ConsumerReports®

Better Health Care:

Changes to Learn About *Now*

Why this guide?

With funding from Atlantic Philanthropies, CONSUMER REPORTS developed this brief guide to help you understand elements of the new health reform law (the 2010 Affordable Care Act, or ACA) intended to make the health system work better for consumers. Specifically, the guide introduces you to three broad initiatives aimed at improving the quality of care, limiting spending growth, and empowering consumers. The initiatives focus on:

- Paying providers for the quality of care they deliver, instead of just the quantity of care;
- Putting more "actionable" information about providers, treatments, insurers, and prices into consumers' hands so they can make better-informed choices;
- Applying the digital information and social media revolutions to health care.

At CONSUMER REPORTS we believe that the more involved you are in your care, the better the outcome will be. That's why we've been actively engaged in recent years in providing you with information and tools to make better health-care decisions and choices. We now rate prescription drugs, health insurance plans, hospitals, and, in selected states, doctors. See page 15 for a list of our resources; you'll also find there a list of 8 things you can do to make sure you and your loved ones get the best possible care.

We hope you find this guide helpful. If you do, please share it! Go to *ConsumerHealthChoices.org/GettingHealthCareRight* to download the free PDF. For print copies, contact us at *HealthImpact@cr.consumer.org*.

Jim Guest
PRESIDENT
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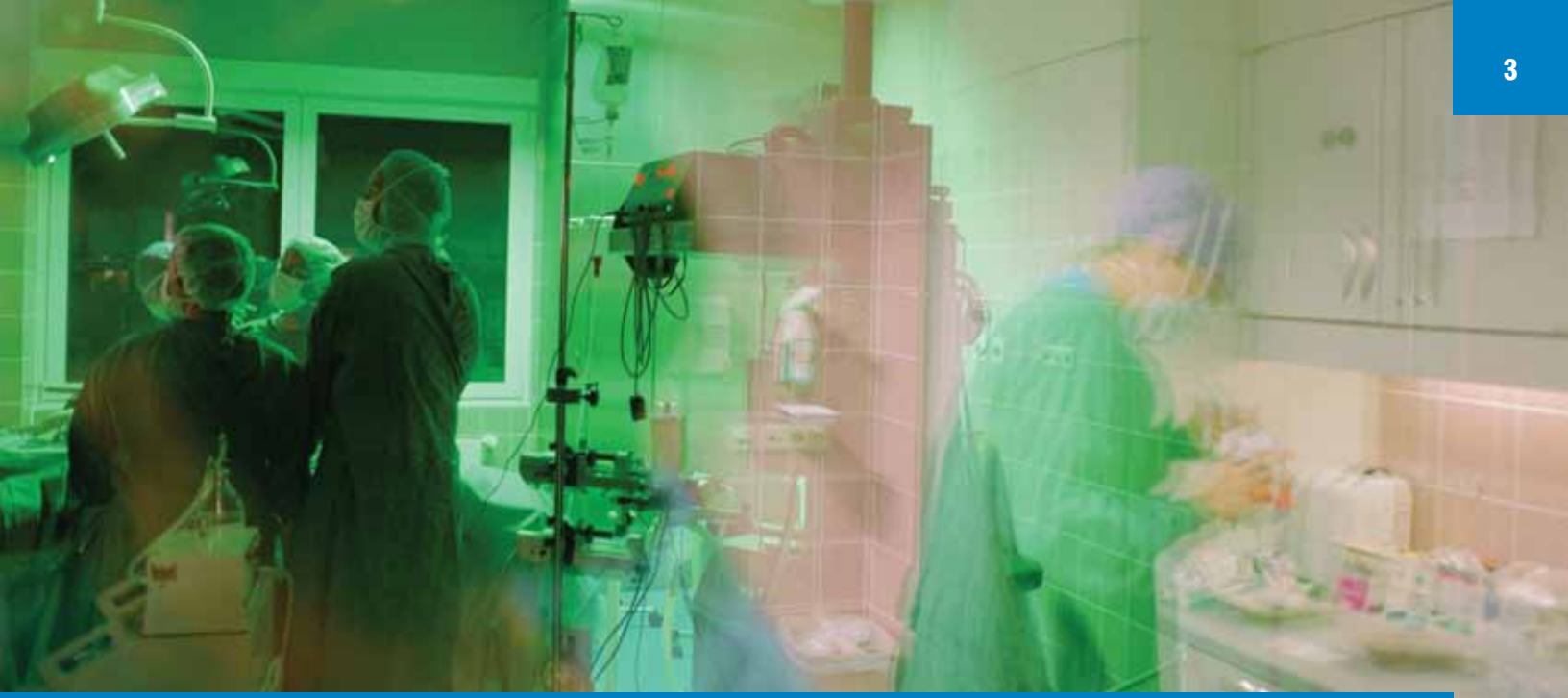


Our health care system—on the mend

There's overwhelming evidence that health care in the U.S. is wasteful, error-prone, and unsustainably costly. We have the most expensive system in the world, but it delivers disappointing results. In overall health, life expectancy, and other measures, we rank well below many other industrialized nations.

The Institute of Medicine has estimated that 30 percent of all spending on health care in the U.S. is unnecessary, wasteful, or misdirected (see chart, page 6). In 2014, that percentage will translate to $930 billion. As citizens we all pay the tab—out of our own pockets, in higher insurance premiums, and through taxes that support Medicare, Medicaid, and the Veteran's Administration and military health-care programs.

Meanwhile, as we spend wastefully, millions of families are at financial risk every year from medical bills they can't pay. In 2009, a fifth of middle-income people under age 65 reported spending 10 percent or more of their incomes on health care. Health-care expenses are the leading cause of personal bankruptcies. And health-care spending is straining business and government budgets, too, as it steadily rises. As a nation, we now spend $1 out of every $6 on health care, a figure projected to grow to $1 in $5 by 2021.

The good news is there's broad agreement on the need for change. Over the past decade, businesses, insurers, government, providers, unions, and consumer groups have launched hundreds of experiments and new models of care to:

- Reduce wasteful spending and unnecessary care and treatments;
- Pay doctors and hospitals for the results they achieve and not just the volume of services they deliver;
- Improve the quality of care by measuring health outcomes more carefully and holding doctors and hospitals more accountable;
- Reward providers for achieving better outcomes at lower cost;
- Empower consumers and patients with more and better information to make informed choices and with new tools to help manage their own care;
- Bring medicine into the digital 21st century through the use of information technology and electronic medical records.

The Affordable Care Act builds on many of the marketplace experiments already underway. And it has launched a few of its own. The emerging efforts will inform and drive more pervasive changes in the years ahead.

In this guide, we highlight some of the most important initiatives coming soon to doctor's offices and hospitals near you.

Paying for quality

The way we pay doctors, hospitals, and other providers is flawed and expensive.

The problem: insurance companies, Medicare, and Medicaid pay most providers for each individual visit, test, and procedure; but the payments don't necessarily reflect the results achieved. The system is called "fee-for-service." Studies show that it:

- Emphasizes the volume and quantity of services, not quality of care or how patients fare over time;
- Gives providers an incentive to do more than is medically necessary;
- Promotes higher prices, bill padding, fraud, overly complex billing, and duplication of services;
- Encourages fragmented care, because providers have no financial incentive to coordinate with each other.

Fee-for-service payment can also endanger patients. For example, excessive radiation from X-rays and CT scans can add to your risk of cancer. The tests are valuable when used correctly and judiciously, but studies indicate they are now being overused, in part because they are big moneymakers for hospitals and diagnostic centers. One in 10 Americans now gets a CT scan every year, and overall radiation exposure increased sixfold between the 1980s and 2006.

Fee-for-service prices are highly variable and often excessive. Even in a single city, the price for some procedures can vary manyfold for no good reason. For example, the average hospital charges for the treatment of heart failure ranged from a low of $21,000 to a high of $46,000 in Denver, Colo., and from $9,000 to $51,000 in Jackson, Miss., according to a Medicare study. And an analysis by *The New York Times* found that the highest price charged for a colonoscopy in 17 cities ranged from $2,116 in Nashville, Tenn., to $8,557 in New York City.

Insurance companies and Medicare are now testing alternatives to fee-for-service. But the transition will take time. In this section, we introduce you to some of the leading experiments now underway or about to launch.

Bundles of care

One of the most promising innovations is called a "bundled" payment for an "episode of care." In 2012, Medicare began experimenting with bundled payments for 48 conditions, including heart attacks, strokes, and major joint replacements. It works like this: if a patient is hospitalized for heart bypass surgery, for example, Medicare will pay the hospital one preset amount for *all* of the care the patient receives while in the hospital, and in some cases for follow-up care after discharge.

Some 140 hospitals and provider organizations are participating in Medicare's "Bundled Payments for Care Improvement" initiative. They must report financial and performance information so that Medicare can test whether bundled payments not only save money but also motivate providers to deliver efficient and effective care. Private insurers are also testing bundled payments. Currently, most only pay a bundled fee for organ-transplant surgery.

Stopping hospital churn

Almost one in five hospitalized Medicare beneficiaries ends up back in a hospital within 30 days. Many of those return trips are medically necessary. But studies show that a sizable number should have been avoided and were the result of poor inpatient care or poor care after discharge. This "hospital churn" increases costs and potentially puts patients at risk.

Medicare recently changed its policies to pay hospitals less—up to 2 percent less in 2013 and up to 3 percent less in 2014—if their readmissions are excessive. Some

2,200 hospitals were penalized a total of $280 million in 2013, based on their 2012 performance. In 2014, about 2,225 hospitals will be docked $227 million. Early evidence indicates that the program has moved the needle. The number of people readmitted within 30 days dropped in 2012 and 2013 for the first time in six years, to 17.5 percent in 2013 from 19 percent in 2007.

Here come ACOs

Accountable Care Organizations represent a new way to organize care and promote care innovations. An ACO is a group of doctors, hospitals, and other health-care providers that have banded together in an effort to provide coordinated care at lower cost. ACOs are not health-insurance plans like HMOs or PPOs. Instead, an ACO contracts with insurance companies and Medicare to provide care.

As their name implies, ACOs are accountable for the quality and efficiency of the care they provide. They must measure quality and patient outcomes, and payments are tied to their performance: for example, how well the ACO controls patients' blood pressure, cholesterol, and blood sugar, and how well they take care of patients with chronic conditions.

Early experiments with ACOs began about seven years ago. The new health law adapted the concept for Medicare, and that program has grown rapidly. At the end of 2013, 360 ACOs around the country were serving 5.3 million Medicare beneficiaries. Results to date are positive but preliminary. In one evaluation, 54 out of 114 ACOs that had completed a full year of operation produced savings of $126 million. In total, some 600 ACOs now enroll an estimated 18.2 million Americans.

Preventing unnecessary hospitalizations

Jeff Wienburg, 60, has diabetes and high blood pressure. He's had three strokes since 2000 and has been hospitalized twice. His last stroke, in 2011, left him disabled and depressed. He lost his job as an electrical technician in April 2012. With Wienburg's health still fragile, a year later his son took him to a primary care physician affiliated with Mercy Health, a five-hospital system in Cincinnati.

The trip turned his life around, Wienburg says. He started participating in a program Mercy Health launched in early 2012. The program provides intensive outpatient care and support services to high-risk patients to help keep them out of the hospital.

Unnecessary hospitalizations are one of the most vexing and costly problems in health care. Spurred on by new incentives, hospitals across the country are tackling the problem. These efforts target four problems in today's health-care system:

- Failure to proactively identify patients at risk of being hospitalized;
- Reliance on doctors alone to keep people healthy;
- Poor follow-up care after major medical events;
- Poorly coordinated care after hospital discharge.

Mercy Heath initially recruited 310 people into its program. Most had diabetes or heart disease. The hospital formed teams of caregivers that included physicians, nurses, nutritionists, care coordinators, and social workers. Nurse care coordinators make home visits and they follow up with patients routinely by phone, monitoring health status, medications, progress toward health goals, and recovery after a hospital stay.

Wienburg's care coordinator was Kathy Baxter, a nurse practitioner. "She was wonderful," he says. "I had almost daily contact with her for the first few months. She made a big difference. She taught me how to take better care of myself." Wienburg's diabetes and high blood pressure are now under control, and his depression has lifted.

"The emphasis is on forging a partnership between caregiver and patient," says Nanette Bentley, a Mercy Health spokeswoman. "The closer that bond is, the better we think patients do."

In 2013, Mercy Health expanded the program to its new ACO and "medical home" primary care practices. By the end of that year, Mercy Health says it saw a 16 percent decline in hospital admissions, a 47 percent decline in acute care hospital days, and a 34 percent decline in cost per patient.

"We are keeping people out of the hospital who don't need to be there," says Bentley. Mercy Health calculates that, when the program is fully implemented, every $1 it spends on care coordination and other program costs will yield $5 in savings for Medicare and private payers.

The 2 percent initiative

Medicare recently created a "value-based purchasing" program for hospitals. The purpose: test a payment system in which hospitals are rewarded for high-quality care and penalized if they perform poorly.

To do so, Medicare created a $1 billion pot of money in 2013 and another $1 billion pot for 2014, by taking a sliver out of Medicare's fee-for-service payments to hospitals. The sliver was 1 percent in the first year of the program and 1.25 percent in the second year. Medicare then used data from the existing Hospital Compare program to score hospitals' performance in three areas: patient experience, clinical standards of care, and mortality rates for heart attack, heart failure, and pneumonia. Adjustments to hospital payments were based on the scores.

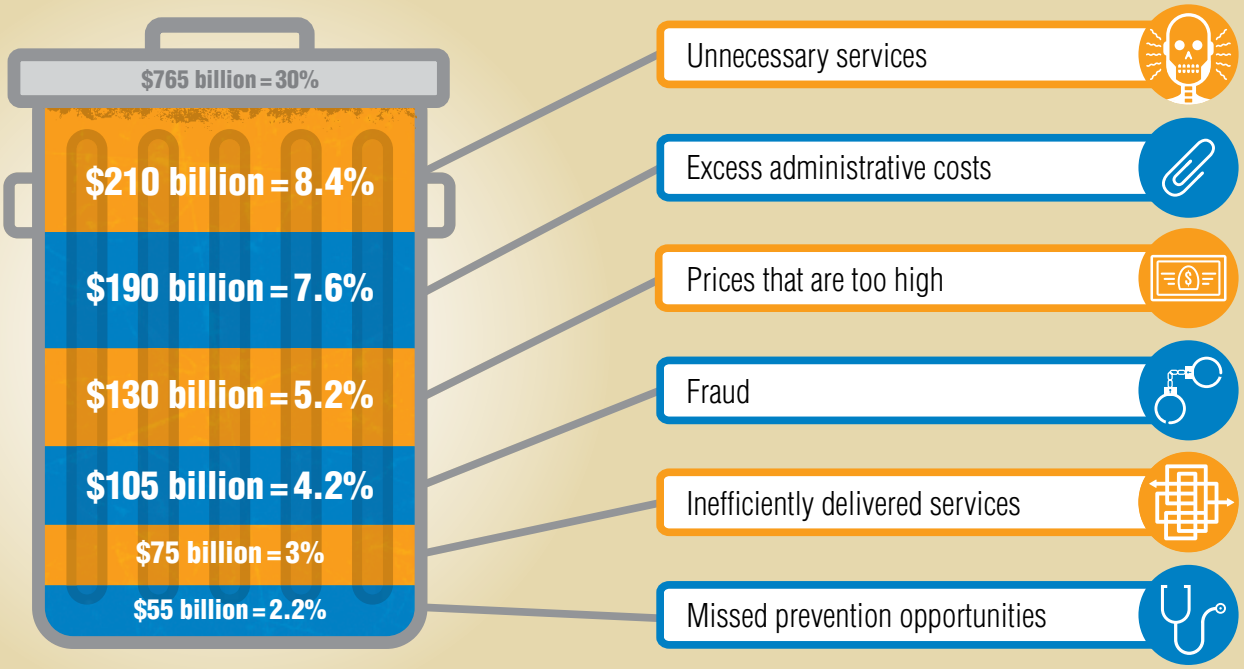
The majority of the nation's 5,700 hospitals are participating. In 2014, 1,451 hospitals will get back less than they forfeited and 1,231 hospitals will get back the full amount plus a bonus. Over the next four years, the set-aside pot of funds will be increased to 2 percent of hospital payments. If the program improves care and results—and saves money for Medicare—the incentive pool is very likely to be increased. Hospitals, which operate on low margins, are already taking value-based purchasing seriously. But many experts believe that if the set-aside pool of funds were to reach 10 percent or more of hospital payments, Medicare would significantly enhance its ability to change hospital practices.

Doctors, too

Medicare is set to launch a value-based purchasing program for doctors as well, in which cost and quality data will be taken into account when calculating payments. It will roll out in three stages, starting in 2015 with medical groups of 100 or more doctors. The program will trim 1 percent from every doctor's payments. That deduction will rise to 2 percent in 2016, when the program will be expanded to doctors practicing in groups of 10 or more. In 2017, the program will expand to the rest of the roughly 600,000 doctors who participate in Medicare.

Wasteful spending in health care

Of the $2.5 trillion spent on health care in the U.S. in 2009, an estimated **$765 billion–30%**–was wasteful, unproductive, or unnecessary[1].



[1]Health-care spending in 2014 is projected to be $3.1 trillion. Most experts believe the magnitude of wasteful spending remains unchanged from 2009. In 2009 $2.5 trillion was 17% of the nation's gross domestic product (GDP). In 2014, $3.1 trillion is projected to be 18.3% of GDP.

Source: Institute of Medicine, *The Healthcare Imperative: Lowering Costs and Improving Outcomes–Workshop Series Summary,* February 2011. National Academy of Science Press. http://iom.edu/Reports/2011/The-Healthcare-Imperative-Lowering-Costs-and-Improving-Outcomes.aspx.

Can lower-cost care be high quality?

Yes. Studies find no consistent relationship between the cost of care and the outcome or results. That is, high-priced hospitals and doctors don't necessarily deliver better or higher-quality care compared with lower-cost providers. Comparison shopping in health care can save you money.

As in the hospital program, doctors who score above average on a batch of performance, quality, and resource-use measures will get the withheld funds back plus a bonus. Doctors who score average will see no change in their payment, and doctors who score below average (or don't participate) will see their payments reduced. About a third of doctors already report to Medicare on their quality of care.

More primary and preventive care

Regular primary care and preventive screenings detect diseases earlier, keep people healthy, and increase longevity. But our health-care system spends too little on both primary and preventive care. Only 5 percent or so of national health-care spending is for primary care. In Medicare, primary care is now being promoted through seven initiatives and pilot programs involving more than 1,000 organizations. Medicare, for example, is paying 497 practices in eight states to be the "medical homes" for 315,000 Medicare beneficiaries. In addition to providing primary and all preventive care, those practices must coordinate care for patients with chronic conditions.

On the prevention front, the new health law requires insurers to cover certain preventive services, such as mammograms and colonoscopies, at no cost to the patient. Medicare providers, too, are barred from charging co-payments or coinsurance for preventive services and screenings such as immunizations and blood-pressure, blood-sugar, and cholesterol tests. For all those, Medicare now covers the cost in full.

Care in your home

Many Medicare beneficiaries want to recover from an illness, surgery, or period of hospitalization in their own home rather than a hospital or nursing home. And studies indicate that care in the home usually saves money for both patient and Medicare. The ACA includes an initiative to pay primary care providers and nurse practitioners for care at home for patients with multiple chronic conditions—a high-cost group. The Independence at Home Demonstration project will test whether home-based care can reduce the need for hospitalization, improve patient and caregiver satisfaction, lead to better health, and lower Medicare costs. For now, 17 primary care practices are participating. If successful, the project will be expanded.

More bang for your insurance buck

Before the new health-care law went into effect, some health insurers had been spending less than 70 percent of their revenue on actual medical care for enrollees. The rest went to overhead, marketing, and profits. The ACA now requires insurers to spend at least 85 percent of revenue on actual care *and quality improvement* in plans sold to businesses and at least 80 percent in plans sold to individuals and families. If the insurer does not spend this minimum percentage, it has to rebate the difference to its customers. The provision's primary intent is to enhance people's access to care, but it also encourages health insurers to invest in quality improvement—new ways to make care better, more efficient, and more cost-effective.

More information, better choices

Medical information is abundantly and easily available on the Web and mobile devices. But there are still significant gaps. There's too little, or muddled, information on:

- Individual doctors and the quality of care they deliver;
- The prices of treatments and procedures;
- The pros and cons of treatment options for specific conditions and diseases.

The information gaps have persisted for years, for good and bad reasons. It's expensive and difficult to accurately measure quality and to compare treatments. Comparing doctors is also a challenge, because they may treat quite different populations of patients. But at the same time, doctors have long resisted efforts to probe their performance.

That's changing. New information technology tools—such as electronic health records (EHRs)—make it easier and cheaper to measure performance and track treatment outcomes. And an increasing number of physicians welcome those initiatives that improve care and help them better serve patients.

More than ever before, consumers are armed with information—on health-care plans, doctors, hospitals, nursing homes, home health care, treatment options, and medical research. The goal is to give consumers information they can act on much the way we now use online information and tools to choose, rate, or buy hotels, restaurants, travel destinations, books, movies, appliances, and thousands of other goods and services.

Notable efforts are described over the next four pages.

Comparing hospitals

Medicare already posts performance data on more than 4,000 hospitals and thousands of nursing homes, home care programs, and kidney dialysis centers. The data, at *Medicare.gov*, is a rich body of information, allowing direct comparisons between facilities. And it has become increasingly sophisticated over time. The information on hospitals, for example, includes data on:

- Complication rates for selected diseases and procedures;
- Timeliness of care;
- Readmission rates;
- Results of patient surveys.

The Choosing Wisely initiative

Do you really need that MRI? Overuse and misuse of certain diagnostic tests and treatments is one of the most costly problems in medicine.

To address this issue, over 58 medical specialty groups representing some 500,000 doctors have teamed up with the American Board of Internal Medicine (ABIM) Foundation to identify overused tests and treatments. CONSUMER REPORTS is participating in the initiative, called *Choosing Wisely*.

To date, the specialty groups have made some 150 recommendations, with about 100 more coming in 2014.

The ABIM Foundation publishes this information for doctors and other providers. CONSUMER REPORTS has produced over 70 reports for consumers, in partnership with AARP and other groups (*ConsumerHealthChoices.org*).

The reports cover a wide range of topics: brain scans for Alzheimer's disease, bone density tests, cancer screening, heart tests before surgery, testosterone treatment for erectile dysfunction, heartburn drugs, antibiotics, and X-rays or MRIs for back pain.

The ABIM Foundation and CONSUMER REPORTS urge patients to discuss the questionable tests and treatments with their doctor.

How good are physician ratings?

Be wary. On some commercial websites, ratings of individual doctors are based on just a few consumer reviews, often fewer than 10. That undermines their statistical validity. Ratings of doctors with hundreds of reviews are more meaningful. Also, physician ratings sites often yield varying "grades" for the same doctor. The Informed Patient Institute rates physician report card initiatives.

The hospital information is used by many organizations, including CONSUMER REPORTS, which distills it to help consumers choose hospitals.

The health law strengthens measurement of hospital performance. Hospitals must now report more outcome measures, and more measures of care for people with chronic diseases. More facilities have to report performance data, too. For the first time, psychiatric, rehabilitation, and cancer hospitals, as well as hospice providers, must report on their quality of care.

Comparing physicians

Choosing a doctor is one of the most important health-care decisions you have to make. Helping people do this hasn't been easy. Most people choose their doctors based on the advice of colleagues, friends, or other doctors. You may still want to get that advice, but new resources are available now, and more are coming soon.

A growing number of states, foundations, and consumer organizations have launched initiatives that compare physician groups. For example, CONSUMER REPORTS has partnered with professional medical associations and others to rate heart surgery groups nationwide and primary care doctors in California, Massachusetts, Minnesota, and Wisconsin. (At *ConsumerReports.org* click on "Health" then "Doctors & Hospitals.")

The Robert Wood Johnson Foundation describes more than 200 rating initiatives on its website, (*rwjf.org*), searchable by state. The Informed Patient Institute (*informedpatientinstitute.org*) can help guide you to the most reliable physician ratings. Several commercial sites use patient reviews to rate individual doctors nationwide. The sites are modeled on product review sites and earn money from advertising and fees for searches. Along with ratings, they provide basic information on doctors, such as age, address, credentials, hospital affiliation, and specialty. Most prominent among the sites: *Healthgrades.com*, *RateMDs.com*, *ZocDoc.com*, and *Vitals.com*.

The ACA requires the government to create a new website that will permit consumers to comparison shop for doctors nationwide based on performance measures and patient reviews. By the end of 2014, Medicare must begin posting performance ratings of physician group practices on the site, which is called Physician Compare. In years to come—when is not yet certain—the agency will have to post performance information on individual doctors. For now, the site contains a massive directory of about 900,000 providers who participate in Medicare; the list includes most of the nation's doctors. You can search for a doctor by specialty, distance from your home, and hospital affiliation.

Spotting conflicts of interest

Drug and medical-device companies often hire doctors as consultants, give them research grants, or pay them to promote products. Such relationships can foster innovations and spread knowledge, but they also create conflicts of interest. Almost all doctors receive industry gifts, including free samples of drugs. However, about 30 percent of doctors say they receive payments for consulting or to conduct research. In some cases, these payments run to tens or even hundreds of thousands of dollars per year.

Pro Publica, a nonprofit investigative journalism organization, publishes data from 15 drug companies. The companies have begun reporting their payments to doctors, either voluntarily or as part of legal agreements with the federal government after being charged with inappropriate marketing of their products. If you live in Maine, Massachusetts, Minnesota, or Vermont, your state requires drug and device companies to report payments to doctors. Those states post the information on public websites. Just enter the state's name and the phrase "drug company payments to doctors" into a search engine.

In 2014, such reporting will go nationwide. New rules in the ACA require pharmaceutical and device companies to report *all* payments or gifts to doctors that exceed $10. Dubbed the "Sunshine Act," the provision took effect in August 2013. Companies submitted the first six months of payment information to Medicare in March 2014; and it's due to be posted on the Web in a consumer-friendly format by September 30.

Comparing insurance plans

Since 2011, CONSUMER REPORTS has partnered with the nonprofit National Committee for Quality Assurance (*ncqa.org*) to publish and interpret for consumers NCQA's nationwide ratings of more than 1,000 insurance plans. NCQA rates HMOs and PPOs available through employers, the Medicare Advantage program, and Medicaid. NCQA has been accrediting health plans since 1990 and has rated them for consumers since 2005.

But it's been much harder for consumers to get reliable and independent information and ratings on insurance plans sold directly to individuals and families. That is now changing. The new state-based health insurance marketplaces established by the ACA are charged with rating the plans they offer, on services and quality of care, by 2016. Consumers can already compare premiums, deductibles, out-of-pocket maximums, and benefits among plans offered in the state exchanges.

A few states—California, Colorado, Connecticut, Maryland, Massachusetts, Minnesota, New York, Oregon, and Rhode Island—hope to be ahead of the game. They plan to display preliminary performance data on their health plans during open enrollment at the end of 2014 (for coverage in 2015). But most states are not expected to offer such information until 2016.

Eventually, the insurance exchanges are also expected to become important sources of comparative information on doctors and hospitals.

Comparing treatments

Thousands of medical research studies are published every year in the U.S. and around the world. But experts have long agreed that too few studies directly and rigorously compare treatments in ways that enable doctors and patients to make fully informed treatment decisions.

To address this critical gap, the new health law created the nonprofit Patient-Centered Outcomes Research Institute to fund research that directly compares treatments. PCORI was launched in 2010 and has spent more than $400 million on some 300 studies, with another $500 million allotted for 2014.

PCORI funding comes from federal taxes and a fee levied on Medicare, private health insurance companies, and large employers that fund their own health plans. As part of its patient-centered approach, you can use PCORI's website (*pcori.org*) to suggest the treatments you think need to be studied. PCORI will start making study results available to doctors and consumers in late 2014.

In the meantime, check out treatment guidelines and other resources available at the Agency for Healthcare Research and Quality (*ahrq.gov*).

Comparing prices

Comparing medical fees and prices is still difficult, especially compared with price shopping for almost all other goods and services. But it's getting better and it's on the right path.

Medicare has posted select information on hospital costs at *Medicare.gov* for many years. And in 2013, the agency released a large set of data on some 3,000 hospitals, listing the average charges for the 100 most common inpatient visits and for 30 types of outpatient visits. Currently, Medicare and outside groups are working to present this data in a more user-friendly way for consumers.

In April 2014, Medicare took the first steps toward releasing its vast trove of data on payments to individual doctors. Previously, the government had been prevented from releasing that data by a court decision in the 1970s protecting individual physician privacy. The decision was overturned in May 2013. Analysis of the first batch of data, by news outlets and others, yielded startling results: some 4,000 doctors received more than $1 million in payments from Medicare in 2012. Consumer groups, media, and researchers are expected to use the Medicare data to compare how often individual doctors perform certain procedures and how much they are reimbursed.

States and insurance companies are also testing ways to get price information to consumers, with mixed results to date but promise for the future. The nonprofit group Catalyst for Payment Reform, in a study released in March 2014, found that only a handful of states (Colorado, Maine, Massachusetts, Vermont, and Virginia) have provided consumer-friendly information on medical prices to consumers. The good news: many states now have laws on the books that require the release of this data.

In another study, Catalyst for Payment Reform found that almost all major insurance companies offer their enrollees online cost calculators. The study found that these initiatives vary widely, but that many enable enrollees to accurately determine their out-of-pocket costs for most services and procedures. You can also find price ranges for almost all common medical services and procedures at *Healthcarebluebook.com*.

Improving cancer treatment

A landmark 2013 report on the state of cancer care in the U.S. dramatically illustrates the need for the systemwide changes discussed in this guide. The 315-page report, published by the prestigious Institute of Medicine, is titled *Delivering High-Quality Cancer Care–Charting a New Course for a System in Crisis*.

The report concludes that cancer care is fraught with waste, ineffective treatments, fragmented care, and skewed financial incentives.

"Many cancer patients get excellent care, of course," says Dr. Patricia Ganz, director of cancer prevention and control research at UCLA's Jonsson Comprehensive Cancer Center and chair of the 17-member committee that wrote the report. "But far too many suffer needlessly from a system that does not provide consistently high-quality patient-centered care."

Among the report's recommendations:

- Provide better information to patients on treatment options and side effects;
- Focus on improving quality of life through pain management and psychological support;
- Ensure that every patient has a health professional coordinating his or her care;
- Help cancer doctors keep up with the most important clinical advances;
- Improve the affordability of cancer care by applying current payment reforms and eliminating waste.

The report also recommends tracking cancer patients' treatment outcomes much more meticulously in disease registries.

One widely touted model of such tracking is the Children's Oncology Group, a collaborative effort of some 8,000 childhood cancer doctors and researchers worldwide. Since the late 1990s the collaborative has tracked the treatment results of almost every child with cancer who enters a clinical trial. The effort is funded primarily by the National Cancer Institute. The registry is credited with helping to sharply increase five-year cancer survival rates in children—from 58 percent in 1977 to 80 percent in 2003—by identifying treatments that work.

Health care's digital revolution

Many of the initiatives discussed in this guide depend on wider use of electronic health records (EHRs) and other health information technology (HIT) tools. For example, ACOs and primary care medical homes must have EHR systems to track quality measures and communicate with patients.

Health care has lagged behind other industries in using information technology to improve products and results. That's finally changing.

The big push began in 2009 with passage of the Health Information Technology for Economic and Clinical Health Act. HITECH, which was part of the 2009 economic stimulus package, committed $30 billion to create near-universal EHR adoption in the U.S. Hospitals and doctors get direct subsidies for purchasing an EHR system if they show they have used it "meaningfully," based on a set of specific measures.

The law's effect has been dramatic. EHR systems can cost $40,000 to $70,000 for a doctor's office and many millions of dollars for a hospital. Before the law passed, only 16 percent of hospitals and 20 percent of primary care providers had a basic EHR. By 2012, 56 percent of hospitals and 44 percent of primary care providers had one. And as of February 2014, 4,711 hospitals and 355,500 doctors and other health providers had received $21.6 billion in subsidies under HITECH.

Adding up the benefits

Among those receiving EHR funds were the seven doctors at Desert Ridge Family Physicians in Phoenix. They have fully integrated an EHR into the office's clinical operations, says Dan Nelson, the practice's manager. What's more, 70 percent of their 13,000 patients are now active users of the EHR's patient portal. "And it's not just the tech-savvy folks, either," he says. "People who have chronic diseases are especially active users. The portal makes it easier for them to communicate with us." Desert Ridge's patients can see summaries of visits and lab results, request prescription refills, and e-mail their doctors.

Medicare is getting on board, too. People on Medicare can access their doctors' patient portals, but they can also download all or part of their medical records through a new "Blue Button" on Medicare's portal for beneficiaries. As of early 2014, some 900,000 Medicare beneficiaries had done so.

What's an EHR?

Electronic health records are essentially software into which data is entered. They have four broad goals:

1. **Replace paper records.** Paper files are usually incomplete, disorganized, and duplicative. And they are time-consuming to copy and transmit from place to place.
2. **Improve health-care quality.** EHRs give doctors faster, easier access to a patient's record. This improves quality of care, reduces errors and duplication of tests, and promotes better treatment decisions.
3. **Facilitate a new kind of research.** Researchers can extract information from thousands or even millions of EHRs—while protecting patient privacy—to understand disease patterns, treatment successes or failures, and provider performance.
4. **Engage consumers.** Many EHRs now have user-friendly portals where patients can access, with a password, treatment summaries, lab results, and other features.

Ideally, each of us would have a single, secure EHR for life. It would hold our complete medical history and be available anywhere at any time—for example, in an emergency room while on a trip.

Using new technology to empower patients

When Melissa Marote needs to look up the medical histories of daughters Amelia, 4, or Scarlett, 2, she pulls out her smart phone. She taps her health plan's app, enters a password, and soon finds the information she needs.

Marote is on the cutting edge of "patient informatics." "It's all literally at my fingertips," she says. Her health plan is Kaiser Permanente, a leader in EHR adoption. Kaiser, with 9.1 million members nationwide, was the first health plan in the country to build a systemwide EHR. Launched in 2004, it's still the largest nongovernmental EHR in the U.S. All of Kaiser's 16,942 doctors use it.

So do many enrollees. The EHR's portal for patients is called "My Health Manager." It now has more than 4.4 million users. In 2013, Kaiser patients used the system to view 34.5 million lab tests, fill 14.8 million prescriptions, and send almost 15 million e-mails to their doctors. Kaiser launched the mobile app version in 2012. As of early 2014, the app has been downloaded just over a million times.

Marote says she uses both the mobile app and the Web portal. "I e-mail Amelia's and Scarlett's doctor regularly and always get a pretty prompt response," says Marote, 42, who lives in Canoga Park, Calif. She also makes appointments and gets prescription refills. Kaiser says 33 percent of its primary care encounters are now made via e-mail.

Kaiser also uses its EHR to do research and improve care. One recent study found that when diabetes patients and Kaiser doctors and nurses used the EHR to communicate and track treatment progress, the patients' blood-sugar levels, cholesterol, and other vital signs improved more, compared with patients who didn't use the EHR system.

Terhilda Garrido, vice president for health information technology transformation and analytics at Kaiser, says the insurer has documented "improvements in care across the board" attributable in whole or part to its companywide EHR system. "It really is empowering patients as we hoped it would," says Garrido. "And I think the benefits are just beginning to accrue."

Obstacles remain

Challenges remain, and three loom largest.

First, consumers continue to worry about the privacy of their medical information. Compared with paper records, EHRs are exposed to more people and are more vulnerable to computer theft and hacking. Thousands of breaches have occurred. In one of the largest to date, the medical records of more than 100,000 veterans were compromised. The breaches occurred at 167 Veteran's Administration facilities between 2010 and early 2013.

Still, encryption-protected medical records are now being viewed and transmitted electronically millions of times a day in the U.S. without incident, just like banking and credit-card information. And the general consensus is that the benefits of EHRs outweigh the risks. You can read more about EHR privacy at *Healthit.gov* and *Privacyrights.org*.

The second obstacle is that many doctors are unhappy with the systems they've bought. In a 2013 study of 656 doctors, sponsored by the RAND Corporation, more than half said their EHRs had poor "usability."

Third, most EHR systems still can't talk to each other. For example, a hospital in Boston cannot access the EHR of a patient being treated at a doctor's office in Los Angeles—or vice versa. Indeed, even doctors in the same city usually can't access the records of each other's patients unless they are in the same health-care system.

Intense efforts are under way to address the problem. Some 200 initiatives around the country are knitting EHR systems into regional networks. For example, all of Delaware's doctors and hospitals can now securely access 1.7 million patient records through the Delaware Health Information Network.

The health information technology growing pains are not a surprise, and there's little doubt they'll be overcome eventually. Many experts now predict that by 2020, medical records will be almost fully electronic, with consumers having broad access to their records.

Glossary

Here are some words and phrases to help you understand the changes under way in health care. For a comprehensive health-care glossary that also includes insurance terms, go to *ConsumerHealthChoices.org/reform-glossary*.

Big data. Shorthand for the very large datasets generated by new health information technologies and analyzed with powerful computer networks and software. Big data is being used to evaluate and improve care and to empower consumers to make better health-care decisions.

Care coordination. Providers (such as doctors, physician assistants, nurses, physical therapists, nutritionists) working together, in a formal and structured way, to provide patients with the full range of needed care. Well-coordinated care has been shown to improve results and patient satisfaction and to reduce duplicate and unnecessary services.

Clinical guidelines. Standards of care based on the latest evidence and science. The guidelines aim to help doctors choose the best treatments for patients. Thousands of guidelines covering most major diseases and conditions now exist. The federal Agency for Healthcare Research and Quality (*ahrq.gov*) keeps a list.

Comparative effectiveness research. Studies that compare two or more treatments for a given disease or condition. They are designed to show as clearly as possible which treatment, if any, has better outcomes for patients. The ACA created an institute, PCORI (*pcori.org*), to fund CER.

Evidence-based medicine. Medical practice based on the latest scientific evidence and results from comparative effectiveness research. Years of research have revealed that doctors don't always base treatment on the latest evidence. EBM is attempting to change that.

Integrated health systems. Organizations of insurers or providers that agree to take full responsibility for the health of enrollees. Typically today, an integrated system takes on all or some of the financial (and insurance) risk, entering into contracts as needed with hospitals, doctors, and other providers to deliver all medical services.

Never events. Serious errors in hospitals that should never happen because they are preventable and can have dire effects, including death. The National Quality Forum lists 29 never events, such as contaminated drugs or surgery on the wrong body part.

Outcomes research. Research to determine the success or failure of a treatment from the patient's perspective. It considers the patient's full experience of care and the return to full health and normal functioning (or not) after treatment.

Overtreatment. When providers undertake treatments or perform services that are deemed useless, unhelpful, or even harmful.

Patient engagement. The push to get consumers more involved in their medical care—for example, reviewing research on treatments and discussing it with their doctors; using online ratings to choose doctors and hospitals; tracking medical records more carefully; and creating an advance directive or living will.

Reference pricing. A payment tool used to restrain health-care costs, generally those of non-urgent care. For example, experts might determine that the average or fair charge for a colonoscopy is $4,000, and set that as the reference price. If a patient then goes to a provider who charges $4,000 or less, the full cost is covered. If the provider charges $5,000, the patient pays the extra $1,000. The point: putting pressure on providers over time to lower their price at least to the reference price.

Value-based purchasing. A strategy used by employers and the government to get better value for the dollars spent on health care. It aims to hold providers accountable by measuring costs and patient outcomes, and paying providers based on their results and quality of care.

8 ways to make the health system work better for you

1 **Check medical bills** and insurance company explanation-of-benefit (EOB) forms carefully. Mistakes happen. If you see something that looks suspicious (such as charges for a test you don't think you received), call your health plan provider. If you have Medicare, call the Medicare fraud hotline (877-601-9542). Learn more at Medicare's fraud website.

2 **Compare prices for medical services** when you have to pay a substantial portion of the bill, even if most of the tab is being picked up by your insurer. Hospital and doctor fees vary widely. Find the average prices for most major medical services and procedures at *Healthcarebluebook.com* and *Fairhealthconsumer.org*.

3 **Bargain with hospitals and doctors** for reduced fees if you are paying out-of-pocket—for example, if you have not yet met your insurance deductible or a procedure is not covered by insurance.

4 **Get a surgical safety checklist** when having scheduled surgery (outpatient or inpatient), and a hospital safety checklist when you know you'll be spending time in a hospital. An Internet search on both terms will yield resources. If you need to go to the hospital, try to have a relative or friend keep close watch on your care. Mistakes in hospitals, even the best ones, can occur.

5 **Compare treatment options** with your doctor if there's more than one way to treat your condition. Ask about risks and benefits. See the resources at the Agency for Healthcare Research and Quality (*ahrq.gov*, under "for Patients and Consumers"). Also: prepare for every physician visit with notes and questions.

6 **Check out doctor and hospital ratings** and report cards online. Be cautious, however; some sites use weak methodologies to rate providers, and ratings often vary from site to site. The Robert Wood Johnson Foundation lists online provider report cards by state, and the Informed Patient Institute rates provider report cards. Also: consider rating your providers online. The more people who do this, the more reliable the ratings will become.

7 **Track your medical history** in a notebook, computer document, or file. You can do so electronically, too, through a personal health record (PHR). Find more information at *Myphr.com* or *Medicare.gov* (search for "PHR"). Also: ask your doctor if he or she has an electronic health record (EHR) with a "patient portal" that lets you look up test results and treatment plans, make appointments, fill out forms, and contact the doctor by e-mail. Know, too, that you have a legal right to your medical records and can now get them in electronic form if your doctor has an EHR.

8 **Create an advance directive** specifying the kind of care you want in case you cannot make, or become unable to make, medical decisions for yourself. And choose someone to make medical decisions for you if you become incapacitated. You can create an advance directive without hefty legal fees at sites such as *Legalzoom.com* or download your state's form free at *Caringinfo.org*.

Consumer Reports Resources

Select health insurance carefully using the ratings of almost 1,000 health plans from the National Committee for Quality Assurance that we publish and interpret. At *ConsumerReports.org,* click on "Health" then "Insurance."

Compare hospitals & doctor's groups and prepare for a hospital visit or surgery. At *ConsumerReports.org,* click on "Health" then "Doctors & Hospitals."

Check out the overused treatments & tests we examine through the *Choosing Wisely* initiative at *ConsumerHealthChoices.org.*

Compare prescription drugs at Consumer Reports Best Buy Drugs. At *ConsumerReports.org,* click on "Health" then "Drugs."

Learn about the new health-care law with Health Law Helper and our health insurance blog at *ConsumersUnion.org/topic/health-care.*

Engage in our Safe Patient Project at *SafePatientProject.org.*

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GETTING HEALTHCARE RIGHT

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