From Electronic Health Records to Digital Health Biographies

Robert F. Graboyes and Darcy N. Bryan, MD

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George Mason University

3434 Washington Blvd., 4th Floor, Arlington, Virginia 22201
www.mercatus.org

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ABSTRACT

Electronic health records (EHRs) are widely perceived as having great potential for improving the quality of healthcare and diminishing the costs of that care. Present-day EHRs, however, are widely perceived as disappointing. Many doctors consider them time- and money-wasting nuisances that interfere with their interactions with patients. This paper explores how and why potential and reality diverge. We lay out a dozen broad principles for creating a new generation of EHRs that fulfill their long-hypothesized promise. To emphasize the magnitude of the difference between our proposal and today's EHRs and to simplify the narrative, we use the label "digital health biographies" (DHBs) for the alternative we envision.

JEL codes: I1, O2, O3

Keywords: technological innovation, doctors, medical care, electronic health records, EHR, electronic medical records, EMR, patient data, decentralization, HITECH Act, health care, healthcare, digital health

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Electronic health records (EHRs) are widely touted as critical for improving healthcare in this century. Enthusiasts predict that they will help lower the costs of healthcare and improve its quality. There is widespread sentiment, however, that today's EHRs are doing precisely the opposite: increasing costs and detracting from the quality of care. Our purpose here is to investigate this divergence of promise and reality and to offer an alternative vision. To differentiate our vision qualitatively from the reality of today's EHRs (and for brevity in differentiating the two in writing), we use the label "digital health biographies" (DHBs) for our hypothetical health data system.

We note here that we have deliberately chosen to refer to current technology as "electronic health records" rather than the similar term "electronic medical records" (EMRs). There is no universal agreement about the distinction between the two terms, and in fact they are often used interchangeably. But EMR is generally a narrower term, describing the record of a clinical visit—a record that is accessible only by clinicians. EHR often describes a broader concept—records that encompass data collected outside the clinician's purview and perhaps offer advice directly to patients.

The federal government's health information technology website sets out a basic vision of what EHR proponents hope to gain from the technology:

> Medicine is an information-rich enterprise. A greater and more seamless flow of information within a digital health care infrastructure, created by electronic health records (EHRs), encompasses and leverages digital progress and can transform the way care is delivered and compensated.[1]

Congress attempted to give EHRs a significant boost in the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009—a component of the American Recovery and Reinvestment Act of 2009 (ARRA),

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[1] "Benefits of Electronic Health Records (EHRs)," HealthIT.gov, last updated July 30, 2015.

commonly known as the stimulus.[2] Many physicians subject to the HITECH Act's strictures, however, did not see EHRs in this positive light.

A high percentage of doctors view EHRs as costly, burdensome distractions that interfere with the doctor-patient relationship and make the practice of medicine less desirable.[3] Tending to EHRs may occupy half the time or more during a typical primary care visit, interfering repeatedly with the doctor's concentration and rapport with the patient.[4] This is time that the doctor would otherwise spend examining, observing, analyzing, conversing with, and empathizing with the patient.[5] After a long day of seeing patients, physicians typically spend even more time checking the data entered over the day to ensure regulatory compliance.[6] Owing to EHRs, doctors see themselves as reduced to data-entry and clerical functions.

Compounding the problem are the aesthetics of present-day EHRs. The systems often feature unpleasant color schemes, unappealing fonts, and arrays of tedious drop-down menus.[7] While these complaints may sound trivial, there is good reason why non-EHR software companies devote enormous resources to visual characteristics of their products. Interacting for half a day with an eye-straining screen can take a psychological toll on a practitioner. Indeed, it is not unusual to hear EHRs cited as a reason for doctors' retirement.[8]

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[2] Pub. L. No. 111-5, 123 Stat. 115 (2009).

[3] See, for example, Donna Marbury, "EHRs Distracting Physicians from Patient Encounters, Study Says," *Medical Economics*, February 3, 2014.

[4] Gregory Twachtman, "Study: One Hour with Patients Means Two Hours on EHR," *Family Practice News*, September 11, 2016.

[5] Onur Asan, Paul D. Smith, and Enid Montague, "More Screen Time, Less Face Time—Implications for EHR Design," *Journal of Evaluation in Clinical Practice* 20, no. 6 (2014).

[6] Two excellent essays on the promise and failure of EHRs are K. Patrick Ober and William B. Applegate, "The Electronic Health Record: Are We the Tools of Our Tools?," *The Pharos*, Winter 2015; and Richard L. Byyny, "The Tragedy of the Electronic Health Record," *The Pharos*, Summer 2015.

[7] Svetlana Lowry et al., "Technical Evaluation, Testing, and Validation of the Usability of Electronic Health Records," *National Institute of Standards and Technology* 7804 (February 2012). See also President's Council of Advisors on Science and Technology, *Report to the President: Realizing the Full Potential of Health Information Technology to Improve Healthcare for Americans: The Path Forward* (Washington, DC: President's Council of Advisors on Science and Technology, 2010), 10. "The current structure of health IT systems makes it difficult to extract the full value of the data generated in the process of healthcare. Most electronic health records resemble digital renditions of paper records. This means that physicians can have trouble finding the information they need, and patients often wind up with poor access to their own health data and little ability to use it for their own purposes. . . . Market innovation has not yet adequately addressed these challenges to the usability of electronic health records."

[8] For example, see Kristen Schorsch, "This Is the Reason Your Doctor Might Retire Early," *Crain's Chicago Business*, April 26, 2014.

A fundamental reason for doctors' dissatisfaction is that today's EHRs are designed neither for them nor for their patients. The primary beneficiaries of today's systems are arguably financial stakeholders—insurers and administrators. Patients are even more distant from EHRs than their doctors, and the typical patient has little awareness of or access to his or her own EHR data.[9]

We believe shifting away from EHRs and toward DHBs is important for a variety of reasons. First, EHRs are not fulfilling their promise. They are not lowering the costs of care,[10] nor are they markedly improving its quality.[11] The anticipated EHR benefits of coordinated care have yet to be realized because of significant barriers to health information technology interoperability.[12] Second, today's EHRs, as we have noted, are doing actual harm—distracting doctors from patients and lessening doctors' enjoyment of medicine as a profession. They impose significant costs on healthcare with insufficient return. Third, doctors' distaste for EHRs may be souring physicians on digital technologies in general at a time when digital technologies are offering new and promising modalities of care. And fourth, focusing on DHBs instead of EHRs could potentially compound the therapeutic and economic benefits of emerging digital technologies.

In other words, EHR enthusiasts and detractors both have valid points, because the EHRs physicians encounter today bear little resemblance to the type of system that technologists envision.

In this paper, we hope to reach a number of different audiences. Physicians need to understand that EHRs offer enormous promise and that the EHRs of the future need not resemble those of today. Policymakers need to gain an appreciation for spontaneous, competitive, voluntary development of EHRs—and an understanding of the pitfalls of micromanaging the process. The information technology community needs to think outside the box—to envision the EHRs of the future, rather than tweaking those of the present. And the general public

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[9] Michael Furukawa et al., "Despite Substantial Progress in EHR Adoption, Health Information Exchange and Patient Engagement Remain Low in Office Settings," *Health Affairs* 33, no. 9 (2014).

[10] Julia Adler-Milstein, Carol E. Green, and David W. Bates, "A Survey Analysis Suggests That Electronic Health Records Will Yield Revenue Gains for Some Practices and Losses for Many," *Health Affairs* 32, no. 3 (2013); Neil Fleming et al., "The Impact of Electronic Health Records on Workflow and Financial Measures in Primary Care Practices," *Health Services Research* 49, no. 1 (2013).

[11] Hospital EHRs are in some ways qualitatively different from those found in physicians' offices but suggest the potential benefits of the latter. An example is Cerner's St. John Sepsis Agent, described in Robert F. Graboyes, "Passion, Persuasion and Serendipity in Innovation—St. John Sepsis Agent," *Inside Sources*, December 21, 2016.

[12] Jonathan Perlin, "Health Information Technology Interoperability and Use for Better Care and Evidence," *JAMA* 316, no. 16 (2016).

must see how EHRs, when set up properly, can give them greater control over their own health and care.

“With the advent of EHRs, physician-patient communication has eroded as doctors spend a significant amount of time facing a computer screen rather than actively listening to their patients and observing deeply meaningful nonverbal cues.”

PATHOLOGY OF ELECTRONIC HEALTH RECORDS

To understand where EHRs stand today, it helps to understand where, when, and why they originated. One of the first medical records taught surgical techniques and was written on Egyptian papyrus around 1600 BC.[13] For the next 3,500 years, doctors wrote case histories, mostly for themselves and for their students. In other words, these histories were written for practitioners alone, and not for outside observers. The purpose of medical records changed around the 1880s, when administrators at New York Hospital, motivated by concerns about the medical record as a legal document in insurance and malpractice cases, began to supervise records’ quality and content.[14] From that point forward, the structure and function of the medical record became increasingly influenced by third parties. Patients, however, were not consulted about the use of their medical records.

The third-party focus of EHRs was arguably codified by the 2009 passage of the federal HITECH Act, which financially supports EHRs as a means of achieving improvements in healthcare costs and quality through “meaningful use” mandates.[15] While EHRs may serve the needs of healthcare managers and administrators, they are not well aligned with the needs of healthcare providers or patients.[16] One 2003 study estimated that, by adopting EHRs, a healthcare organization providing ambulatory primary care

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[13] Qais Al-Awqati, “How to Write a Case Report: Lessons from 1600 B.C.,” *Kidney International* 69, no. 12 (2006).

[14] Richard F. Gillum, “From Papyrus to the Electronic Tablet: A Brief History of the Clinical Medical Record with Lessons for the Digital Age,” *American Journal of Medicine* 126, no. 10 (2013).

[15] David Blumenthal and Marilyn Tavenner, “The ‘Meaningful Use’ Regulation for Electronic Health Records,” *New England Journal of Medicine* 363, no. 6 (2010).

[16] The awkward rigidity of electronic health records’ structure and function harks back to the minutely controlled etiquette of Louis XIV’s court.

stood to benefit $86,400 per primary care physician in savings over three years through decreased laboratory testing, the prevention of medication errors, and improved billing capture.[17] Meanwhile, EHRs have been funded by laying off clerks and transcriptionists, thereby transferring the clerical burden to physicians by requiring self-entry of notes, orders, and billing.[18] Doctors are burning out under the heavy load of new administrative tasks without reaping any economic benefits.[19]

As Marshall McLuhan stated, "The medium is the message." In the case of medical records, the EHR profoundly shapes the doctor-patient encounter. With the advent of EHRs, physician-patient communication has eroded as doctors spend a significant amount of time facing a computer screen rather than actively listening to their patients and observing deeply meaningful nonverbal cues. In turn, patients' satisfaction declines as they fail to feel respected and valued during interactions with their doctor. For many patients, EHRs are an inaccessible benefit. As physicians meet the administrative obligations of electronic documentation, patients' narratives of illness and how it affects their lives are lost.[20] Harvard business professor Clayton Christensen has shown that disruption in any industry will arise from those least served by the current paradigm.[21] In the case of healthcare, the most underserved stakeholder is the patient. Thus, patients will likely be the most supportive of any new technology that improves their health and increases their autonomy.

THE ETHOS OF THE INTERNET

The internet's development was inspired in the 1960s by Cold War fears of nuclear war. Defense officials feared that a command-and-control center might be knocked out early, rendering the military unable to coordinate the use of its nuclear arsenal. Fears of total destruction gave rise to a new ethos of decentralized communication, where hierarchies are flattened and power is placed at the level of the user. No single facility would be essential to military operations.

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[17] Samuel J. Wang et al., "A Cost-Benefit Analysis of Electronic Medical Records in Primary Care," *American Journal of Medicine* 114, no. 5 (2003).

[18] Tait D. Shanafelt et al., "Relationship between Clerical Burden and Characteristics of the Electronic Environment with Physician Burnout and Professional Satisfaction," *Mayo Clinic Proceedings* 91, no. 7 (2016).

[19] Shanafelt et al., "Relationship between Clerical Burden and Characteristics of the Electronic Environment."

[20] Beth Lown and Dayron Rodriguez, "Lost in Translation? How Electronic Health Records Structure Communication, Relationships, and Meaning," *Academic Medicine* 87, no. 4 (2012).

[21] Christensen is credited with coining the term "disruptive innovation" in 1995.

This new network would be cheap, free of central administrative censorship, and resilient to system failure.[22] To put it in the vernacular, the military would no longer be putting all its eggs in one basket.

The success of the internet's development hinged on the US military's willingness to provide funding to outside research institutions while ceding direct government control over the research itself. The sustaining values of openness and interdisciplinary study can be found in the 1945 seminal report *Science: The Endless Frontier*,[23] which laid the foundations for the creation of the RAND Corporation and the National Science Foundation. Subsequently, in the 1990s, the federal government relinquished control over ARPANET, the internet it had created, and offered a standard protocol for data exchange that was both universally available and entirely voluntary. A further blossoming of entrepreneurial software development saw competition spur the creation of better, more intuitive products for use on the new network, greatly benefiting consumers.

The relative freedom that characterized the internet's development can be contrasted with the development of the telephone industry. In the early 1900s, AT&T successfully argued for the creation of a government-sanctioned monopoly under the regulation of the Federal Communications Commission. Its 1908 marketing slogan was "one policy, one system, universal service."[24] Not until a 1975 ruling against AT&T by the Federal Communications Commission would consumers be allowed to attach whatever device they wished to the telecommunications network.[25]

Like the telecommunications industry, the healthcare sector is heavily regulated, and political pressure to give it public utility status invites still greater regulation. Policy and legal barriers have significantly contributed to EHRs' failure to achieve the goals of cost reduction and quality improvement in healthcare. A major cause of this failure is a lack of accessibility, functionality, and interoperability in health information technology. Unlike the seamless platform of the internet, healthcare information is siloed across a diverse array of institutions. This lack of interoperability significantly inhibits healthcare coordination,[26] resulting in lost opportunities for cost reduction and quality improvement. As an example of unintended policy consequences, a 2009 public

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[22] Johnny Ryan, *A History of the Internet and the Digital Future* (London: Reaktion Books, 2010).

[23] Vannevar Bush, *Science: The Endless Frontier* (Washington, DC: US Government Printing Office, 1945).

[24] Tim Wu, "The Great American Information Emperors," *Slate*, November 7, 2010.

[25] 47 C.F.R. Part 68.

[26] Lipika Samal et al., "Care Coordination Gaps Due to Lack of Interoperability in the United States: A Qualitative Study and Literature Review," *BMC Health Services Research* 16 (2016): 143.

policy study published in *Management Science* finds that the presence of privacy regulation inhibits technology adoption by hospitals.[27]

The historical model furnished by contrasting the decentralized internet with the telephone industry monopoly provides a useful template for policymakers. Time and again history shows that regulations smother innovation, inhibit competition, drive away investment, and ineffectively predict the future direction of technological change.[28] Government policies repeatedly are made obsolete by unpredictable changes in market structure driven by innovations. The impact of technology on medicine will be no different, with digital health biographies one component of a seismic shift away from traditional institutional hierarchical control and toward a more patient-centric market.[29] The values of openness, transparency, and democratization of information—which have sustained the internet—must be considered in future policy decisions regarding patients' autonomy over their health records.

TOWARD DIGITAL HEALTH BIOGRAPHIES

We offer here a dozen general principles for the structure, ownership, and uses of digital health biographies. In a later, expanded paper, we intend to offer a more comprehensive and detailed set of principles. One reason for writing this briefer document is to generate discussions and questions that will feed into this later, larger document.

1. As a default, patients, not doctors, should own the DHBs and the data contained within them.

As of August 20, 2015, there was only one state out of the 50—New Hampshire—where patients owned their own medical data. In 21 states, the data belonged to hospitals or physicians. Laws in the other 28 states left ownership unspecified.[30] Some states guarantee patients access to their data, but other states do not. As patients move from provider to provider throughout their lives, they leave vital,

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[27] Amalia Miller and Catherine Tucker, "Privacy Protection and Technology Diffusion: The Case of Electronic Medical Records," *Management Science* 55, no. 7 (2009).

[28] Ev Ehrlich, "A Brief History of Internet Regulation" (Policy Memo, Progressive Policy Institute, Washington, DC, March 2014).

[29] Jonathan Sallet, "The Creation of Value: The Broadband Value Circle and Evolving Market Structures" (working paper, 2011).

[30] George Washington University's Hirsh Health Law and Policy Program and the Robert Wood Johnson Foundation, "Who Owns Medical Records: 50 State Comparison," *Health Information & the Law*, last updated August 20, 2015.

potentially life-saving data behind—often irretrievably.[31] (There may be specific situations in which patients voluntarily forfeit access to organizations that accumulate portions of their data.)

2. Each patient should have precisely one DHB.

In keeping with the history of medical record development, today's EHRs are organized around the provider, not the patient. Hence, one patient's electronic health data are strewn across an array of providers. There is no venue where the whole of a patient's data comes together. So individual providers have no way to assemble a relatively complete picture of a patient's health status—a picture that includes past treatments, family history, genetic information, biometrics taken during a doctor visit, and biometrics gathered between visits (e.g., daily weight and blood pressure measurements, data from health tracker devices, everyday patient concerns).

3. A patient's DHB should incorporate data from multiple providers—primary care physicians, specialists, hospitals, nurse practitioners, emergency rooms, pharmacists, therapists, and so on.

Ideally, a DHB would accumulate a given person's data from cradle to grave, from location to location. (One can imagine it structured something like a wiki.) When a patient lies unconscious on an emergency room gurney, the attending physicians ought to have immediate access to childhood data that might be key to the patient's survival. Of course, the system must be designed to extract only the data of immediate interest, with more available upon request.

4. The DHB should also incorporate data from wearable telemetry such as Fitbits, insulin pumps, and heart monitors.

One of the authors of this article (Robert) experienced a single episode of atrial fibrillation. Afterward, he began wearing a Fitbit Charge[32] that records his heart rate nearly 24 hours a day (as well as recording sleep patterns and other data). In addition, he carries an AliveCor Kardia[33]—a smartphone-based device that performs an electrocardiogram in 30 seconds. His phone now carries nearly a year of data, and he periodically shares printouts with his primary care physician and cardiologist. But neither doctor has access to those readings on a regular

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[31] An outstanding article on this point is Leonard J. Kish and Eric J. Topol, "Unpatients—Why Patients Should Own Their Medical Data," *Nature Biotechnology* 33 (2015).

[32] Fitbit charge product page, accessed October 10, 2017, https://www.fitbit.com/charge.

[33] Kardia Mobile product page, accessed October 10, 2017, https://www.alivecor.com/en/.

basis, and the data are not organized for easy access. As the "internet of things" burgeons, individuals will possess treasure troves of data on themselves—data that will never be available to providers through current EHRs.

5. The DHBs should incorporate subjective data entered by patients, including family history, childhood illness recollections, fears, and feelings.

Individual patients possess great amounts of information on themselves, clues to their health that are mostly lost or forgotten over the course of time:[34] an allergic reaction at age 4, a grandmother's breast cancer 50 years ago, a powerful medication taken in sixth grade, a period of depression-like symptoms in college, a long-term cycle of weight gain and loss. Patients should have the capacity to enter information into their own DHBs—with the source of the information clearly discernible to a provider accessing the data.

6. To the greatest extent possible, data entry should use natural language (ordinary spoken or written sentences) rather than structured queries (such as drop-down menus).

One reason current EHRs are so wearying for practitioners is that data are entered in ways that are remote from natural speech or thought processes. The software requests highly standardized data rather than possibly idiosyncratic information from the physician's observation. The need to conform to the software's queries may force the provider to follow suboptimal patterns of observation—a constant distraction during the physician-patient encounter.[35]

7. Machine learning capabilities should extract and organize output for specific users, limiting the output as much as possible to the needs of each specific provider or of the patient.

The total data from an individual's life is enormous. No provider ever needs the sum total of the data. An emergency room physician treating a broken wrist does not need information on the patient's cardiological or psychiatric history. Ideally, machine learning would enable a DHB reader to extract only the information necessary for a given intervention (with the capacity to expand the search, should the provider request it). To preserve privacy, it would also be desirable

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[34] Jeanne Madden et al., "Missing Clinical and Behavioral Health Data in a Large Electronic Health Record (EHR) System," *Journal of the American Medical Informatics Association* 23, no. 6 (2016).

[35] Marbury, "EHRs Distracting Physicians from Patient Encounters."

to have the means to verify that a given provider only accessed those parts of the data record containing information which he or she had a need to know.[36]

8. Input and output should be recognized as very different functions that require different software, allowing vendors at both ends of the system to compete on the basis of functionality and aesthetics.

Current EHR software is generally vertically integrated. A given vendor designs the portal through which data are entered, the manner in which they are organized and stored, and the portal through which the they are read by a provider. This contrasts sharply with, say, the structure of the internet. The owner of a website may compose and upload web pages using Dreamweaver but read them with a Firefox browser. Users can choose among a variety of products for either function. This structure recognizes that users at either end of the system may have very different needs and preferences.

9. A common protocol or protocols should be set up to minimize the cost and difficulty of shifting from one input or output vendor to another.

Shifting from one software system to another for composing and reading DHBs should be as seamless as possible—it should feel similar to the way internet users can effortlessly shift from Dreamweaver to Microsoft Word for web page composition or from Firefox to Chrome for browsing. This, not rigid homogenization, is the essence of interoperability. But achieving optimal interoperability will be a fine balancing act. There are advantages to accommodating a broad range of data structures, but the outputs that patients and providers receive from EHRs must be sufficiently clear and standardized to be trusted for self-care and for clinical decision support. Ultimately, the quality of treatment data must approach the quality of clinical trial data. At present, treatment data is highly error ridden, incomplete, and low quality. Clinical trial data is timely, reliable, precise, and relevant.[37]

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[36] In a piece generally optimistic about healthcare IT, one author expresses concern about an interconnected world where employers and others gain excessive access to the intimate details of one's life: "A choice between privacy and health may quickly be approaching us as individuals and as a society." Roy Wyman, "The Federal Vision for Healthcare IT: A Dystopian Paradise," *TechCrunch*, December 31, 2015.

[37] A superb and scathing article on why the effort has fared so poorly is Patrick Caldwell, "We've Spent Billions to Fix Our Medical Records, and They're Still a Mess. Here's Why," *Mother Jones*, October 21, 2015. The American Medical Association's efforts to resolve these problems is described in Mark Friedberg, Francis J. Crosson, and Michael Tutty, "Physicians' Concerns about Electronic Health Records: Implications and Steps Towards Solutions," *Health Affairs Blog*, March 11, 2014.

10. To maximize competition among vendors, the government should not mandate or subsidize any particular vendors or data requirements.

The model for this principle lies in the shift in the early 1990s from the federal government's tightly controlled ARPANET to the wide-open internet. The government made a set of interoperability protocols available to the public but did not mandate or heavily tilt the market toward the adoption of those protocols. The code was merely available for web developers and users. Adoption was widespread because the code worked, it was relatively unobtrusive, and these protocols passed the test of the market.[38] The question of whether clinical-quality EHRs can emerge from decentralized processes rather than from a centralized command may be the most contentious point in determining the success or failure of EHRs or DHBs. More on this in the caveats below.

11. DHB usage should be voluntary on the part of healthcare providers so that the systems must continually prove their worth.

Mandates are an important reason for EHR adoption today—which suggests EHRs are unwanted and unloved by providers. Looking once again to web applications, quality and utility are determined by fierce competition. Importantly, patients, too, should have access to their own DHBs, as they do to their own financial and legal records. An important component should be routine "clinical encounter receipts" (CERs); each provider would routinely send an account of a patient-provider encounter to the patient's DHB. Routine, high-quality CERs would encourage patients to use their DHBs, and routine patient use of DHBs would encourage providers to issue CERs. (Thus there may be a chicken-and-egg problem involved in building a reliable, voluntary DHB function.)

> "The question of whether clinical-quality EHRs can emerge from decentralized processes rather than from a centralized command may be the most contentious point in determining the success or failure of EHRs."

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[38] For a brief history of internet and email protocols, see Ian Peter, "History of the Internet Protocols," in *Ian Peter's History of the Internet*, accessed October 11, 2017.

12. The prime motivation of DHBs should be improved patient health and provider efficiency.

To acquire voluntary users, therapeutic value must drive the design and usage of DHBs. In other words, DHBs should help improve patients' health and help providers to deliver care more efficiently—which, we argue, is not the case with today's EHRs. Over time, DHBs should lead to powerful algorithms (confirmed over many years by clinical confirmation) that enable patients to self-manage a broad portion of their own care—with the results rivaling the quality of today's physician care. In other words, DHBs will only flourish when and if they allow patients to care for themselves in situations that formerly required a physician, and when and if they result in outcomes comparable to what physicians today provide. Billing and other reimbursement-related functions are important, but they are secondary functions.

CAVEATS TO THE 12 PRINCIPLES

The above principles are, as stated previously, aspirational. In this section, we address some of the practical and ethical conundrums associated with these principles.

Patient ownership of data could impact the production and quality of such data. For instance, would a psychiatrist's notes on a patient necessarily be a part of the DHB? If so, would psychiatrists then hesitate to include information that might anger or embarrass the patient? Is it optimal for patients to have access to all their data?[39]

If DHBs included data from, say, Fitbits, would patients then own their Fitbit data? Currently, those data are owned by Fitbit itself and are valuable corporate assets. Could patient ownership of data impact the value of those assets and disincentivize companies from producing such data?

Are there some items that ought to be excluded from the DHB? If a teenager has a pregnancy test or a sexually transmitted disease test at a public health clinic, must that information follow her around in perpetuity?

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[39] For a discussion of prior attitudes toward fully informed patients, see Robert F. Graboyes and Eric Topol, "Anatomy and Atrophy of Medical Paternalism" (Mercatus Research, Mercatus Center at George Mason University, Arlington, VA, 2017). Graboyes and Topol argue that modern technology is lessening the ancient perception that patients ought to be kept in the dark on some matters, but the question is whether such paternalism ought to completely go away.

A great deal of the hypothetical value of EHRs or DHBs lies in the accumulation of clinical trial–quality data. Can natural language processing and artificial intelligence attain those levels of quality? If not, how much of the data input should be of a highly structured form, and how can that be entered with the least effort needed on the part of physicians and other providers?

To what extent should a provider's access to a patient's DHB be limited? Should AI-driven culling limit the extent of accessibility, or should each provider have broad privilege to access DHBs?

How much centralized control over data and communications protocols is necessary (at least at the initial stages) in order to achieve interoperability? As noted above, this may be the central question policymakers must face. Under the Affordable Care Act, the presumption was that workable interoperability would necessarily come from the federal government and would require usage mandates. In this paper, we assert as an aspirational principle that the spontaneous order of competitive markets can lead to workable standards of interoperability—superior to the standards that would arise from a government mandate. But we acknowledge that this might prove infeasible. The University of Michigan's Julia Adler-Milstein frames it as a coordination problem, in which all parties involved must simultaneously adopt the standard. She suggests that health information is intrinsically more complex than, say, financial information. She also contends that "only policymakers have a clear, strong interest in promoting interoperability."[40]

CONCLUSION

Implementing a DHB system promises two important benefits. First, by bringing together health data from many different sources, a DHB would provide a complete, accurate picture of each person's health—equipping both patients themselves and their healthcare providers with compact, coherent, and targeted information. Second, the DHB system would aggregate the data of myriad individuals, giving researchers a previously unavailable opportunity to analyze the factors that contribute to health and sickness.

The pathway we envision to such DHBs resembles the conditions that led to the explosive development of the internet since around 1990. In the early to mid-1990s, a series of congressional actions relaxed the federal government's tight control of ARPANET, allowing individuals and organizations to use the

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[40] Julia Adler-Milstein, "Moving Past the EHR Interoperability Blame Game," *NEJM Catalyst*, July 18, 2017.

network more or less as they pleased. The government played a limited but vital role in ARPANET's development. ARPANET's government developers offered the protocols that allowed vastly differing machines to upload and download vastly differing types of data.

The government did all this with the understanding that a vast, decentralized network would unleash considerable risks. A pessimist in 1990 might have warned that cell phones and internet would provide new and powerful tools to terrorists, thieves, and all manner of predators—and that pessimist would have been correct. But, to a great extent, the government green-lit what our colleague Adam Thierer calls "permissionless innovation"[41] and dealt with problems through existing legal structures, such as tort and contract law. Congress did not insist, for example, that a regulatory body preapprove software before its launch.[42]

As a thought exercise, we can imagine how things might otherwise have gone. The first internet search engine was Aliweb, launched in 1993. In its time Aliweb was a stunning technological achievement, but looking at it with 2017 eyes we see a screen filled with unattractive colors, difficult-to-read fonts, and a host of drop-down menus. Searching was a laborious activity, and the output was often remote from what the user wanted. Aliweb was soon surpassed by competitors like Web Crawler, AltaVista, Yahoo, and the 20th search engine—Google. Each of these competitors had to fight its way to the top of the market and was never safe from successors.

Today, Google offers a simple, attractive input mechanism lacking menus. Its output is sometimes frighteningly on target with what the user desires. There are no drop-down menus in part because Google has invested enormous resources in big data and artificial intelligence, such that the search engine knows far better than the user which menu options the user *would have* clicked.

In an alternative universe, it is not difficult to imagine a 1993 Congress deciding to regulate the internet as it had regulated the telephone industry, seeing the immense potential of search engines, passing legislation to pour funding into Aliweb, mandating additional menus, and adopting regulatory standards that any future search engine competitors would have to meet. In doing so, Congress could well have stifled the furious race that has brought us vastly improved capabilities in a very few years.

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41. Adam Thierer, *Permissionless Innovation: The Continuing Case for Comprehensive Technological Freedom*, rev. ed. (Arlington, VA: Mercatus Center at George Mason University, 2016).

42. Encouragingly, Congress recently scaled back the FDA's role in preapproving certain healthcare IT. See Michele L. Buenafe and M. Elizabeth Bierman, "21st Century Cures Act and Its Effect on Digital Health," *National Law Review*, December 9, 2016.

Scott Gottlieb, now commissioner of the Food and Drug Administration, noted that Apple and other companies "dumb down" the health applications on their smartphones to avoid falling under the bailiwick of the FDA. He argues that the same fear explains the inadequacies of today's EHRs.[43]

> If EMRs aim to do much more than collect, store and report health data, FDA has said it will regulate any interpretive tools as a medical device subject to the agency's oversight. So the big EMR providers made a deliberate decision not to build clinical support tools into their products—cognizant that this would cross a line that FDA had drawn. The EMR providers deliberately dumbed down these platforms. A health record can report to the doctor that a patient's heart enzymes were elevated, but couldn't interpret when these results meant that the patient was more likely to be having a coronary infarction than an episode of heart failure. While third-party developers create these sorts of diagnostic tools, the adoption of obvious capabilities is far slower than it should be.[44]

Other analysts, such as the Standard Health Record Collaborative,[45] are proposing visions similar to what we suggest in this paper. Scholars at the National Institutes of Health are in particular investigating the use of natural language processing and machine learning to improve EHRs.[46] We hope a creatively destructive version emerges—or more than one emerge—to foster an era in which various DHB platforms compete for the hearts and minds of providers and patients as furiously as search engines and other web applications have competed on the internet.

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[43] Gottlieb uses the term "EMR" rather than "EHR." The distinction is addressed near the beginning of this paper. Assuming Gottlieb adheres to the distinction as described above, he implies here that big vendors prevented EMRs from becoming EHRs and suggests they did so for fear of FDA responses.

[44] Scott Gottlieb, "Why Apple Dumbs Down Your Smartphone," *Forbes*, December 4, 2015.

[45] Standard Health Record Collaborative home page, accessed October 11, 2017, http://standardhealthrecord.org/.

[46] See, for example, Lucila Ohno-Machado, "Realizing the Full Potential of Electronic Health Records: The Role of Natural Language Processing," *Journal of the American Medical Informatics Association* 18, no. 5 (2011): 539.

ABOUT THE AUTHORS

Robert F. Graboyes is a senior research fellow and healthcare scholar at the Mercatus Center at George Mason University. Author of "Fortress and Frontier in American Health Care," his work asks how we can we make healthcare as innovative in the next 25 years as information technology was in the past 25. His earlier work involved extensive travel in sub-Saharan Africa, Central Asia, and Europe. He received his PhD in economics from Columbia University.

Darcy N. Bryan, MD, is an associate clinical professor at the University of California, Riverside, School of Medicine and has an active practice in obstetrics and gynecology at Riverside Medical Clinic. Her research is in technological and organizational innovation in healthcare with a particular focus on public policy, women's health, and unmanned aerial systems. She is a cocreator of the Mercatus Center's Healthcare Openness and Access Project, and she coauthored a medical humanities book, *Women Warriors: A History of Courage in the Battle against Cancer*. Bryan earned her MD from Yale School of Medicine and her MPA from the University of Texas at Arlington.

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