



HEALTH AFFAIRS BLOG

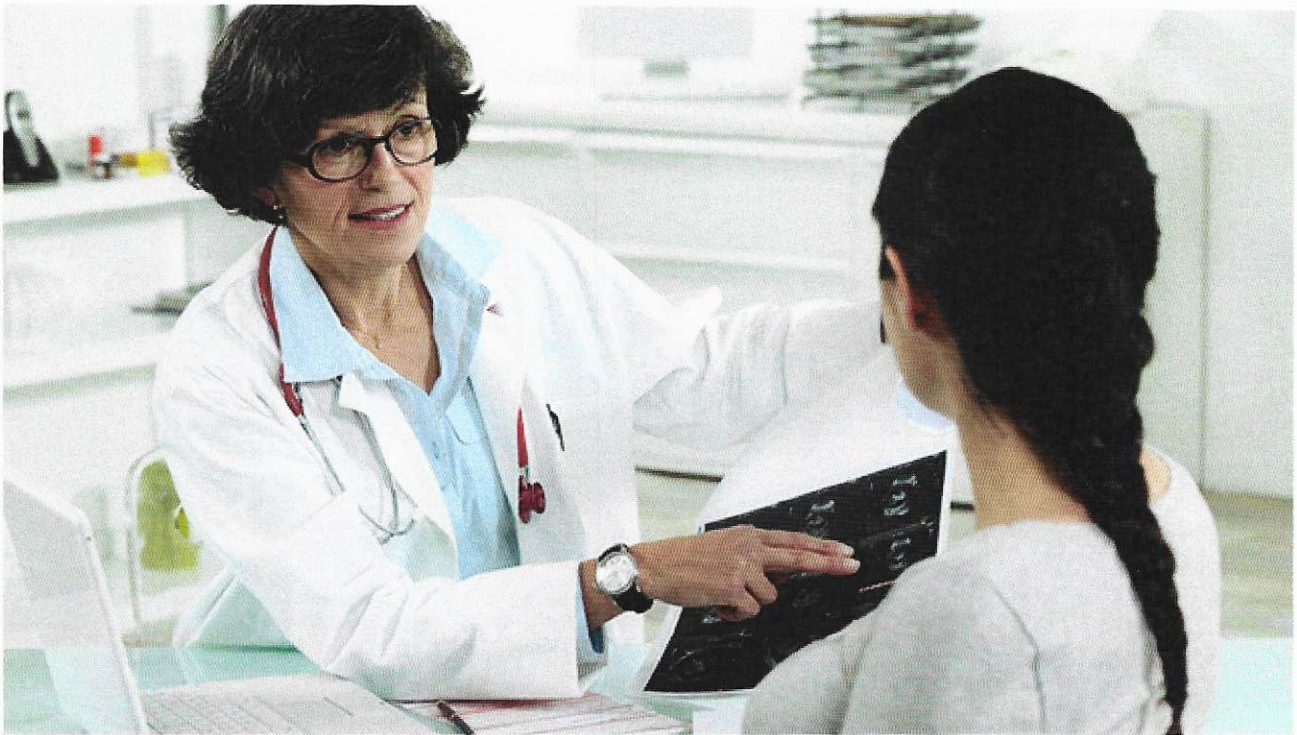
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Will Patients Be Better Consumers When They Can Access Their Health Data?

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On February 11, 2019, the Office of the National Coordinator for Health Information Technology and the Centers for Medicare and Medicaid Services released [two highly anticipated rules focused on increasing patient access to their own health information](#)—both clinical (that is, electronic medical records) and administrative (that is, health insurance claims). These rules relate to several different initiatives, including [MyHealthEData](#), [Blue Button](#), and [patient-facing application programming interfaces](#) under 21st Century Cures. They share a common goal of allowing patients to go online and download a copy of their health information for themselves or to share with others (including patient transmission of data directly to a third party).

The focus on patient data access is motivated by the hope that data access will translate into a more informed and savvy health care consumer. In theory, the information could improve quality

of care if it helps patients avoid duplication of tests and services or communicate with their providers about their medical history. Another intention is that the information will improve understanding of health and health care needs; patients could incorporate this understanding into their choices about whether and where to seek health care, as well as more broadly into behavior and lifestyle choices.

There are, of course, concomitant risks related to privacy, security, and control of data, all of which are important, frequently noted, and have an associated set of strategies to address them. Just as concerning—yet not receiving much attention—is the hand-waving concerning just how giving patients access to their health data will lead to changes in either consumption or lifestyle choices. What specific types of information are most useful to help patients be better informed consumers? How does that information need to be analyzed and presented? On these critical questions, there are few definitive, evidence-based answers.

It is critical to consider what we already know about how consumers use other types of health information, including on cost and quality differences across providers and about health behaviors, to make decisions about health and health care. Such insights offer a more concrete and realistic assessment of how to approach the new era of broad-based access to individual health information.

What We've Learned Doesn't Work

Simply providing information does not lead to “smart shopping.” Despite strong evidence that consumers care about and want more information on health care price and quality, quality report cards and price transparency tools—even when web-based and personalized—are rarely used and have not been found to influence choices. This is true even among patients who could most directly benefit from the information. For example, a recent survey found that among patients in a high-deductible health plan—a plan with strong financial incentives to choose lower-cost care—only 4 percent reported shopping and considering costs across providers.

Consumers have more experience and hold more levers that can be pulled to change their behavior or improve their health. Yet, in these contexts too, simply providing information may not change health behaviors for the better. Behavioral economics finds that consumers' continuation of “unhealthy” behaviors, such as smoking and poor nutrition, is due to challenges choosing between large but far off future benefits and smaller rewards today. In addition, consumers make different choices about treatment depending on how information is presented (for example, describing outcomes in terms of potential gains versus losses). Greater access to information is unlikely to overcome these decision-making errors.

What We've Learned Does Work

First, evidence suggests simplicity is better. Consumers make more informed choices and demonstrate greater comprehension [when the presentation of health care information is less complex](#) (for example, uses non-technical language). Second, delivering information to guide consumers through decision making when a decision is salient is helpful. A health plan was able to trigger patient switching behaviors (and cost savings) by [informing patients of lower-price imaging facilities](#) when they already had appointments with high-price providers nearby.

Finally, alignment with financial incentives matters. Patients with full insurance that requires little to no, out-of-pocket payment for care have little incentive to avoid duplicative tests. Consumers are much more likely to engage in using their health information to reduce duplication or waste if they receive some of the benefit from doing so (for example, shared savings).

Implications For Patient Access To Individual Health Information

Early signs suggest that we are not heeding these important lessons. The formatting and content of patient data available for download are not user friendly or designed explicitly for interpretability by non-clinicians. There are few tools available that take downloaded data and turn them into actionable

recommendations for patients. Finally, few patients have incentives to wade through their data and do this work on their own.

It is therefore not surprising that levels of [patient uptake of access to, and downloading of, their health data](#) are [dismally low](#). Patient data access is necessary, not sufficient, to make patients better consumers. We therefore cannot declare victory simply because we have made electronic access to individual patient data broadly available.

What Might Change This Picture?

There is great hope that patients will move from having the ability to download their data (as most now can) to be able to load the information onto their smartphones (as some now can) and ultimately connect them to apps to make the data understandable and actionable. Less than a year ago, Apple announced the ability to [link health records to Apple's HealthKit](#). Substantial growth in the availability of related apps is undoubtedly not far behind.

Smartphone apps have brought us value and profoundly changed behavior in many ways. It is exciting to think what the health-focused version of these apps might bring to patient consumption of health care and health behaviors. Moreover, consumers do not have to make all decisions on their own; clinicians could be leveraged as partners when it comes to patients navigating their data.

However, there is no clear roadmap for the unique considerations that come with the transition to the health domain and little understanding of how these tools will be used by consumers. Heeding lessons of the past could dramatically increase potential for positive results; ignoring them risks profound unintended consequences for both patients and providers.

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