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Consumer-Facing Data, Information, And Tools: Self-Management Of Health In The Digital Age

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ABSTRACT Consumers have greater access to data, information, and tools to support the management of their health than ever before. While the sheer quantity of these resources has increased exponentially over the past decade, the accuracy of consumer-facing resources is variable, and the value to the individual consumer remains uncertain. In general, the quality of these resources has improved, mostly because of improvements in web and mobile technologies and efforts to restructure health care delivery to be more patient centered. We describe the major initiatives that have led to consumers' increased access to both their own health data and performance data for health care providers and hospitals. We explore how search engines and crowdsourced review websites help and hinder the dissemination of medically accurate information. We highlight emerging examples of websites and apps that enable consumers to make medical decisions more in concert with their preferences. We conclude by describing key limitations of consumer-facing resources and making recommendations for how they may best be curated and regulated.

The doctor-patient relationship historically has been heavily imbalanced, with doctors being the sole party with direct access to patients' health and medical information about diagnoses and treatments. The maturation of electronic health records (EHRs), patient portals, and websites targeting health care consumers has led to a rapid expansion in the number and types of resources that consumers can use in making decisions about their health. At the same time, health systems are in the midst of a major cultural shift, recognizing that empowering consumers with easier access to health data, information, and tools may have a number of downstream benefits for health outcomes and satisfaction.^{1,2} As these resources become more accessible, patients can take a more active role in managing their care. Thus, patients are increasingly finding themselves in the role of consumers, where they have the opportunity (and are

often expected) to make choices about their care in partnership with providers.

In the context of health, we use the term *data* to refer to facts or observations about one or more patients, such as the results of a laboratory test. *Information* consists of data that have been aggregated or summarized in some way that makes them usable by consumers. Examples of health information include results from search engines on health topics or information about the quality and cost of care. *Tools* are interactive representations of data or information that provide a deeper level of ongoing engagement, such as consumer-facing health apps.

Consumers Have Greater Access To Their Health Data Than Ever Before

The adoption of EHRs and accompanying patient portals has greatly increased consumers' access to their own health data. The adoption of

EHRs was largely driven by financial incentives put in place by the Health Information Technology for Economic and Clinical Health (HITECH) Act, part of the American Recovery and Reinvestment Act of 2009. The incentives were designed to drive health care professionals to adopt “certified” EHRs designed to meaningfully improve patient care, although the set of functions required for certification was not defined at the outset. Discussions organized by the Consumer Engagement Workgroup of the Markle Foundation, a nonprofit organization focused on health care quality improvement and adoption of emerging technologies, led to the idea of making patient records downloadable at the click of a button.³ This idea came to be known as the Blue Button initiative. When the Office of the National Coordinator for Health Information Technology was tasked with defining functions of an EHR that would constitute “meaningful use” under the HITECH Act, the ability to view online, download, and transmit patient health data within four business days of the data being available to the provider was included as a core objective, enshrining the Blue Button initiative in national policy. Inclusion of Blue Button functionality in an EHR became a required prerequisite for health care professionals to become eligible for incentive payments, which drove EHR vendors to quickly add this functionality. The Veterans Health Administration (VHA) added the Blue Button to its patient portal in 2010. This was significant because the VHA is the largest integrated health system in the United States and does not stand to benefit from the financial incentives included in the HITECH Act. Subsequent evaluations found that a third of veterans had used the Blue Button, and that nearly three-quarters of users felt that using it helped them better understand their health.⁴ One veteran’s experience with the Blue Button illustrates its potential impact on self-management of health: “The first time I used it I was really happy because I was participating in my health care. I mean you can actually see real time what’s going on.”⁵ With the success of Blue Button as a way of downloading patient records, the focus of the initiative—now termed Blue Button 2.0—has shifted toward integrating patient records with apps to support patient care and research.⁶

Although the Blue Button initiative gave patients direct access to much of their health information,⁴ one area that this initiative avoided altogether was access to doctors’ notes because of concerns over potential negative consequences related to patients not understanding medical jargon in the notes.⁷ To explore these issues, over 100 primary care physicians at Beth Israel Deaconess Medical Center, Geisinger Health, and

Harborview Medical Center volunteered to participate in the OpenNotes demonstration project, which was designed to explore the impacts of easily accessible doctors’ notes on both the patients and providers. The project was founded by Tom Delbanco and Jan Walker of Harvard Medical School and initially funded by the Robert Wood Johnson Foundation. Surveys demonstrated that while patients favored open notes, primary care physicians’ opinions of sharing their notes varied.⁸ A follow-up quasi-experimental study evaluating the impact of OpenNotes found that “patients accessed visit notes frequently, a large majority reported clinically relevant benefits and minimal concerns, and virtually all patients wanted the practice to continue.”⁹ Through adoption by EHR vendors, over thirty-three million patients now have access to their doctors’ notes.¹⁰ Organizers of the OpenNotes demonstration say that doctors should allow patients to provide feedback on the notes to further reinforce the collaborative relationship between doctors and patients.¹¹

Patients are increasingly generating their own health data as well, ranging from step counts to electrocardiograms. Pedometry has long been available through specialized devices, but its introduction into iOS and Android smartphones in 2013 has turned most modern smartphones into relatively accurate pedometers.¹² In 2014 Apple’s HealthKit enabled apps to store, access, and exchange tracked health data directly on the iOS operating system. This is particularly beneficial for consumers using digital health-oriented devices such as weight scales and glucometers. These devices typically share their data wirelessly with companion smartphone apps using Bluetooth, and easing information exchange between apps makes it possible for one app to provide medical advice based on a measurement taken by a different app.

More advanced medical sensing capabilities are also being incorporated into consumer-friendly devices. In 2012 AliveCor released a smartphone case—approved by the Food and Drug Administration (FDA)—with the capability of measuring a single-lead electrocardiogram for the identification of cardiac arrhythmias. In November 2017 this functionality was extended to smartwatches when KardiaBand became the first FDA-approved medical device accessory for Apple’s smartwatch for the detection of atrial fibrillation.¹³ In less than a year Apple integrated this functionality directly into its smartwatches alongside other health-oriented functionality enabling the detection of falls.¹⁴ Thus, smartwatches appear poised to give consumers access to health data that previously required specialized medical devices.

Online Tools Make Accurate Health Information More Accessible To Consumers

The internet has long been a source of health information for consumers. Although the beginnings of this phenomenon are not well documented, the Pew Research Center's first poll on the subject, conducted in 2000, found that 55 percent of internet users had searched for health information online at a time when only 43 percent of Americans had used the internet.¹⁵ By 2013, 59 percent of US adults had searched for health information online, and 77 percent of such searches began on a general web search engine such as Google or Bing.^{16,17} The phrase "Dr. Google" has been used to describe the phenomenon of relying on a general search engine to find health information.¹⁸ In 2013 over a third of US adults reported going online to determine what medical condition they or someone else might have.¹⁷

Over the past twenty years a number of specialized search engines have also been developed to help patients understand and make decisions based on the quality and cost of care. Hospital Compare was developed in 2002 by the Centers for Medicare and Medicaid Services (CMS) to help patients select hospitals.^{19,20} Since Hospital Compare's inception, its scope has expanded to include process outcomes, patient satisfaction measures, readmission rates, and surgical outcomes. Hospitals are incentivized to measure and report these data to CMS through the Hospital Value-Based Purchasing Program, which rewards hospitals for strong or improving performance on a variety of quality measures. The *U.S. News and World Report* hospital rankings use this data along with Medicare administrative claims data, American Hospital Association Annual Survey data, and publicly available clinical registry data to rank hospitals across multiple specialties.²¹ There is mounting evidence that websites such as Yelp, where consumers rate restaurants and other businesses, may be useful in measuring aspects of hospital quality directly relevant to patients. Studies evaluating both the Yelp star ratings as well as the textual content of Yelp reviews found significant correlations with items in the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey, which is used by Hospital Compare to provide a consumer perspective on hospital quality.²²⁻²⁴ In 2015 the nonprofit organization ProPublica released a surgeon scorecard to help consumers compare case volume and complication rates for individual surgeons across a large spectrum of surgeries.²⁵ In contrast to other data-driven review sites, the ProPublica scorecard was notable because it enabled consumers to com-

The largest area of growth is the development of interactive apps and websites that enable consumers to directly participate in self-management.

pare individual physicians.

A number of search engines also focus on price transparency in health. Individualized price information is often difficult for consumers to obtain because costs are often negotiated between providers, hospitals, and insurance companies, and these vary by region. Well-known resources for comparing prices include Healthcare Bluebook, which provides price information for procedures; FAIR Health, which uses billed records to estimate medical and dental costs; Amino, which uses claims data from both private and government insurers to estimate procedure costs; GoodRx and Blink Health, which provide price information on generic prescription medications; ClearHealthCosts, which was created by journalists and draws from a combination of cash, government, and crowdsourced prices; and Guroo, which provides national, state, and local cost and quality information for common health conditions and services.²⁶⁻²⁸ Search engines for prescription medications have emerged as a result of both the rising popularity of online shopping and the opaque pricing at retail pharmacies.²⁹

Interactive Tools Have Potential To Transform How Consumers Manage Their Health

The largest area of growth in digital health in the past five years is the development of interactive apps and websites that enable consumers to directly participate in self-management. A Pew Research Center survey conducted in 2012 revealed that 69 percent of US adults keep track of at least one health indicator (such as weight, diet, exercise routine, and symptom), and 21 percent of those who track indicators do so using some

Consumer-facing websites focused on health have evolved to engage patients in receiving and providing peer support.

form of technology.³⁰ The number of health-related mobile apps is steadily rising and now exceeds 318,000.³¹ Smartphone apps are uniquely positioned to affect consumers' management of their health because they are often within physical reach; are constantly connected to the internet; and can provide real-time notifications to the consumer, thus enabling a real-time feedback loop. These apps are more accessible than ever, as over three-quarters of Americans own smartphones, and smartphone ownership is rising among older adults (46 percent among people ages sixty-five and older) and people with low household incomes (67 percent among households earning less than \$30,000 per year).³² Populations targeted by these apps span the spectrum of high-need, high-cost populations, with functionalities ranging from educating patients and tracking health measures to rewarding users for good health behaviors.³³ Examples of health-oriented apps rated highly by consumers include MyFitnessPal, Mango Health, Lose It!, and the mySugr Diabetes Tracker Log. The most robust literature supporting the role of apps in patient care is in diabetes mellitus, where apps have been shown to reduce hemoglobin A1c in randomized controlled trials.^{34,35}

Consumer-facing websites focused on health have also evolved to engage patients in receiving and providing peer support. Patient-led communities and support groups are proliferating through specialized platforms (such as Patients-LikeMe) and traditional social media (for example, Facebook groups).^{36,37} Patients using such platforms have reported a number of benefits, including feeling better informed on choice of treatments and side effects.³⁶ A minority of patients with mood disorders reported that use of a peer support platform led to decreasing hospitalizations. This finding, although preliminary and in need of further confirmation, is consistent

with published literature showing that peer support workers may reduce hospital admissions.³⁸

Shared decision making, an activity that usually involves a significant time commitment by providers,³⁹ is also becoming streamlined through implementation via online platforms. Shared decision making involves clinicians and patients working together to develop a care plan informed both by patients' priorities and medical evidence. Shared decision making is most relevant to decisions among multiple medically appropriate treatments with different risk-benefit profiles. A prototypical example of this is prostate cancer, where the decision to treat with surgery or radiation or to monitor the disease depends on a variety of patient factors. The Personalized Patient Profile (P3P) is a platform for shared decision making that helps men newly diagnosed with prostate cancer choose among surgery, radiation, or watchful waiting based on their priorities and preferences.^{40,41} Other examples of tools for shared decision making include decision aids for the primary prevention of heart disease and the choice of dialysis modality for end-stage kidney disease.^{42,43}

Limitations Of Digital Consumer Health Resources

In the face of remarkable growth in the digital data, information, and tools available to consumers, these resources have limitations with important societal implications.

Patient portals have lowered the barrier for consumers to access their health data, but the portals' use is not clearly linked to impacts on health outcomes, costs, and use of health services.⁴⁴ A systematic review identified twelve randomized controlled trials of patient portals that spanned several patient populations (that is, people with diabetes, heart failure, hypertension, or depression and those who used preventive services) with mixed results. While use of a patient portal alone did not consistently demonstrate health benefits, the small number of studies that combined case management with portal use did show benefits.⁴⁴ Given that patients' interest in and ability to use portals is linked to multiple demographic factors, using portals to engage patients could worsen disparities in care.⁴⁵ A systematic review found that patients who are younger than age thirty-five, members of ethnic minority groups, healthier, or less educated are the least likely to use patient portals, whereas people with disabilities and chronic conditions, frequent users of health services, and caregivers of elderly parents or children are the most likely to use them.

Managing consumer-generated data in patient

portals is another potential problem. In October 2014 Epic Systems, the largest EHR vendor in the US, integrated its MyChart patient portal application with Apple's HealthKit. Duke University and Mayo Clinic are known to be using the HealthKit functionality in conjunction with the MyChart patient portal app, but most health systems are still grappling with whether to integrate this consumer-generated data into the EHR when it may be inaccurate and disrupt the clinical work flow.^{46,47} Instead of waiting for health systems to figure out how to integrate consumer-derived data into the EHR, Apple is bringing the EHR data directly to consumers: In March 2018 Apple announced that thirty-nine hospitals would be integrating their EHRs directly into consumers' iOS devices.⁴⁸

The role of search engines as initial and sometimes final sources of health information is another area of concern. Searches have the potential to harm consumers if search results are inaccurate or misleading, and the term *cyberchondria* has been used to describe an inappropriate escalation in patients' health concerns resulting from a web search.⁴⁹ Focusing on the worst case at the expense of the commonplace is one of the core conundrums in the realm of consumer-facing data and information. Another problem lies in lay interpretation of scientific information. Google has been combating this problem by partnering with Mayo Clinic and other health partners. Since mid-2016 searching on Google for symptoms or medical conditions results in the display of reputable Mayo Clinic-derived health information alongside the usual search results.⁵⁰

While public quality reporting is well intentioned, the caveats associated with each of the quality-reporting tools might not be sufficiently communicated to consumers. For instance, the star rating system used by Hospital Compare may penalize hospitals that serve people of lower socioeconomic status, who have worse health outcomes compared to people of higher socioeconomic status.⁵¹ Linking hospital payments to quality measures has the potential to disproportionately affect vulnerable populations by penalizing the hospitals that serve them, further marginalizing these populations.

Another example comes from ProPublica, whose ratings have problems with both validity and reliability. Patients cannot make an informed decision when the underlying information is inaccurate.⁵²⁻⁵⁴

Issues of transparency also extend to proprietary algorithms and decision tools that drive decisions about health care and insurance. For instance, a patient's health insurance rate may be determined by an algorithm, and the factors

considered by the algorithm could have large impacts on the patient's premium. In Europe the General Data Protection Regulation mandates a "right to explanation" for algorithms that have a substantial effect on users, giving consumers a right to know how the algorithm works and to potentially opt out.⁵⁵ No such regulation exists in the United States.

Providers' attempts to identify high-quality health tools for patients have been a challenge. Prior efforts to curate digital tools have largely failed to increase physicians' adoption of high-quality tools in their practices. A recent effort led by the American Medical Association, the Healthcare Information and Management Systems Society, the American Heart Association, and the DHX Group is attempting to tackle this problem through the formation of a group called Xcertia.⁵⁶ In 2018 Xcertia released preliminary guidelines for app privacy and security, and the group plans to finalize these and release app content, operability, and usability guidelines in 2019.^{57,58}

Recommendations For Addressing Limitations And Risks In Digital Resources

Addressing the limitations and risks in consumer-facing digital resources should be a priority. The Federal Trade Commission (FTC) regulates deceptive claims, while the FDA regulates apps that function like medical devices. Much else can be done to improve the usefulness and safety of digital resources for consumers.

Health systems should integrate consumer-generated data into their EHRs, giving priority to data elements most likely to benefit patients' health. Health systems should transparently report quality measures directly to consumers to alleviate concerns about inaccurate data being used by public reporting websites. The FTC should take a more active role in the enforcement of its existing authority through the FTC Act (signed into law in 1914 and since amended) pertaining to misleading claims made by app developers. Guideline-making bodies should include examples of apps or tools to engage consumers in the implementation of recommendations related to the tracking of health information. The rationale underlying these recommendations is in the online appendix.⁵⁹

Conclusion

Newly empowered through data, information, and tools, consumers are better able to monitor their health and engage health care providers in informed discussions about their care. As

patients increasingly exercise their autonomy in medical decision making as a result of more readily available resources, health professionals have a duty to support consumers in ways that go well beyond the bedside. While access to digital consumer resources is steadily growing, a culture shift will be required—particularly among health professionals—before consumers and patients

fully realize the benefits. This culture shift will need to occur in several different areas, including the integration of consumer-generated data into clinical care, embracing transparency around quality of care, and health care providers' curation of tools that consumers can use to follow through on health-focused recommendations. ■

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Appendix

Recommendations for Addressing Key Gaps in Consumer Resources and Rationale

We propose 4 recommendations to address some of the key gaps we have highlighted in the availability and quality of consumer resources.

1. Health systems should integrate consumer-generated data into the EHR, giving priority to data elements most likely to benefit patients' health.

Health systems are struggling with how to integrate consumer-generated data into the EHR due to workflow concerns. However, health systems are already well-equipped to monitor certain types of health information in high-risk populations where that information is likely to result in action (e.g. daily weight monitoring in congestive heart failure patients may lead to changes in diuretic dosing). Giving high priority to integration of consumer-generated data in these specific patient populations is likely to cause the least amount of workflow disruption with the greatest amount of patient benefit.

2. Health systems should transparently report quality measures directly to consumers to alleviate concerns about inaccurate data being used by public reporting websites.

One of the biggest concerns with sites that publicly report on physician- and hospital-level quality is that they are based on incomplete, flawed, or incorrect data. This is a valid concern in light of previously noted problems with ProPublica's surgeon scorecard. Health systems have granular access to their own health outcomes data across all payers but typically do not make this data available public in a systematic way. Health systems are well-equipped to report the overall performance and physician-level performance on quality measures directly to consumers. In the face of inaccurate publicly available information, health systems should directly report this information to consumers.

3. The Federal Trade Commission (FTC) should take a more active role in the enforcement of its existing authority through the FTC Act pertaining to misleading claims made by app developers.

With the 21st Century Cures Act removing the FDA's regulatory authority over informational apps, the FTC is the sole national governmental body with the authority to address apps making deceptive or misleading medical claims. While the FTC has exercised this authority on rare occasions as described above, the lack of strong enforcement in the face of exponential growth in health-oriented apps may lead to problems with misinformation akin to "fake news," which could have devastating health consequences.

4. Guideline-making bodies should include examples of apps or tools to engage consumers in the implementation of recommendations related to the tracking of health information.

Prior efforts focused on curating apps have not involved medical professional groups or patient groups in a meaningful way. Medical guidelines focused on managing conditions such as hypertension, diabetes mellitus, and depression rely on repeated measurements of disease markers over time (e.g. blood pressure, glucose, and depression symptom assessments), most of which are collected by patients directly. Since guideline-making bodies have a large influence over how diseases are generally treated based on available evidence, they are also well-positioned to influence more specifically how the guidelines are implemented. When a guideline relates to the tracking of health information that could be done by a consumer directly, guideline-making bodies should strongly consider giving specific examples of apps that could be used by consumers to perform the desired action. This should involve input from relevant medical professional groups and patient advocacy groups.

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