

Privacy from Doctors

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We are moving rapidly towards a world of de facto comprehensive cradle-to-coffin electronic medical records. Though welcome in many respects, this shift has a crucial drawback: it comes with grave risks to patients' privacy. Discussions of medical privacy to date have tended to focus on the potential for misuse of medical records or the risk that records will be used outside of the medical context. But patients also have deep interests in controlling medical information within the healthcare context. In the past, patients were able to control the narrative of their medical histories or seek care without fully disclosing the contents of their records simply by going to new providers. Going forward, unless protections are put in place, this sort of functional privacy safeguard will become obsolete.

This Article explores what will be lost if that comes to pass. It provides a rich account of the benefits of "privacy from doctors" and explores the promise and perils of all-encompassing, easily shared health records. Protecting this form of privacy promotes intrinsic values, such as respect for patients' autonomy and dignity, and has the potential to positively affect outcomes and

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PRIVACY FROM DOCTORS

the doctor-patient relationship. As regulations regarding information-blocking practices and interoperable platforms go into effect, we should avoid throwing out the baby with the bathwater. To that end, the paper sets forth some practical avenues to protect the benefits of privacy from doctors. It closes with broader reflections on what our policy approach to patients' personal information says about the direction of our medical system more broadly.

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What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about.

-Hippocratic Oath (Classic)¹

I will respect the privacy of my patients, for their problems are not disclosed to me that the world may know.

-Hippocratic Oath (Modern)²

INTRODUCTION

Patients curate the information they share with their doctors all the time.³ Sometimes, this curation takes the form of overt lies; more often, it takes the form of omissions, understatements, and intentional limits on the information revealed to a particular doctor when seeking treatment. In other words, patients seek to control the narrative that informs their medical care. They seek a measure of privacy from their doctors.

This curated privacy will soon be impracticable. We are marching towards a world of comprehensive, easily-shared health records. Even now, medical records—which contain enormous amounts of personal information—proliferate far more widely than patients are likely to

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1. Peter Tyson, *The Hippocratic Oath Today*, PBS NOVA (Mar. 27, 2001), <https://www.pbs.org/wgbh/nova/article/hippocratic-oath-today> [<https://perma.cc/2YFR-N45U>].
 2. *Id.*
 3. See, e.g., Andrea Gurmankin Levy, Aaron M. Scherer, Brian J. Zikmund-Fisher, Knoll Larkin, Geoffrey D. Barnes & Angela Fagerlin, *Prevalence of and Factors Associated with Patient Nondisclosure of Medically Relevant Information to Clinicians*, JAMA NETWORK OPEN (2018) (noting that more than half of patients in two nation-wide studies admit to intentionally declining to disclose medically relevant information to treating physicians); see also Israel T. Agaku, Akinyele O. Adisa, Olalekan A. Ayo-Yusuf & Gregory N Connolly, *Concern About Security and Privacy, and Perceived Control Over Collection and Use of Health Information Are Related to Withholding of Health Information from Healthcare Providers*, 21 J. AM. MED. ASS'N 374, 375 (2014) (finding that 12.3% of survey respondents withheld information from a healthcare professional).

realize,⁴ and that dynamic is set to intensify in the near future. Recently-finalized regulations will soon mandate that medical providers, tech companies, and others share records in many circumstances, and efforts to establish ever-larger nationwide networks of interoperable electronic records are also nearing fruition.⁵

Right now, the rules and norms surrounding patient privacy are in flux. We are confronted with an urgent question: What do we lose when we lose privacy from doctors?

The answer is: a lot. Privacy from doctors has real and under-appreciated upsides. First, and most importantly, ensuring that patients have control over the information that is accessible to their treating physicians vindicates autonomy, dignity, and privacy values, which are of particular importance in the medical context. Patients' straightforward interest in avoiding the undesired disclosure of such personal information

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4. As others have noted, there is strikingly little good evidence regarding U.S. patients' actual understandings of or preferences for how their medical information is shared. See Leslie Francis, *Privacy and Confidentiality: Bill of Health at Five Years and Beyond*, BILL OF HEALTH (Oct. 2, 2017). International studies—even in places where the health data infrastructure is comparatively simpler—indicate that patients have little knowledge about how their data is used and generally underestimate how much is collected or shared. See, e.g., *Understanding Public Expectations of the Use of Health and Care Data*, CURVED THINKING 21 (July 2019), <https://understandingpatientdata.org.uk/sites/default/files/2019-07/Understanding%20public%20expectations%20of%20the%20use%20of%20health%20and%20care%20data.pdf> [<https://perma.cc/622D-S6US>] (finding that only 30% of respondents in United Kingdom survey agreed that they were aware of who had access to their personally identifiable health data); *The One-Way Mirror: Public Attitudes to Commercial Access to Health Data*, IPSOS MORI 44-45 (Mar. 2016), <https://wellcome.org/sites/default/files/public-attitudes-to-commercial-access-to-health-data-wellcome-mar16.pdf> [<https://perma.cc/ER4Q-W83G>] (noting that patients in the U.K. are confused and underestimate what data is collected and used in healthcare); Mart Wetzels et al., *Patient Perspectives on Health Data Privacy and Management: "Where Is My Data and Whose Is It?"*, 2018 INT'L J. TELEMEDICINE & APPLICATIONS 1, 2-3 (2018) (indicating that patients in the Netherlands had little insight into who had access to their data).
 5. See *infra* Part I (describing, for example, rulemakings pursuant to the 21st Century Cures Act, which will prohibit "information blocking" practices and mandate record-sharing under penalty of significant financial fines, and ongoing agency proceedings to establish a framework for a nationwide network of interoperable health records).

extends to doctors, just as it extends to others. More broadly, privacy—as well as the concomitant ability to make decisions about what information to reveal and when—plays a foundational role in people’s self-understanding, and indeed in the formation of identity in a social world. Patient privacy from doctors promotes patient autonomy in a rich sense, enabling not only choice but also a certain kind of self-authorship. It provides a measure of agency over the narrative that forms the basis for medical decision-making within the doctor-patient relationship.

Privacy from doctors can also have benefits for the doctor-patient relationship and, potentially, patient health outcomes. Patient-centric privacy norms are part of the groundwork on which trust is built. When patients have trust, and when they are assured that their care is responsive to their lived experience (as opposed to boxes checked in an electronic medical record), they may have greater buy-in to their own medical care. Moreover, when patients control their own health information, they can seek genuinely fresh second opinions with doctors whose views have not been colored by the notations or impressions of every doctor to have come before, thereby heading off path-dependent treatment spurred by incorrect early diagnoses. They may also be less likely to be deterred from seeking treatment for stigmatized conditions and more likely to share potentially embarrassing information when it *is* relevant to their care. Many of these upsides, moreover, may disproportionately benefit patients from relatively disenfranchised groups. At the broadest level, norms around patient information both reflect and shape all of the participants in the medical system. When patients control their narrative, they are in some sense insisting that the medical system treat them as full subjects, rather than objects of a paternalistic approach to care.

These benefits are at risk of being unthinkingly lost.⁶ Commentators and policy makers have, of course, recognized that electronic health records

6. It has long been widely assumed that comprehensive cradle-to-coffin medical records will improve medical care. See, e.g., *Report on Uniform Data Standards for Patient Medical Record Information*, NAT’L COMM. ON VITAL & HEALTH STAT. (NCVHS) 5 (June 2000), <https://ncvhs.hhs.gov/wp-content/uploads/2014/05/hipaa000706.pdf> [<https://perma.cc/6FNS-SMBX>] (“High quality health care depends on complete and comprehensive patient medical record information (PMRI). This information is essential to support diagnosis and treatment, measure and improve quality of care, advance public health, enhance healthcare productivity, and facilitate reimbursement.”). For a discussion of the current status of the movement towards interoperable health records, see *The Thirteenth Report to Congress on the Implementation of the Administrative Simplification of Provisions of the Health Insurance Portability and Accountability Act (HIPAA) of 1996*, NCHVS ii

(EHRs) create enormous privacy concerns.⁷ But the discussion has focused primarily on the risk that private medical information will be shared *outside* of the patient-care context and used, for instance, for medical research or commercial purposes without patient consent.⁸ To the extent that patient

(Mar. 14, 2019), <https://ncvhs.hhs.gov/wp-content/uploads/2019/03/13th-Report-to-Congress.pdf> [<https://perma.cc/UF3R-GACN>] (“Our central message in this report is that revisions to the current HIPAA rules would facilitate the agility industry needs to keep pace with the opportunities and challenges of today’s ever-changing health care landscape. While the processes HIPAA set in motion were absolutely essential at the time, they have not kept pace with the rate of change in policy, health care, and technology. Indeed, they actually have come to constrain complete administrative simplification and clinical interoperability. In short, the U.S. needs more agile ways to advance the goals of the Act.”).

7. See, e.g., Bonnie Kaplan, *Patient Health Data Privacy*, in BEYOND IP: THE FUTURE OF PRIVACY (Schlomit Yanisky-Ravid ed., 2014); Jos Aarts, et al., *Protecting Patient Privacy in Cyber Environments*, AM. MED. INFORMATICS ASS’N ANN. SYMP. (2016); Nicholas P. Terry & Leslie P. Francis, *Ensuring the Privacy and Confidentiality of Electronic Health Records*, 2007 ILL. L. REV. 681 (2007); SHARONA HOFFMAN, ELECTRONIC HEALTH RECORDS AND MEDICAL BIG DATA (2016); Sharona Hoffman & Andy Podgurski, *Finding a Cure: The Case for Regulation and Oversight of Electronic Health Records Systems*, 22 HARV. J. L. & TECH. 1, 20-21 (2008) (describing security concerns and regulatory responses).
8. See, e.g., Jessica Jardine Wilkes, *The Creation of HIPAA Culture: Prioritizing Privacy Paranoia over Patient Care*, 2014 BYU L. REV. 1213, 1234-37 (2015) (focusing privacy discussion on privacy protection, electronic storage and transfer, and breaches); Janine Hiller, Matthew S. McMullen, Wade M. Chumney & David L. Baumer, *Privacy and Security in the Implementation of Health Information Technology (Electronic Health Records): U.S. and EU Compared*, 17 B.U. J. SCI. & TECH. L. 1, 6-7 (2011) (providing an overview of risks to individual privacy, focusing on medical identity theft, information disclosure, and data sharing); Daniel J. Gilman & James C. Cooper, *There is a Time to Keep Silent and a Time to Speak, the Hard Part is Knowing Which is Which: Striking the Balance Between Privacy Protection and the Flow of Health Care Information*, 16 MICH. TELECOMM. & TECH. L. REV. 279, 321 (2010) (“The key privacy concern surrounding [health information technology] . . . involves the storage of large amounts of personal health information in data files that may be susceptible to breach[.]”); see also Sharona Hoffman & Andy Podgurski, *Balancing Privacy, Autonomy, and Scientific Needs in Electronic Health Records Research*, 65 SMU L. REV. 85 (2012); Lawrence O. Gostin & James G. Hodge Jr., *Personal Privacy and Common Goods: A Framework for Balancing Under the National Health Information Privacy Rule*, 86 U. MINN. L. REV. 1439 (2002); Mark A. Hall, *Privacy, Property, and the Pursuit of Interconnected Medical Records*, 95 IOWA L. REV. 631 (2010); Dunata Mendelson and Gabrielle Wolf,

privacy from treating physicians is considered at all, the typical approach carves out especially sensitive categories of information (like substance abuse or mental health information).⁹ Even commentators who argue that the medical system should provide more patient autonomy and privacy say relatively little about why those values matter in the medical context, taking it largely for granted that respecting those values will trade off against patient health outcomes.¹⁰ In short, the interests served by patient privacy from doctors are far richer than the current literature suggests.

This Article explores the values promoted by privacy from doctors and the related perils of the shift towards all-encompassing, easily-shared electronic health records.

Part I examines the current lay of the land with respect to electronic health records and patient privacy. Part I also sets forth the—very good!—reasons for this push towards more interoperable, easily-shared medical

Health Privacy and Confidentiality, in TENSIONS AND TRAUMAS IN HEALTH LAW (Freckelton & Petersen eds., 2017) (arguing that technology is diminishing the age-old expectation of confidentiality in medical information); Lawrence O. Gostin, *Health Information Privacy*, 80 CORNELL L. REV. 451 (1995) (arguing that societal need for health data is incompatible with patient privacy interests); Bonnie Kaplan, *How Should Health Data Be Used? Privacy, Secondary Use, and Big Data Sales*, 25 CAMBRIDGE Q. HEALTHCARE ETHICS 312 (2016); Danuta Mendelson and Gabriel Wolf, *My [Electronic] Health Record: Cui Bono (For Whose Benefit?)*, 24 J.M.E. (2016) (arguing that Australian national electronic health records system is being used by the government for improper purposes).

9. See, e.g., Justine N. Carr, NCVHS, Letter to Kathleen Sebelius, Sec. of Dep't of Health and Human Servs., (Nov. 10, 2010) at 7-14, <https://ncvhs.hhs.gov/wp-content/uploads/2014/05/101110lt.pdf> [<https://perma.cc/WBJ4-3Q9Z>] (suggesting specific categories of medical information that should be defined as sensitive health information and provided with special treatment) [hereinafter NCVHS, Letter to Kathleen Sebelius]; Mark A. Rothstein, Stacey A. Tovino, *Privacy Risks of Interoperable Electronic Health Records: Segmentation of Sensitive Information Will Help*, 47 J.L.M.E. (2019) (tracing NCVHS's efforts and arguing in favor of the segmentation approach, but noting that it has not yet been adopted).
10. See, e.g., Terry & Francis, *supra* note 7, at 701; Leslie P. Francis, *When Patients Interact with EHRs: Problems of Confidentiality and Privacy*, 12 Hous. J. OF HEALTH L. & POL. 171 (2012) (noting, for instance, that patients may not be aware that information emailed to providers through web portals may be included in medical records and made available to other physicians); Kaplan, *supra* note 7 ("Withholding information from one's clinician is neither in the public interest nor beneficial to that patient's interest in proper health care.").

records. It closes by explaining, however, that privacy protections are surprisingly weak.

Part II adds the missing piece of the puzzle: It examines what would be lost if patient privacy from doctors is further reduced and uses a number of colorful case studies to flesh out the circumstances where these interests become relevant. Patients might have good reason to want information or treatment from a doctor that is independent of the patient's prior interactions with the medical system. There is frequently a gendered or racial component to these situations. More broadly, Part II explores how privacy from doctors comports with core medical values, and it considers the profound implications of patient privacy norms for the doctor-patient relationship.

Part III considers the practical question: How could we better account for patient privacy going forward? The individual patient interests at stake in privacy from doctors are fundamental, but they do run up against other interests (including patients' own interests in minimizing decision-making burdens in an overwhelming medical system). And myriad interested parties have offered competing long-term aspirations for the other purposes that medical records could serve, ranging from cost-cutting to medical research to law enforcement. Offering concrete proposals in this area is thus perilous. We can begin to cut through this Gordian knot, however, by keeping the focus on the individual patient experience. As in other areas where individual interests trade off against other systemic goals, the response to that tradeoff should not be to throw up our hands and ignore the individual interests or pay them mere lip service. Rather, it should be to protect those interests as much as possible and to ensure that, where other especially important interests trump, there are responsive processes for tough cases. I propose a number of potential approaches to resolve these problems, while acknowledging that the governance of medical records presents a genuine thicket.

In closing, Part IV takes a step back and briefly considers privacy from doctors as a lens into deeper questions about the direction of our healthcare system. This question has political stakes: How do we, as a society, want patients to be oriented towards the medical system, and how do we want that system to be oriented towards us?

I. THEY'RE COMING: THE REGULATORY MARCH TOWARDS INTEROPERABLE, WIDELY-SHARED, CRADLE-TO-GRAVE ELECTRONIC MEDICAL RECORDS

Comprehensive, easily transportable electronic medical records are coming. For policymakers, such records have been a longstanding aspiration. A decade ago, in the Health Information Technology for

Economic and Clinical Health (HITECH) Act of 2009,¹¹ Congress made clear that improving the flow of electronic patient medical records was a national goal.¹² The first phase focused on incentivizing providers to make “meaningful use” of electronic records.¹³ That effort was largely a success; the vast majority of providers now use electronic health records.¹⁴

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11. The HITECH Act was enacted as part of the American Recovery and Reinvestment Act of 2009 (ARRA), Pub. L. 111-5, 123 Stat 115 (2009) and is codified at 42 U.S.C. 201 (note) and in various U.S. Code provisions addressing Medicare and Medicaid.
 12. The HITECH Act established the Office of the National Coordinator for Health Information Technology (ONC), who was directed to establish milestones and standards for, among other things, “the electronic exchange and use of health information and the enterprise integration of such information” and “the utilization of an electronic health record by each person in the United States by 2014.” *Id.* § 3001(3)(A)(ii).

The federal entity that has directed the most attention to issues of patient privacy is not a lawmaker, but an advisory committee: the NCVHS. The Committee was established by statute at 42 U.S.C. § 242k (2018). It is composed of 18 “persons who have distinguished themselves in the fields of health statistics, electronic interchange of health care information, privacy and security of electronic information, population-based public health, purchasing or financing health care services, integrated computerized health information systems, health services research, consumer interests in health information, health data standards, epidemiology, and the provision of health services.” *Id.* § 242k(k). Among other things, it is tasked with studying “the issues related to the adoption of uniform data standards for patient medical record information and the electronic exchange of such information.” *Id.* § 242(k)(B). While the Committee’s broad statutory mandate does not expressly include any express commitment to patient privacy, it regularly addresses those issues.

13. *See, e.g.*, 42 U.S.C. § 1395w-4(a)(7) (2018) (setting forth incentives for “meaningful use” of certified electronic health records); 42 C.F.R. §§ 495.20-24 (setting forth meaningful use requirements for pre-2015; 2015-2018; and 2019 and subsequent years for certain categories of providers).
14. Usage rates vary by type, but approximately 99% of large hospitals currently use EHRs. *See* Heather Landi, *Nearly All U.S. Hospitals Use EHRs, CPOE Systems*, HEALTHCARE INNOVATION (Sept. 11, 2017); *see also* Fredric Evan Blavin and Melinda Beeuwkes Buntin, *Forecasting the Use of Electronic Health Records: An Expert Opinion Approach*, 3(2) MEDICARE & MEDICAID RESEARCH REVIEW E1, E12-E13 (2013) (projecting that 80% of primary care physicians in large group practices, 65% of primary care physicians in small group practices, and 66% of all other specialists would achieve “meaningful use” of EHRs by 2019); *cf.* Stephen T. Mennemeyer et al., *Impact of the HITECH Act on Physicians’*

We are now in a new phase, and although both technological and practical barriers persist, momentum towards widespread sharing of comprehensive records remains strong, even inexorable. This momentum is in no small part due to the IT-related provisions in the expansive 21st Century Cures Act,¹⁵ which Congress enacted in 2016, and their regulatory progeny. As of this writing, thanks to that Act, federal efforts to establish the first truly nationwide information-sharing arrangement between the various entities that currently manage electronic medical records are nearing fruition.¹⁶ At the same time, a rulemaking finalized in the spring of 2020 mandates for the first time that doctors and others share patient health records in most circumstances.¹⁷ That rulemaking implements rather remarkable pro-information-sharing legislation within the 21st Century Cures Act. The Act prohibits health care providers, technology developers, and others from “information blocking”—that is, from engaging in any “practice that . . . is likely to interfere with, prevent, or materially discourage access, exchange, or use of electronic health information.”¹⁸ The Act authorizes various penalties, including fines of up to \$1 million “per violation” in some cases.¹⁹ Once the implementing regulations go into

Adoption of Electronic Health Records, 23(2) J. AM. MED. INFO. ASS’N 375, 378 (2016) (finding weak evidence of the impact of the HITECH Act on use of EHRs).

15. 42 U.S.C. § 300jj-52(a)(1)(A) (2018).
16. See ONC, TRUSTED EXCHANGE FRAMEWORK AND COMMON AGREEMENT (TEFCA) (Draft 2) (June 19, 2019), discussed further in Part III *infra*. ONC is “the principle federal principal federal entity charged with coordination of nationwide efforts to implement and use the most advanced health information technology and the electronic exchange of health information.” See *id.* With TEFCA, ONC is establishing a framework for a multi-party agreement with minimum requirements that will enable the myriad different “health information networks” that currently manage medical records to easily share information with each other. Health information networks do not generally share information with each other in the absence of such an agreement, in part because many of them are competitors with each other.
17. See The 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification, 85 Fed. Reg. 25,643 (May 1, 2020) (codified at 45 C.F.R. Parts 170 and 171).
18. 42 U.S.C. § 300jj-52(a)(1) (2018).
19. *Id.* § 300jj-52(b)(2)(A)-(B) (authorizing fines on developers, networks, and exchanges who engage in information blocking and directing that providers be referred to appropriate federal agencies and subject to disincentives in accordance with notice-and-comment rulemaking).

effect,²⁰ in other words, it will be illegal for healthcare providers, tech companies, and others to create policies that slow down or create practical barriers to data sharing. And in July 2019, the House of Representatives voted to eliminate a decades-old prohibition on the use of federal funds for creating a unique patient identifier system—a code, like a social security number, that could be assigned to each and every American to ensure that their medical data is accessible anywhere.²¹ While that ban remains on the books for the time being, the private sector is developing substitutes (especially patient-matching algorithms) to accomplish similar results,²² and other regulatory efforts to enable the matching of longitudinal health records to particular patients are underway.²³

These legislative and regulatory efforts respond to the unfortunate reality that healthcare and technology industries have long had perverse incentives to make the exchange of health information difficult. Surveys of industry insiders indicate that hospitals and health systems routinely decline to share data (or shared only partial patient data) because by “controlling patient referrals and having exclusive access to patient data, they could potentially improve their revenue and enhance their market dominance.”²⁴ Vendors who sell electronic health record technologies also have incentives to design products that could not transfer data easily, or

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20. Most of the information blocking provisions were initially set to go into effect six months after the rule was published in the federal register, but that deadline has been further extended in light of the coronavirus pandemic. See *CMS Interoperability and Patient Access Final Rule*, CTRS. MEDICARE & MEDICAID SERV. (July 17, 2020), <https://www.cms.gov/Regulations-and-Guidance/Guidance/Interoperability/index> [<https://perma.cc/6NS9-754B>].
 21. H.R. Labor, Health and Human Services, Education, Defense, State, Foreign Operations, and Energy and Water Development Appropriations Act, H.R. 2740, 116th Cong. (2019) (H. Amd. 286 (Foster Amendment) passed by vote of 246-178 on June 12, 2019).
 22. See Michelle M. Mello, Julia Adler Milstein, Karen L. Ding & Lucia Savage, *Legal Barriers to the Growth of Health Information Exchange—Boulders or Pebbles?*, 96 MILBANK Q. 110, 128 (2018).
 23. See Adrian Gropper, *ONC’s Proposed Rule is a Breakthrough in Patient Empowerment*, BILL OF HEALTH (Feb. 19, 2019), <https://blog.petrieflom.law.harvard.edu/2019/02/19/oncs-proposed-rule-is-a-breakthrough-in-patient-empowerment> [<https://perma.cc/XDE7-S4RV>] (explaining how proposed ONC rule would allow patient-matching and enable better longitudinal medical records).
 24. Miriam Reisman, *EHRs: The Challenge of Making Electronic Data Useable and Interoperable*, 42 PHARMACY & THERAPEUTICS 572 (2017).

that require expensive add-ons to enable information-sharing. For instance, doctors' offices that used a system for electronic health records may be surprised by surcharges of tens of thousands of dollars to "unlock" data and allow it to be connected to laboratory services.²⁵ The information-blocking provisions of the 21st Century Cures Act (and its aggressive enforcement mechanisms) were intended to counteract these perverse incentives.²⁶

Practically, the push towards interoperable, easily- (or automatically-) shared health records holds the promise of enormous benefits. Not least is that the annual costs created by the lack of interoperable medical records are probably in the billions.²⁷ In its ideal form, a more uniform system of medical records with better information sharing could reduce redundant tests or procedures, save overburdened doctors time and energy, and enable better care coordination, all of which could conceivably reduce the high costs of healthcare today.²⁸ More broadly, a better infrastructure for health information could allow electronic health records to be used more easily for purposes well beyond individual patient care, for broader public health and research purposes—a prospect that is especially appealing to many in the context of the COVID-19 pandemic.²⁹

Comprehensive, interoperable records also have clear upsides for patient care. Most obviously, enabling doctors to easily access full medical records can avoid duplication of care or even serious treatment errors.

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25. See, e.g., Arthur Allen, *Doctors Say Data Fees Are Blocking Health Reform*, POLITICO (Feb. 23, 2015), <https://www.politico.com/story/2015/02/data-fees-health-care-reform-115402> [<https://perma.cc/3THQ-7CLK>].
 26. The 21st Century Cures Act was enacted in part in response to a 2015 report issued by the Office of the National Coordinator for Health Information (ONC) explaining that information-blocking practices were dramatically reducing the gains that had been anticipated as the result of the industry's movement towards electronic health records. *Report to Congress: Report on Information Blocking*, ONC (Apr. 2015), www.healthit.gov/sites/default/files/reports/info_blocking_040915.pdf [<https://perma.cc/99KZ-3DZ3>].
 27. HHS has estimated that the benefits of its ongoing rulemaking on information-blocking alone would be in the range of \$3.08 billion to \$9.15 billion per year. 84 Fed. Reg. 7424, 7431 (proposed Mar. 4, 2019).
 28. See, e.g., Yosefa Bar-Dayana, *Using Electronic Records to Save Money*, 20 J. AM. MED. INFORM. ASSOC. 17 (2013).
 29. See, e.g., Subha Madhavan et al., *Use of Electronic Health Records to Support a Public Health Response to the COVID-19 Pandemic in the United States: A Perspective from 15 Academic Medical Centers*, 28 J. AM. MED. INFORMATICS ASSOC. 393, 400 (2021) (arguing that we need to make hard decisions about how data "will be used beyond individual patient care").

Missing or inaccurate information can lead to worse medical treatment, all the more likely when it is a hassle to transfer information between providers. And if doctors have ready access to their patients' records, and practices are relieved of some of the burden of taking new medical histories, they may be able to devote more time and energy to patient care itself. More accurate, comprehensive information-sharing and medical records also has the potential to improve machine-learning algorithms, which are destined to play a key role in the future of healthcare.³⁰

Better information-sharing could also reduce hassle for patients and caretakers. At least in their ideal form, automatically- or nearly-automatically shared records would reduce the—often enormous—bureaucratic burden of managing medical care. Ask anyone who has dealt with a genuinely complex medical issue or helped a family member deal with multiple providers, or even just anyone who has needed to access old medical records after a move, and you will find stories involving fax machines, inexplicable delays, or hours spent on the phone.³¹ Even then-Vice President Joe Biden famously encountered rather extraordinary hassles thanks to poor interoperability of records system when his son Beau was transferred from a Maryland hospital to a Texas hospital during his treatment for stage 4 brain cancer. During a speech, Biden explained: "I'm the vice president of the United States . . . I have a . . . very influential son-in-law who's a first-rate, well-known surgeon. It took all that and more to get [Beau's data] *put on a disk and flown down to Anderson.*"³² For the less-well-connected among us, this sort of hassle can be insurmountable or come at enormous cost, and it can be a true matter of life and death.

Finally, in its ideal form, effectively automatic information-sharing could reduce the administrative burden placed on doctors, which comes at great cost, financial and otherwise. The burden placed on doctors by administrative and data-entry tasks is already enormous, and widely recognized as a source of serious doctor burnout and professional

30. See W. Nicholson Price II, *Artificial Intelligence in Health Care: Applications and Legal Issues*, 14 *SciTECH LAW*. 10 (2017); Charlotte A. Tschider, *Deus ex Machina: Regulating Cybersecurity and Artificial Intelligence for Patients of the Future*, 5 *SAVANNAH L. REV.* 177 (2018).

31. As of 2012, 63% of physicians were using fax machines as a primary means of sharing medical information. See Reisman, *supra* note 24, at 572.

32. Dan Bowman, *Joe Biden: Sharing of Health Data 'A Matter of Life and Death'*, *FIERCE HEALTHCARE* (May 10, 2016), <https://www.fiercehealthcare.com/it/joe-biden-sharing-health-data-a-matter-life-and-death> [<https://perma.cc/3UVX-GF7S>].

dissatisfaction.³³ An oft-cited 2013 study suggested that emergency room physicians spent an average of 43% of their time on data entry, and just 28% of their time in direct contact with patients—and had mouse clicks totaling 4,000 per shift (or about 400 per hour).³⁴ To whatever extent that better information sharing reduces, rather than compounds, this burden, it will be a boon to doctors, patients, and the healthcare system more broadly.

The global coronavirus pandemic has rendered all of these potential upsides especially urgent and appealing. The prospect of the seamless communication of key medical information is tantalizing to a system stretched to its breaking point, and there have been efforts to improve interoperability for purposes of improving the pandemic response since its earliest crisis days.³⁵ Interoperability, and a more coordinated

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33. See, e.g., Jeff Hecht, *The Future of Electronic Health Records*, 573 NATURE 114, 115 (2019) (“[M]any physicians have come to hate their computers. Overwhelmed by administrative work, they now spend more time attending to data entry than they do interacting with patients. So far, electronic health records have not been the panacea to efficiency and safety that many expected them to be.”); Editorial, *What’s Ruining Medicine for Physicians: Paperwork and Administrative Burdens*, MED. ECON. (Nov. 12, 2018) (describing survey in which physicians were asked, “what’s ruining medicine for physicians?” and administrative burdens and paperwork were the most frequent answer); Sandhya K. Rao, Alexa B Kimball, Sara R. Lehrhoff, Michael K. Hidrue, Deborah G. Colton, Timothy G. Ferris & David F. Torchiana, *The Impact of Administrative Burden on Academic Physicians: Results of a Hospital-Wide Physician Survey*, 92 ACAD. MED. 237 (2017) (finding that 24% of physician hours in 2014 were spent on administrative tasks); Edward R. Melnick, Liselotte N. Dyrbye, Christine A. Sinsky, Mickey Trockel, Colin P. West, Laurence Nedelec, Michael A. Tutty & Tait Shanafelt, *The Association Between Perceived Electronic Health Record Usability and Professional Burnout Among US Physicians*, 95 MAYO CLINIC PROCEEDINGS 476 (2019) (indicating that poor “usability” of EHRs is strongly associated with physician burnout).
34. R.G. Hill, Jr., L.M. Sears, & S.W. Melanson, *4000 Clicks: A Productivity Analysis of Electronic Medical Records in a Community Hospital ED*, 11 AM. J. EMERG. MED. 1591 (2013).
35. Dina N. Greene, David S. McClintock & Thomas J. S. Durant, *Interoperability: Covid-19 as an Impetus for Change*, CLINICAL CHEMISTRY (2021), <https://doi.org/10.1093/clinchem/hvab006> [<https://perma.cc/SB5E-BQQZ>] (“Interoperability took center stage in New York State’s response to the early pandemic, with the state and local government health departments collaborating with private tech companies and state-wide public and private laboratories to rapidly leverage technology expertise to deploy and communicate COVID-19 laboratory testing solutions.”).

infrastructure more generally, could in principle assist public health entities in contact tracing and containing the spread of contagious diseases both now and in any future public health emergencies.³⁶ It could also improve individual outcomes in emergency situations when patients seek care in emergency rooms away from their usual provider or help with some aspects of vaccine management.³⁷ In practice, the pandemic has served as a stress-test, revealing just how far there is to go before the more aspirational prospects for genuinely interoperable EHRs are actually realized.³⁸

But while there is little doubt that better records-sharing, done right, holds the promise of enormous benefits, it will also compound serious, under-appreciated gaps in health privacy. There is a widespread public belief that patient medical information is well-protected by existing privacy laws. (This is in no small part due HIPAA's only partially-deserved reputation as burdensome and stringent).³⁹ In practice, however, patient medical records can already be shared, without consent, with an enormous number of people.⁴⁰ HIPAA *permits* patient health records to be shared for purposes of patient-care. The information-blocking rule, on the other hand,

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36. Subha Madhavan, Lisa Bastarache, Jeffrey S. Brown, Atul J. Butte, David A. Dorr, Peter J. Embi, Charles P. Friedman, Kevin B. Johnson, Jason H. Moore, Isaac S. Kohane, Philip R. O. Payne, Jessica D. Tenenbaum, Mark G. Weiner, Adam B. Wilcox & Lucila Ohno-Machado, *Use of Electronic Health Records to Support a Public Health Response to the Covid-19 Pandemic in the United States: A Perspective from 15 Academic Medical Centers*, 28 J. AM. MED. INFORMATICS ASSOC. 393 (2021).
 37. Drew Ivan, *How Covid-19 is Accelerating Interoperability*, MEDCITY NEWS (Jan. 2021), <https://medcitynews.com/2021/01/how-covid-19-is-accelerating-interoperability/> [<https://perma.cc/CY7Y-PQT8>] (arguing that “seamless transmission of patient data is essential to a successful [vaccine] rollout”).
 38. Electronic health records have received mixed reviews on this front. *See, e.g.*, Fred Schulte, *As Coronavirus Strikes, Crucial Data in Electronic Health Records Hard to Harvest*, KAISER HEALTH NEWS (Apr. 30, 2020), <https://khn.org/news/as-coronavirus-strikes-crucial-data-in-electronic-health-records-hard-to-harvest/> [<https://perma.cc/XT6B-QJV7>].
 39. As Richard Sobel explained, the HIPAA privacy regulations give thousands of providers, health care plans, clearing houses, and HMOs permission to use patient information for payment, treatment, and operational purposes without consent. *See* Richard Sobel, *The HIPAA Paradox: The Privacy Rule That's Not*, 37 HASTINGS CTR. REP. 40, 41 (2008); *see also id.* at 40 (“Most physicians, patients, policy analysts, and journalists believe that the HIPAA ‘privacy rule’ protects medical confidentiality. They are mostly incorrect.”).
 40. *See* 45 C.F.R. §§ 164.502, 164.504, 164.506.

requires it⁴¹—from a wide array of actors, in some cases on pain of significant financial penalties.⁴²

The information-blocking rule’s protections for patient privacy are strikingly less forceful.⁴³ *If* a patient has expressly requested that their information *not* be shared, including for treatment purposes, doctors *may* honor that request without being penalized—most of the time.⁴⁴ The bottom-line is that the new rule risks creating a serious incentive to err on the side of sharing patient information with or without patients’ consent, or even over patients’ objections.⁴⁵ And while privacy advocates may find

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41. As the preamble to the proposed rule explained: “the HIPAA Privacy Rule permits health care providers to exchange ePHI for treatment purposes, but does not require them to do so. Under the information blocking provision, unless an exception to information blocking applies, or the interference is required by law, a primary care provider would be required to exchange ePHI with a specialist who requests it to treat an individual who was a common patient of the provider and the specialist.” 84 Fed. Reg. 7424, 7527 (proposed March 4, 2019); *see also* 85 Fed. Reg. at 25,845-25,846 (May 1, 2020) (reiterating this point in final rule).
 42. 42 U.S.C.A. § 300jj-52(b)(2) (2018) (allowing for penalties up to \$1 million per violation). HHS has issued a separate proposed rule specifically addressing enforcement which confirms the \$1 million maximum penalty and identifies factors that will be considered in assessing enforcement. 85 Fed. Reg. 22,979, 22,991 (Apr. 20, 2020). Monetary fines will generally not be imposed on providers in their capacity as providers, except when those providers also meet the regulatory definitions of “health information exchanges” or “health information networks.” *Id.* at 22981.
 43. In a few discrete areas, federal laws provide special privacy protections for narrow carve-outs of patient information. For instance, extra protections apply to certain substance abuse programs. *See* 42 C.F.R. § 164.502(a)(5)(i). Mental health providers’ notes are also entitled to additional protections. *See* 45 C.F.R. § 164.508(a)(2) (requiring patient authorization for release of psychotherapy notes in most circumstances); 85 Fed. Reg. at 25,955 (defining electronic health information to exclude psychotherapy notes).
 44. To qualify for the sub-exception that permits providers (in their discretion) *not* to share information at an individual’s request, the request must be made by the individual “without any improper encouragement or inducement of the request” and be documented in writing in a reasonable period of time. The provider is protected for respecting such requests only if it generally treats requests “in a consistent and non-discriminatory manner.” 85 Fed. Reg. at 25,849; 45 C.F.R. § 171.202(e).
 45. There are, however, some state and federal laws that require patient consent before certain categories of sensitive information can be shared. *See* 84 Fed.

solace in the fact that the current proposed requirements for exchange networks would require that patients be provided an opportunity to opt out of information sharing, those privacy protections are both so blunt and toothless that it is unclear how helpful they will be to most patients.⁴⁶

The contents of electronic health records (EHRs) are extremely broad.⁴⁷ As the federal government's website on health IT boasts, an EHR is "more than just a computerized version of a paper chart in a provider's office. It's a digital record that can provide comprehensive health information about

Reg. at 7528. While the proposed regulations allow providers to avoid penalties if they comply with laws requiring them to obtain patient consent before sharing information, providers can avail themselves of that exception only if they have provided patients with a "meaningful opportunity" to provide that consent. On the other hand, there is no similar requirement (under federal law) that patients be provided with any meaningful opportunity to opt out of information sharing. The requirement is intended to ensure that patient privacy is not used as a pretextual excuse for engaging in information-blocking practices. *Id.* at 7531.

46. Under the proposed minimum requirements, networks that want to join the TEFCA agreement would need to demonstrate that patients have "meaningful choice" over whether their data is shared with other providers. This is certainly better than nothing (assuming that the proposal makes it into the final requirements), but as currently drafted, the requirement does not provide for any level of granularity. In other words, it appears to suffice if patients could opt out of ever allowing their data to be shared with other providers—but that preference could apply to their entire medical history, and to all providers. *See id.*
47. Though the terms are sometimes used interchangeably, as used by ONC, the narrower term "electronic medical records" (EMRs) refers to something more akin to a digitized version of a single practice's paper medical records; they are less comprehensive and not generally designed for sharing. *See* Peter Garrett & Joshua J. Seidman, *EMR vs EHR-What is the Difference?*, HEALTH ITBUZZ (Jan. 4, 2011), <https://www.healthit.gov/buzz-blog/electronic-health-and-medical-records/emr-vs-ehr-difference> [https://perma.cc/U37X-5XEC] ("Some people use the terms 'electronic medical record' and 'electronic health record' (or 'EMR' and 'HER') interchangeably. But here at the Office of the National Coordinator for Health Information Technology (ONC), you'll notice we use electronic health record or EHR almost exclusively."); *see also* M.K. Ross, Wei Wei & L. Ohno-Machado, "Big Data" and the Electronic Health Record, 9 YEARBOOK MED. INFORM. 97 (2014) (documenting the scope of EHRs); George Hripcsak & David J. Albers, *Next-Generation Phenotyping of Electronic Health Records*, 20 J. AM. MED. INFO. ASS'N 117 (2013) (estimating that one billion patient visits are documented per year in the United States).

your patients,” one that is “built to share information with other health care providers and organizations.”⁴⁸ They can include not only treatment information, diagnoses, and lab results, but also demographic details, billing or administrative records, progress descriptions and other notes by doctors.⁴⁹ They may also include correspondence between patients and providers and information about “social determinants of health” like homelessness, gun ownership, social support systems and loneliness, seatbelt-wearing habits, stress levels, exposure to domestic violence or violence more generally, and food insecurity.⁵⁰ One major provider, Epic, offers EHRs for pediatricians that include checkboxes noting, for instance, who a child’s primary caretaker is and whether the family has need of job training resources.⁵¹ And while I focus in this Article on the privacy concerns of patients, in practice the privacy stakes extend even more broadly, as electronic health records frequently include family histories and genetic information.

In short, patient medical records are becoming more comprehensive and, at the same time, more widely and easily shared. In many respects, this is for the better, but the approach so far is flawed. Despite the extraordinary

48. *What Information Does An Electronic Health Record Contain?*, HEALTH IT, <https://www.healthit.gov/faq/what-information-does-electronic-health-record-ehr-contain> [https://perma.cc/T9EH-LHWC].

49. *Id.*

50. *See, e.g.*, Michael N. Cantor & Lorna Thorpe, *Integrating Data On Social Determinants Of Health Into Electronic Health Records*, 37 HEALTH AFFAIRS 585 (2018); Nancy E. Adler & William W. Stead, *Patients in Context — EHR Capture of Social and Behavioral Determinants of Health*, 372 N. ENGL. J. MED. 698 (2015) (recommending twelve social and behavioral domains to be incorporated into EHRs); *see also* Megan Sandel, Mark Hansen, Robert Kahn, Ellen Lawton, Edward Paul, Victoria Parker, Samantha Morton & Barry Zuckerman, *Medical-Legal Partnerships: Transforming Primary Care By Addressing The Legal Needs Of Vulnerable Populations*, 29 HEALTH AFFAIRS 1697, 1699 (2010) (describing system in which EHRs prompt providers to screen for legal needs); Andrea C. Maciejewski, Comment, *Medical Records and Privacy Rights: The Unintended Consequences of Aggregated Data in Electronic Health Records*, 90 U. COLO. L. REV. 1111 (2019). In future work, I plan to take up the question of how the medicalization of social issues, and the increasingly blurred lines between medical and other personal information, intersects with the special privacy considerations usually afforded to medical privacy.

51. *See* Laura M. Gottlieb, Karen J. Tirozzi, Rishi Manchanda, Abby R. Burns & Megan T. Sandel, *Moving Electronic Medical Records Upstream: Incorporating Social Determinants of Health*, 48 AM. J. OF PREVENTIVE MED. 215, 216 (2015).

amount of personal information at issue—and despite widespread public belief that privacy is especially important in the medical context—privacy protections for patients are lacking. While every health data regulation mentions concern for patient privacy as a matter of course, all too often, the practical upshot amounts to little more than lip service, especially *within* the patient-care context. Missing from the discourse is a rich account of whether and why patients might have genuine interests in preventing their information from being automatically available even to those from whom they seek treatment.

II. PATIENTS' INTERESTS IN PRIVACY FROM DOCTORS

The impending approach to health records privacy is premised on the idea that patients have little interest in privacy from their doctors. In what follows, I challenge the assumptions underlying that premise. To some extent, the value of privacy is abstract, and it can seem incommensurable with the other goals of the healthcare system like efficiency and treatment success—but that does not mean that it is unimportant. Moreover, while there is a widespread assumption that better information-sharing among treating physicians is a categorical good, there are times when allowing patients to shield information from their providers can be expected to improve care in very practical ways. Better sharing of comprehensive patient health information, in short, is full of promise, but it is not a *categorical* good—and privacy from doctors can have real benefits.

Put simply, there are times when the disclosure of information about a patient will lead reasonable patients to believe that their privacy has been invaded, and can have concrete negative impacts on the patient. Yet both the law and the literature tend to assume this interest away; this type of information-sharing among treating providers occurs as a matter of course and is generally permitted under federal law.⁵² The biggest limitation on the sharing of medical information among providers is an accidental one: medical records are fragmented and, for the moment, not very easily shared across healthcare systems.⁵³ As discussed above, that will not be the case

52. See *supra* notes 39, 41.

53. See, e.g., Nicolas P. Terry, *Pit Crews with Computers: Can Health Information Technology Fix Fragmented Care?*, 14 HOUS. J. HEALTH L. & POL. 131, 166-169 (2014) (cataloguing failures in reaching interoperability); Nat'l Comm. on Vital and Health Statistics, *The Thirteenth Report to Congress on the Implementation of the Administrative Simplification Provisions of the Health*

for long.⁵⁴ So as a matter of federal law, in these scenarios, the patient's privacy rights have not been violated. But as a matter of common parlance and experience, the patient has experienced a violation of privacy, and all the more so if the patient had taken efforts to prevent their information from being shared or did not expect it.

We should take this type of experience seriously. The upsides of privacy from doctors—the reasons these sorts of violations matter—can be divided into two categories: those related to fundamental values about the way that the medical system should approach patients, as a normative matter, and those related to more instrumental values. In general, while theorists who discuss privacy tend to describe it as rooted in ethical principles, health privacy policy and practice have tended to protect patient privacy only to the extent it is instrumentally valuable for public health or other purposes.⁵⁵ Within the treatment context, even those instrumental values are underappreciated. The Sections that follow explicate both the normative and instrumental values of privacy from doctors.

A. Privacy Values: Autonomy, Identity, and Self-Authorship

The question of what, precisely, privacy means, and what it means for privacy to be violated, is notoriously thorny and unresolved.⁵⁶ This Article

Insurance Portability Act (HIPAA) of 1996 viii (2019) (noting that HIPAA itself serves as barrier to interoperability).

54. See *supra* text accompanying notes 15-23.
55. For an incisive discussion of this phenomenon and the disjunct between the ethical foundations of privacy and its place in practice, see Nicholas P. Terry, *What's Wrong With Health Privacy?*, V J. OF HEALTH & BIOMEDICAL L. 1, 1-32 (2009).
56. An enormous amount of ink has been spilled on the question of what constitutes a privacy interest. For a helpful overview, see Daniel J. Solove, *A Taxonomy of Privacy*, 154 U. PA. L. REV. 477 (2006). Under a "control"-based definition of privacy, under which the core of the privacy interest is a right to exercise autonomous control over access to one's personal information, one might ask whether the patient had authorized the information-sharing. Under this definition, the absence of something akin to informed consent might be the problem. See, e.g., Adam D. Moore, *Coercing Privacy and Moderate Paternalism: Allen on Unpopular Privacy*, 13 APA NEWSLETTER 1, 10-11 (2013) (arguing in favor of "control-based" theory of privacy). Or, in a similar spirit, the question might be whether the available decisional infrastructure allowed the patient to exercise an appropriate degree of boundary management. See Margot E. Kaminski, *Regulating Real-World Surveillance*, 90 WASH. L. REV. 1113

does not purport to resolve that question.⁵⁷ The key point is that privacy and the other commitments with which it is intertwined are important in profound and personal ways—and that remains just as true when doctors are added to the equation.

A commitment to privacy flows from a commitment to individual autonomy—a core value in the field of biomedical ethics, if not always in the

(2015). Others would ask whether the disclosures between doctors violate norms that enable a desirable form of self-construction. *See, e.g.*, Julie Cohen, *What Privacy Is For*, 126 HARV. L. REV. 1904 (2013).

57. If, for instance, the existence of a privacy injury depends on the existing norms within a particular context, then the fact that the sharing of medical information among medical providers (especially within the same broad medical system) is commonplace and expected—indeed, encouraged as a matter of federal law—suggests that our perturbed patients are perhaps oversensitive. *See, e.g.*, HELEN NISSENBAUM, *PRIVACY IN CONTEXT* (2009). To be clear, I do not take it as a given that these scenarios would be A-OK under a “contextual integrity” approach. As Professor Nissenbaum describes that inquiry in her influential book, the relevant question would be whether the information flows between doctors were normatively desirable and expected within the context of medical patient care; to the extent that patients are surprised by where the information has ended up, it might suggest a violation of the relevant privacy interest. For a particularly helpful summary of Professor Nissenbaum’s approach, see Andrew D. Selbst, *Contextual Expectations of Privacy*, 35 CARDOZO L. REV. 643 (2013).

So too if meaningful privacy injuries are limited, for instance, to those that create a risk that information will be widely dispersed in the broader community (and we assume that doctors generally abide by their professional duties of confidentiality). More broadly, if the existence of a privacy right depends on a descriptive account of expectations of privacy, then there is no need to worry about privacy from doctors, no matter what patients would desire or be comfortable with in the abstract. If patients know that information is broadly shared within the patient-care context, the argument would be, any experienced violation is irrational or responding to something outside the scope of any relevant privacy interest. On another axis, if the normative core of privacy is its role in preserving limited government and preventing surveillance or overreach, patient privacy from doctors may be of limited relative importance (although the question of medical privacy more broadly certainly intersects with that concern, as international experience has already demonstrated). *See* Mendelson & Wolf, *My [Electronic] Health Record*, *supra* note 8 (discussing Australian experience with national medical records).

practice or law of medicine itself.⁵⁸ The principle of autonomy suggests that people should have some say in what happens to information about themselves.⁵⁹ Autonomy is of special, if fraught, importance in the historically paternalist medical context. For instance, the classic bioethics text, Beauchamp and Childress's *Principles of Biomedical Ethics*, sets forth four guiding principles that have become something like "hornbook" law for bioethics: the first among these is "respect for autonomy." (The other three are non-maleficence, beneficence, and justice). American courts have similarly stressed autonomy's importance in delineating the boundaries of medical malpractice and tort law,⁶⁰ although they have not always managed to adopt rules that actually promote meaningful autonomy.⁶¹ While the primacy of autonomy in medical ethics has its critics and on any view may run up against limits (for instance, when extremely scarce resources like organs are at issue, or when a patient directly threatens others' health or safety),⁶² few disagree that it is at least *an* important value.

The harms incurred when a patient's autonomy is violated may be diffuse, but that does not mean they are not real. Human flourishing depends upon a sense of agency and control, and privacy protects against a sense of powerlessness over intimate information. Because of its relationship to our sense of identity, control over the disclosure of especially intimate information about ourselves seems especially important. As scholars like Julie Cohen have argued, control over intimate information enables a kind of boundary-drawing and exploration that permits a sense of autonomous selfhood, and thereby plays a role in the construction of our identities as an autonomous adults. We define ourselves

58. For a description (and critique) of how modern law of medical confidence has taken an instrumentalist, rather than autonomy-based, approach, see Terry & Francis, *supra* note 7, at 698-700.

59. See Cohen, *supra* note 56.

60. See, e.g., Lauren Scholz, *Privacy Remedies*, 94 IND. L.J. 653, 680 (2019) (exploring the role of autonomy in traditional privacy torts).

61. For an incisive critique of the role of autonomy in the American legal system, see Roger B. Dworkin, *Getting What We Should From Doctors: Rethinking Patient Autonomy and the Doctor-Patient Relationship*, 13 HEALTH MATRIX 235, 245 ("[F]or all the talk . . . the law does not support patient control over medical decisions, sometimes for good reasons and sometimes for bad. The rhetoric of autonomy facilitates treading on the interests of individual patients while providing an excuse for ignoring important interests of other persons.").

62. See, e.g., *id.*

and construct our identities in relation to each other, leading to a “dynamic, emergent subjectivity” that shapes and is shaped by our interactions with those around us.⁶³ For this reason, “[p]rivacy is one of the resources that situated subjects require to flourish.”⁶⁴ As a practical matter, we manage our relationships—including relationships with caregivers or providers—by, among other things, managing the information we disclose .

Privacy protects against the senses of vulnerability and powerlessness that come when information about us is transferred or used in ways that we do not understand and cannot control. The current discourse tends to treat medical privacy as though the privacy harms that must be protected against are the relatively concrete harms that might arise if medical data is misused or escapes the medical context. But the reality is more subtle than that. Daniel Solove put the point well: the best metaphor for understanding what privacy protects against is not always Big Brother—it is Kafka’s *The Trial*, representing “a more thoughtless process of bureaucratic indifference, arbitrary errors, and dehumanization, . . . without any meaningful form of participation in the collection and use of their information.”⁶⁵ The cognitive science literature supports Kafka’s literary instinct: there is evidence that the need for control and choice is not only important for human health and functioning but is “a biological imperative for survival” with physical implications.⁶⁶

In encounters with the medical system, both actual agency and a sense of autonomous selfhood can be in short supply. The patient experience can be one of profound objectification and fragmentation, all the more so if care seems disconnected from the patient’s own experience of their illness.⁶⁷ One woman described her prolonged medical treatment for Crohn’s disease: “Throughout my medical experiences my body was erased. My emotions, worries, hopes, and fears were erased from the doctor-patient dialogue and

63. Cohen, *supra* note 56, at 1905.

64. *Id.* at 1911.

65. Daniel J. Solove, *Privacy and Power: Computer Databases and Metaphors for Information Privacy*, 53 STAN. L. REV. 1393, 1398 (2001) (internal footnote omitted).

66. Lauren A. Leotti et al., Review, *Born to Choose: The Origins and Value of the Need for Control*, 14 TRENDS IN COGNITIVE SCI. 457 (2010).

67. For a useful discussion of the tension between evidence-based medicine practices and patient-centered practices that better respect patients’ subjective experiences of their illnesses, see Carl May et. al, *Technogovernance: Evidence, Subjectivity, and the Clinical Encounter in Primary Care Medicine*, 62 SOC. SCI. & MED. 1022, 1023-26 (2006).

omitted from my files.”⁶⁸ When care is based on electronic records that are themselves wholly outside the patient’s control, and which may or may not track the patient’s experience of their illness, the loss of agency is even more acute. Even if patients would nearly always allow full access to their medical records, the knowledge that the patient *could* adjust access if something went awry can be profoundly empowering. In those cases where a patient believes that their medical care or relationships are being compromised by something in their records, some element of control could restore a sense of agency and control in a context when it can otherwise be quite lacking.⁶⁹

It may be tempting to treat the medical context as a marginal, isolated one in which privacy concerns can be set aside with few broad social ramifications. For many, that assumption may be true, at least for most of their lives. For others, however, frequent—or prolonged—contact with the medical system is a fact of life. When people do come into contact with the medical system, it is frequently at especially vulnerable moments, with existentially fraught ramifications.

Moreover, the lived experience of doctor-patient interactions (which, at least for the moment, generally involve in-person encounters between recognizable human beings) is much more personal and intimate than the more disembodied encounters—like the use of information for research or commercial purposes—that raise more widely-acknowledged privacy concerns.⁷⁰ Doctors are people, and encounters with them raise the normal spectrum of human emotions. Their quasi-authoritative status might raise especially complicated anxieties or social experiences for many patients. There is little reason to think that patient encounters with doctors would be

68. Nicole L. Defenbaugh, “Under Erasure:” *The Absent Ill Body in Doctor-Patient Dialogue*, 14 *QUALITATIVE INQUIRY* 1402, 1417 (2008).

69. Atul Gawande has observed that while older adults are generally happier, “when they lost that happiness is when they no longer were having some control over their own story, that they were not getting to be the shapers of their own story.” Atul Gawande, *What Matters in the End*, *ON BEING*, at 12:14 (Oct. 26, 2017), <https://onbeing.org/programs/atul-gawande-what-matters-in-the-end/#transcript> [<https://perma.cc/87UT-MSM4>].

70. In this paper I do not take up the question of whether patients in the healthcare system should be understood to have meaningful privacy rights over their (generally de-identified) health data vis-à-vis public health and medical researchers. Glenn Cohen, for instance, has argued that patients have an affirmative duty to share (anonymized) health information with big-data companies for purposes of improving medical care to society as a whole. See I. Glenn Cohen, *Is There a Duty to Share Healthcare Data?*, in *BIG DATA, HEALTH LAW, AND BIOETHICS* 209, 209-22 (I. Glenn Cohen et al. eds., 2018).

any less formative for a patient's self-understanding than other encounters or contexts in which private information may be used. If anything, there is a certain irony in the absence of patient privacy from doctors, given that medical information is often held up as a paradigm of sensitive, private information.

The evidence, such as it is, suggests that patients, by and large, seek and prefer some degree of privacy from their doctors. There is remarkably little empirical research on patient views of medical privacy. As philosopher Leslie Francis put it, "The absence of good research in the area opens the door to unsubstantiated claims about how everyone has just gotten over the privacy they don't have."⁷¹ But we can draw some inferences from the ways in which patients exercise the limited control they have over the information they share with doctors, even when they exercise that control in ways that are potentially detrimental to their treatment. Patients can conceal information from their doctors, outright lie, or find other ways to control their narrative, including by seeking care from providers far afield from their local communities or regular doctors when confronting particularly sensitive issues.⁷²

On that question, there is some empirical evidence. One recent study indicated that well over half of approximately 5,000 surveyed patients had avoided disclosing to doctors information that might have been relevant to their care.⁷³ The reasons that patients cited in that survey are telling: "the most commonly reported reasons for [withholding medically relevant information from their clinicians] were that patients did not want to be negatively judged by their clinician, did not want to hear how harmful the behavior in question was, or were embarrassed."⁷⁴ Patients also frequently report that they "wanted the health care provider to like [them]."⁷⁵ While

71. Leslie Francis, *Privacy and Confidentiality: Bill of Health at Five Years and Beyond*, PETRIE-FLOM CTR. FOR HEALTH L. POL'Y, BIOTECHNOLOGY, & BIOETHICS AT HARV. L. SCH.: BILL OF HEALTH (Oct. 2, 2017), <https://blog.petrieflom.law.harvard.edu/2017/10/02/privacy-and-confidentiality-bill-of-health-at-five-years-and-beyond> [<https://perma.cc/HT93-7R6M>].

72. See generally Evan Selinger & Woodrow Harzog, *Obscurity and Privacy, in SPACES FOR THE FUTURE: A COMPANION TO PHILOSOPHY OF TECHNOLOGY* (Joseph C. Pitt & Ashley Shew eds., 2018) (recentering concepts of privacy around "obscurity," or "the idea that information is safe—at least to some degree—when it is hard to obtain or understand").

73. See Levy et al., *supra* note 3.

74. *Id.* at 6; see also *id.* at 5-6 & tbl.2 (presenting the authors' empirical data).

75. *Id.* at 5.

the response that patients did “not want to hear how harmful the behavior in question was” probably relates largely to a separate set of issues, the other responses suggest that patients are deeply attuned to their relationship with doctors as fellow humans who are part of their social world, like any other member of the community.

Comprehensive, longitudinal medical records also implicate another more controversial value intricately connected to privacy, the freedom *from* information about oneself.⁷⁶ The ability to forget serves a role in enabling people to change over time, or to leave their pasts in the past.⁷⁷ This type of value may seem counterintuitive in the medical context, but even there, information has the capacity to hurt as well as to help. Medical issues are not separate from the rest of life. The simplest examples are also, perhaps, the most extreme: those injured in especially traumatic incidents, for instance, may have a deep interest in forgetting the incident, even at potential risk to their medical treatment. More trivial examples also abound: in looking at my own vaccination records for a trip abroad, I was amused, but not entirely happy, to be reminded that I came down with pink eye the day before my college graduation (a slightly embarrassing inconvenience that I had managed to forget).⁷⁸ One way of thinking about comprehensive, cradle-to-grave records of any sort is that they force us to confront reality of our pasts, however cold and hard that may be. But they may also keep us tethered to those pasts, by reminding ourselves of what happened to us and who we were at different times in lives. Perhaps even in the medical realm there should be some room for reinvention.

76. Cf. Jane Bambauer, *Freedom From Thought*, 65 EMORY L.J. 219, 221 (2015) (theorizing “freedom from thought,” which “may be a promising form of privacy and dignity rights”).

77. This line of thinking is probably most developed by scholars of the European Union’s developing “right to be forgotten” in the internet context. See, e.g., Norberto Nuno Gomes de Andrade, *Oblivion: The Right to be Different . . . From Oneself: Re-Proposing the Right to be Forgotten*, in THE ETHICS OF MEMORY IN A DIGITAL AGE 65-81 (Alessia Ghezzi et al. eds., 2014). See generally Andrew Tutt, *The Revisability Principle*, 66 HASTINGS L.J. 1113 (2015) (tracing similar themes in U.S. law).

78. Apparently, not so embarrassing that I’m unwilling to include it here.

B. Practical Upsides: Privacy, the Doctor-Patient Relationship, and Patient Care

“Privacy’s loftier sides may be all well and good,” the reader might be thinking at this point, “but in the medical context, do we really care about such abstractions when patient health could be at stake?” There can be little doubt that in many—perhaps most—circumstances, enabling a more seamless flow of patient information will benefit patient care. And the benefits of the free transmission of patient information seem especially stark when set against the backdrop of fragmented approach to electronic health records currently in effect—just ask anyone who has changed jobs or cities frequently how much of their medical history they can easily access, or how much time they have spent compiling records.⁷⁹

But the choice between patient privacy and patient care is a false one. In several ways, and in a variety of circumstances, privacy from doctors can actually improve patient care and outcomes.

1. The Doctor-Patient Relationship

Privacy, along with autonomy, plays an important role in the modern doctor-patient relationship. Empowering patients to control what information is shared with doctors may significantly benefit that relationship at both theoretical and practical levels. Focusing on the primacy of the individual patient—who often seems like an afterthought in the hundreds of Federal Register pages purportedly devoted to medical record and privacy issues—can add consistency and clarity to the normative structure of that (complex and under-theorized) relationship. And more practically, empowering patients seems likely to promote trust in their doctors and buy-in with their treatment plans.

The medical profession’s current approach to medical records—including, for instance, health care providers’ assertions that they own patient data⁸⁰—harken back to an outdated vision of the doctor-patient

79. As Mark Hall has put it, “Medical information is one of the most prominent, puzzling, frustrating, and entrenched aspects of dysfunction in U.S. health care finance and delivery.” Hall, *supra* note 8, at 633.

80. *Cf.* Raj Sharma, *Who Really Owns Your Health Data?*, FORBES (Apr. 23, 2018), <https://www.forbes.com/sites/forbestechcouncil/2018/04/23/who-really-owns-your-health-data/?sh=609da9396d62> [<https://perma.cc/DG55-Z9QW>] (“Under federal and state law, patients have legal privacy, security and accuracy rights related to their health information. However, once that information is captured and documented in written or electronic form (e.g.,

relationship. Since at least the time of Hippocrates, the model of the doctor-patient relationship has included a core of forthright paternalism.⁸¹ The Hippocratic Oath itself reflects a deep assumption that physicians have superior knowledge to which patients should defer.⁸² In its early days, the American Medical Association made this explicit, codifying the following principle in its Code of Medical Ethics:

The obedience of a patient to the prescriptions of his physician should be prompt and implicit. He should never permit his own crude opinions as to their fitness, to influence his attention to them.⁸³

That approach no longer prevails in its most explicit forms. In the last half-century, thanks to the “modern bioethics sweep”⁸⁴ (and, more cynically, to the economic advantages of a consumer-centric model of healthcare⁸⁵) the medical profession’s appreciation for patient autonomy

paper chart or electronic data file), and since the health care provider owns the media in which the information is recorded and stored, the health care provider gains the property right of possession of data. In essence, the health care provider becomes the legal custodian of your health care record and is given specific legal rights and duties relating to possession and protection of that health record.”).

81. See, e.g., Robert F. Graboyes & Eric Topol, *Anatomy and Atrophy of Medical Paternalism*, MERCATUS CTR. AT GEORGE MASON UNIV. 3 (July 6, 2017), https://www.mercatus.org/system/files/mercatus-graboyes-medical-paternalism-v3_1.pdf [https://perma.cc/3NLX-LHTT] (“[Medical paternalism] dates at least as far back as Egypt’s [H]igh [P]riest and [C]hancellor Imhotep (ca. 2600 BCE).”).
82. The classic version of the Oath, for instance, reads in part as follows: “I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice. I will neither give a deadly drug to anybody who asked for it, nor will I make a suggestion to this effect. Similarly I will not give to a woman an abortive remedy. In purity and holiness I will guard my life and my art.” See Tyson, *The Hippocratic Oath Today*, *supra* note 1. The contemporary version reads: “I will apply, for the benefit of the sick, all measures [that] are required, avoiding those twin traps of overtreatment and therapeutic nihilism.” *Id.*
83. AM. MED. ASS’N, CODE OF MEDICAL ETHICS art. 2, § 6 (1847).
84. Susan M. Wolf, *Conflict Between Doctor and Patient*, 16 L. MED. & HEALTH CARE, 197, 197 (1988).
85. See, e.g., Nan D. Hunter, *Rights Talk and Patient Subjectivity: The Role of Autonomy, Equality, and Participation Norms*, 45 WAKE FOREST L. REV. 1525,

has increased dramatically.⁸⁶ The concept of informed consent, for instance, is now a hallmark of modern medical practice.⁸⁷

But ambivalence remains, and the relationship between patients' autonomy and doctors' responsibilities remains complex.⁸⁸ Few argue, for instance, that doctors should be required to provide patients with risky treatment for a condition that the patient does not, as a clinical matter, have,

1545-47 (2010) (discussing “medical consumerism” and some of the economic advantages that accrue because of it).

86. Cf. Susan M. Wolf, Response, *Doctor and Patient: An Unfinished Revolution*, 6 YALE J. HEALTH POL'Y, L., & ETHICS 487, 500 (2006) (arguing that there is a trend toward greater autonomy, but that there is an “unfinished revolution”).
87. See, e.g., *Canterbury v. Spence*, 464 F.2d. 772, 780 (D.C. Cir. 1972) (“Suits charging failure by a physician adequately to disclose the risks and alternatives of proposed treatment are not innovations in American law. They date back a good half-century, and in the last decade they have multiplied rapidly.”) (internal footnotes omitted); cf. *id.* at 782 (“[A] disclosure requirement, on analysis, reflects much more of a change in doctrinal emphasis than a substantive addition to malpractice law. It is well established that the physician must seek and secure his patient’s consent before commencing an operation or other course of treatment. It is also clear that the consent, to be efficacious, must be free from imposition upon the patient. It is the settled rule that therapy not authorized by the patient may amount to a tort—a common law battery—by the physician. And it is evident that it is normally impossible to obtain a consent worthy of the name unless the physician first elucidates the options and the perils for the patient’s edification. Thus the physician has long borne a duty, on pain of liability for unauthorized treatment, to make adequate disclosure to the patient. The evolution of the obligation to communicate for the patient’s benefit as well as the physician’s protection has hardly involved an extraordinary restructuring of the law.”) (internal quotations omitted); Laura Sedig, *What’s the Role of Autonomy in Patient- and Family-Centered Care When Patients and Family Members Don’t Agree?*, 18 AM. MED. ASS’N J. OF ETHICS 12, 13 (2016) (noting the role that informed consent plays in patient independence, which “is traditionally the highest priority in American bioethics”).
88. John C.P. Goldberg has noted, for instance, that informed consent doctrine’s focus on patient autonomy seems at odds with doctors’ role as fiduciaries. He suggests that this apparent tension can be resolved by conceptualizing doctors’ fiduciary duty of loyalty as “in part a requirement that the physician embrace the ‘intersubjectivity’ of the physician-patient relationship—i.e., that she *work with each patient* toward the goal of the patient’s good health.” John C.P. Goldberg, *The Duty of Care*, in THE OXFORD HANDBOOK OF FIDUCIARY LAW 405, 414 (Evan J. Criddle et al. eds., 2019).

no matter how much the patient requests it.⁸⁹ And while doctors might be viewed merely as subject-matter experts who purvey information to patients, many argue that doctors should have a more robust role in shaping patient expectations and preferences.⁹⁰ Patients are at an enormous informational disadvantage, and doctors who do no more than provide information in a neutral matter while at the same time declining to provide further guidance are abdicating a profound responsibility.⁹¹

Scholars have proposed various models for the modern doctor-patient relationship,⁹² and questions about both its ideal form and the extent to which practitioners actually live up to those ideals are the subject of ongoing discussions. As a practical matter, of course, the lived experience of the doctor-patient relationship may be far removed from any theoretical model, driven instead by practical considerations like billing, scheduling, sheer exhaustion, and the complicated intermixing of personality traits. As

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89. A particularly fascinating limit-case for this idea arises in the context of “self-demand amputations,” in which otherwise healthy patients with a type of body dysmorphia request amputations to conform their body to their conceptions of themselves as amputees. For a discussion of the ethical implications of such a practice, see, for example, Floris Tomisini, *Exploring Ethical Justification for Self-Demand Amputation*, 22 ETHICS & MED. 99 (2006).
90. As a practical matter, for instance, “[a]lthough individuals have the right to make their own treatment decisions in many settings, they often defer to providers and insurance companies because of information asymmetry, uncertain health risks, and limits on benefits.” Prah Ruger, *Health, Capability, and Justice: Towards a New Paradigm of Health Ethics, Policy, and Law*, 15 CORNELL J. L. & POL. 403, 425 (2006).
91. Further limitations on the autonomy model include: that patient autonomy may bump up against distributive concerns (for instance if patients demand expensive or scarce treatments), and the simple fact that some amount of paternalism is inevitable as physicians and other providers necessarily make decisions that structure patients’ choices, for instance in describing the array of treatment options available. See generally Cass R. Sunstein & Richard Thaler, *Libertarian Paternalism*, 93 AM. ECON. R. 175 (2003) (exploring when paternalism should be deployed).
92. See, e.g., Ezekiel J. Emanuel & Linda L. Emanuel, *Four Models of the Physician-Patient Relationship*, 267 JAMA 2221 (1992). For further background on these themes, see, for example, M. GREGG BLOCHE THE HIPPOCRATIC MYTH: WHY DOCTORS ARE UNDER PRESSURE TO RATION CARE, PRACTICE POLITICS, AND COMPROMISE THEIR PROMISE TO HEAL (2011), which argues that, in practice, doctors play a variety of public roles and that their appropriate role should be the subject of a more robust democratic discussion about the role of healthcare. See also Wolf, *supra* note 84.

one young doctor recovering from a twenty-four-hour residency shift on a Saturday morning explained to me in March 2019, “Talking about the form of the doctor-patient relationship feels sort of like talking about high military strategy when I’m just a soldier with a shovel digging trenches.”⁹³

But under virtually all models, patient autonomy is important, even if other considerations—including, for instance, the ethical and professional views of the practicing physician and the needs of the healthcare system more broadly—are also part of the equation. So too with trust. “Trust has both intrinsic and instrumental value,” and it is a key component in the doctor-patient relationship.⁹⁴ As Mark Hall has put it, intrinsically, trust is “the core, defining characteristic that gives the doctor-patient relationship meaning, importance, and substance,” and so “preserving, justifying, and enhancing trust is the fundamental goal of much of medical ethics.”⁹⁵ As a practical matter, there is reason to think that trust affects everything from “patients’ willingness to seek care . . . [and] adhere to treatment regimens,” to the success of medical treatments (in part because of its role in the placebo effect).⁹⁶ The “soldiers in the trenches,” as well as the academic bioethicists, should care about this point.

Trust, in turn, is deeply intertwined with privacy.⁹⁷ The strength of our relationships can be measured in part by the extent to which we share personal information. Privacy rules can create the groundwork that allows

93. Telephone Interview with Jean M. Lopez, M.D. (May 4, 2019).

94. Mark Hall, *The Importance of Trust for Ethics, Law, and Public Policy*, 14 CAMBRIDGE Q. HEALTHCARE ETHICS 156, 156 (2005); see also Council on Ethical & Jud. Affs., Am. Med. Ass’n, Council Report, *Ethical Issues in Managed Care*, 273 JAMA 330, 331 (1995) (“The foundation of the patient-physician relationship is the trust that physicians are dedicated first and foremost to serving the needs of their patients.”).

95. Hall, *supra* note 94, at 156; see also Ian Goldberg et al., *Trust, Ethics, and Privacy*, 81 B.U. L. REV. 407 (2001) (using ethical concepts to probe issues of trust and privacy).

96. Mark Hall et al., *Trust in Physicians and Medical Institutions: What Is It, Can It Be Measured, and Does It Matter?*, 79 MILBANK Q. 613, 614 (2003).

97. For a helpful discussion of the implications that interoperable records may have for both sides of the doctor-patient relationship—that is, doctors’ trust in their patients, as well as patients’ trust in their doctors—see Leslie Pickering Francis, *The Physician-Patient Relationship and a National Health Information Network*, 38 J.L. MED. & ETHICS 26, 39-42 (2010).

trust to flourish.⁹⁸ By the same token, when privacy rules do *not* match expectations, the result is distrust—and in the medical context, where vulnerable patients are effectively forced to place trust in doctors regardless of their attitude towards the doctor, the result can be an even stronger sense of betrayal.⁹⁹

Empowering patients creates more space for genuine trust, as opposed to mere obedience. In the information technology context, for instance, Neil Richards and Woodrow Hertzog acknowledge that people “disclose even more information when we have privacy settings.”¹⁰⁰ In the medical context, there may be even more benefits: when patients feel confident that doctors are responding to their actual experience they may be more inclined to actively participate in their care.¹⁰¹ Imagine, for instance, a person who is concerned about how their alcohol intake (a commonly reported issue about which people lie to their doctors) is affecting some aspect of their medical care, but who is also worried that disclosing their alcohol intake will result in a permanent checked box in their record that will affect their care in unpredictable ways down the road. Perhaps they fear, for instance, that their ability to get strong painkillers after a surgery will be hampered. They may even just have an inchoate fear that future doctors will judge them

98. Neil Richards and Woodrow Hertzog make this point nicely in the context of digital information privacy rules. See Neil Richards & Woodrow Hertzog, *Taking Trust Seriously in Privacy Law*, 129 STAN. TECH. L. REV. 431, 457-71 (2016).

99. Cf. Hall, *supra* note 94, at 160 (“[D]ue to the strength and emotional tenor of trust in physicians, patients are capable of extraordinary levels of forgiveness, but are subject to extreme feelings of betrayal once the limits of trust are breached.”); Craig M. Klugman, et al., *The Ethics of Smart Pills and Self-Acting Devices: Autonomy, Truth-Telling, and Trust at the Dawn of Digital Medicine*, 18 AM. J. OF BIOETHICS 38, 43-44 (2018) (discussing the potential impact of digital medicine on trust within the doctor/patient relationship, and noting that while eliminating uncertainty (and the ability to deceive a doctor) may promote trust to some extent, other patients may prefer to retain the ability to deceive their doctors).

100. Richards & Hertzog, *supra* note 98, at 454.

101. One might argue that this dynamic runs the other way. For a patient who is already distrustful of the medical establishment or of a particular doctor, the sense that information is being shared behind the scenes might only strengthen that mistrust. For a patient who has not given much thought to the question, however, a sense that information-sharing between treatment providers is inevitable could conceivably promote a sense of trust in the establishment.

and take their concerns less seriously. A culture of patient information control could go a long way to enabling an honest conversation in the present encounter.

In the modern doctor-patient relationship, moreover, it makes sense to encourage patients to engage with and understand their own health information—and that depends at least in part on understanding what information doctors are considering as they make recommendations.¹⁰² For all of modern medicine's focus on informed consent, the experience of being a patient can be quite passive, and patients may feel helpless to do anything other than what the doctor recommends. Increasing patients' sense of control over their medical information may well increase their sense of agency and engagement over their health decisions, even if most patients would choose to share information with their doctors to obtain the most fully informed care possible most of the time. Likewise, a culture in which patients are empowered to withhold information may encourage doctors to work harder to hear patients' stories, and to explain relevant considerations to the patients. The resultant conversations could, perhaps, make a shift towards a more humane culture for both doctors and patients. This is not just an abstract good. It has enormous practical value both for the quality of care individual patients receive, and, in all likelihood, for the availability of high-quality patient care in the future. Patient outcomes are significantly better when there is a strong doctor-patient relationship, especially when the patients view their doctor as empathetic.¹⁰³ Doctor burnout is inversely correlated to the amount of time doctors can spend with patients.¹⁰⁴

Ultimately, resolving the tradeoffs surrounding patient privacy requires taking stock of how society should respond to larger trends in the medical system. In the face of increasing pressures from myriad directions to

102. See, e.g., Jeremy Laurance et al., *Patient Engagement: Four Case Studies That Highlight The Potential for Improved Health Outcomes and Reduced Costs*, 33 HEALTHAFFAIRS 1627 (2014) (“To play an active role in their health care, patients need information and motivation.”); cf. Julia James, Health Policy Brief, *Patient Engagement*, HEALTHAFFAIRS (Feb. 14 2013), <https://www.healthaffairs.org/doi/10.1377/hpb20130214.898775/full> [<https://perma.cc/N2CF-KSXB>] (summarizing findings that more informed and engaged patients had reduced healthcare costs).

103. For background and a useful literature review, see generally Frans Derksen et al., *Effectiveness of Empathy in General Practice: A Systematic Review*, 63 BRITISH J. GEN. PRAC. 76 (2013).

104. See, e.g., Jeffrey Bendix, *The Real Reason Docs Burn Out*, MED. ECON., Jan. 16, 2019, at 14 (exploring the dynamics of physician burnout, including the exacerbating role that EHRs play in particular).

process patients rapidly and efficiently, it is tempting to throw up our hands: doctors have too much to do and too little time in which to do it, and we should not expect deeper or more complicated engagements with patients given that the system works as it does. Yet to take as a premise that any assessments of what medical care should look like must be no bolder than can be shoehorned into the strictures of our present financing systems is to assume the answer to a complex political conversation about tradeoffs. Further, such a stance seems likely to only reinforce and reify the pressures emanating from those present systems. Thus, it is better to take an affirmative vision of the doctor-patient encounter as the starting point.

In short, as we think about how financing concerns, technology, and the medical professions intersect, we should aim to preserve the doctor-patient relationship as a true *relationship*, and we should avoid approaches that lead either party to view the other as an interchangeable automaton or compilation of datapoints. Granting patients more power over their own narratives within the medical system would promote a more authentic form of communication and a more authentic doctor-patient relationship. Doctors do not treat medical records—they treat people, with stories and goals and self-understandings that may not be reflected in a comprehensive medical record. On the other side of the coin, doctors are not machines for hire—they are experts in a healing, helping profession; as such, they should be permitted and expected to probe areas where a patient may be leaving out information. That, however, is not the same as suggesting that doctors are entitled to everything in patient records. Respect for autonomy requires that formal power ultimately rests in the patient in the mine run of cases. Rather, it means that rules should be designed to enable doctors and patients to develop authentic trust and comfort. Often, the easy sharing of a comprehensive medical history may expedite that process. But when that sharing leads patients to feel like powerless objects being funneled through an impersonal system, or, especially, when the story contained in the medical record does not match the patient's lived experience, empowering patients to control the flow of their information and share their story with a new doctor could be invaluable to the ability to create a useful relationship. The medical system should be willing to bear some costs for that outcome.

More concretely, the absence of patient privacy may have chilling effects both on patients' willingness to seek treatment and be candid when they do. When patients have control over their medical information, they may be more likely to honestly disclose sensitive information—which can be critically important to patient care. When patients lie about or understate their use of substances, for instance, it can have dire effects. One doctor recounted an instance in which he was about to bring a patient into an

operating room for an appendectomy—and only then learned that the patient was, in fact, using methamphetamine, which “can present the same way as appendicitis.”¹⁰⁵

Of course, some patients may be unwilling to share information that they are ashamed or embarrassed about—or for which they may suffer legal repercussions—with any doctor, regardless of whether they retain control over their information.¹⁰⁶ But for at least some, informational norms seem likely to make a difference. In the nationwide studies discussed above, more than thirty percent of patients who reported intentionally withholding relevant information from their doctors identified “I didn’t want this information in my medical record” as a reason.¹⁰⁷ “[C]oncern about the information being in their medical record” is one of the top three reasons that patients cite in explaining why they failed to report depression to their treating physicians.¹⁰⁸ Along similar lines, patients may also be more likely to seek treatment in the first place if they have a greater sense of control over their medical information, especially for sensitive issues.

Nor is this effect limited to those with diseases or histories categorized as sensitive; for instance, in one study, while patients with HIV expressed stronger preferences for privacy of medical records than the general public, so did those with colon cancer.¹⁰⁹ In any event, the question of what

105. Dennis Thompson, *Most Americans Lie to Their Doctors*, WEBMD (Dec. 4, 2018), <https://www.webmd.com/a-to-z-guides/news/20181204/most-americans-lie-to-their-doctors> [<https://perma.cc/9WMP-6KRY>] (quoting Dr. John Cullen, President, Am. Acad. of Physicians).

106. Patients may have many practical reasons to avoid disclosing substance abuse, for instance, from avoiding criminal sanctions to retaining housing or other public benefits.

107. See Levy et al., *supra* note 3, 5 tbl.2.

108. *Id.* at 2. In another survey, “12.3% . . . of respondents reported ever withholding information from a healthcare professional out of concern for the security or privacy of their medical records. Agaku et al., *supra* note 3, at 375 (internal citation omitted). While it can be difficult to compare results from different surveys conducted with different methodologies, the daylight between the number of patients who reported concern for “security and privacy” in the Agaku study and the larger number in the Levy study who reported simply not wanting a given piece of information in their medical records at all suggests that some patients are concerned about information being in their medical records full-stop, regardless of the risks of security breaches.

109. Terry & Francis, *supra* note 7, at 697 (citing Nancy E. Kass et al., *Medical Privacy and the Disclosure of Personal Medical Information: The Beliefs and*

constitutes a “sensitive issue” can be widely variable, and may be both culturally contingent and dependent on patients’ particularized fears about being typecast or stereotyped. A gay man experiencing an anal fissure, for instance—a relatively common problem that is usually caused by constipation—may be concerned about stigma and chilled from seeking care in a way that another person would not be. A person who is concerned about being perceived as lazy—perhaps for fear of being branded with a racially-tinged stereotype— may be less inclined to share how neurological symptoms like “brain fog,” dizziness, or fatigue are affecting their work or lives. And a patient who fears being permanently branded as drug-seeking may downplay pain or anxiety. Moreover, while the dissemination of information about certain types of care is already limited by law,¹¹⁰ those limitations may do little to limit patient anxiety that information will be spread, especially if patients’ overall sense is that medical records are entirely outside of patient control. A culture of patient empowerment over medical records could limit these chilling effects.

Even in areas where many reflexively believe that doctors should have more access to patient records—prescribing opiates, for instance, or in identifying malingers—we should be cognizant of the downsides and disparate impacts that taking control away from patients may have. Imagine suffering immensely and being denied appropriate treatment because you have so frequently sought help, or perhaps because, for any number of culturally contingent reasons, a doctor misunderstood or did not believe your experience. These circumstances have the capacity to transform the doctor-patient relationship from one of hope, care, and trust to one of despair, fear, and distrust. While there may be difficult balances to be struck when there are serious risks of harm, some of these difficult policy-level

Experiences of Those with Genetic and Other Clinical Conditions, 128 AM. J. MED. GENETICS 261, 264 (2004)); cf. NCVHS, Letter to Kathleen Sebelius, *supra* note 9 (making reference to certain categories of health information as sensitive).

110. For instance, federal regulations restrict the use of information that a patient has received or applied for substance abuse treatment, *see* 42 C.F.R. pt. 2 (2021), and psychotherapists’ notes are subject to more protections under HIPAA (although diagnoses of mental illnesses and related prescriptions or appointments may still be apparent in medical records). *Compare* 45 C.F.R. § 164.508(a)(2) (2020) (requiring patient authorization for most disclosures of psychotherapy notes), *with id.* § 164.501 (“*Psychotherapy notes* excludes medication prescription and monitoring, counseling session start and stop times, the modalities and frequencies of treatment furnished, results of clinical tests, and any summary of the following items: Diagnosis, functional status, the treatment plan, symptoms, prognosis, and progress to date.”).

circumstances may be precisely where privacy from doctors is most important for a patient's ability to engage in a meaningful doctor-patient relationship.

2. "Clean Slate" Second Opinions

Perhaps counterintuitively, enabling patient control over medical information can also promote the accuracy of medical diagnoses. Consider, for instance, the following real-life story from a recently published, best-selling memoir:

A writer experiences a series of unsettling and gradually escalating symptoms ranging from nerve damage and balance issues to trembling hands and dry eyes, and seeks care from a number of physicians and specialists over the course of several months. Tests continually reveal clear abnormalities, but the specialists are, for a time, unable to pull the threads together with a clear diagnosis. Upon being referred to a new specialist, he takes one look at the length of her medical record, comments that she has "seen everyone in town," and—before asking a single question—tells her that her symptoms are psychosomatic (specifically diagnosing her with "conversion disorder," which she characterizes as "modern day hysteria"). That diagnosis in her medical record follows her to every subsequent doctor appointment, to her great dismay.¹¹¹

And another real-life story:

An unusually tall woman sees an obstetrician-gynecologist during her first pregnancy. The woman does not "show" very much—but, on the other hand, the same has been true for generations of women in her family. The ob-gyn designates the patient as high risk, leading to a significantly more invasive course of prenatal care, and preventing her from giving birth in a birthing center rather than a hospital. (The birth is entirely smooth). Upon becoming pregnant a second time, the woman shops a number of different ob-gyn practices but is unable to convince new doctors *not* to categorize her as high-risk, given the diagnosis in her medical record, though

111. Lori Gottlieb, *MAYBE YOU SHOULD TALK TO SOMEONE: A THERAPIST, HER THERAPIST, AND OUR LIVES REVEALED* 219 (2019).

at least some agree that they would not independently categorize her that way absent the notation regarding her first pregnancy.¹¹²

One thing these anecdotes suggest—along with common sense and an ample body of cognitive science research¹¹³— is that doctors’ diagnoses may depend not just on patients’ symptoms and test results, but also on what happens to be noted in the medical record. A doctor who knows that a patient has sought care from dozens of other providers may be less inclined to take the patient seriously (or less inclined to think the problem can be solved); a doctor aware of past diagnoses may be more inclined, on the margins, to concur. Imagine, for instance, that a patient is referred to a well-known specialist for a specific issue—say, the local Lyme disease expert, after presenting with muscle aches and a rash—but something about the encounter goes awry. Perhaps the doctor seemed inattentive, or the patient began the encounter by accidentally insulting or otherwise alienating the doctor (say, by self-diagnosing). Regardless of the outcome of the visit, the patient might want to be able to get a second opinion from another doctor who did not know that they’d already seen the local expert.

By allowing patients to obtain genuinely fresh second opinions, privacy from doctors can enhance the value of second opinions. Both the prevalence of and the practices for obtaining second opinions varies widely by subspecialty.¹¹⁴ It is more straightforward, for instance, to obtain a “blind” independent second opinion on the interpretation of a single radiology scan than when making a diagnosis with less discrete inputs. But where they are used, second opinions (including patient-driven second opinions) appear to have a significant impact on diagnoses and treatment decisions.¹¹⁵ And

112. Interview with anonymous source in Hartford, Conn. (April 3, 2020) (on file with author).

113. See, e.g., Gustavo Saposnik et al., *Cognitive Biases Associated with Medical Decisions: A Systematic Review*, 16 BMC MED. INFORMATICS & DECISION MAKING 138 (2016) (summarizing the literature on the influence of cognitive biases on medical decision-making); see also Myrna L. Friedlander & Susan J. Stockman, *Anchoring and Publicity Effects in Clinical Judgment*, 39 J. CLINICAL PSYCH. 637 (1983) (conducting such an empirical study to test cognitive biases).

114. Cf. Sabrina C. Heuss et al., *Second Opinions in Psychiatry: A Review*, 24 J. PSYCH. PRAC., 434, 440 (2018) (noting that the “use of second opinions in psychiatry is still in the early stages”).

115. See, e.g., Vaios Hatzoglou et al., *Second-Opinion Interpretations of Neuroimaging Studies by Oncologic Neuroradiologists Can Help Reduce Errors in Patient Care*, 122 CANCER 2708, 2710-11, 2713 (2016) (finding that blinded,

generally, the value of second opinions at promoting accuracy is correlated with their degree of independence.¹¹⁶ When medical records are automatically shared, however, “information cascades” may form. “An information cascade arises when a second or subsequent opinion giver rationally ignores her private information and free-rides on opinions given earlier in the sequence, producing a series of highly correlated but unreliable opinions.”¹¹⁷ Even setting aside the rational impetus to engage in

independent second opinion review of radiology reports led to divergent opinions in 19% of cases, and also finding that difference would impact clinical care or stage of cancer reported in 15% of cases); Ashley N.D. Meyer et al., *Evaluation of Outcomes From a National Patient-Initiated Second-Opinion Program*, 128 AM. J. MED. 1138.e25, 1138.e30 (2015) (finding that, in a nationwide study of participants in an employee benefit plan that enabled patients to get independent second opinions at the patient’s request, “[p]atient-initiated second opinions led to recommended changes in diagnosis for about 15% of participants, changes in treatment for about 37% of participants, and changes in both diagnosis and treatment for more than 10%. Additionally, the second opinions were estimated to have moderate or major clinical impact on patients’ diagnoses in more than 20% of cases and on the patients’ treatments in more than 30%. Second opinions within certain specialties were more likely to result in changes in diagnosis and treatment than others. Similarly, second opinions within certain specialties were more likely to have a moderate or major clinical impact than others.”). The accuracy of the second opinions, as compared to initial assessments, however, is unclear from the literature. See Velma L. Payne et al., *Patient-Initiated Second Opinions: Systematic Review of Characteristics and Impact on Diagnosis, Treatment, and Satisfaction*, 89 MAYO CLINIC PROC. 687, 693-95 (2014) (noting problems in existing studies on second opinions).

116. See, e.g., Adrian Vermeule, *Second Opinions and Institutional Design*, 97 VA. L. REV. 1435, 1454 (2011) (“The main issue is the degree to which the opinions are correlated or independent; the greater the correlation, the lower the benefit of additional opinions because the less likely it is that random errors or systematic biases will wash out.”); cf. Geva Vashitz et al., *Do First Opinions Affect Second Opinions?*, 27 J. GEN. INTERN. MED. 1265, 1269 (2012) (determining, after testing a sample of oncologists and neurologists, “that awareness of another opinion shifted orthopedic surgeons’ choices towards a previously given more interventional opinion,” and that this was contextually dependent, while “[t]he neurologists were unaffected by previously given opinions,” with one posited explanation being that “the orthopedic scenarios [of the study] had a wider treatment spectrum (i.e., the range between the least interventional to most interventional treatment” as compared to the neurologist scenarios).

117. Vermeule, *supra* note 116, at 1455.

the free-riding that is the information cascade,¹¹⁸ doctors, like all of us, are subject to cognitive biases, including confirmation bias that may cause doctors who are presented with a complete medical record to overvalue evidence that the information contained in that record is correct.¹¹⁹

This problem is only compounded by the fact that the information in the medical record may or may not be correct. Take, for instance, the diagnosis of conversion disorder recorded in the memoirist's medical record. That label may well have made it more difficult to obtain an accurate diagnosis later, if subsequent doctors were more inclined to ascribe her symptoms to anxiety. It could also lead to different treating decisions in unexpected ways—for instance, if a doctor down the road considered the conversion disorder diagnosis when deciding which of several medications to prescribe.

Even apart from affirmative misdiagnoses, medical records may be inaccurate for any number of reasons, as—in their current form—electronic medical records serve many masters.¹²⁰ One doctor explained that in practice, when doctors make notes in patient records, the audiences are, in roughly the order of importance, (1) insurance companies; (2) billing departments; (3) other doctors; (4) patients (if the records are available to them in the relevant EHR system).¹²¹ What is more, inaccuracies—so-called “EHR viruses”—may persist for years, leading to concrete negative impacts on patient care.¹²²

118. *Id.* at 1455-56.

119. See Saposnik et al., *supra* note 113.

120. Cf. Robert H. Miller & Ida Sim, *Physicians' Use of Electronic Medical Records: Barriers and Solutions*, 23 HEALTHAFFAIRS 116, 117 (2004) (“An EMR can provide the electronic infrastructure for eight types of clinical and administrative activities normally conducted in physician practices.”); Mark Savage & Lucia Clara Savage, *Doctors Routinely Share Health Data Electronically Under HIPAA, and Sharing With Patients and Patients' Third-Party Health Apps is Consistent: Interoperability and Privacy Analysis*, 22 J. MED. INTERNET RSCH. 1, 5-7 (2020) (providing twelve scenarios, for purposes of illustrating principles of HIPAA liability, in which EMR data is shared).

121. Lopez Interview, *supra* note 93.

122. Cf. C.M. McMahon et al., *Inappropriate Documentation of Heparin Allergy in the Medical Record Because of Misdiagnosis of Heparin-Induced Thrombocytopenia: Frequency and Consequences*, 15 J. THROMBOSIS & HAEMOSTASIS 370, 373 (2016) (“[I]nappropriate listing of heparin as an allergy in the EMR because of misdiagnosis of [heparin-induced thrombosis] is common, is associated with substantial rates of unnecessary alternative parenteral anticoagulant use and major bleeding, and tends to persist beyond

To put it a different way, patients who believe that their medical treatment has gone down the wrong path may want a fresh start. This seems especially likely for patients who are struggling to figure out what is going on with long-term or chronic issues, which may be overlooked by the medical system. For instance, it frequently takes years for patients to be diagnosed with celiac disease—an autoimmune disorder in which a person’s immune system injures their intestines whenever they consume gluten, with results ranging from gastroenterological issues to depression, memory loss, and infertility—after first consulting a doctor, and many report initially being diagnosed with stress, anxiety, or mood disorders.¹²³

In other cases, a patient may believe that a quick look at their medical record is likely to mislead a doctor. To stick with the celiac disease example, one recent case report describes a woman who was diagnosed via intestinal biopsy only after checking into a hospital’s psychiatric inpatient unit and not responding to a variety of treatments, including antipsychotics.¹²⁴ She experienced near-complete recovery upon adopting a strict gluten-free diet (as reported four years later).¹²⁵ Years later, such a patient may quite reasonably want to be able to obtain medical care without having to explain this whole history, whether for fear of being stigmatized or for fear that prescription and other medical decisions will unduly be affected.

The inability to get this fresh start, moreover, may well have important distributive consequences. Members of marginalized groups may have good reason to be skeptical of their doctors’ interpretations of their experiences.¹²⁶ For instance, it is well-documented that women are less

the index admission.” (emphasis added)). As a general example, a doctor might initially make a note—say, “medically complicated”—for purposes of communicating something to the billing department. Later, when summarizing the patient’s condition, the doctor might note that the patient had a disease “with complications.” Years later, that notation could lead a later physician to recommend a more aggressive course of treatment if a similar situation occurred. *See* Lopez Interview, *supra* note 93.

123. *Mental Health*, CELIAC DISEASE FOUND., <https://celiac.org/about-celiac-disease/related-conditions/mental-health/#:~:text=Initially%20those%20with%20celiac%20disease,Fatigue> [https://perma.cc/CAW6-BTVA].

124. Albino J. Oliveira-Maia et al., *Case of Coeliac Disease Presenting in the Psychiatry Ward*, 2016 BMJ CASE REPS. (Dec. 21, 2016).

125. *Id.* at 2-3.

126. *See generally* Craig Konnoth, *Medical Stereotypes* (February 12, 2021) (unpublished manuscript) (on file with author).

likely to receive aggressive treatment or accurate diagnoses for a number of issues.¹²⁷ Women who report pain, for instance, are much more likely than men to be prescribed sedatives rather than painkillers, and in one study of patients who underwent coronary bypass surgery, women were half as likely to receive prescription painkillers than men who underwent the same procedures.¹²⁸ Women also experience longer lag times between seeking care and being accurately diagnosed with a number of cancers.¹²⁹

Similar effects have been demonstrated for racial minority populations.¹³⁰ Even if there are reasonable explanations for particular instances of these disparities, patients' experiences of the health care system are shaped by them nonetheless. For a patient who believes they have been dismissed as essentially hysterical or that a doctor approached their care differently because of their race, the ability to seek later treatment unaffected by documentation of that episode may be especially important.¹³¹

Fresh starts may also help combat another potential source of faulty second opinions. Doctors may be reluctant—consciously or not—to provide second opinions suggesting another doctor committed malpractice or

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127. See, e.g., Laura Kiesel, *Women in Pain: Disparities in Experience and Treatment*, HARV. HEALTH PUBL'G: HARV. HEALTH BLOG (Oct. 9, 2017 10:30AM), <https://www.health.harvard.edu/blog/women-and-pain-disparities-in-experience-and-treatment-2017100912562> [<https://perma.cc/5VQ4-VTNJ>].
128. See Maya Dusenbery, 'Everybody Was Telling Me There Was Nothing Wrong,' BBC: FUTURE (May 19, 2019), <https://www.bbc.com/future/article/20180523-how-gender-bias-affects-your-healthcare> [<https://perma.cc/47K7-5CGY>] (collecting studies to this effect).
129. See, e.g., Karel-Bart Celie et al., *Socioeconomic and Gender Disparities in Anal Cancer Diagnosis and Treatment*, 26 SURGICAL ONCOLOGY 212 (2017) (anal cancer); Harun Fajkovic et al., *Impact of Gender on Bladder Cancer Incidence, Staging, and Prognosis*, 29 WORLD J. UROLOGY 457, 458 (2011) (regarding bladder cancer, "women present with more advanced disease and have worse survival"); Reza Rahbari et al., *Thyroid Cancer Gender Disparity*, 6 FUTURE ONCOLOGY 1771 (2010) (thyroid cancer).
130. See, e.g., Kimani Paul-Emile, *Blackness as Disability?*, 106 GEO. L.J. 293, 310 nn.96-98 (2018) (collecting many studies demonstrating the inequality in care received by African American patients).
131. See generally DAYNA MATTHEW, *JUST MEDICINE: A CURE FOR RACIAL INEQUALITY IN AMERICAN HEALTHCARE* (2018) (arguing that unconscious racial and ethnic biases are a critically important contributor to health inequality in America).

otherwise made mistakes.¹³² As an article in the *New England Journal of Medicine* recently explained, although there is a “consensus” that doctors have an ethical duty to communicate openly about medical errors with patients, “physicians struggle to fulfill this responsibility.”¹³³ This is only heightened when the prior doctor was a colleague or friend. As the working group of physicians behind that article put it, “there is a natural reluctance to acquiring an unfavorable reputation with colleagues, disrupting relationships among and within care teams, or harming one’s institution.”¹³⁴

This effect is only compounded if doctors have any whiff that a patient is contemplating litigation. Doctors’ reluctance to help patients they believe to be contemplating litigation may both affect patients’ access to care and also frustrate meritorious malpractice suits. In *Parete v. Mully*, for instance, the plaintiff had undergone dental and orthodontic work that she alleged was improperly performed.¹³⁵ She became suspicious when her front teeth began to overlap and she suffered jaw pain, but when she sought a second opinion, the new doctor asked if the visit was “related to litigation,” and despite her negative response, informed her that he did not want to get involved and advised her to return to the former dentist.¹³⁶ After seeking further second opinions with similar results, the defendant attempted to avoid producing medical records by lying to a new dentist and stating that her old dentist had died. That dentist explained that he could not “help her out” without seeing all of her prior records, and her case was ultimately dismissed on statute of limitation grounds.¹³⁷

To be sure, enabling patients to control exactly what information providers see has downsides. In particular, allowing “doctor-shopping” and controlling the flow of information risks gamesmanship in at least two forms. First, patients may manipulate their record to obtain a diagnosis in

132. See, e.g., Thomas H. Gallagher et al., *Talking with Patients About Other Clinicians’ Errors*, 18 N. ENGL. J. MED. 1752, 1752-53 (2013) (discussing the problems that arise when physicians must address the errors of others). On the efficacy of second opinions, see Monica Van Such et al., *Extent of Diagnostic Agreement Among Medical Referrals*, 23 J. EVAL. CLINICAL PRAC. 870, 871 (2017), which, with respect to the instances sampled therein, “found that diagnoses changed in 21% of cases and were confirmed or further refined for most cases.”

133. Gallagher et al., *supra* note 132, at 1752.

134. *Id.*

135. 719 A.2d 702 (N.J. Sup. Ct. App. Div. 1998).

136. *Id.* at 704.

137. *Id.*

order to obtain external benefits. For better or for worse, the medical establishment plays an important gate-keeping function for a variety of non-medical social benefits, ranging from accommodations for standardized testing and schooling to sick-day validation. As vivid proof, we need look no further than the recent college admissions scandal, in which wealthy families faked disabilities in order to provide their children with extra time on college admissions tests—and, potentially, on tests throughout college.¹³⁸ It's at least imaginable that such misuses would be facilitated or made easier in an atmosphere of increased control, for instance if those seeking to “doctor shop” for illicit ends were better able to obscure the details of their medical encounters over time.

Patients may also manipulate their records to obtain illicit ends *within* the medical system. This is of special concern when there are genuine scarcity concerns at play. Mark Rothstein points out, for instance, that permitting patients total control over their medical information could risk allowing an alcoholic patient on a liver transplant list to modify (otherwise disqualifying) evidence that he continued to drink heavily.¹³⁹ And, of course, allowing patients total control over their records could enable patients to obtain prescriptions for opioids and other controlled substances with significant abuse potential (and resale value), even if a comprehensive look at their medical record would make reasonably clear that this is what was going on.¹⁴⁰

These concerns highlight that the medical profession is often called to play a gatekeeping role for purposes beyond patient treatment—a dynamic

138. In a transcript of recorded phone call, the primary operator of the scheme explains that when child “gets tested [for a qualifying disability],” she should be “stupid” and not act “as smart as she is.” Affidavit of Laura Smith, at 25, https://www.washingtonpost.com/college-admissions-bribery-scheme-affidavit/d216435e-e073-41f6-b6fa-33ed835d053d_note.html?questionId=c2ba5e52-6a22-42ed-a0c9-05c83ee5f83d [<https://perma.cc/X8F6-R8XB>].

139. Mark A. Rothstein, *Debate Over Patient Privacy Control in Electronic Health Records*, BIOETHICS F. (Feb. 17, 2011).

140. Importantly, while the public narrative about the opioid crisis focuses on opioid abuse, many in the public health field believe that at this point, *under-prescription* of opioids to those who suffer from chronic pain is a significant public health problem. Mark Rothstein, *The Opioid Crisis and the Need for Compassion in Pain Management*, 107 AM. J. PUB. HEALTH 1253-54 (2017). To the extent that patients who are genuinely in pain are denied treatment from fearful doctors concerned about over-prescription, privacy from doctors could play a hortatory role even in this context.

I take up further below. Devising systems that strike the appropriate balance between preventing gamesmanship and respecting patients' interest in fresh second opinions will require clarifying the relative importance of the different facets of the physician's role.¹⁴¹ To the extent that respectful, patient-focused medical care is primary in the doctor's role, however, we should be willing to accept costs to doctors' ability to serve these external social functions.

3. Play in the Joints: Strategic Privacy

Finally, and perhaps more complicatedly, privacy from doctors is a precondition for a sort of informational flexibility, or play in the joints, that plays an important part in our medical system. There is an editing process in the interplay between and among doctors, patients, and insurers: patients edit what they tell doctors; doctors edit what information makes it into the record and what information is relayed to insurers; and so forth. This type of editing is inevitable, as the myriad potential information inputs from any doctor/patient interaction must be distilled into a record. It can also serve any number of purposes; doctors' entries may be made with an eye towards shielding the doctor from malpractice liability or towards making sure that insurance will cover a particular procedure. And patients' editing of the information they share with their doctors may likewise serve any number of purposes, from protecting the patient's own ego or avoiding embarrassment to helping focus the visit on the concerns of most importance to the patient.

In one especially stark instantiation of this phenomenon, patients may instrumentally shield doctors from information, or even lie, in order to obtain treatments that would be effectively barred because of rules or guidance from third parties that affect treatment decisions. For instance, patients may seek to avoid the consequences of the liability regime that currently operates in the backdrop of treatment decisions. This could obviously have problems—but it may also allow for optimal outcomes, where well-informed patients wish to take risks that doctors will not permit for liability reasons, even if the doctor might otherwise agree that the approach was warranted.

Take, for instance, the first example above, involving the woman who firmly believed that her second pregnancy was not high-risk. Imagine this

141. For background on different conceptions of the doctor-patient relationship, see, for example, Janet Dolgin, *The Legal Development of the Informed Consent Doctrine: Past and Present*, 19 CAMBRIDGE Q. HEALTHCARE ETHICS 97 (2013).

woman was, in fact, a trained midwife who had done extensive research on the risks and benefits of different prenatal approaches. Given the risk-averse approach taken by many obstetrician-gynecological practices, stemming from the very real liability concerns and rules imposed by insurers, there may be no realistic way for a patient to disclose all relevant information and then consent to a course of treatment that the doctor's insurer would not bless. If the patient is truly well-informed, shielding information from the doctor may well lead to the optimal outcome, enabling a woman with a low-risk pregnancy to give birth in a lower-cost, more comfortable birthing center rather than in a hospital. Similar dynamics may arise any time insurers, professional associations, or others impose rules that are overly protective for some number of patients.

The point is simply that, in some instances, sophisticated patients who shield information and work around liability regime perversions achieve outcomes that doctors likely agree are optimal. They evade the impersonal limitations imposed at a systems level. This dynamic may, of course, indicate that the underlying policy should be adapted—and yet, there may also be times when there are policy reasons to err on the side of accepting stronger policies while recognizing that some may circumvent those policies, rather than doubling down in search of perfect enforcement.

There are other similarly fraught examples of when patient privacy may also be of practical value to patients who seek to evade oversight. As Michele Goodwin and others have argued, for instance, the recent spate of fetal protection state laws “inspires (and sometimes requires) medical officials to breach confidentiality when treating pregnant women.”¹⁴² There is an alarming catalogue of reports of pregnant women being arrested after seeking medical treatment—including, for instance, a woman who fell down the stairs and a woman who took a single Vicodin before learning she was pregnant.¹⁴³ A pregnant woman might be willing to confide in a trusted long-term doctor in order to obtain needed care if she had accidentally taken an action that was marginally risky to her fetus—but not if that information will be shared widely or result in a “downstream” doctor deciding that information needs to be sent to the authorities. Or, a pregnant woman seeking an abortion in a jurisdiction with time-based abortion restrictions may seek to avoid having information in her medical record

142. See, e.g., Michele Goodwin, *Fetal Protection Laws: Moral Panic and the New Constitutional Battlefield*, 102 CALIF. L. REV. 781, 781 (2014).

143. *Id.* at 792; see also *Ferguson v. City of Charleston*, 532 U.S. 67 (2001) (reviewing similar programs from the 1990s related to pregnant cocaine users).

about the date of her last menstrual cycle in order to obtain medically-appropriate, but legally problematic, care.

There may also be times when the norms of the medical profession have not caught up to social norms. For instance, early in the transgender rights movement, people within the transgender community would pass around the medical standards required to obtain a diagnosis that would authorize gender reassignment surgeries.¹⁴⁴

One thing these—admittedly disparate—examples have in common is that they involve relatively disenfranchised groups. While analogous situations not involving such groups also certainly arise, it seems worth noting that privacy can serve as a tool of empowerment vis-à-vis the medical establishment.

As medical records are rendered more static and comprehensive, however, this type of editing becomes both more important and more difficult. To the extent that record entries follow the patient, doctors' editing decisions are more likely to have consequences down the road.¹⁴⁵ It becomes more difficult for patients to limit the information they share for one purpose from affecting other aspects of their care.

These scenarios raise complicated questions involving responsibility, liability, the limits of consent, and health care financing and insurance, among other things. Most importantly, the lion's share of healthcare is paid for not by patients, but by insurance companies, employers, and state or federal programs like Medicare and Medicaid. The problem of privacy from doctors is closely intertwined with the question of how much control third-party payors have over medical decision-making. Any proposal for increased patient control over medical information must contend with this

144. See Farah Kahn, *A History of Transgender Healthcare*, SCI. AM. (Nov. 16, 2016), <https://blogs.scientificamerican.com/guest-blog/a-history-of-transgender-health-care/> [https://perma.cc/9G5C-MFV2].

145. As a simple example, if a patient's blood pressure is taken twice during a visit with different results, the doctor may face a decision of whether to check the box classifying a patient as having high blood pressure. (This can come up, for instance, when the patient's blood pressure is elevated due to anxiety early in the appointment.) Future doctors, looking at that record, may then make treatment recommendations based on that notation. *Cf., e.g.,* The Birth Hour, *Ep. 402: Empowering Birth Despite Cascade of Interventions*, at 13:45-17:00 (Sept. 20, 2020) (discussing decision to induce childbirth rather than waiting for spontaneous birth later because of multiple high blood pressure readings over the course of the patient's pregnancy, which were usually attributed to anxiety because lower readings were obtained at the end, rather than beginning, of doctors' appointments); see also McMahon et al., *supra* note 122.

reality. If patients are permitted to lie to their doctors, resulting in different treatment decisions, the outcome could be akin to insurance or Medicare/Medicaid fraud.¹⁴⁶ If, for instance, a patient lies or obfuscates and is sent for testing that insurance pays for, but insurance would not have covered the testing with fuller information,¹⁴⁷ the insurance company may be reasonably aggrieved.¹⁴⁸ In practice, the balance struck by our current system already permits this sort of dynamic. Insurers generally cannot see more information than needed to support a particular claim, which therefore prevents insurers from seeing entire medical records.

Ultimately, however, the scale of additional costs that would be incurred by good-faith patients exercising greater control over their medical information seems likely to be dwarfed by larger scale inefficiencies and problems in the existing public programs.¹⁴⁹ In at least some instances,

146. In the context of Medicare, Medicaid, or other public programs, any solution would have to be regulatory or statutory rather than contractual. As a practical matter, the privacy rights of patients who are on public programs are already attenuated. To some extent, this is a predictable and perhaps unavoidable tradeoff that those on public assistance make. It is probably reasonable for the public to require, at minimum, reasonable verification that beneficiaries are actually qualified to receive benefits. (In practice, these programs go far beyond what is necessary—Khiara Bridges, for instance, has effectively argued that the operation of Medicaid in combination with other social programs means that poor women effectively have no privacy rights whatsoever. *See* KHIARA M. BRIDGES, *THE POVERTY OF PRIVACY RIGHTS* (2017). But the larger point remains. Nevertheless, that public interest in fraud avoidance need not be the be-all end-all—respecting the autonomy and privacy interests, even of public assistance beneficiaries, should also be at least part of the equation.

147. It bears noting that, as a practical matter, insurance companies generally do not see patients' comprehensive medical records; rather, they receive billing requests with documentation related to specific requests, and presently have relatively few tools for addressing treatment decisions based on patient deceit.

148. *See, e.g.,* Anya Prince, *Tantamount to Fraud: Exploring Non-Disclosure of Genetic Information in Life Insurance Applications as Grounds for Policy Rescission*, 26 *HEALTH MATRIX: J. HEALTH L. & MED.* 255 (2016) (tracing analogous dynamics in the context of life insurance).

149. Centers for Medicare and Medicaid Services (CMS) estimates that in 2019, Medicare and Medicaid paid out \$28.1 billion "improper payments," an estimate that encompasses both fraud and other payments that the programs should not have made. *2019 Estimated Improper Payment Rates for Centers for Medicare & Medicaid Services (CMS) Programs*, *CTRS. FOR MEDICARE & MEDICAID*

moreover, patients—who are experts in their own symptoms (and empowered with publicly available information as never before)—will use this privacy to get better outcomes. In any event, even publicly funded systems should be willing to accept some additional costs in support of patient privacy. Every healthcare funding system respects patient autonomy, and thereby incurs additional costs, to some extent. Typically, for instance, patients can refuse medication even if, down the road, that choice ends up necessitating a more expensive procedure. Along similar lines, our legal and ethical commitments to informed consent principles apply notwithstanding the prospect that informed consent requirements may cause patients to decline surgeries or procedures that would lead to more efficient care. Accepting public healthcare hardly nullifies patients' autonomy interests. The same should be true of their privacy interests.

* * *

The point is not that privacy from doctors is an absolute good; it undoubtedly comes with costs. When it comes to the doctor/patient relationship, for instance, enhanced privacy from doctors could in principle undermine doctors' trust in their patients. If doctors' sense is that patients are likely to be hiding information from them, or that they cannot rely on medical records, they may retreat to a sense of cynicism or be less motivated or empowered to help the patient.¹⁵⁰ Similarly, fuller access to medical records may empower doctors to more confidently engage with patients, and make the practice of medicine feel more holistic, useful, and professionally satisfying for doctors.¹⁵¹ Efforts to empower patients also

Svcs. (Nov. 18, 2019), <https://www.cms.gov/newsroom/fact-sheets/2019-estimated-improper-payment-rates-centers-medicare-medicare-services-cms-programs>. [<https://perma.cc/GX5H-W958>].

150. This would not, however, be much of a change from the status quo. Doctors already widely assume that patients lie about a variety of issues, and until the very recent past it has been practically difficult to obtain many old patient records. If anything, to the extent we hope to engender a culture of respect, rather than entitlement, towards patient information, this is a reason to make sure that expectations are set properly as we transition to comprehensive EHR, rather than allowing a norm of total access to ossify.

151. Anecdotally, doctors at health maintenance organizations (HMOs) such as Kaiser express relief and satisfaction with easy-to-use, uniform, comprehensive medical records that let them feel confident that they have a clear sense of what might be going on for a patient. Studies suggest that trainings that enable doctors to use EHRs efficiently and confidently have significant impact on patient care and provider professional satisfaction. *See, e.g.*, Kenneth E. Robinson & Joyce Kersey, *Novel Electronic Health Record*

always run the risk of making the doctor/patient relationship more consumerist and transactional, at the risk of reducing doctors' sense of responsibility (and professional satisfaction).¹⁵² Privacy from doctors may also add to doctors' practical burdens.¹⁵³ For instance, it would reduce, at least on the margins, one of the benefits of comprehensive EHRs, namely preventing every doctor from having to take a full medical history of a patient.¹⁵⁴ More generally, promoting privacy from doctors could reduce, on the margins, the impact of many of the potential benefits inspiring the shift towards more comprehensive, interoperable records.¹⁵⁵

Education in Large Healthcare Organization Improves Quality, Efficiency, Time, and Impact on Burnout, 97 MED. 38 (2018). A sense of holistic understanding of the contents of a record could in principle result in excessive hubris—but it could also cognitively free doctors up to engage more fully with patients and explore together how new symptoms intersect with past issues.

152. In a more transactional medical world, it is easy to imagine a doctor who suspects that something is amiss in a patient's medical record, or who suspects that she lacks full information, throwing her hands up in the name of patient privacy instead of digging deeper to get more of the story. In at least some circumstances, however, this could amount to a deep abdication of responsibility. Imagine, for instance, if the doctor realized that an appendectomy patient may not have shared information about his illegal drug use, yet she did not make an extra effort to confirm whether he was in fact on methamphetamine, because she felt constrained not to push the patient's privacy preferences.
153. This is not a trivial concern, from either a patient-care or a public health perspective. A study released in January 2020, for instance, indicated that doctors' exceedingly high levels of burnout are correlated to how poorly the doctors rated their EHR systems. *See, e.g.*, Brita Belli, *Doctors Give Electronic Health Records an "F"*, YALE NEWS (Nov. 14, 2019), <https://medicine.yale.edu/news-article/21820/> [<https://perma.cc/C2XD-YMKK>].
154. Moreover, digging deeper to figure out if anything important is missing from the record (or the patient's account) takes time, effort, and a distinct (and possibly unfamiliar) set of skills for doctors. And forcing doctors to think carefully and draw out a medical history that is accurate in the ways that are most likely to affect the appropriate treatment, while respecting patients' right to privacy, may well feel a bit like walking a tightrope. Walking that tightrope effectively may be practically impossible in an already-crammed 12-15 minute patient meeting. *See, e.g.*, Hill, *supra* note 34 (providing background on these patient-interaction dynamics).
155. *See supra* Part I.

The point, rather, is that we should avoid throwing the baby out with the bathwater. The risk of doing so is especially high in the medical privacy context, where there are enormous financial interests at stake in patient data, and the benefits to patients may seem diffuse or hard to quantify. But those benefits are real, and it is worth factoring them into the systems that will establish the norms of the medical profession for years to come.

III. THE WONKY PART: WHAT SHOULD WE DO DIFFERENTLY?

Aspirations for the electronic medical records of the future are lofty, varied—and not always fully compatible with each other. Interoperable electronic records hold the promise of benefiting the health system at multiple levels. In theory, there are benefits to be won for patients (by, e.g., reducing errors, improving communication, decreasing hassle, and enabling better use of clinical decision support tools); organizations like hospitals and insurers (by increasing efficiency and decreasing costs); and society more broadly (by reducing overall health costs and providing information for research).¹⁵⁶ The mechanisms by which these benefits could be achieved likewise vary and suggest competing on-the-ground solutions; the policies that best promote user-friendliness and comprehensibility for patients and doctors, for instance, are not necessarily the same as those that would be most useful for optimizing clinical decision support tools or machine-learning diagnostic algorithms.

The upshot is that offering any concrete proposals is perilous, with so many potential benefits trading off against each other and so many interested players. One way to begin to cut through this Gordian knot, however, is to keep the focus on the individual patient experience. Because of the life-and-death stakes in the medical arena, it may be tempting to sacrifice any number of loftier goals—autonomy, privacy, individualization, even respect—on the altar of efficiency or measurable health outcomes, at the individual or population level. But this tradeoff, at its core, is not so different from those made in other policy contexts. At minimum, we should

156. See, e.g., John Glasser, *It's Time for a New Kind of Electronic Health Record*, HARV. BUS. R. (June 12, 2020), <https://hbr.org/2020/06/its-time-for-a-new-kind-of-electronic-health-record> [<https://perma.cc/M7KD-9V63>] (arguing that electronic health records need to be reimagined to focus primarily on automated, forward-looking decision support, rather than records of what has happened, and suggesting that, ideally, forward-looking records be continuously updated using artificial intelligence algorithms that incorporate information about patient behavior, treatments, and to-the-minute medical developments).

have a clear-eyed view of what it would look like to prioritize patient-empowering informational norms.

As a starting point, I propose a two-part approach to address these tradeoffs with the aim of maximally empowering patients while leaving some mechanisms for enabling critical social or other interests to override patient preferences. First, patients should be given as much control as possible over their medical information. This means that providers should be required to respect patient requests not to share information, and that patients should have the ability to meaningfully segment, withhold, and even annotate their records. To both guard against decisional overload and ensure that privacy protections are empowering rather than overwhelming or alienating, policy-makers should look to literature in behavioral economics so as to construct choice architectures that aid in meaningful engagement.

Second, in rare circumstances where pressing countervailing societal considerations require information to be shared over a patient's wishes, procedures should be created to ensure that patients are given a genuine and individualized opportunity to protect the interests served by privacy from doctors—a sort of procedural justice in the medical context. It may be that the individual interest loses in some instances, but—as in other contexts where important individual interests run up against important policy considerations—there should be an opportunity for patients to tell their side of the story.

A. Empowering Patients

1. Autonomy-Enhancing Choice Architecture

A protective choice architecture for privacy within the medical system should account for at least two major goals. First, it should be designed to empower patients to easily make meaningful choices about their information. Second, the architecture should account for the fact that some patients may not have the interest, bandwidth, or ability to make those choices, especially in stressful moments in the medical system, and so it should include appropriate default rules.

First, regulations should be amended to require that providers generally respect patient requests not to share information. As discussed above, under the information-blocking rule (and HIPAA) this is optional;¹⁵⁷ it should not be, except perhaps in narrowly defined circumstances. The

157. 45 C.F.R. § 171.202(e); *see supra* notes 39, 41.

optional approach embodied in the current regulations is a response to concerns that if protecting patient preferences were mandatory, providers and others would use that requirement as a pretextual shield to engage in information-blocking practices—i.e., providers would make it harder to seamlessly share patient information, generally because doing so is financially beneficial.¹⁵⁸ (That this practice has been widespread should certainly give us pause about the motivations of the entities to which we entrust our medical care). Solving that problem—which, at its core, is one of providers and IT companies putting their bottom lines ahead of patient needs¹⁵⁹—by effectively authorizing those same entities to ignore patient needs in the other direction seems backwards. To control against the pretext problem, protections like directly prohibiting providers from “improper . . . inducement” of patient requests and requiring that such requests be documented might well be warranted.¹⁶⁰ But for both expressive and practical reasons, the bottom line should be that when patients request that information not be shared, that request should be respected.

Second, lawmakers and policymakers should endeavor to create choice architectures that are genuinely empowering for patients, while also being sensitive to the difficulties that arise in the healthcare context. The foundational principle of autonomy suggests that patients should ultimately be in control of who sees their medical information. And yet, focusing exclusively on formal control or consent is insufficient to protect a more robust form of patient empowerment. All too frequently, what starts as a commitment to autonomy is implemented by simply creating burdensome, or pro forma, paperwork that purports to vindicate an autonomy interest but in fact functions as a bureaucratic hurdle designed to protect institutions, not patients.

Take, for instance, the dynamics at play when hospitals obtain informed consent to medical treatment.¹⁶¹ As Nicholas Terry has pointed out, while

158. See The 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification, 84 Fed. Reg. 7,424, 7,531 (proposed March 4, 2019).

159. See *supra* text accompanying notes 24-26.

160. 45 C.F.R. § 171.202(e).

161. See, e.g., TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 410 (4th ed. 1994). Nicholas Terry has helpfully analogized ongoing debates about medical privacy and confidentiality to Beauchamp and Childress’s discussion of two ways in which the concept of “informed consent” is used.

the doctrine of informed consent has its roots in an autonomy-based ethic, there is a “serious disconnect” between that rationale and the legal regulations that actually implement informed consent principles on the ground. In practice, informed consent regulation focuses on a narrow notion of “consent” to particular procedures rather than on promoting disclosures that would actually promote patient participation and choice.¹⁶² It is easy to imagine a similar dynamic in the regulation of patient privacy, especially considering the constant, and constantly ignored, check-box waivers of privacy rights in other contexts, which can function more to provide a veneer of individual choice that protects those who collect and use the data, rather than to practically protect individuals.¹⁶³

In short, there can be such a thing as “too much choice” to promote real agency as a practical matter, and that may be especially true in the healthcare context. Patients’ actual ability to meaningfully exercise autonomy has limits. Most importantly, attention is a limited resource,¹⁶⁴ and asking patients to delve into the minutiae of how myriad pieces of medical information can be used could quickly become overwhelming. This concern is heightened by the fact that patients are often faced with grave decisions in moments of high stress, and they may have widely varying familiarity with the medical system in general. They may have little sense of what it will mean as a practical matter to allow information to be shared across parties. Moreover, patients may be poorly positioned to judge both what medical information is true or relevant and how medical actors are likely to use that information.

But the fact that respecting autonomy can be easier in theory than in practice is not a reason to disregard it. Rather, we should be all the more careful to distinguish between genuine respect for a robust form of autonomy that empowers patients, on the one hand, and formalistic, click-a-waiver policies that do not actually function to empower patients, on the other. The burgeoning literature on choice architecture provides a starting

See Nicholas P. Terry, *What’s Wrong with Health Privacy?* V J. HEALTH & BIOMEDICAL L. 1, 9-10 (2009).

162. Terry, *supra* note 161, at 10.

163. For an in-depth discussion of this phenomenon, see generally Daniel J. Solove, *Introduction: Privacy Self-Management and the Consent Dilemma*, 126 HARV. L. REV. 1881 (2013).

164. See, e.g., Sunstein & Thaler, *supra* note 91, at 176-77; TIM WU, THE ATTENTION MERCHANTS (2016).

point for making headway in addressing these issues.¹⁶⁵ The key takeaway is that the environment in which we make decisions—especially the ways our options are framed—will affect our ultimate decisions, and so those who frame the decisions have a responsibility to be thoughtful in constructing those environments.

This requires, at minimum, ensuring that patients actually understand that they have the ability to control their information, perhaps by posting notices at physicians' offices and including a pop-up when patients log onto their online portals. The most obvious option would be simply to provide patients with complete granular control over who sees their data. But in practice, even patients with a strong preference for greater privacy may be daunted (or thwarted) by the practical difficulty of managing complicated questions about how and when their data should be shared, especially at a granular level. One possibility is an approach that allows for the categorical segmentation of especially sensitive sets of information—mental health treatment, reproductive or sexual histories, addiction treatment, and so forth.¹⁶⁶ This approach, however, fails to account for a number of important

165. See generally Richard H. Thaler, Cass R. Sunstein, & John P. Balz, *Choice Architecture*, in *THE BEHAVIORAL FOUNDATIONS OF PUBLIC POLICY* 428-30 (Eldar Shafir, ed., 2012). The literature on nudges and choice architecture has been extraordinarily influential and subject to criticism. See, e.g., Ryan Bubb & Richard H. Pildes, *How Behavioral Economics Trims Its Sails and Why*, 127 *HARV. L. REV.* 1513 (2014) (arguing that behavioral economists' policy proposals do not go far enough; the movement is premised on social science revealing the limits of human decision-making, which suggests that the appropriate policy solution in many instances should be to limit choice, rather than promoting it).

166. See, e.g., Mark A. Rothstein, *Access to Information in Segmented Electronic Health Records*, *J. L. MED. & ETHICS* 394 (2012). Federal law already requires medical providers to provide special protection for a few categories of information. For instance, providers cannot share substance abuse disorder records even for treatment purposes without patient consent, except in accordance with limited exceptions. See 42 U.S.C. § 290dd-2 (2018); 42 C.F.R. pt. 2 (frequently referred to as the Part 2 regulations). Similar restrictions apply to Department of Veterans Affairs records related to drug use, HIV, or sickle-cell anemia. 38 U.S.C. § 7332 (2018). And state laws create a patchwork of further protections for specific categories of information. Along similar lines, a federal advisory committee has suggested that, currently, that patchwork of laws protects categories including domestic violence, genetic information, mental health information, reproductive health, substance abuse, and certain information about adolescents and minors, see NCVHS, Letter to Kathleen Sebelius, *supra* note 9, and that regulators should use these

privacy considerations. Individuals will have different views about what information is sensitive to them, which may or may not track these categories.¹⁶⁷ An approach that limits control to sensitive categories of information, moreover, does not help address dynamics around relationships or second opinions that arise in seeking treatment outside of those categories.

A third way might be ideal. The goal should be to find ways to present patients with a manageable, digestible set of options for meaningfully managing their data. Rather than simply providing patients with a choice between a default option and an overwhelming and burdensome data-management task, patients could be presented with a choice between several different template privacy settings for their electronic medical records. One could even imagine presenting patients with options for template settings recommended by different interest groups—say, the American Medical Association, the National Institute for Health, and Privacy International—and allowing patients to choose between these default rules based on the organization’s statements and reputation. This approach would have the advantage of allowing patients to both exercise meaningful control over their information and also to rely on others’ expertise in figuring out the minutiae of how to operationalize those concerns.

At the same time, a default option will, in all likelihood, have to be available. For many patients, reduced hassle and increased ease of communication may be more important than bolstered privacy; more practically, others will encounter the system at a moment when making a privacy decision is near-impossible, or the very last thing on their minds. Patients have an independent interest in not having to make privacy decisions every time they have an encounter with the medical system, and so keeping the in-the-moment decisional burden low is also important.¹⁶⁸

categories “as a basis for research, technical development, pilot testing, and potential future demonstration projects,” *id.* at 14.

167. See, e.g., Melissa Goldstein & Alison Rein, Off. Nat’l Coordinator for Health IT, *Data Segmentation in Electronic Health Information Exchange: Policy Considerations and Analysis*, DEP’T HEALTH HUMAN SERVS. 24-27 (Sept. 29, 2010), https://publichealth.gwu.edu/departments/healthpolicy/DHP_Publications/pub_uploads/dhpPublication_168F948B-5056-9D20-3D2C53BEED88834B.pdf [<https://perma.cc/LTC6-45C3>].

168. Others have made a similar point when it comes to patient cost-sharing decisions. Patients have a rather strong independent interest in not having to make rational cost-benefit tradeoffs on their own behalf in deciding what medical care to pay for. See Christopher T. Robertson & David V. Yokum, *The*

But even for patients who stick with the default, being informed that they have the option to later log on and control their privacy settings in a simple, straightforward manner may be a significant autonomy-affirming event. Ideally, the default rule would be crafted to track patient expectations and preferences—perhaps by allowing for automatic sharing of most information, but allowing more limited sharing of sensitive information.¹⁶⁹

2. Control Over the Content of Medical Records (with Backstops)

If we really take patients' interest in their own medical story seriously, patients should, in many circumstances, have a right not only to control who has access to their records, but also what information is in those records at all. This prospect raises a number of thorny issues.

The prospect of patients being able to simply delete or modify their medical records (or particular details) comes with obvious, non-trivial risks. These range from the risk of fraud, to gamesmanship in an effort to exploit limited health resources, to the risks of thoughtless decision-making (e.g., carelessly deleting records that, it turns out, would be diagnostically useful down the road). The extent to which we can or should be willing to bear those risks turns on a number of factors: How significant or fundamental is this privacy right? Who exactly owns, or deserves ultimate control over, patient medical information? The latter question has spawned a robust, ongoing debate.¹⁷⁰

There is a serious argument that patients do *not* have the main, or primary, interest in their own medical records. Arguably, part of the tradeoff that people make when they accept medical care from these systems is that the provider—like almost any other service professional—will make and keep records. Furthermore, broader societal interests may be at play: in some cases, surely, the public has an interest in the accuracy of medical records, especially to the extent those records are increasingly to

Burden of Deciding for Yourself: The Disutility Caused by Out-of-Pocket Healthcare Spending, 11 IND. HEALTH L. REV. 609, 617, 622-32 (2014).

169. As noted previously, there is a dearth of good research on what exactly patients' preferences in this domain actually are. *See supra* note 4.

170. *See, e.g.*, Jane B. Baron, *Property as Control: The Case of Information*, 18 MICH. TELECOMM. TECH. L. REV. 367, 368-70 (2012) (summarizing debate and arguing that while patients will likely be granted some control over medical data, those rights will be divorced from more traditional "property rights," and highlighting the difficulty in using property concepts for information more generally).

be used for big-data projects designed to advance medical science.¹⁷¹ In a public health emergency like the COVID-19 pandemic, moreover, the public has an especially heightened interest in at least the details of an individual's personal health history, like the fact of a positive COVID diagnosis.

And yet: once again, the practice of medicine is not the same as the field of public health; the former focuses on the treatment of individual patients.¹⁷² Providers should, of course, be entitled to keep their own records of the treatment they provide. Any other approach seems impracticable. Providers have to submit claims to third-party payors and may be subject to audits or malpractice litigation, for instance. Moreover, American society and law has a deep hostility to restrictions on the collection of data, or requirements that information be erased—it is no coincidence, for instance, that scholars generally agree that the E.U.'s “right to be forgotten” would face significant barriers to becoming law in the United States.¹⁷³ But as our system of interoperable records develops, it is not necessarily clear that the records providers keep will be the same as the records that are shared and become part of the patients' permanent paper trail. While doctors may need to keep their own business records, patients

171. How patient records should be used for public health research is an enormously complex topic, and the potential impact that allowing patients to modify or delete information from their records would have on the validity of any research raises both practical and ethical concerns. But, in principle, it seems possible that permitting patient control even over some contents of medical records would be less detrimental than it might at first seem. For instance, doctors' notations are not 100% accurate, and to the extent that much excitement about the prospects for research based on EHRs involves the use of machine-learning artificial intelligence, those technologies may be able to draw equally useful inferences from records regardless of whether they have been modified (or, if the fact of the modification is noted in the record, they may be able to learn important medical details based in part on the modifications themselves).

172. *See, e.g.*, LAWRENCE O. GOSTIN, *PUBLIC HEALTH LAW: POWER, DUTY, RESTRAINT* 11-14 (2000) (distinguishing medicine from public health on this basis).

173. *See* Amy Gajda, *Privacy, Press, and the Right to Be Forgotten in the United States*, 93 WASH. L. REV. 201 (2018) (exploring U.S. sensibilities around the right to be forgotten and arguing that First Amendment considerations must cabin any such right); Jack Balkin, *Free Speech in the Algorithmic Society: Big Data, Private Governance, and New School Speech Regulation*, 51 U.C. DAVIS L. REV. 1149, 1201-09 (2018).

have a far stronger interest than their providers in shared records, and that should be protected to the maximum extent practicable.¹⁷⁴

To fully protect this set of patients' interests, patients would have some ability to modify their records, at least with respect to the version that is shared across providers. What is practicable will depend, in part, on both the conceptual framework for, and the technological form of, longitudinal EHRs in the coming years. While limitations on what information should be included in the patients' longitudinal record (the version that is shared or transmitted to different requirements) are more practicable than requiring providers to change or delete information in their possession,¹⁷⁵ it should also be possible for patients to request providers delete information about them, and those requests should be respected where possible: for instance, after a set period of time, and upon condition that the patient waive any

174. One important complication to this dichotomy is that what constitutes a single medical provider or practice is not entirely clear, and the units can be quite large. For example, at a corporate level, dozens or even hundreds of practice groups, or, indeed, hundreds of entire hospitals, might all be under a single umbrella organization. See, e.g., *Who We Are*, HCA HEALTHCARE, <https://hcahealthcare.com/about/> [https://perma.cc/4KKK-XCZ3] (explaining that HCA Healthcare consists of more than 180 hospitals and more than 2,000 sites of care). If the provider were defined at the level of the umbrella organization and records are shared throughout that organization, the value of any distinction between the providers' business records and the patient's shareable records would be far less useful. But even if patient records were stored at the organizational level to the extent necessary for business purposes, patients' records for treatment purposes could presumably be siloed by practice group.

175. Any legal requirement that private actors delete or decline to share information may encounter First Amendment challenges. However, relatively broad prohibitions on information-sharing that contain only minor carve-outs for particularly compelling cases are more likely to withstand scrutiny than more variegated approaches. For instance, in *Sorrell v. IMS Inc.*, the Supreme Court struck down a statute prohibiting the sale of information about physicians' prescribing practices under the First Amendment, in large part because the restriction singled out particular speakers and particular content. 564 U.S. 552 (2011). The Court expressly contrasted the provision it struck down with the "more coherent policy" expressed in the far broader HIPAA, explaining that the defendant state could have better "advanced its asserted privacy interest by allowing the information's sale or disclosure in only a few narrow and well-justified circumstances." *Id.* at 573; see also *United States v. Caronia*, 703 F.3d 149 (2d Cir. 2012) (holding that regulations limiting the ability of pharmaceutical representatives to promote off-label uses violated the First Amendment).

malpractice claims related to their treatment. For especially compelling reasons, backstops limiting patient control could be put in place.

If enabling patients to independently modify their records is a bridge too far, patients' interests in control over contents could be respected in weaker forms. HIPAA, in principle, provides that if patients disagree with something in a medical record, they be given an opportunity to request that it be changed and add a notation to the record if the request is denied—but even if the proposed correction is accepted (far from a sure thing), the covered entity responsible for changing the record can comply with its obligation simply by leaving the original information and appending a link to an amendment.¹⁷⁶ This protection could be made more meaningful and supplemented. For instance, the record itself could be changed, with a link explaining the change, rather than vice versa. Or doctors could be required to share what they were notating in records at the end of meeting, to give the patient an opportunity to discuss any concerns about the entry. Or the ability to more significantly modify the record could be subject to oversight by an independent third party. The solution need not be absolutist, but it should respect the reality that the contents of the record affect and reflect the patient far more than anyone else.

Practical limitations could be baked into the system, while preserving patients' core privacy interests. Defined treatment teams, for instance, could be treated as a single unit when patients decide with whom to share information. To take a simplified example, in a hospital setting where doctors frequently change shift, the default should be that the doctors on the overnight shift see the same information that daytime doctors see. Providers working closely together to coordinate care have an interest in being able to communicate freely about the patients—and a contrary rule seems likely to be professionally stifling. Patients also likely benefit from such free communication. In emergencies, moreover, when there is no opportunity for a physician to ask about information that she suspects might not have been shared from a patient's record, there should also be a default rule in favor of enabling access to the information.

Other backstops could also limit potential downsides for patient outcomes. Certain information could be preserved in the EHR, but only revealed on an "as-needed" basis to prevent defined adverse outcomes. For instance, EHRs already have the capacity to alert providers when a drug prescription is likely to interact with an old drug prescription. In cases where patients have not revealed a medication they are taking to a provider (which might include, for instance, medications that would clearly signal a

176. 45 C.F.R. § 164.526(c)(1).

mental health issue, or hormones indicating that a trans patient was transitioning), the medication interaction warnings could still operate in the background and flag potential adverse interactions, with or without revealing the underlying medication. This type of system might result in the revelation of information the patient would rather keep to themselves, all things equal—but the patient could be assured, at a minimum, that the information was genuinely relevant to a treatment decision. Similar backstop-type systems might play an analogous role in automatically checking or flagging particular issues before procedures.

B. Procedural & Other Practical Protections

Yet patient control is no panacea. There are sure to be technological and practical limitations, and any backstop or override system, while practically quite valuable, would of course compromise the individual patient's (stated) interests. Another layer of protection may be useful to ensure that backstops are not deployed arbitrarily, especially insofar as providers and health exchange networks have vastly more power and, as repeat players, less at stake in each individual case than patients.

Procedural protections could take a number of forms. At minimum, there should be an opportunity for patients to contest decisions to share their information (even if such contestations necessarily occur after the fact of disclosure for medical reasons), ideally before a neutral third party—an outside auditor or mediator, or perhaps a government board.¹⁷⁷

Alternatively, or in addition, patient advocates or care coordinators could be trained to help manage and coordinate privacy concerns, both by explaining patients' rights and helping patients to understand the risks of declining to share information with doctors in particular circumstances. Compared to the status quo, it would be empowering for patients to be able to discuss concerns about accuracy, bias, or the consequences of declining

177. Some states have offices that might serve as useful models for this sort of health intermediary role. For example, the State of Connecticut has an Office of the Healthcare Advocate (OHA), an independent agency that helps Connecticut residents navigate the healthcare system. In particular, the OHA offers free, confidential consultations to help consumers understand their options and fight for additional coverage when insurance has declined to cover medical treatments. For background on the OHA, see, for example, Amanda Hunt, *The Office of the Healthcare Advocate: Giving Consumers A Seat at the Table*, ALTARUM (Apr. 2018), <https://www.healthcarevaluehub.org/advocate-resources/publications/office-healthcare-advocate-giving-consumers-seat-table> [<https://perma.cc/QE75-48KQ>].

to share information in particular circumstances with a single, informed person—a “privacy advocate,” for present purposes—whose role is to help and advocate for the patient. This, of course, would require that patients or their advocates have access to their full records. Ideally, as with other patient advocates,¹⁷⁸ privacy advocates would be independent from insurance companies or hospitals, but—also as with other types of patient advocates—they could potentially still have great utility even if they were not entirely independent. These intermediaries could take multiple forms, ranging from private advocates hired by individual patients, to specialized staff members at hospitals or providers’ offices, to consultants in government offices. There has already been, and presumably will continue to be, a proliferation of professionals dedicated to managing information in the medical field (as in many other fields). Perhaps at least some subset of those professionals could be devoted to helping patients manage their own records and navigate the system with their preferences in mind.¹⁷⁹

Introducing these sorts of intermediaries could have downsides, the extent of which would vary with implementing details. They might create a fractal version of the same sorts of privacy concerns at issue in doctor-patient relationships. In other words, patients will have a similar interest in narrating their own story to any privacy advocate as they would to a doctor. The effectiveness of any such approach may thus depend on the prospect that privacy advocates would be acculturated with a different set of norms and priorities than other medical professionals—with a more deferential

178. Patient advocates (by which I mean groups or persons who help individual patients manage care, as distinct from advocacy organizations like the American Cancer Association that engage in higher-level policy advocacy) in practice take a number of forms. Most often, they work for private agencies and are hired individually by patients to help manage complex medical problems. Hospital customer service representatives often and can, in an ideal form, play a similar function. For background on the concept of patient advocacy, see Barbara L. Atwell, *The Modern Age of Informed Consent*, 40 U. RICH. L. REV. 591, 608-10 (2006).

179. Within the medical system, any proposal that threatens to create any new costs is likely to raise eyebrows. But there is no reason to think that privacy health consultants would be exorbitantly expensive. Presumably most questions or discussions, even in complicated cases, would require relatively few total hours of service. And in some cases, it seems possible that adding this element of care or information coordination could decrease costs overall. For instance, if a patient believes that they have been wrongly diagnosed and wants to optimize what information they should share before getting a second opinion.

and less paternalistic approach to patient preferences, for instance. But doctors and other medical professionals will inevitably retain greater practical power over treatment decisions, and providing patients a lower-stakes opportunity for informed conversation may still prove useful, if imperfect.

The utility of this sort of intervention would also depend upon how it was framed to, and received by, the medical profession and the public. If doctors perceive advocates as a tool for patient manipulation or deception, rather than as a useful form of empowerment, it may diminish trust and openness within the doctor-patient relationship. By the same token, if otherwise trusting or ambivalent patients take an intervention as a sign that doctors are not to be trusted and that information *must* be managed, the intervention may unduly undermine the doctor-patient relationship. Ideally, we could design interventions that are responsive to patients who have concerns about the contents or sharing of their record without undermining the doctor-patient relationship for others more generally. But to the extent that providing avenues for informing or empowering patients itself is unsettling to some visions of the doctor-patient relationship, that may be a bullet that we ought to bite in the service of patient self-authorship and autonomy, while hoping that the cultural expectations for the doctor-patient relationship will equilibrate over time to accommodate any change.

C. Some Thoughts on How to Get There from Here

As a practical matter, there are a number of possible levers that could be pulled to better protect patient privacy. Even though the federal government does not operate the programs on which electronic data is stored, in practice, it has significant influence on what data-sharing will look like in future years. For instance, as of this writing, ONC is in the process of revising the minimum requirements that health information networks will have to meet in order to join the nationwide interoperable network envisioned by the 21st Century Cures Act. Those requirements will be embodied in an agreement called the Trusted Exchange Framework and Common Agreement, or TEFCA.¹⁸⁰ The current draft's provisions for patient privacy protections are limited to a requirement that networks provide

180. For background, see OFF. OF THE NAT'L COORDINATOR OF HEALTH INFO. TECH., A USER'S GUIDE TO UNDERSTANDING THE TRUSTED EXCHANGE FRAMEWORK AND COMMON AGREEMENT (2019), <https://www.healthit.gov/sites/default/files/page/2019-04/TEFCADraft2UsersGuide.pdf> [<https://perma.cc/PH4F-SZ2L>].

some mechanism for patients to opt out of information sharing entirely.¹⁸¹ This is certainly an improvement on the last draft (which included essentially no protections for patients)—but it is also insufficient to protect patients’ interests in more granular control. A patient being treated for complex medical issues may want or even need to allow most of their record (or their record related to a particular health issues) to be transferred while preferring a different approach for, say, the designation in the record describing their risk for domestic violence, or an abortion, or whatever else. While participation in TEFCA will be voluntary, if it is successful in creating a nationwide interoperable network, its minimum requirements stand to be quite influential.¹⁸² A minimum requirement allowing for categorical and granular control and an appeal process would go a long way towards establishing widespread norms.¹⁸³ Both federal and state governments could also deploy their usual bundles of financial sticks and carrots to incentivize providers who receive government funds to adopt protective systems.¹⁸⁴

Another approach, of course, would be to enact comprehensive legislation. Others have convincingly argued that the benefits of electronic health records will exceed their costs only if they are subject to rigorous regulation akin to that the Food and Drug Administration provides for drugs,¹⁸⁵ given their safety-critical functions. Although patient empowerment could be baked into any such regulatory efforts, they may still encounter the practical and legal challenges endemic to significant

181. *Id.*

182. See Julia Adler-Milstein, *How to Safely Make Interoperable Health Information Exchange A Reality*, 68 DEPAUL L. REV. 197, 201 (2019) (noting that although adoption of the system “will be voluntary, to the extent that [TEFCA] is embraced by the market, it would vastly reduce the fragmentation of the varied networks that currently exist”).

183. See *id.*; Maciejewski, *supra* note 50, at 1119 (offering a similar prognostication). I do not mean to understate the thorniness of the technological and political-economic barriers. The problem of how to balance the interests of myriad stakeholders, and how the federal actors may or should intervene in the development of this market is a truly wicked one.

184. For background on the pressure points that different government entities use to influence the operation of private healthcare, see Mark Lemley et al., *The Medicare Innovation Subsidy*, 95 N.Y.U. L. REV. 75 (2020).

185. See Sharona Hoffman & Andy Podgurski, *Finding a Cure: The Case for Regulation and Oversight of Electronic Health Records Systems*, 22 HARV. J. L. & TECH. 1, 24-30 (2008).

legislative efforts.¹⁸⁶ The broader point is simply that if patient privacy is prioritized, there are places for more immediate intervention that could make a significant difference—which could be especially important in this transition period, as informational norms governing the relationships between doctors, patients, medical information, and the rest of the medical system crystallize.

IV. CONCLUDING THOUGHTS

The issue of privacy from doctors is a lens into deeper questions about relationships in the medical system. How should the healthcare system be oriented towards patients? How, in turn, should patients be oriented towards that system? What is the role of the individual doctor, and what is the role of the individual patient? In an arena with enormous stakes, urgent problems, and developing technologies, both broad questions and subtle human dynamics risk getting lost in the fray. But they are worth engaging with. We are in a moment of flux for medical information and electronic health records, and the norms that take hold now may have ripple effects on healthcare in the future by shaping us into more or less empowered participants in our healthcare and the health system more broadly.¹⁸⁷

Ultimately, the appropriate balance of power between providers and patients should depend at least in part on the aspirations we have for the medical system going forward. The proposals in this Article proceed from the assumption that it is—and will continue to be—important to respect a robust form of autonomy, and that it matters whether patients are engaged and empowered with respect to their care (and, perhaps, with respect to the healthcare system more broadly). This seems especially important in the context of the current political economy of healthcare, where there is good reason for patients to be skeptical of the interests driving medical decision-

186. While health privacy is traditionally a bipartisan issue, efforts to legislate in this area must contend with both the ordinary partisan gridlock and the reality that business interests have enormous financial stakes in patient medical information that run counter to policy interests. Moreover, it seems likely that mandatory restrictions on how private providers, tech companies, and other private parties can use information will run into First Amendment challenges, though it is far from clear that they would be successful. *See supra* note 175 (discussing *Sorrell v. IMS Inc.*, 564 U.S. 552 (2011)). Using TEFCO's model of a voluntary agreement with minimum requirements may be an especially appealing prospect for this reason.

187. For a powerful account of the essential role of privacy in shaping the self and creating the conditions for civic engagement, see Cohen, *supra* note 56.

making. Essentially every player—from insurance companies and hospitals to pharmaceutical companies and data brokers—has at least some economic interests at odds with individual patients’ interests.¹⁸⁸ Even doctors, in practice, face pressures from many directions.¹⁸⁹ Against this backdrop, empowering patients with respect to information in their records—the narrative that forms the basis for decisions about their care—seems like an important backstop.

The values and assumptions that underpin these proposals are, of course, not the only plausible ones. We can imagine, for instance, a more techno-utopian ideal for healthcare of the future, as machine learning advances and as the political economy evolves—a future in which patients largely defer to decision-making based on the data from their medical records (or far beyond) and are processed through a medical system designed to optimize outcomes with little active navigation. If that goal is desirable, then developing rules for electronic records may not go far enough.

This Article leaves for another day the question of our larger aspirations for the medical system of the future, and assumes that the better approach would be a culture of empowerment that permits patients to obtain treatment responsive to their own self-understanding, even as we seek the many practical benefits that will come with interoperable records. The approach raises many further questions. Some are practical: What information should insurers be able to access? What are the implications for how courts should treat medical records in litigation? And what, exactly, should the role of individual medical records be in managing a pandemic or other public health crisis? Others are fundamental: What will it mean for patient privacy if the contents of medical records expand, as new technologies and public health insights blur the boundary between “medical” information and other information? How should these developments affect how we think about the role of doctors and health care more broadly in society? These are fundamentally political questions and the answers are not obvious. But we should be clear-eyed about our values and goals, because it will only become harder to shift course as norms

188. For an especially dismaying example of this dynamic, see Robin Feldman, *Perverse Incentives: Why Everyone Prefers High Drug Prices—Except For Those Who Pay the Bills*, 57 HARV. J. ON LEGIS. 304 (2020).

189. For a compelling account of the conflicts faced by doctors, see BLOCHE, *supra* note 92. For a summary and trenchant critique of that book’s takeaways, see Frank Pasquale, *The Hippocratic Math: How Much Should Society Spend on Health Care?*, 32 J. LEGAL MED. 529, 529-45 (2011).

around the use of data in the medical system and beyond become entrenched.