviors, preferences, and purchases out there now than ever before. Even if your information was anonymous in the beginning, when pieced together from multiple sources your data can be used to identify and profile you. In the parlance of the trade, that's called the "mosaic effect."

Although your privacy can still be compromised with paper medical records, breaches and identity theft have grown along with digitized record keeping in hospitals, doctors' offices, and insurance companies. From 2009 through 2014 health-care businesses reported more than 1,100 breaches affecting the medical records of an estimated 41 million people, according to ProPublica (propublica.org). And two large-scale breaches of personal information, both involving insurance companies—Anthem in several states and Premiera Blue Cross in Washington State—occurred in 2015.

Medical information is a target for fraudulent activity because there's money to be made from using or selling it. Thieves can use data on Medicare beneficiaries, for example, to submit fake bills to the government—or sell it to others who will use it that way. Medicare or private insurance ID numbers, along with other identity information, help scammers illegally access medical services or obtain prescription drugs.

EHRs are vulnerable in a number of ways. As they rapidly replace paper records, more health professionals and support staff have ready access to enormous quantities of digital information. In general, that's a good thing, helping doctors and nurses coordinate your care and improve quality and efficiency. But unscrupulous workers or hackers can steal and sell the information in EHR systems.

Federal and state laws provide for stiff penalties for people caught stealing medical data or defrauding Medicare and other insurers. And a 1996 federal law called HIPAA (the Health Insurance Portability and Accountability Act) bars health-care providers, insurers, and health-care

businesses from disclosing information in medical records to unauthorized personnel and for any reason other than treatment, billing, or 'health care operations,' under penalty of law.

But even with HIPAA there are significant gaps in patient privacy laws. HIPAA applies only to information held by health-care providers and insurers, and their business associates. It doesn't apply to the myriad companies that have launched products and services that collect people's personal health data—such as Web-based patient communities, smart-phone apps, and wearable devices. HIPAA also doesn't apply to medical information held by companies offering life, disability, or long-term care insurance. So, if there is a breach of privacy at any of those entities, then your information may be released to others.

A group called Privacy Rights Clearinghouse (privacyrights.org) sums it up: "There is no one law that protects the privacy of *all* medical or health-related information in *all* situations."

Notably, a 2008 law filled an important gap left by HIPAA. The Genetic Information Nondiscrimination Act bars employers and health-insurance companies from basing employment or coverage decisions on genetic information. Also, the 2010 Affordable Care Act prohibits health insurers from using information about people's medical status to make coverage decisions.

The upshot is that you need to be a savvy consumer both to get the most from the potential benefits of big data and to protect your medical information in a way that reflects your values. Vigilance regarding your medical information is no longer optional in the digital age. The box below lists resources to help you learn more about health-data privacy issues. And see the next page for our recommendations to protect your medical privacy.

- Privacy Rights Clearinghouse (privacyrights.org)
- The Center for Democracy & Technology (cdt.org)
- Office of the National Coordinator for Health Information Technology (healthit.gov)
- Office of Civil Rights at the U.S. Department of Health & Human Services (hhs.gov/ocr/office)
- The Summit Health Institute for Research and Education (shireinc.org)
- Consumers Union (ConsumersUnion.org)

Our Recommendations

■ Know what's in your medical record.

Find out if your doctor and insurer have EHRs or a patient portal, and learn how to get secure access to your data. Check those records for accuracy and omissions. Under HIPAA, you have the right to see or obtain *all* the information in your medical records, in either paper or electronic form.

You can be charged a “reasonable” fee for that, including charges for paper copies if you ask for them. Check the Blue Button Connector website (bluebuttonconnector.healthit.gov) to find out if your provider participates in the Blue Button Initiative, which would let you download your records electronically. You also have the right to request a correction to your medical records if you find information you think is inaccurate.

■ Be smart when visiting health-related websites.

Online patient forums or social-media platforms such as Facebook can be valuable resources, but you should be attuned to potential privacy issues. Your Web searches are trackable, and all websites—even those that are password protected—are hackable.

Use a pseudonym in medical chat rooms, and refrain from posting any sensitive information that you would not want seen by acquaintances or your boss. Be aware that even if you do those things, your computer's IP address can be traced.

■ Use only secure e-mail.

Don't put medical information you don't want made public in *unsecure* e-mails or text messages; both are hackable. Pick up the phone instead. If you e-mail with your doctor—which is very convenient and more and more common these days—ask if he or she has a secure e-mail server or a patient portal that allows for secure messages.

■ Don't keep electronic copies of medical documents, files, or notes on your computer at work.

Your company computer belongs to the company, and others can access it. If you track your medical history or keep medical bills and files on your computer at home, consider using software to encrypt them. And if those files are backed up to a cloud or storage service, make sure they are encrypted.

■ Monitor your medical bills and explanation of benefits (EOB) statements.

Checking those bills and statements is a good general practice to detect mistakes, but it also might alert you to medical fraud or identity theft.

■ Don't provide private information over the phone.

Unless you are absolutely certain you know who you are speaking with and that he or she has a legitimate need for the information, do not give your social security, insurance, bank, credit card or insurance plan ID numbers over the phone.

Being cautious about providing that information helps you avoid falling victim to digital “phishing”—a scheme whereby a criminal has your name, address, telephone number, and health insurance carrier's name (all easily obtainable these days) and masquerades as an employee of your insurance company to get your medical ID number or social security number.

■ Use health and fitness apps with care.

Smart-phone health and fitness apps and wearable devices are useful tools, but they generate data that can be anonymized (stripped of identifying information) and sold to third parties for marketing and other purposes. Indeed, many websites and some e-mail services and device and app vendors routinely sell to data brokers.

If you are comfortable with your (de-identified) data on diet, exercise, blood-sugar readings, sleep habits, menstrual cycle, or any other personal information being disclosed, then you may not care. Regardless, it's a good idea to understand how the companies you trust with your information treat that information. Always check to see if the website or app has a “terms of use” statement that clearly describes what it does with the data it collects. Review the company's privacy statement, as well as any information on whether—and, if so, how—you too can gain access to your own data collected through the app or device.

A study by Privacy Rights Clearinghouse (privacyrights.org) found that some 40 percent of the health-care-related mobile apps it tested were “high risk” in terms of the sensitivity of the information they contained, lack of adequate encryption, and third-party access to the data. Always review the terms of use or other policies before signing up.



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