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THE LIVED EXPERIENCE OF HEALTH INSURANCE: AN ANALYSIS AND PROPOSAL FOR REFORM

*By Jacqueline R. Fox**

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* Professor of Law, University of South Carolina School of Law. The author would like to thank Nicholas Bagley, Janice Baker, Aparna Polavarapu, Jesse Cross, Etienne Toussaint, and Marie Boyd for their generous comments and my stupendous research assistant, Gabrielle Rife.

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Abstract

People in the United States are carrying tens of billions of dollars of medical debt, much of it in collections. We delay going to the emergency department while having a heart attack because it may cost too much. Doctors try to help insured patients find the best coupon to offset the high copayment for a necessary prescription drug. For inexpensive drugs, insurers make a profit by clawing back copayments that exceed what the drug costs. People who are already arbitrarily disadvantaged because of factors such as race, gender, actual and perceived health status, sexual orientation, gender identity, and weight stigma, are disproportionately burdened by all of this.

No one would design a system to end up this way. This article, through a series of case studies, does a close analysis of the healthcare insurance system from the perspective of people who use it, revealing a breathtakingly opaque, counter-intuitive, and burdensome muddle. The Patient Protection and Affordable Care Act (ACA) did much good, as have subsequent reforms, but we can do better. I argue that we do not appropriately center the lived experience of people when we design and reform healthcare financing and show how doing so can ameliorate much of the harm that is currently occurring.

Centering people does not pose an inherent conflict with conservative or liberal values. Bioethical principles such as autonomy, justice, integrity, and respect for dignity ought to be reflected in any plan. These principles can only be pursued by acknowledging how people truly experience systems they must interact with. While specific reform proposals may differ based on political preferences, the need for reform and the goals of reform ought to spring from the needs of the people a system is meant to serve. This article seeks to serve as a reminder of this first principle and a call to adjust how we approach reform in the future.

Introduction

Even before the COVID-19 pandemic, almost eighteen percent of the country had medical debt in collections.[1] A smaller proportion of people suffering from heart attacks who have insurance but are worried about their finances arrive at a hospital within two hours of symptom onset than those who are not worried.[2] Health insurance companies change the insulin brands they cover when they find one at a better price, forcing diabetics to change their medications or pay large amounts of extra money to stay on the one that is currently working. The list of problems like this is long and extends into many areas of healthcare.[3] The burden lands on many people, falling particularly hard on those already carrying the burdens of inequity.

It is time for us to reconsider how we look at health care financing, mindfully centering the perspective of people in the discourse. Other concerns have recently dominated the conversation and, as a result, the system is imbalanced, leaving people in impossible situations. Debates about health care and healthcare payment systems have increasingly become detached from the world that people live and seek care in, which arguably has played a role in the exploding amounts of medical debt[4] and poor outcomes from delayed care.[5]

We cannot assume that people have the money to pay coinsurance[6] or the sophistication and information to make complex insurance

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[1] Raymond Kluender et al., *Medical Debt in the US, 2009-2020*, 326 JAMA 250, 251 (2021).

[2] *See* Kim G. Smolderen et. al., *Health Care Insurance, Financial Concerns in Accessing Care, and Delays to Hospital Presentation in Acute Myocardial Infarction*, 303 JAMA 1392, 1396 (2010).

[3] Consider, as another example, that one in four American families have turned down medical care. Monica Chin, *1 in 4 Americans Refuse Medical Care Because They Can't Afford It*, N.Y. Post (June 7, 2017), https://nypost.com/2017/06/07/1-in-4-americans-refuse-medical-care-because-they-cant-afford-it/.

[4] A recent study showed the scope of this debt, tying it to poor insurance coverage. *Survey: 79 Million Americans Have Problems with Medical Bills or Debt*, Commonwealth Fund, https://www.commonwealthfund.org/publications/newsletter-article/survey-79-million-americans-have-problems-medical-bills-or-debt (last visited May 16, 2022).

[5] The reasons and problems springing from delaying care are not new, and the causes have been available for policy makers to consider since at least the 1980s. *See* Joel S. Weissman et al., *Delayed Access to Health Care: Risk Factors, Reasons, and Consequences*, 114 Annals Internal Med. 325 (1991).

[6] *Report on the Economic Well-Being of U.S. Households in 2018*, Bd. Governors Fed. Rsrv. Sys. (May 28, 2019), https://www.federalreserve.gov/publications/2019-economic-well-being-of-us-households-in-2018-dealing-with-unexpected-expenses.htm.

purchasing decisions.[7] Nor can we assume they have a choice of insurer,[8] access to procedures that are covered in insurance contracts,[9] or access to sophisticated care providers capable of negotiating with insurers.[10] Finally, we cannot assume they have the time to negotiate byzantine systems.[11]

Centering people, however, does not magically do away with other concerns, but rather puts those concerns in an appropriate place so that we grapple with them for the purpose of making people's lives better. For example, we have had every reason to worry about cost,[12] and there is nothing inherently wrong with utilizing the considerable engine of financial incentives within a functioning market to drive improvement while constraining expenses.[13] Likewise, it is always rational to consider

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[7] For a discussion on how extensive the literacy problem is in health insurance, *see 4 Basic Health Insurance Terms 96% of Americans Don't Understand,* Policygenius (Jan. 24, 2018) [hereinafter *Health Insurance Terms*], https://www.policygenius.com/health-insurance/health-insurance-literacy-survey/#survey-results.

[8] In 2018, eight states only have one insurer offering coverage. Daniel McDermott & Cynthia Cox, *Insurer Participation on the ACA Marketplaces, 2014-2021*, Kaiser Fam. Found. (Nov. 23, 2020), https://www.kff.org/private-insurance/issue-brief/insurer-participation-on-the-aca-marketplaces-2014-2021/. Additionally, many employers do not offer choices of insurers. Seventy-five percent offer only one type of health plan to their employees. Gary Claxton et al., Kaiser Fam. Found., Employer Health Benefits 2020 Annual Survey 71 (2020), https://files.kff.org/attachment/Report-Employer-Health-Benefits-2020-Annual-Survey.pdf.

[9] The tension between narrow networks of physicians and hospitals, on the one hand, and patient need for specialty care, leads to ongoing state efforts to address the problem, as tracked here. *See Insurance Carriers and Access to Healthcare Providers—Network Adequacy*, Nat'l Conf. State Legislatures (Feb. 1, 2018), https://www.ncsl.org/research/health/insurance-carriers-and-access-to-healthcare-providers-network-adequacy.aspx.

[10] Physicians definitely feel burdened by these negotiations and have varied methods and skills for coping. Rachel M. Werner et al., *The "Hassle Factor": What Motivates Physicians to Manipulate Reimbursement Rules?*, 162 Arch. Internal Med. 1134 (2002), https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/211437.

[11] The phrase "time tax" has been used to describe how people with limited means and less free time often spend more time negotiating government programs than those with the means and less need of the programs. Annie Lowrey, *The Time Tax: Why Is So Much American Bureaucracy Left to Average Citizens?*, Atlantic (July 27, 2021), https://www.theatlantic.com/politics/archive/2021/07/how-government-learned-waste-your-time-tax/619568/. The same concept readily applies to health insurance, where those who are sick or injured and have fewer financial resources or less communal support are often compelled to spend more time accessing the insurance benefits to which they are entitled.

[12] The price of medical care has dramatically increased since 1979. *See Consumer Price Index (CPI) for Medical Care*, Health Res. & Servs. Admin. (June 2021), https://www.hrsa.gov/get-health-care/affordable/hill-burton/cpi.html (noting how the CPI for medical care between 1979 and 2020 has risen 668.8%).

[13] Using financial incentive is tricky, as it is a powerful engine that can distort a system. Scholarly study of this type of incentive tends to show it requires sophistication and

politics and to strive to build consensus among those who have differing visions of the appropriate scope of federal and state power.[14] Improving quality through tracking metrics, seeking to incentivize providers to perform better by identifying what is best, and paying accordingly, also has merit.[15] Efficiency and effectiveness matter as well, as waste is harmful to patients and to a strained system, especially problematic and indefensible when we have to constrain good care because waste has drained coffers. However, all of this—all of what we do in the name of healthcare reform—must be measured by what happens to the people the system is meant to serve, and we are currently failing them in ways that are readily apparent with even a cursory examination.[16]

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nimbleness to ensure it truly leads to improvement, but the potential appears to be there. *See, e.g.*, Douglas A. Conrad & Lisa Perry, *Quality-Based Financial Incentives in Health Care: Can We Improve Quality by Paying for It?*, 30 Ann. Rev. Pub. Health 357 (2009), https://www.annualreviews.org/doi/abs/10.1146/annurev.publhealth.031308.100243.

[14] For a discussion of how federalism both helps and hurts the quality of the healthcare system, see Abbe R. Gluck & Nicole Huberfeld, *What Is Federalism in Healthcare for?*, 70 Stan. L. Rev. 1689 (2018), https://www.stanfordlawreview.org/print/article/what-is-federalism-in-healthcare-for/. Political rhetoric can, of course, also distort the debate about health care. Elizabeth Weeks Leonard has written extensively about this problem, see, for example, *The Rhetoric Hits the Road: State Resistance to Affordable Care Act Implementation*, 46 U. Rich. L. Rev. 781 (2012).

[15] The Centers for Medicare and Medicaid Services collect the various types of quality measures currently in effect. *What Is a Quality Measure?*, Ctr. for Medicare & Medicaid Servs., https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/NTM-What-is-a-Quality-Measure-SubPage (last visited Apr. 24, 2022). There are, of course, debates about the efficacy of any one specific measure. *See* Joanne Greenhalgh et al., *The Use of Patient Reported Outcome Measures in Routine Clinical Practice: Lack of Impact or Lack of Theory?*, 60 Soc. Sci. & Med. 833 (2005), https://doi.org/10.1016/j.socscimed.2004.06.022 (for a discussion examining problems with utilizing patient reports of outcomes); J. Olivarius-McAllister et al., *How Can Never Event Data Be Used to Reflect or Improve Hospital Safety Performance?*, 76 Anaesthesia 1563 (May 1, 2021), https://associationofanaesthetists-publications.onlinelibrary.wiley.com/doi/full/10.1111/anae.15476 (looking at never events in England and delineating statistical flaws in how they are utilized for quality tracking).

[16] As studies have shown, people who do this also have a propensity of avoiding care even when a physician would have told them care was necessary. This, in turn, leads to poorer outcomes among people with less means and high deductibles. Overall, ten and a half percent of Americans delayed or did not get care in 2019 because of cost concerns. Jared Ortaliza et al., *How Does Cost Affect Access to Care?,* Health Sys. Tracker (Mar. 14, 2022), https://www.healthsystemtracker.org/chart-collection/cost-affect-access-care/#item-costaccesstocare. This implies that some necessary care is not received in a timely manner because of cost, and studies of specific conditions bear that out, showing, for example, delays in receiving emergency treatment for heart attacks because of cost concerns, with subsequent poorer outcomes. *See* Smolderen et. al., *supra* note 2. The opposite is also true—people without cost concerns have better access. *Id.*; *see also* Rachel Garfield et al., *The Uninsured and the ACA: A Primer -Key Facts*

The passage of the ACA[17] in 2010, and its implementation since then, has done much good for people.[18] Covering preventive care,[19] eliminating pre-existing conditions,[20] ensuring guaranteed issue,[21] providing premium and copayment subsidies,[22] all of these, and more, have improved people's lives. The goals of getting people insured, bending the cost curve, and improving quality of care are laudable, and much in the ACA helps accomplish this. As with any large-scale undertaking, however, the law is not perfect and can be improved. Refocusing on patient and member experiences is a necessary corrective to problems in the healthcare system that have been resistant to being fixed or have worsened since the ACA's passage.

Looking at our current healthcare financing system from the perspective of the insured reveals significant problems. By closely examining some common interactions people have with this system, one quickly realizes the system can be both complex and irrational, as well as riddled with feints and opacity calculated to mislead people as to what they are truly entitled.

The way health insurance is structured, with its financial burdens, complexity, and demands on patients,[23] makes it more likely that any person already suffering from societal mistreatment and bias is going to have a more difficult time in our current insurance system.[24] This may be as simple as

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About Health Insurance and the Uninsured Amidst Changes to the Affordable Care Act, Kaiser Fam. Found. (Jan. 25, 2019), https://www.kff.org/report-section/the-uninsured-and-the-aca-a-primer-key-facts-about-health-insurance-and-the-uninsured-amidst-changes-to-the-affordable-care-act-how-does-lack-of-insurance-affect-access-to-care/.

[17] Patient Protection and Affordable Care Act (ACA), Pub. L. No. 111-148, 124 Stat. 119 (Mar. 23, 2010) (codified as amended in scattered sections of the U.S. Code).

[18] *See, e.g.*, Laxmaiah Manchikanti et al., *A Critical Analysis of Obamacare: Affordable Care or Insurance for Many and Coverage for Few?*, 20 Pain Physician 111 (Mar. 2017), https://pubmed.ncbi.nlm.nih.gov/28339427/ (also noting some of the ACA's shortcomings).

[19] Coverage of Certain Preventive Services Under the Affordable Care Act, 80 Fed. Reg. 41318, 41334 (July 14, 2015) (to be codified in 26 C.F.R. pt. 54, 29 C.F.R. pts. 2510, 2590, 45 C.F.R. pt. 147).

[20] 45 C.F.R. § 147.108 (2016).

[21] 45 C.F.R. § 147.104 (2014).

[22] Refundable Credit for Coverage Under a Qualified Health Plan, 26 U.S.C. § 36B (2012); American Rescue Plan Act of 2021, Pub. L. No. 117-2, §§ 9661–63, 135 Stat. 4, (Mar. 11, 2021) (providing for extended premium and copayment subsidies originally in the ACA).

[23] The word "patient" is used in this Article to mean those seeking insurance, insured people, patients, and family members of patients.

[24] *See Access to Health Services*, Off. Disease Prevention & health promotion, https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/access-to-health#10 (last visited Apr. 24, 2022) (stating how "[v]ulnerable populations are particularly at risk for insufficient health insurance coverage; people with lower incomes are often uninsured, and minorities account for over half of the uninsured population").

having less money to spend on health care because one is paid less than others,[25] as complex as navigating a poorly designed system when one has the burdens of multiple medical issues and a disability, or as problematic as not having providers be willing to tackle insurance problems on their behalf because someone is arbitrarily perceived as having less intrinsic value and so is not worth their time.[26]

We recognize that underinsurance is a significant problem,[27] yet we sell plans that place hundreds, if not thousands, of dollars of financial obligations on a population where the majority do not have the resources to pay them.[28] We have high level theoretical arguments about what comparative effectiveness research (CER) can and ought to do,[29] but have insurance companies who irresponsibly claim to be using it to make widespread benefit determinations, masking what are essentially cost saving decisions in language that incorrectly implies it is justified by concrete research findings, when no such findings exist. We allow a byzantine and unnavigable system of prescription medication coverage to increasingly dominate over appropriate patient care, with step therapy often requiring patients to engage in suboptimal care against their physician's advice to prove they are entitled to the prescribed medicine.[30]

The measure of a healthcare system ought to be whether it functions and is sustainable. Functionality and sustainability are not

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[25] *See, e.g.*, *Quantifying America's Gender Wage Gap by Race/Ethnicity*, Nat'l P'ship for Women & Fams. (Jan. 2022), https://www.nationalpartnership.org/our-work/resources/economic-justice/fair-pay/quantifying-americas-gender-wage-gap.pdf.

[26] *See, e.g.*, Laura VanPuymbrouck et al., *Explicit and Implicit Disability Attitudes of Healthcare Providers*, 65 Rehab. Psych. 101 (2020), https://pubmed.ncbi.nlm.nih.gov/32105109/.

[27] Sara R. Collins et al., *U.S. Health Insurance Coverage in 2020: A Looming Crisis in Affordability*, Commonwealth Fund, (Aug. 19 2020), https://www.commonwealthfund.org/publications/issue-briefs/2020/aug/looming-crisis-health-coverage-2020-biennial.

[28] *See* Jeff Ostrowski, *Survey: Fewer Than 4 in 10 Americans Could Pay a Surprise $1,000 Bill from Savings*, Bankrate (Jan. 11, 2021), https://www.bankrate.com/banking/savings/financial-security-january-2021/.

[29] For a discussion of the complexity in conducting this research, see Brian L. Strom, *Methodologic Challenges to Studying Patient Safety and Comparative Effectiveness*, 45 Med. Care S13 (Supp. 2 2007). For a discussion of the complexity of applying this research, see Jason John Luke, *The Role of Comparative Effectiveness Research in Developing Clinical Guidelines and Reimbursement Policies*, 13 Virtual Mentor 42 (Jan. 2011), https://journalofethics.ama-assn.org/article/role-comparative-effectiveness-research-developing-clinical-guidelines-and-reimbursement-policies/2011-01.

[30] *See, e.g.*, Laura Joszt, *How Prior Authorization, Step Therapy Result in Medication Discontinuation and Worse Outcomes*, Am. J. Managed Care (Nov. 12, 2019), https://www.ajmc.com/view/how-prior-authorization-step-therapy-result-in-medication-discontinuation-and-worse-outcomes-. Step therapy as imposed by insurers against a physician's advice is shocking yet common. It is discussed further infra.

achieved if patients and insured people are at significant financial and financially-influenced medical risk. Assessing a healthcare payment system from the patient perspective requires looking at how the entire process of the insurance-member relationship is conducted to understand the sources of problems and the sources of repair. This undertaking ought to be embedded in contract language, state and federal regulations, and culture. There are complex market forces that patients never interact with that can have important effects as well, such as those within the prescription drug marketplace.[31]

Health insurance is different than many areas of the law because, while litigation is an option, it is not a reasonable one in almost every situation.[32] If problems occur, the existing internal and external appeals processes make most litigation unnecessary, but these appeals still lead to delay and can create unbearable temporary financial or medical burdens.[33]

It is caring and empathic to acknowledge patients are vulnerable due to being sick or injured and are often untrained in medicine and law.[34] They need to be able to navigate the system for resolving health insurance disputes efficiently, of course, but they also need to be protected from a system that can harm them in oblique and subtle ways even as it functions as it is designed to. Patients require systems analyses that identifies what will harm a patient, considers such harm a real problem, and works towards preventing those problems from occurring rather than needing recourse

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[31] *See infra* Section I.C.

[32] Fully addressing the availability of or methods for acquiring damages when insurers behave improperly and a person suffers harm is outside of the scope of this Article. In other words, this is not directly about the Employee Retirement Income Security Act (ERISA) preemption. As has been brilliantly addressed, however, almost everything in health law is, to some degree, about the ERISA preemption. *See generally* Elizabeth Y. McCuskey, *ERISA Reform as Health Reform: The Case for an ERISA Preemption Waiver*, 48 J.L. MED. ETHICS 450 (2020) (discussing how the ERISA affects most if not all aspects of health law). Suffice it to say, even putting aside ERISA preemption concerns, litigation is expensive and time-consuming, qualities that make it a poor fit for people seeking medical care in time sensitive circumstances.

[33] Almost no insurance denials lead to formal appeals that go through the entire process, let alone end up in litigation. *See* Karen Pollitz & Daniel McDermott, *Claims Denials and Appeals in ACA Marketplace Plans*, KAISER FAM. FOUND. (Jan. 20, 2021), https://www.kff.org/private-insurance/issue-brief/claims-denials-and-appeals-in-aca-marketplace-plans/ ("[C]onsumers rarely appeal claims to their issuer, and when they do, issuers usually uphold their original decision."). In 2019, less than one tenth of a percent of healthcare.gov consumer denials were even appealed. *Id.*

[34] We are all patients, current, past, and future, and all deserving of this compassion. This is not meant to imply lessened autonomy or dignity, as all of these are part of treating a person ethically.

afterwards.[35]

This Article contains a series of case studies that discuss specific aspects of the current healthcare financing system, giving targeted suggestions for improving them. Each case study highlights an important problem that has a substantial impact on tens of millions of people's day to day lives. However, the central goal of this Article is to articulate why these types of problems should be identified and ameliorated, arguing that we should refocus our analysis to center people so that, first, potential problems are prevented from becoming part of our system in future iterations of reform and, second, that we look for unanticipated consequences when we implement reform, responding nimbly when problems arise in the future.

By hearing the lived experience of patients and of people seeking insurance, we can identify the problems they face.[36] Bringing a sophisticated assessment of the quality and feasibility of the decisions we expect people to make adds to our understanding of their lived experience by situating these experiences within what is happening around them. We must also seek to understand if people can bear the burdens we place on them. All of this, together, reveals the environment we are creating or sustaining for patients and insurance members, and whether that environment does good or harm to the overall undertaking. While specific reform proposals may differ based on political preferences, the need for reform and the goals of reform ought to spring from the needs of the people a system is meant to serve. This Article seeks to serve as a reminder of this first principle and a call to adjust how we approach reform in the future.

Examining these case studies reveals an absurdly complex, risky, and counterintuitive set of problems to be grappled with by people with little to no actuarial, legal, or medical training, even as training in all three would make their decisions more informed and likely lead to better financial and health outcomes. Part I explains how these case studies are structured, the tools utilized, and addresses potential criticisms of this method. The case studies in this Article are grounded in bioethical principles, empathy, and

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[35] Healthcare payment systems are not unique in terms of having vulnerable populations requiring protection and whose needs must be centered in the discussion for it to be effective. For an excellent example of this perspective in legal jurisprudence, see Emily A. Benfer et al., *Health Justice Strategies to Combat the Pandemic: Eliminating Discrimination, Poverty, and Health Disparities During and After COVID-19*, 19 YALE J. HEALTH POL'Y, L., & ETHICS 122, 125 n.3 (2020).

[36] This is not a new idea. It is accepted in computer systems design, for example, that user interface is an integral part of designing a system that functions well, this is referred to as User Centered Design in that field. *User Centered Design*, INTERACTION DESIGN FOUND., https://www.interaction-design.org/literature/topics/user-centered-design (last visited Mar. 15, 2022).

justice, but also utilize a practical, economic, actuarial, and legal lens. Using these tools, each case study includes proposals for reform of the specific problem while highlighting overarching concerns they illustrate. Part II examines the process of picking an insurance plan from the perspective of people with some or little means and a variety of potential healthcare costs, who must make rational decisions with little funding and no capacity to accurately project future heath care needs. Part III focuses on an insured person's decision to seek care, given the plan that was purchased in Part II, showing how the financial burdens a person must internalize when buying insurance can greatly alter how they decide to seek medical care, often leading to poorer outcomes than would be likely to occur without monetary considerations influencing the decision. Part IV looks at health insurance contract terms. Section IV.A explains the various sources of law that are used to draft, regulate, and interpret insurance contracts. Section IV.B parses the language of medical necessity clauses, particularly focusing on the inappropriate use of CER language and provisions that force patients to use less optimal care to prove they deserve access to more expensive treatments. Section IV.C examines prescription drug coverage, showing it is byzantine and results in unjust distributions of benefits and burdens among insured persons. This section builds on the analysis of step therapy from the prior section to show how step therapy clauses lead to poorer patient outcomes. Section IV.D examines coverage of psychiatric and substance use disorders (SUD),[37] using the vulnerabilities of dual diagnosis patients to show how state statutes, vulnerabilities of these patients, and insurance incentives can lead to poorer outcomes.

I. Methods of Analysis

The case studies that follow are analyzed from a particular perspective, delineated here. The first goal is to describe who people are and the abilities and resources they have. Second is identifying their concerns, recognizing that these can overlap with those of policy makers but can also be different in meaningful ways. Third, specific ethical commitments are expressly stated so judgments of wrongdoing are contextualized, while also acknowledging that someone with a different ethical or policy framework can challenge the assumptions upon which these judgments rest. Analyzing healthcare financing reform from the patient perspective builds on existing

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[37] SUD is a term that refers to a variety of disorders, with addiction being the most severe on a continuum. *See DSM-5 Criteria for Addiction Simplified*, Addiction Pol'y F. (Aug. 17, 2020) (updated Aug. 20, 2020), https://www.addictionpolicy.org/post/dsm-5-facts-and-figures.

literature in some ways, but also must be situated within some facially conflicting theories. Other frameworks that have been used in the past and are addressed here include a primary focus on financing as the significant driver of healthcare reform debates, freedom of contract, and a view that access to healthcare is a private, individual concern rather than a systemic issue.

Interacting with the healthcare financing system is unavoidable because people become ill, suffer from injury, and need preventive care. The concerns they have in these unavoidable interactions include worries about pain and death, certainly, but also worries about money. The specific details of these concerns ought to be better informing healthcare insurance regulation and reform. Another way of saying this is that the health reform issues that matter for people who are interacting with the insurance and healthcare systems as plan members and as patients are different than those that are foremost in the minds of politicians or health policy experts. Fully recognizing that the current system puts extraordinary burdens on people that they often have little training or resources to handle, can improve people's lives in important ways by then driving us to shape reform to lessen those burdens.

The goal of the healthcare system, overall, is to improve health and to heal, doing so with respect for the autonomy and dignity of all people. At a macro level, it must also allocate scarce resources and, ideally, expend the level of resources that is appropriate, as well as reduce morbidity and mortality across populations. Efficiency, transparency, and rationality have the benefit of enhancing all these goals.

A system that is unnecessarily hard for people to negotiate, with wasted time, poor outcomes due to hesitancy or confusion about seeking appropriate care, shifting costs to those who have no money and away from those who control the mechanics of pooling, is one that ought to be fixed if possible. Otherwise, it has components that are inefficient, inequitable, and irrational. These qualities ought to trigger change but are not doing so. The broader system clearly needs reforming.

The overarching goals of healthcare reform, generally, are similar for both patients and reformers. Everyone wants quality, access, autonomy, and controlled costs. People tasked with large scale systemic management and reform intellectually recognize the tension inherent in these goals. It is fair to say that any system currently existing requires trade-offs and constant balancing of competing claims to scarce resources as the systems evolve.[38]

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[38] *See* Rajesh Balkrishnan et al., *Global Comparative Healthcare Effectiveness Research: Evaluating Sustainable Programmes in Low & Middle Resource Settings*, 137 Indian J. Med. Rsch. 494, 494 (2013), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3705656/ ("However,

Reform is a constant undertone as a system seeks to shape an ideal balance of competing claims.

Once one recognizes the types of problems people are currently struggling with, however, an argument can be made that reform must also include a more nuanced and explicit attention to people's interactions with financing mechanisms if we are going to improve them. If one of the goals of reform is to identify problems people are facing and lift the burdens they are carrying, the healthcare financing system needs to consistently be examined from their perspective and this perspective needs to color and shape how the overarching goals are achieved.

Goals of reform, from this patient-centric perspective, are relatively straightforward. A proposed reform ought to simplify patient tasks within the payment system in a way that reduces emotional, physical, and financial stress, as well as improves outcomes. An accurate assessment of the likelihood that any healthcare reform goals will be achieved, if one includes this perspective, must reflect who patients and members truly are and the resources they reasonably have access to.

When examining the healthcare financing system to assess if it causes harms to patients, there are a wealth of ethical guidelines one can utilize to assist in making these judgments. This Article seeks to reflect a commitment to bioethical principles such as respect for autonomy, that all persons are deserving of respect, and that vulnerable persons are entitled to vigorous protection of their dignity by those who work in the fields of both health care and health insurance. Furthermore, this Article is premised on an ethic of integrity that views interactions that are exploitative, dishonest, or even passively misleading as presumptively wrongful. Any such interactions certainly require a robust and persuasive explanation as to why they are justified. Furthermore, integrity within the fields of health care and health insurance imposes a positive duty to be forthcoming on those in power, given the vulnerability and dependency of the patients, asymmetries of expertise, and the opacity of the background machinations in these fields from the patient perspective.

The term vulnerability is used to describe patients in this context for

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amidst a lack of clear evidence of comparative effectiveness between disease-specific or system specific strategies, the process of making choices that maximize value to the individual while balancing the needs of society for health care equity becomes challenging or impossible."). Comparative health law has extensive studies about different systems. People often compare the United States to other resource-rich places for purposes of assessing quality or relative expense, but the tension and trade-offs are apparent in every system, including those in countries with little to no functioning healthcare infrastructure. *See id.*

specific reasons, much of which has to do with challenging other academic perspectives on healthcare financing, such as freedom of contract. Patients are vulnerable because they are often uninformed about how best to protect themselves, many times as they are also in pain and frightened. The current insurance system asks people to make rational choices that require medical, legal, and actuarial information that is often not available, and, even when it is, requires training in all three disciplines to avoid costly and damaging errors. People must make these uninformed decisions when they need care and need it in a timely manner, often struggling with significant financial constraints, and, because of these constraints, facing extraordinary risks to their overall security when suffering from illness or injury.

Vulnerability can be found in multiple aspects of health care financing. It is critically important to be mindful of how much money people have, and that quite often, they have very little. Asking people to make choices requires understanding what must be known in order to make a choice. This, in turn, requires understanding what is truly knowable. For example, it is not possible to know, in advance, how much medical care will cost. We routinely ask patients or plan members to make decisions when some aspect of their decision rubric cannot be accurately ascertained. When something is knowable in theory, we ought to then consider if it is reasonable to ask people to do the work of knowing, especially when they or a family member is sick or injured.[39] Finally, we must consider if the system allows for insurers to mislead patients so they do not understand what they are entitled to or tricks them into paying more than they would fairly anticipate doing.

This vulnerability echoes the vulnerability of English farmers during the time of the Enclosures Acts in England, when they often

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[39] This type of work is already being done to improve informed consent; guided decision assistance is being adopted in recognition of how complex and difficult these decisions can be for patients to make. *See, e.g.*, Cindy Brach, *Making Informed Consent an Informed Choice*, Health Affs. (Apr. 4, 2019), https://www.healthaffairs.org/do/10.1377/hblog20190403.965852/full/; *see also* Frank Gieseler, *Decisions in the Shadow of Life: "Guided Decision-making"–A Classical Concept Adapted to Modern Times*, 14 Diversity & Equal. Health & Care 63, 63, 65 (2017) (discussing a proposal to adapt the previous "shared decision-making concept" in oncology, which "involves including both the patient's knowledge about his cancer-related issues and also his personal needs in the process of reaching a decision and is accepted as the gold standard of patient-doctor relationship," to a "guided decision-making model," which takes into account, in part, socio-economic disparages between patients and doctors as well as variety of treatments available). The same complexity, stress, and concerns apply to insurance and other financial decisions that occur in similar circumstances. Guidance can be helpful, and some is available, but guidance in the absence of accurate information is not able to be dispositive.

ended up stripped of their land and given little in return.[40] The idea of the tragedy of the commons is well known, but this is a different tragedy that sprang from the enclosures. The commons were an integral part of life in the English countryside for hundreds of years, with people meeting their needs through farming and grazing on these commonly held lands.[41] The impetus for enclosing them was a belief that advances in agriculture could greatly increase yield if significant improvements were put in place. This required financing for large scale infrastructure developments, which would be difficult to achieve if the land were kept in its separate parcels. To summarize the Enclosure Acts, the rules of enclosure envisioned people sharing in the advances and improvements by allotting to them a share of the improved Commons that reflected their true claim, based on complex understandings of custom and entitlement.[42]

The farmers in England were vulnerable. They were illiterate, for the most part, and lived in a hierarchical system that generally gave them little power.[43] They were dependent on the nobility to explain what they were entitled to, and, even if the farmers did accurately assess what they were entitled to, did not have the ability to retain counsel and bring suit to protect those rights.[44] Instead, many accepted small cash payments and found themselves without land and in unempowered positions of servitude.[45] Using the land as they had always done before became a capital offense.

The laws offered farmers some protection of their interests and, at least arguably, had sound policy justifications for passage. Having a protective system that required farmers to utilize skills, resources, and power

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[40] *See generally* Briony McDonagh & Stephen Daniels, *Enclosure Stories: Narratives from Northamptonshire*, 19 CULTURAL GEOGRAPHIES 107 (2012), https://www.jstor.org/stable/44251455 (discussing in part how Enclosures Laws in medieval England stripped commoners of their traditional use of common space to benefit private use, which led to social unrest); Nicholas Blomley, *Making Private Property: Enclosure, Common Right and the Work of Hedges*, 18 RURAL HIST. 1, 5 (2007), https://www.researchgate.net/publication/232025602_Making_Private_Property_Enclosure_Common_Right_and_the_Work_of_Hedges (arguing the importance of hedges as a device through which new spatial Enclosures were enforced). Between 1604 and 1914, there were over 5,000 individual enclosure Bills covering 6.8 million acres. *Enclosing the Land*, U.K. PARLIAMENT, https://www.parliament.uk/about/living-heritage/transformingsociety/towncountry/landscape/overview/enclosingland/#:~:text=Enclosure%20by%20Act&text=From%20the%201750s%20enclosure%20by,to%20some%206.8%20million%20acres (last visited Mar. 16, 2022).

[41] McDonagh & Daniels, *supra* note 40, at 108.

[42] Blomley, *supra* note 40, at 2.

[43] *Id.* at 11.

[44] *Id.* at 2.

[45] McDonagh & Daniels, *supra* note 40, at 112.

they did not possess made the protections essentially worthless. In a similar way, people are vulnerable in the face of the current healthcare financing system, often lacking the resources, sophistication, and empowerment to get whatever benefits they are entitled to and thus adequately protect their health. Creating a system that is good, in its written form, does little if people's lived experience of the process is predictably problematic.

Describing people as vulnerable in this way does push back against a particular view of autonomy that can be called economic autonomy. A proponent of economic autonomy would assert that the ability to bargain, to shape one's life according to one's own concerns and arrange one's economic conditions in a way that suits one's own preferences, is a significant part of liberty that has value. This is important, overall, and this Article does not seek to devalue those attributes of an individual's life. Healthcare financing, as it is currently structured, is not an appropriate place in which to overvalue these concerns, however, given the life-or-death stakes. In a recent article closely examining the theoretical foundations for many of these claims, Professor Cogan has done an excellent job of showing that they are not particularly robust or persuasive, which makes sense, given that so called "consumer driven healthcare" has failed to create a financing system that meets the needs of its participants.[46]

Proponents of economic autonomy do have a role to play in healthcare financing reform even as reform adapts to centering a patient's experience. Protecting the vulnerable in healthcare financing does, at times, call for positive paternalism, constraining a person's contract choices to protect them. For those who are wedded to freedom of contract as a pre-eminent value, no arguments will suffice to change their minds, as they view freedom of contract as more important than other values and so are willing to suffer any consequences that result. For those who seek to maximize freedom of contract but recognize it can be constrained when it is reasonable to do so, however, this form of autonomy is open to balancing with other values.[47] Patient vulnerability can play an important role in informing this

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[46] John Aloysius Cogan Jr., *The Failed Economics of Consumer-Driven Health Plans*, 54 U.C. DAVIS L. REV. 1353 (2021). In this article, Cogan explicitly examines and critiques the various theories that have been used to justify supporting this approach to financing health care. The theories, and the resulting systems we are currently struggling with, have not resulted in systems that function well for many, if not most, people. They do, however, consistently generate profit for investors.

[47] Realistically, it is difficult to know exactly how to characterize scholars who write about freedom of contract and economic autonomy in terms of how welcoming they would be to balancing in this way. David Hyman and Charles Silver, for example, argue that freedom of contract can save the healthcare financing system, so appear to be saying it is important because it is useful, but they also seem comfortable with the turmoil

balancing even as economic autonomy can work to protect people from overly paternalistic impulses.

When policy makers are more informed about patient experiences, constraints can be tailored to maximize financial and contract autonomy. At the same time, these values can be placed in their proper place, not utilized to bar reforms because of reflexive or misguided concerns about rights to contract. There is little to no negotiating over contract terms between a patient and an insurance company. People do not have the capacity to self-fund medical care and so must participate in pooling mechanisms controlled by others. People also do not have the training to assess the care they will need, and so cannot reasonably be expected to properly choose the type of care they should be insured for. Finally, our experiences under the Emergency Medical Treatment and Active Labor Act (EMTALA),[48] which requires all facilities with emergency departments to triage and stabilize all patients, without regard to ability to pay for the care they receive, have shown us that people seek care in medical emergencies even when they cannot pay for that care. It is unreasonable to expect a person to calmly accept suffering and death because they did not have the forethought or resources to arrange for financing healthcare beforehand, and our laws recognize that.

A patient-centric perspective can lead to counterintuitive results in this analysis. For example, narrow provider networks, when viewed from the perspective of a person freely contracting with an insurer, are justified because that person could be seeking a less expensive plan and is willing to accept fewer choices of care providers so they can make that bargain. Properly recognizing that person as having limited choices of insurer and limited funds could alter the analysis, as promoting wider networks with all insurers would increase that person's capacity to contract with a wider variety of providers. From this perspective, expanding networks increases a person's financial autonomy. It also may give patients greater bargaining power with providers since they can choose to see who best suits their needs. Bargaining power with providers is something they likely care more about than theoretical bargaining power with insurance companies, since the quality of a provider can play a role in a person's health.

Finally, this Article asserts that, if there is a hierarchy of concerns in healthcare finance reform, patient experience and patient outcomes

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and poor results such a system could cause for some individuals functioning within it, implying they have a strong commitment to placing contracting high in a hierarchy of what they value in the public sphere, making it unlikely they would welcome the balancing envisioned here. *See* CHARLES SILVER & DAVID A. HYMAN, OVERCHARGED: WHY AMERICANS PAY TOO MUCH FOR HEALTH CARE 14–15 (2018).

[48] 42 U.S.C. § 1395dd.

belong at the top, even as cost is a significant and important constraint on the system overall. Much that harms patients could be fixed with money.[49] Where that money comes from and how much it is appropriate to spend are unavoidable problems in healthcare financing. It is possible and necessary to discuss money without losing track of the inherent dignity of people and the importance of their healthcare needs.

Those invested in focusing on money as the primary first question in healthcare reform can argue they are doing so to protect patients by ensuring there is a functioning and financed system to meet future patient needs. This stance risks doing harm in the debate, and risks missing opportunities to improve the overall quality of the system. A rigid refusal to consider money when proposing healthcare financing reforms is unrealistic, certainly, but beyond responding to that extreme stance, merely claiming that there is not enough money to meet needs is unsophisticated and problematic.

Consider the debate about forms of universal healthcare coverage, where people opposed to these programs commonly assert that having such a system would be too expensive or would increase waiting times for care. Whatever the true concerns of those making these arguments are, by focusing on money in such a way as to bar further discussion, the arguments appear to be premised on protecting a system that currently reduces cost and waiting times by not providing care for some people. That is a big problem if one considers all people to have inherent worth. Furthermore, these statements are made within a society and healthcare financing system that measurably disadvantages people because of race, gender, class, health status, and myriad other factors.[50] "Some people" are these people, for the most part. Using cost as a gatekeeping metric in this way reinforces to people that they do not matter, and that the system is not constructed to prioritize their needs.

It is possible to talk about money properly, but it is hard. Transparently making trade-offs in a healthcare financing system is so politically fraught as to be referred to as the "third rail" of politics and it may be that it is truly impossible to engage in making these trade-offs without some subterfuge.[51]

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[49] Money is used to fund the provision of health care, but it is also used as an incentive to spur innovation and quality. The appropriate use of this incentive in health care, particularly for returns on capital investment when there are scarce resources to meet people's healthcare needs, is an important question within the debate about funding the healthcare system overall but is outside the scope of this Article.

[50] For a study examining how race and wealth influence access to care, see Jacob Wallace et al., *Changes in Racial and Ethnic Disparities in Access to Care and Health Among US Adults at Age 65 Years*, 181 JAMA INTERNAL MED. 1207 (2021).

[51] *See* Richard Sorian, *Is Medicaid the New 'Third Rail?' History Suggests It Has Been for Some Time*, HEALTH AFFS. (July 20, 2017), https://www.healthaffairs.org/do/10.1377/

However, discussions about money can be more properly embedded in the goals of the system overall while acknowledging the values the system seeks to embody. Doing this requires thinking through how one's claim effects all people and justifying the harm it could cause to some. Not doing this work allows the debate itself to cause harm and results in missed opportunities for more defensible proposals to be considered.

Understanding the way cost, quality, access, and choice are experienced by patients requires a leap of empathy, certainly, but it also requires truly grasping the details of the complex environment that must be negotiated. To make it even more tricky, true empathy requires understanding this complexity while also recognizing that the patient likely does not fully understand the same but is, instead, buffeted by a sense of being forced to rapidly make weighty decisions with insufficient information and power.

Better understanding and centering the patient in healthcare finance reform does not require a complete reordering of health policy. Rather, using this information adds important perspectives to how reform is structured and assessed, creating opportunities for meaningful improvement.

II. PICKING A PLAN

A. *The Process*

As explained below, the choice of a health insurance plan can require an extraordinary degree of sophistication and a high level of risk tolerance. Having enough money to pay premiums is not necessarily the same as having the sophistication required to make the best choices, especially when those choices are obscure. The stakes become higher when a person has less discretionary income and when a plan has more potential costs a person might have to pay. Picking a health insurance plan when someone has choice requires income that is sufficient to handle the expenses that are fixed, such as the out-of-pocket cost of premiums. It also requires accurately anticipating how much and what types of medical care will be needed in the following year.[52] This gets hard very quickly.

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forefront.20170720.061122/full/.

[52] *See Your Total Costs for Health Care: Premium, Deductible & Out-of-Pocket Costs*, HEALTHCARE.GOV, https://www.healthcare.gov/choose-a-plan/your-total-costs/ (last visited Mar. 25, 2022). Healthcare.gov offers guidance for picking a plan and includes in that guidance an acknowledgment, of sorts, that this is unknowable: "Of course it's impossible to predict the exact amount [of healthcare you will need next year]. So think about how much care you usually use, or are likely to use." *Id.* Citing these directions here is not a criticism of them, they are written in a manner that will help guide people who are faced with doing the best they can in this imperfect situation.

For people purchasing an individual plan, certain numbers must be added up to make a rational choice, but the addition is often exceptionally complex. Plan costs vary based on premiums (minus any premium subsidies from the federal government),[53] but also vary based on deductibles, co-payments (or co-insurance), types of copayments, and maximum out-of-pocket costs, which include copayments and co-insurance, but may not include deductibles.[54] If a person's healthcare costs are generally relatively high, the math is straightforward. One assumes the deductible will have to be paid, then adds that to the maximum out of pocket cost, adds the annual premium, and comes to an accurate cost for a specific insurance plan, which can then be compared to other plans. If a person is considering a plan with a very high deductible and pays significant amounts of taxes, they can also consider setting up a Health Savings Account (HSA), putting tax-protected dollars in it, and using that money to pay the deductible.[55] Doing this reduces the cost of the deductible because it is paid in pre-tax dollars. To ascertain the actual cost of the deductible, a person seeking to purchase insurance must calculate the tax rate for the money that would go in the HSA, calculate what the after-tax dollars would be, and use that as the value of the deductible. For example, with a plan with a $10,000 deductible and a person whose tax rate can reach 25%, the after-tax value of the $10,000 HSA-funded deductible is $7,500. When calculating cost, the deductible value is reduced to reflect any tax savings because, absent an HSA, it would be paid with post-tax income. This allows someone to compare the cost of lower deductible plans with higher deductible plans.

A much harder determination comes in when a person cannot, with any assurance, predict that they will have large amounts of medical costs in any given year. Assuming people are buying coverage through the

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[53] *See generally* 26 U.S.C. § 36B (pertaining to tax credits for healthcare premiums).

[54] *What is an Out-of-Pocket Maximum and How Does it Work?*, CIGNA (May 2019), https://www.cigna.com/individuals-families/understanding-insurance/what-is-an-out-of-pocket-maximum. For people purchasing insurance on the exchange and who earn between 100–250% of the federal poverty level, a silver plan will come with cost-sharing subsidies as well as premium subsidies, so the actual cost of health care is reduced. The website will calculate what the actual deductibles, copayments, out-of-pocket maximums, etc. are based on the income the applicant provides. *Explaining Health Care Reform: Questions About Health Insurance Subsidies*, KAISER FAM. FOUND. (Oct. 29, 2021), https://www.kff.org/health-reform/issue-brief/explaining-health-care-reform-questions-about-health-insurance-subsidies/. These cost-sharing subsidies are not available for people earning the same income but who receive insurance through their employer, rather than the exchange, which could be described as arbitrary or unjust.

[55] *Health Savings Accounts*, NAT'L CONF. STATE LEGISLATURES (Aug. 31, 2020), https://www.ncsl.org/research/health/hsas-health-savings-accounts.aspx.

exchange, many fixed medical costs for preventive care are required to be covered in full, with no deductible, so these do not have to be considered in the calculations.[56] The choice between deductible amounts, in this case, requires a person to calculate the extent to which they will self-insure and calculate how much they can spend on premiums, which tend to be more expensive for lower deductibles. The larger the amount they self-insure, the less they will spend on insurance premiums but the greater their financial exposure if an event occurs. For people who often have little or no medical costs, they must make risk calculations about the likelihood of an accident or sudden illness occurring then calculate if they can absorb the costs if such a thing occurs. This is frustrating, as these are the exact actuarial calculations insurance companies make and have tremendous difficulty doing if an insured population is too small.[57]

This calculation is impossible to make with any accuracy for a single, relatively healthy person or a small, relatively healthy family, so a person is, instead, ascertaining their own risk tolerance and capacity to absorb sudden expenses.[58] A large deductible means foregoing insurance of any kind for the amount of the deductible. A prudent, risk-averse person of means will save to cover any such risk, but this is far from ideal. If they do not need to use the money for healthcare costs, they have inefficiently foregone using the money for other expenses that could have a higher societal or personal utility.

For those without means, even if prudent and risk-averse, the calculations can be much more problematic. Someone prudent, risk averse, and with little income that can go towards medical costs, will seek insurance

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[56] Affordable Care Act § 2713, 124 Stat. 131 (2010) (codified at 42 U.S.C. § 300gg-13(a)).

[57] Accurately assessing future health care costs for individuals would be extremely useful for many participants in healthcare financing, but it is in its early stages and does not seem to be even attempting to ascertain these costs at the precise level needed here. *See, e.g.*, Mohammad Amin Morid et al., *Supervised Learning Methods for Predicting Healthcare Costs: Systematic Literature Review and Empirical Evaluation*, 2017 Am. Med. Informatics Ass'n Ann. Symp. Proc. 1312, 1312, 1320 (2018), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5977561/.

[58] A good example of the numbers can be found here:

> Two individuals are looking for health insurance. Person A decides to purchase a high-deductible policy with a $2,500 annual premium and $5,000 deductible, while Person B decides on a higher annual premium ($3,500) and lower deductible ($2,000). If both individuals incurred $5,000 medical expenses during the year, Person B would save $2,000 compared to Person A.

Jamie Cattanach, *High-Deductible Health Plans Continue to Grow in Popularity, but Are They Right for You?*, Valuepenguin, https://www.valuepenguin.com/enrollment-changes-to-high-definition-health-insurance-plans (Jan. 24, 2022).

because they recognize its importance but may rationally choose a plan that has a high deductible that cannot be paid to afford the lower premium. This is rational because merely having insurance may be necessary to get access to many kinds of care,[59] so a person's health is protected better by making the purchase even if potentially ruinous costs have been kicked down the road.[60] To further economize, they may also choose a plan with high copayments they cannot afford and a high maximum out-of-pocket cap, all of which can bring the premium down further,[61] but this alters the overall risk calculation.[62] Unaffordable copayments can have a rapid negative effect on access to care, as unpaid copayments can cause physicians to refuse treatment,[63] making this more problematic for overall health than high deductibles.

If a person chooses to purchase insurance under the assumption that they will not get sick or injured, they are likely inclined to choose a plan

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[59] *See* Kathleen T. Call et al., *Barriers to Care in an Ethnically Diverse Publicly Insured Population: Is Health Care Reform Enough?*, 52 Med. Care 720, 720–27 (2014) (finding that barriers to receive certain types of care often relate to costs and access to coverage).

[60] As studies have shown, people who do this also have a propensity of avoiding care even when a physician would have told them care was necessary. This, in turn, leads to poorer outcomes among people with less means and high deductibles. About half of adults have reported delaying or going without care in the past year due to cost. *See* Audrey Kearney et al., *Americans' Challenges with Health Care Costs*, Kaiser Fam. Found. (Dec. 14, 2021), https://www.kff.org/health-costs/issue-brief/americans-challenges-with-health-care-costs/. This implies that some necessary care is not received in a timely manner because of cost, and studies of specific conditions bear that out, showing, for example, delays in receiving emergency treatment for heart attacks because of cost concerns, with subsequent poorer outcomes. Smolderen et al., *supra* note 2. The opposite is also true: people without cost concerns have better access. Rachel Garfield et al., *The Uninsured and the ACA: A Primer*, Kaiser Fam. Found. 13–14 (2019), https://files.kff.org/attachment/The-Uninsured-and-the-ACA-A-Primer-Key-Facts-about-Health-Insurance-and-the-Uninsured-amidst-Changes-to-the-Affordable-Care-Act; Katherine Baicker et al., *The Oregon Experiment—Effects of Medicaid on Clinical Outcomes*, 368 New Eng. J. Med. 1713, 1713 (2013) (significant improvements to access shown among adults in study who gained Medicaid coverage); Andrea S. Christopher et al., *Access to Care and Chronic Disease Outcomes Among Medicaid-Insured Persons Versus the Uninsured*, 106 Am. J. Pub. Health 67 (2016).

[61] The interplay between deductibles, copayments, and premium prices is illustrated on Healthcare.gov with the prices for the various metal plans. As they decrease in actuarial value, they decrease in price.

[62] See, for example, the interaction of cost and potential financial exposure in the federal metal plans. *What's the Difference Between Bronze, Silver and Gold Plans?*, Blue Cross Blue Shield Blue Care Network Mich., https://www.bcbsm.com/index/health-insurance-help/faqs/topics/buying-insurance/metal-tiers.html (last visited May 16, 2022).

[63] Michelle Andrews, *Doctors and Hospitals Tell Patients: Show Us the Money Before Treatment*, NPR (Dec. 7, 2016), https://www.npr.org/sections/health-shots/2016/12/07/504589131/doctors-and-hospitals-tell-patients-show-us-the-money-before-treatment.

with the lowest levels of coverage for the least amount of actual premiums, with high copayments and high out-of-pocket caps. They may also not purchase insurance at all.[64]

When deciding whether to purchase insurance, the cost of premiums and deductibles are not the only considerations that individuals weigh. Purchasing insurance gets them access to preventive care with no copayments or deductibles[65] so if they would use this care for birth control, well visits for children, vaccines, etc., they can roughly estimate the cost of that care to help make calculations. Unfortunately, they also have to know how much a doctor or pharmacy charges for something with insurance and without insurance, which is generally impossible to know.[66] Somewhere in this complicated mix, a person also has to assess if it is worth purchasing insurance, even with high out-of-pocket costs for the member, to participate in the discount the insurer has negotiated with care providers.[67] A $10,000 deductible will go further paying for discounted medical care than the same $10,000 paid for care provided to an uninsured person.

Any of these options that result in underinsurance, meaning potential patient payment responsibilities they cannot afford, can be ruinous, as has been well-documented for decades. If they get sick or injured, they are at a

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[64] It seems highly unusual for someone to have the means to purchase insurance and decline. Data from 2019 showed that more than eighty percent of the uninsured population made less than 400% of the federal poverty level. Jennifer Tolbert et al., *Key Facts About the Uninsured Population*, KAISER FAM. FOUND. (Nov. 6, 2020), https://www.kff.org/uninsured/issue-brief/key-facts-about-the-uninsured-population/. Of note, the same study also found that nearly eighty-five percent of the uninsured had at least one person in the family who was employed, so there is some income. *Id.*; *see also* COMM. ON HEALTH INS. STATUS & ITS CONSEQUENCES, INST. OF MED., AMERICA'S UNINSURED CRISIS: CONSEQUENCES FOR HEALTH AND HEALTH CARE 136 (2009); Munira Z. Gunja & Sara R. Collins, *Who Are the Remaining Uninsured and Why Do They Lack Coverage?*, COMMONWEALTH FUND (2019), https://www.commonwealthfund.org/sites/default/files/2019-08/Gunja_who_are_remaining_uninsured_sb.pdf.

[65] Affordable Care Act § 2713, 124 Stat. 131 (2010) (codified at 42 U.S.C. § 300gg-13(a)).

[66] As of January 2021, the federal government is proposing regulations to make cost more transparent. Nisha Kurani et al., *Price Transparency and Variation in U.S. Health Services*, PETERSON-KFF HEALTH SYS. TRACKER (Jan. 13, 2021), https://www.healthsystemtracker.org/brief/price-transparency-and-variation-in-u-s-health-services/. But the expectations for this program are low. The literacy problem in health insurance is extensive. *See Health Insurance Terms*, *supra* note 7.

[67] *See* Sammy Mack, *They Paid How Much? How Negotiated Deals Hide Health Care's Cost*, NPR (Nov. 15, 2014), https://www.npr.org/sections/health-shots/2014/11/15/364064088/they-paid-how-much-how-negotiated-deals-hide-health-cares-cost; *see also Transparency in Coverage Final Rule Fact Sheet (CMS-9915-F)*, CTRS. FOR MEDICARE & MEDICAID SERVS. (Oct. 29, 2020), https://www.cms.gov/newsroom/fact-sheets/transparency-coverage-final-rule-fact-sheet-cms-9915-f.

high risk of debt, financial chaos, homelessness, and personal bankruptcy[68] if expensive care occurs.

It is easy to envision ruinous costs for catastrophic problems, but even if nothing catastrophic happens and someone only suffers a minor surgical emergency such as an appendectomy or a broken bone from a car wreck, almost half of people do not have the financial cushion to absorb thousands of dollars in unexpected expenses.[69] The financial chaos that ensues can be significant.

Once a person decides what they expect their expenses to be in the coming year, the financial calculations become relatively straightforward, even if they are based on necessarily imprecise and arbitrary risk assessments. A calculation of premiums, copayments, deductibles, and the savings of utilizing a HSA can be made, which should help reduce the choices. The next step is to determine if one has preferred physicians or hospitals, and the networks that are offered by different plans. These networks are, to some degree, illusory, as insurers are not bound by the prior year's network for future insured persons, but it does give some sense of scope of coverage. For example, Health Management Organization (HMO)-type plans that require a person to go to a specific place for care, such as Kaiser plans,[70] are very different from preferred provider Blue Cross Blue Shield (BCBS) plans, which tend to allow a member to seek care at most hospitals in the country and still be within the network.[71] A person can also check insurance formularies to see lists of covered prescription medications and calculate copayments, though these too can be illusory, as covered medications and rates of coverage are subject to change without warning. Pricing the purchase of medications can be shockingly complex and so this is described in a separate section below.

People who receive their insurance through an employer usually

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[68] The level of upheaval is hard to exaggerate. People can lose custody of their children, get evicted, lose their homes, and have destroyed credit scores that can then make it much harder to get employed, buy a home, etc. *See* David U. Himmelstein et al., *Medical Bankruptcy in the United States, 2007: Results of a National Study*, 122 Am. J. Med. 741 (2009); *see also* Sarah Kliff & Margot Sanger-Katz, *Americans' Medical Debts Are Bigger than Was Known, Totaling $140 Billion*, N.Y. Times (July 20, 2021), https://www.nytimes.com/2021/07/20/upshot/medical-debt-americans-medicaid.html.

[69] *Report on the Economic Well-Being of U.S. Households in 2018*, *supra* note 6, at 2 (noting that 40% of Americans would have difficulties covering a $400 expense).

[70] *HMO vs. PPO Plans—What Are the Differences?*, Kaiser Permanente (July 1, 2019), https://thrive.kaiserpermanente.org/thrive-together/health-care-101/hmo-vs-ppo-advantages.

[71] *Coverage that Goes Where You Go: Travel Worry-Free with Blue Cross Blue Shield*, Blue Cross Blue Shield, https://www.bcbs.com/articles/coverage-goes-where-you-go-travel-worry-free-blue-cross-blue-shield (last visited Mar. 18, 2022).

have limited to no choices in their coverage. For those who do have some degree of choice with their employer-sponsored coverage, it is usually a question of a flat amount that is withheld from their pay to offset some of the premiums, and then they choose a plan based on cost of any additional premiums the employee must pay, network, deductible, and copayments. This final decision rubric resembles the calculations for those who are purchasing individual insurance.

B. *Recommendations*

The best way to resolve insurance purchasing problems, and many other problems examined in this Article, is to eradicate all components of self-insurance. Short of that, expansion of the coinsurance subsidies already in use for many Silver plans purchased on the Exchanges could be expanded to better protect a wider population. At the same time, comparable protection from onerous coinsurance burdens for those who receive coverage from employers would help ameliorate inequities across different sources of coverage.

Prior to the passage of the ACA and the concept of valuable preventive care being fully covered, one could argue that health insurance should be reserved for the type of health event that is traditionally considered insurable, meaning something unpredictable for an individual but with a predictable rate of occurrence in a population. Insurance policies were crafted to exclude fixed and predictable costs such as annual exams and deductibles were set to cover the typical illnesses that a person was likely to have over the course of a year.[72] This reserved insurance coverage for truly unusual events and allowed for a pooling mechanism that was relatively affordable. That is not what we currently have. Health insurance policies have the obligation to fund most predictable health maintenance costs at 100%, with no deductible or copayments.[73] At the same time, large deductibles and copayments kick in to cover the costs of the actual care that traditional insurance covered.[74] It is an inversion. It is also inefficient. While most Americans do not have the means to self-insure, which many deductibles and copayments require them to do for substantial amounts, they do have the capacity to participate in proper pooling mechanisms, where small contributions help offset the predictable costs that the pool will have to fund. The premium subsidies envisioned in the ACA play an important role here, because they assist

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[72] Jacqueline R. Fox, *Medicare Should, but Cannot, Consider Cost: Legal Impediments to a Sound Policy*, 53 Buff. L. Rev. 577, 589–90 (2005).

[73] Affordable Care Act § 2713, 124 Stat. 131 (2010) (codified at 42 U.S.C. § 300gg-13(a)).

[74] *Id.*

people's participation in this pooling.

Deductibles and copayments make little sense in this system. As has been shown multiple times, people delay or fail to receive medical care when they need it because the potential cost distorts the decision making,[75] and even if they do seek care, the subsequent costs are tremendously destabilizing to their individual financial well-being.[76] Providers sometimes struggle to collect money from individuals, which likely causes an administrative burden.[77] The concern about payment also fractures the relationship between provider and patient, especially for any treatments that require numerous interactions with a physician and hospital, where the unpaid balance simply increases over time, making it less likely that a patient will receive the full course of treatment that they require, either because they are unwilling to continue seeking care, given the increasing costs they are unable to pay, or because the physician will simply refuse to see them until the outstanding balance is reduced.[78]

One could argue that insurance will simply be too expensive if it insures for these costs. This argument, however, appears to be premised on the idea that the cost of insurance is somehow separate from other healthcare costs and is deserving of privileged consideration, rather than being viewed as a method for paying those costs. Currently, costs are shifted to patients who often cannot pay them. This results in problems for the patients but also for providers, who are left with bills that cannot be collected.[79] The quality of

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[75] Neil M. Kalwani & Alexander T. Sandhu, *High-Deductible Health Plans and Emergency Care for Chest Pain: To Go or Not to Go?*, 144 Circulation 366, 350 (2021).

[76] *Medical Debt Collection*, Nat'l Consumer L. Ctr., https://www.nclc.org/images/Medical-Debt-Collection.pdf (last visited Mar. 25, 2022).

[77] *Fact Sheet: Uncompensated Hospital Care Cost*, Am. Hosp. Ass'n (Feb. 2022), https://www.aha.org/fact-sheets/2020-01-06-fact-sheet-uncompensated-hospital-care-cost.

[78] In some ways, this may actually resemble problems with pay day loans, where people enter into financially burdensome arrangements they know they may not be able to repay in hopes of relieving immediate problems. *See, e.g.*, John P. Caskey, *Payday Lending: New Research and the Big Question*, *in* The Oxford Handbook of the Economics of Poverty 681, 682 (Philip N. Jefferson ed., 2012) ("Do payday lenders, on net, exacerbate or relieve customers' financial difficulties?").

[79] *See* Craig Garthwaite et al., *Hospitals as Insurers of Last Resort* 1–2 (Nat'l Bureau of Econ. Rsch., Working Paper No. 21290, 2015), http://www.nber.org/papers/w21290 (concluding that it costs local hospitals $900 in uncompensated care for every uninsured person that receives care). Garthwaite has noted how "[t]his is not a trivial thing for a hospital to deal with," as hospitals can average around seven percent profit margins, while uncompensated care costs can be more than five percent of their revenue. Maureen Groppe, *Who Pays When Someone Without Insurance Shows Up in the ER?*, USA Today (July 3, 2017), https://www.usatoday.com/story/news/politics/2017/07/03/who-pays-when-someone-without-insurance-shows-up-er/445756001/; *see also Fact Sheet*, *supra* note 70 (defining uncompensated care as "an overall measure of hospital

outcomes suffers as a result, along with spillover effects such as bankruptcy. The costs do not disappear by being shifted; they merely disappear for insurers. A stable, predictable, and efficient system that properly accounts for the true costs of medical care and utilizes pooling methods to cover these costs rather than relying on individual financial burdens is better, according to any metric one could legitimately apply to assess it. Put another way, the job of insurance is to insure, not to create systems for offsetting costs to those who cannot bear them.

For patients who cannot access high quality care with appropriate specialists in their networks, insurance contracts generally allow for the care to be covered at in-network levels even if is received from out of network providers. Patients, however, may not know this is an option, and so it may be helpful to require insurance companies to expressly tell them this when the issue arises. Most contracts also have clauses that protect patients from churn, where physicians, hospitals or medications are added or removed from networks during a course of treatment. Again, expressly notifying patients of these rights ought to be sufficient to ameliorate consequences. It may, however, be helpful to create more robust rules that allow for patients to receive treatment from qualified specialists at qualified centers of excellence and to allow patients to continue being treated by physicians who are already engaged with treating them for a specific condition.

III. Deciding to Seek Care

A. *The Process*

Determining if one should engage with the healthcare system is as, or more complex than choosing an insurance plan. A person must assess if medical care is truly necessary, doing so with no medical training and no diagnostic tools. They also must assess if they can afford to seek care, making that assessment with limited information about what type of care will be required and limited information about the cost of the care.

It is probably fair to say few people seek out medical care if it can be avoided. It is inconvenient at best, and often painful and intrusive.[80] In the

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care provided for which no payment was received from the patient or insurer").

[80] People who risk experiencing implicit and/or explicit bias and disrespect within the medical system are especially likely to hesitate before seeking care, fearing they will not be heard or responded to with respect and care. There are myriad groups who report this concern and have these experiences. Individuals have faced disparate medical treatment based on race, socio-economic status, weight bias, gender identity, sexual orientation, mental and/or physical illness, having a disability, etc.

non-ideal world of the United States healthcare system, many people, even those that are sick and suffering from obvious harms that need treatment, avoid getting medical care as well.[81]

Cost is a dominant concern because of how insurance plans are structured. As described in the previous section, insured people have significant responsibility for their own medical costs due to deductibles, copayments, and coinsurance. They also risk inadvertently receiving care from providers who are outside of their insurance network, even if they seek care within it, which can cause their financial exposure to greatly increase.[82]

Cost concerns, to some degree, are dependent on if someone has satisfied any deductibles or out-of-pocket maximums for the benefit year. The trends in insurance for the last ten years have been to consistently increase member financial responsibility, so this concern extends to ever larger amounts of money and ever later dates in the year. The Kaiser Family Foundation (KFF) has done several studies to understand components of this dynamic more fully. One study has shown, for example, that the dollar amount of deductibles has consistently increased for employer-sponsored insurance.[83] This delays when a person is likely to have satisfied the deductible. As of 2019, the average person with employer-sponsored care will satisfy their deductibles by May 19, a day KFF has dubbed "Deductible Relief Day."[84] So, for this population, most people will have significant expenses if they engage with the system prior to Deductible Relief Day, as their insurance is not yet paying for much of their care.

While deductibles are often quite large,[85] copayments and coinsurance can also be burdensome. In most plans, deductibles go towards the out-of-pocket maximum, but do not, by themselves, satisfy it. Many people do not have the income or savings capacity to handle relatively small sudden expenses, with 61% of the country unable to absorb a $1,000

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[81] *See, e.g.*, Kyle T. Smith et al., *Access Is Necessary but Not Sufficient: Factors Influencing Delay and Avoidance of Health Care Services*, 3 MED. DECISION MAKING POL'Y & PRAC. 1 (2018) (finding that many people delay or avoid non-preventative healthcare, such as doctor visits when you're sick, due in part to costs even if they had insurance).

[82] Erin Duffy et al., Opinion, *Surprise Medical Bills Increase Costs for Everyone, Not Just for the People Who Get Them*, BROOKINGS (Oct. 2, 2020), https://www.brookings.edu/opinions/surprise-medical-bills-increase-costs-for-everyone-not-just-for-the-people-who-get-them/.

[83] *General Annual Deductibles for Single Coverage, 2006-2018 9240*, KAISER FAM. FOUND. (2018) https://www.kff.org/report-section/2018-employer-health-benefits-survey-section-7-employee-cost-sharing/attachment/figure-7-10/.

[84] *"Deductible Relief Day" is May 19*, KAISER FAM. FOUND. (May 16, 2019), https://www.kff.org/health-costs/press-release/deductible-relief-day-is-may-19/.

[85] The average deductible in employee benefit plan coverage 2019 was $1,655 for a single person. CLAXTON ET AL., *supra* note 8, at 107.

expense, and 40% of people unable to absorb a $400 expense.[86] A relatively simple visit to an emergency department or internist that is fully covered by insurance can still cost a patient hundreds of dollars, money most people in the country do not have readily available.[87] A study analyzing medical debt of insured households found that roughly sixteen percent had incurred such debt.[88]

For a person to make this choice before seeing a doctor, they must assess the severity of their own symptoms, how dangerous it would be to avoid or delay care, and if they can afford the care they might need. Doing this with any accuracy is likely impossible. As with how the current system asks people to assess their individual actuarial risk when purchasing insurance, it also asks people to make complex medical determinations about themselves with no training and no diagnostic equipment. The medical determinations are not limited to figuring out if they simply need to see a doctor. Because cost is a real threat, people also must figure out if they can afford the actual care that will be provided. To do this, they must predict, again with no expertise, what their entire interaction with the healthcare system will entail so they can estimate the amounts of copayments and coinsurance they will have to pay. Even if they could determine with some rough accuracy what care is involved, they would then need to figure out if they can afford that care in a system that does not have clear and transparent pricing, making it difficult, if not impossible to assess coinsurance costs.[89]

Given that they have no medical training to inform their decision as to severity of their symptoms or what care is required, no way to ascertain the costs of whatever care is eventually required, and have a financial incentive to not seek care, it is not surprising that cost concerns often lead to bad outcomes. Consider heart attack symptoms. If a person is having a heart

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[86] Jeff Ostrowski, *Survey: Fewer than 4 in 10 Americans Could Pay a Surprise $1,000 Bill from Savings*, BANKRATE (Jan. 11, 2021), https://www.bankrate.com/banking/savings/financial-security-january-2021/; BD. OF GOVERNORS OF THE FED. RSRV. SYS., REPORT ON THE ECONOMIC WELL-BEING OF U.S. HOUSEHOLDS IN 2018, at 2 (2019).

[87] Terry Gross, *Why An ER Visit Can Cost So Much – Even for Those with Health Insurance*, NPR (Mar. 13, 2019), https://www.npr.org/2019/03/13/702975393/why-an-er-visit-can-cost-so-much-even-for-those-with-health-insurance.

[88] Neil Bennett et al., *19% of U.S. Households Could Not Afford to Pay for Medical Care Right Away*, U.S. CENSUS BUREAU (Apr. 7, 2021), https://www.census.gov/library/stories/2021/04/who-had-medical-debt-in-united-states.html. Medical debt is likely far worse than this study revealed. A more recent study assessed all medical debt that was in collections in the country prior to COVID and found that more than seventeen percent of the population had this type of debt, possibly totaling around $140 billion outstanding. Kluender et al., *supra* note 1.

[89] Kurani et al., *supra* note 66.

attack, it is often said that time equals heart muscle.[90] The sooner a person begins to be treated, the more of their heart can be saved from damage. Studies show that people consider both the symptoms they are having and their insurance status when deciding if they should seek care.[91] Those with insurance and the money to pay their costs, seek care faster and have significantly better outcomes than those with insurance but limited money with which to pay high out-of-pocket costs and those without insurance.[92]

For people with chronic conditions, the calculus can be different, though no less difficult. Many people with chronic conditions are very sophisticated about the care they need, its cost, and the structural complexities they need to negotiate to access that care.[93] For them, foregoing care is almost worse, because they are doing it due to cost concerns even as they know it will injure their health or that an intervention could relieve their pain.

Foregoing care, even when it is arguably needed, is not necessarily irrational. People have commitments beyond their own health concerns and often choose to suffer to save money. In a survey, roughly half of all Americans say they delay getting medical care because they cannot afford it.[94] It is difficult to offer any guidance to people who have little in savings or discretionary income when faced with these types of decisions. Not every chest pain is a heart attack but seeing a doctor to find out if the pain is truly a sign of a heart problem will cost something.

B. *Recommendations*

The concerns patients have as described here are primarily about

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[90] *E.g.*, Larry Buchanan et al., *Time Is Muscle: Understanding Heart Attacks*, N.Y. TIMES (June 20, 2015), https://www.nytimes.com/interactive/2015/06/19/health/what-is-a-heart-attack.html.

[91] *See* Smolderen et al., *supra* note 2.

[92] *Id.*

[93] Chronic condition care has gradually shifted towards educating patients, so they are capable of self management, an approach that empowers patients to take a more learned and significant role in their care. Patricia A. Grady & Lisa Lucio Gough, *Self-Management: A Comprehensive Approach to Management of Chronic Conditions*, 104 AM. J. PUB. HEALTH e25 (2014). Seeking care in the United States requires patients to negotiate the financial implications of that care, and patients with chronic conditions, through constant exposure to the limitations of the financing available to them, are thus aware of both the medical and financial implications of their situation in ways people with less experience may not have. *Id.*

[94] Shawn M. Carter, *Over Half of Americans Delay or Don't Get Health Care Because They Can't Afford It—These 3 Treatments Get Put Off Most*, CNBC MAKE IT (Apr. 3, 2019), https://www.cnbc.com/2018/11/29/over-half-of-americans-delay-health-care-becasue-they-cant-afford-it.html.

potential cost, and removing or constraining patient coinsurance, as described in the section on purchasing insurance, would ameliorate them. However, if this does not happen, some other, more modest changes could make the system slightly less arbitrary and worrisome.

To provide some predictability and remove some arbitrary costs, prices must become more transparent. In an ideal world, they would also be fixed so that they are the same among care providers. A national program that sets prices is unlikely to be adopted in the near future, but examining how it would be of benefit to patients is worthwhile, insofar as it helps illustrate further the problems patients grapple with. Currently, providers have amounts that they charge in theory, but then accept greatly reduced payments from insurance providers. Uninsured people pay the full cost unless they negotiate a discount. Insurers who have large market shares are at a competitive advantage in terms of being able to negotiate lower rates than other insurance companies can. These reduced rates are called provider negotiated discounts. These discounts vary among insurers and among different plans sold by a single insurer.

An examination of the discount negotiation process reveals that it is arbitrary and unfair for insured people. People do not have the information or the ability to choose an insurer who has negotiated the best rate, and, even if they could, it would be unusual for an insurer to have the best rate for all services. This rate matters because when a patient receives care, the amount they owe for their deductible and coinsurance is based on the negotiated rate. Given the high amount of self-insurance people are bearing in the current system, this turns into very different amounts they must pay depending on the insurer they have and the contract the insurer currently has with the providers the patient sees. Setting prices across the board would smooth these differences out, so similarly situated people—those who have purchased health insurance, sought care, and currently have outstanding balances not covered by insurance—are treated the same.

The need to negotiate these prices means substantial resources are spent by all market participants—except patients—to protect their financial well-being. It also puts pressure on antitrust enforcement regimes, as a high market share by any one participant can distort cost in these negotiations. We are left expending these resources because we hope the market can achieve the right market share for all participants, the ideal balance that leads to a fair price for all parties. This generally does not happen, as antitrust scholars often point out,[95] but even were we to achieve this, it would still leave all those

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[95] Aimee Cicchiello & Lovisa Gustafsson, *Federal Antitrust Tools Are Inadequate to Prevent Anticompetitive Health Care Consolidation*, COMMONWEALTH FUND: BLOG (May 13, 2021), https://www.commonwealthfund.org/blog/2021/federal-antitrust-tools-are-

who are not covered by the ones with the right share at risk of bearing higher costs for the exact same product or service. The churn in pharmaceuticals is an example of how out of control these market fluctuations are, and how problematic they can be for patients, but the structure that leads to this and problems that result exist across the board.

Furthermore, having set prices would reduce administrative costs across the board and potentially also allow insurers to offer coverage for patients to see a wider variety of providers, increasing autonomy by increasing choice.

Setting prices is not as important for patients as constraining coinsurance responsibility, since their exposure to these price differences would then be lessened, but there would still be some patient benefits. Both limiting coinsurance and setting prices would allow for much simpler actuarial calculations, leading to better predictions as to the cost to insure a given group of people. Currently, we externalize cost to patients, through coinsurance, and providers, through uncollected medical bills, to artificially reduce the amount of a pool that is required to meet insurance needs. This, coupled with wide price fluctuations among all participants, makes the conversation unnecessarily chaotic and obscure. Reducing that chaos should logically lead to a more informed and rational discussion about appropriate methods for funding health care in the country overall.

IV. THE INSURANCE CONTRACT

A. *Types of Insurance and Corresponding Legal Regimes*

There are multiple sources of health insurance.[96] This Article is focused primarily on private insurance, provided by an employer or by an individual purchasing coverage for themselves.[97] Health insurance is a heavily regulated industry and the rules that apply are generally determined by who purchases the insurance. The laws and regulations that govern insurance are not designed to work together but rather spring from different sources in response to different problems, which makes for a complex and

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inadequate-prevent-anticompetitive-health-care-consolidation; Sherry A. Glied & Stuart H. Altman, *Beyond Antitrust: Health Care and Health Insurance Market Trends and the Future of Competition*, 36 Health Affs. 1572 (2017), https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2017.0555

[96] These include privately purchased insurance, Medicare (for people with disabilities or those 65 and over), Medicaid, the Medicaid Expansion, Tricare, Veteran's coverage, catastrophic short-term plans, etc.

[97] Many Americans get coverage through federal or state programs such as Medicare, Medicaid, Tricare and the Veteran's Administration.

idiosyncratic body of rules that are not intuitive. The two main categories are (1) employer sponsored insurance, where a person gets coverage as an employee benefit; and (2) individual insurance, where a person purchases coverage for themselves.

An employer can either purchase a group plan from an insurance company or can self-insure and hire an insurance company to manage claims for them. This company is commonly referred to as Third Party Administrator (TPA).[98] From the employee perspective, what they know as the insurer is either the company that sells the group plan or the plan administrator. Large insurers such as BCBS and Aetna commonly serve in both roles.[99]

The health insurance provisions of the ACA apply to most private health insurance in the United States, with some provisions applying to all plans and some only applying to individually purchased plans.[100] The provisions of the Employee Retirement Income Security Act (ERISA) apply to all employee benefits, so apply to employer-sponsored health insurance.[101] States regulate insurance within their boundaries but have limited power over private employer-sponsored plans.[102]

Group plans purchased by employers are subject to state regulations, but self-insured plans are not.[103] ERISA and the ACA are the source for most rules that govern these plans. ERISA regulations have lengthy and specific requirements for how insurance coverage decisions are made.[104] The ACA has added to these.[105] Because of a broad preemption of state laws that are

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[98] Self-insurance refers to when an employer has enough money to cover anticipated claims for their employees. When employers self-insure, they also generally purchase stop-loss insurance or reinsurance for claims that exceed a specified amount. This amount can vary, with some employers 'self-insuring' in name, but offsetting most of the risk through reinsurance.

[99] For example, Walmart is self-insured, but employees choose from multiple TPAs such as BCBS, Aetna, and United. *See* WALMART 2020 ASSOCIATE BENEFITS BOOK: SUMMARY PLAN DESCRIPTIONS WITH 2021 SUMMARIES OF MATERIAL MODIFICATIONS 45 (Nov. 2020), https://one.walmart.com/content/dam/themepage/pdfsAssociateBenefitsBook-2021.pdf.

[100] A summary of these provisions and the specific types of plans they apply to can be found here, *Affordable Care Act: Coverage Terms*, SOC'Y HUM. RES. MGMT., https://www.shrm.org/resourcesandtools/hr-topics/benefits/pages/aca-coverage-terms.aspx (last visited Mar. 25, 2022).

[101] Employee Retirement Income Security Program, 29 U.S.C. §§ 1001–1461 (1974).

[102] *ERISA Preemption Primer*, NAT'L ACAD. STATE HEALTH POL'Y 5 https://www.nashp.org/wp-content/uploads/sites/default/files/ERISA_Primer.pdf (last visited Mar. 25, 2022).

[103] *Id.* at 3.

[104] 29 C.F.R. § 2560.503–1 (2020).

[105] 45 C.F.R. § 147.136 (2021).

included in ERISA, people who get insurance from their employers and who are harmed by the decisions made by their insurers, cannot sue for damages even if the damages were directly caused by insurer negligence or bad faith.[106] This includes when a denial of coverage leads to death or severe injury. For example, if a person loses a pregnancy because an insurance company negligently refuses to approve a fetal monitor when the doctor recommends it, that person cannot recover any damages from an employer-sponsored plan, whereas the full scope of damages would be available in a suit for damages against an individual's insurer.[107]

Individually purchased plans are governed by the ACA and are also subject to all state laws where they are purchased. State laws include mandated benefits and regulations of the business of insurance.[108] Every state historically had rules about what must be covered in insurance policies sold in the state,[109] but these mandates have become less important or have been repealed since the ACA was passed in 2010. States may still mandate that all insurance policies include specific coverage provisions, but if these provisions increase the cost of the insurance, the state must pay for that increased cost for policies sold on the Exchange.[110]

All insurance plans must participate in external reviews of their decisions once other internal options have been exhausted.[111] Many of these external review services are controlled by state governments,[112] but some insurance plans utilize a federal process as delineated in the ACA.[113] For members, they generally learn of these options through letters sent to them by their insurer, who must inform members of their rights to appeal.[114]

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[106] Paul M. Secunda, *Sorry, No Remedy: Intersectionality and the Grand Irony of ERISA*, 61 HASTINGS L.J. 131, 138 (2009).

[107] Corcoran v. United HealthCare, Inc., 965 F.2d 1321 (5th Cir. 1992).

[108] For a discussion on how states maintain power to regulate health insurance in the current legal environment, see Brendan S. Maher & Radha A. Pathak, *Enough About the Constitution: How States Can Regulate Health Insurance Under the ACA*, 31 YALE L. & POL'Y REV. 275 (2013).

[109] Before the ACA was passed, KFF maintained a list of these mandates and has since created a permanent record of what they were. *Health Insurance & Managed Care*, KAISER FAM. FOUND., https://www.kff.org/state-category/health-insurance-managed-care/pre-aca-state-mandated-health-insurance-benefits/ (last visited Jan. 13, 2022).

[110] Affordable Care Act § 10104(e)(3)(B)(ii), 124 Stat. 896, 900 (2010).

[111] 45 C.F.R. § 147.136(b)(2)(i)(F)(1) (2011).

[112] *Id.* § 147.136(c)(1).

[113] *Id.* § 147.136(d).

[114] *Id.* §§ 147.136(b)(2)(ii)(E), (4).

B. *Medical Necessity and Comparative Effectiveness Research*

i. The Contract

By writing a contract that includes a medical necessity clause, health insurers reserve the right to make decisions about the health care that their members get through their decisions about what to cover. Though a member of an insurance plan may perceive this as the exercise of medical judgment, making this type of determination does not give rise to legal arguments that the company is practicing medicine without a license or is committing medical malpractice.[115] This is counterintuitive, as an insurance decision that a treatment is not medically necessary looks like a determination that it is not good for the patient.[116] It also means it will not be paid for by insurance so, for practical purposes, the patient will not get the care.[117]

Generally, insurance contracts are written so that certain specific medical services are covered under the plan and certain other ones are not. However, these contracts are also drafted to make a finding of medical necessity a condition precedent to any services that are covered. Insurance companies have historically reserved similar rights to themselves. Prior to the wide acceptance of managed care principles, insurance companies would refuse to pay for services that were not reasonably necessary. This language, in fact, is still embedded in the Medicare Act, which uses language taken from an Aetna policy that covered federal employees in 1964. Court opinions from that time interpreted the clause to mean that physicians had

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[115] There was some thought when the ACA was passed that it would regulate the definition of medical necessity, *see, e.g.*, Daniel Skinner, *Defining Medical Necessity Under the Patient Protection and Affordable Care Act*, 73 PUB. ADMIN. REV. S49 (2013), https://onlinelibrary.wiley.com/doi/epdf/10.1111/puar.12068, but this did not happen. An insurer can be liable for bad faith decisions (if these claims are not preempted by federal law) and may also be liable for malpractice if it makes decisions that combine both medical and insurance decisions, but, in a series of ERISA decisions, courts have generally agreed that medical necessity, by itself, is not the practice of medicine. "One distinction drawn by the courts and utilized to avoid preemption of claims against HMO's by Welfare Plan participants and beneficiaries is the 'quality of care or treatment rendered versus quantity of benefits' distinction." Michelle K. Buford, *ERISA Preemption of Claims Against Managed Care Organizations*, SULLIVAN STOLIER SCHULZE, LCC, https://www.sullivanstolier.com/erisa-preemption-of-claims-against-managed-care-organizations/ (last visited Jan. 14, 2022).

[116] COMM. ON UTILIZATION MGMT. BY THIRD PARTIES, INST. OF MED. (US), CONTROLLING COSTS AND CHANGING PATIENT CARE? THE ROLE OF UTILIZATION MANAGEMENT 46, 195 (Bradford H. Gray & Marilyn J. Field eds., 1989).

[117] *See* David Lazarus, *When Your Insurer Denies a Valid Claim Because of 'Lack of Medical Necessity,'* L.A. TIMES (Jan. 23, 2018), https://www.latimes.com/business/lazarus/la-fi-lazarus-healthcare-claim-denials-20180123-story.html.

the authority to determine if the care was necessary, but insurers could argue the cost was unreasonable.[118]

Current jurisprudence recognizes that modern insurance contracts reserve much more power to make qualitative determinations as well as the more quantitative ones concerning cost.[119] These determinations are still not considered medical decisions and are not subject to the legal liabilities that attach to a medical standard of care.[120]

Below is an example of one such contract definition, where the contract uses the term "Medically Appropriate and Necessary," a term that is repeated throughout the contract as a limitation on any care that is covered. This term is defined in the Definitions section of the insurance contract, this example, from a Blue Cross Blue Shield of North Dakota contract in 2021, reads:

> **MEDICALLY APPROPRIATE AND NECESSARY-**services, supplies or treatments provided by a Health Care Provider[121] to treat an illness or injury that satisfy all of the following criteria as determined by BCBSND:
>
> A. The service, supplies or treatments are medically required and appropriate for the diagnosis and treatment of the Member's illness or injury;
>
> B. The services, supplies or treatments are consistent with professionally recognized standards of health care; and
>
> C. The services, supplies or treatments do not involve costs that are excessive in comparison with alternative services that would be effective for diagnosis and treatment of the Member's illness or injury. [122]

Note, first, the phrase "as determined by BCBSND" at the end of

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[118] For a discussion of these cases, see Fox, *supra* note 72, at 594–95.

[119] A robust reservation of discretion is particularly important for ERISA plans, those provided as employee benefits, because federal courts will use an arbitrary and capricious standard of review for benefit determinations for plans that do so.

[120] There is a cause of action for insurance negligence that controls insurance behavior, to some degree, in individual plans. An early study of newer managed care cost control provisions found that courts were unlikely to intercede to protect patients. Peter D. Jacobson, *Legal Challenges to Managed Care Cost Containment Programs: An Initial Assessment*, 18 Health Affs. 69, 76 (1999). But some controls eventually emerged. This has an important caveat, however, which is that most people simply do not sue for benefit denials.

[121] This capitalized term is also defined in the Definitions section.

[122] This clause can be found in a Silver Plan offered in 2021 which could be purchased on the exchange from Blue Cross Blue Shield of North Dakota.

the first clause. This does heavy lifting, giving what appears to be absolute discretion to the insurer. It makes no reference to how it will make such a determination and gives no resources it will consult or be bound by.[123] The remaining parts of the definition have numerous words and terms that beg for clarity, making the breadth of this reservation of discretion obvious.

"Medically required and appropriate" leaps out as an example of indeterminant language. Of course, a person should not get care that is not required or appropriate. If they are sick or injured, they need the care that is going to help them and should not have medical treatments that are unnecessary or unlikely to be of benefit. If such treatments were performed, the patient might suffer from delaying proper treatment, as well as bearing the risks, pain, cost, and inconvenience of bodily intrusions for no defensible purpose.

This phrase is then followed by a requirement that the care be "consistent with professionally recognized standards of health care," which seems, on the face of it, to be a restatement of the first limitation in the definition. It appears that the only way both phrases have meaning separate from each other is if the insurer is reserving the right to determine something is not medically required or appropriate, even if it is consistent with professionally recognized standards of health care.

The third limitation gives some idea of the types of care that might be consistent with professional standards, yet not be medically required or appropriate. The insurer is reserving the right to refuse coverage for care whose "costs . . . are excessive in comparison with alternative services that would be effective for diagnosis and treatment."[124] The words "excessive," "alternative," and "effective" remain undefined, again reserving discretion to the insurer.

Subsection C of this definition is, in its simplest form, a clause allowing for Comparative Effectiveness Research (CER) done on populations to be utilized when making individual coverage decisions. This is a powerful tool that is certainly underutilized in the healthcare system but, improperly wielded, can be very problematic. When CER was publicly proposed for Medicare, the response was primarily negative,[125] and the federal government has taken decades to implement it or fund its collection. CER is currently funded but its use is limited by a process that embeds it within

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[123] In essence, the contract is allowing as much discretion as courts will allow in a subsequent lawsuit.

[124] This language can be found in a Silver Plan offered in 2021 which could be purchased on the exchange from Blue Cross Blue Shield of North Dakota.

[125] Fox, *supra* note 72, at 612–13.

a strict protocol for protecting patients from its potential negative effects.[126]

Here, in a private health insurance contract, it is baldly stated as a right retained by the insurer, a striking statement to a reader familiar with the debates about CMS' proposals and the eventual language creating the Patient-Centered Outcomes Research Institute (PCORI) in the ACA.

Properly done, CER allows for the re-examination of existing treatments, many of which have never been subject to an evidence-based review and allows third party payers to use market power to incentivize the collection of targeted evidence of efficacy before approving coverage for new treatments. A significant utility of CER, in this context, is in gap filling for problems created by the United States Food and Drug Administration (FDA) approval process.

The FDA does not require a drug or device to be tested against existing treatments, merely that a drug or device be safe and effective compared with doing nothing for any specific illness or injury.[127] Once it is

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[126] *Comparative Effectiveness Research*, AM. COLL. PHYSICIANS, https://www.acponline.org/system/files/documents/advocacy/where_we_stand/assets/ii10-comparative-effectiveness-research.pdf (last visited Mar. 25, 2022). The ACA established the Patient-Centered Outcomes Research Institute (PCORI), which

> is required to prioritize the healthcare areas to address, engage in research and evidence synthesis efforts, and disseminate its finding to all stakeholders in an understandable manner. In May 2012, PCORI approved a National Priorities for Research and Research Agenda. The function of the Institute is solely informational; it is specifically precluded from making mandates regarding coverage, reimbursement[,] or other policies for any public or private payer. Nonetheless, it is expected that both private and public payers will over time use the comparative effectiveness information from this trusted source in various policy decisions.
>
> The federal government is permitted only to use the evidence and findings from the Institute to make a Medicare coverage determination if the process is iterative (based on multiple sources), transparent, includes public comment and considers the effect on subpopulations. Furthermore, the federal government is prohibited from using this information in determining Medicare coverage, reimbursement, or incentive programs in a manner that would preclude or have the intent to discourage individuals from choosing health care treatments based on how the individual values the tradeoff between extending the length of life and the risk of disability. The enabling legislation also specifically prohibits the Institute from using cost-effectiveness analyses (e.g.[,] quality adjusted life years (QALY) for establishing as a threshold what health care is cost-effective or recommended).

Id.

[127] *Frequently Asked Questions About the FDA Drug Approval Process*, U.S. FOOD & DRUG ADMIN.,

approved, physicians can use these drugs or devices off-label for treatments other than the ones the FDA was considering in its approval process, limited only by insurance coverage decisions. This approval process, in turn, creates an incentive for drug and device manufacturers to not pinpoint the specific populations their wares are most effective for, but instead to design studies that cast the widest net possible, pulling in the broadest constellation of patients that can achieve a sufficient showing of effectiveness to gain FDA approval.

For conditions that have existing treatments, CER allows insurers to compare the benefit and cost of more and less expensive drugs and devices as well as newer and older ones. This, in turn, can incentivize manufactures to design studies that show when the more expensive drug or device is truly more useful for a specific population, which then minimizes waste and patient risk. The same logic can apply to other medical innovations, with the same goal of increasing quality by encouraging less waste and better outcomes.

Even at its best, however, utilizing CER includes trade-offs. It is being used to compare a treatment that has already been found to be effective with other treatments that have also been found to be effective. Tracking comparative effectiveness of treatments across populations is not the same as a specific person's experience and using population-based studies to dictate what is used on someone may or may not improve their individual outcome.

Embedding CER in coverage and using it to limit the treatments that are available will mean that some people do not receive the best care in a timely manner. Unfortunately, absent the ability to predict accurately how an intervention will work on individual patients, which we do not yet have, this happens with any choice, not just those guided by comparative effectiveness.

This type of research is much more problematic when the scale tips towards cost containment, where evidence of effectiveness is merely part of an overall goal of saving money. The lessons from CER are not designed to merely control cost but are meant to be used to pursue the best overall outcome, allowing for cost considerations. The risk of CER being improperly used is what concerned people when the Centers for Medicare and Medicaid Services (CMS) sought to collect and utilize this type of data starting decades ago.[128] Unsupervised use of CER in private insurance is far

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https://www.fda.gov/drugs/special-features/frequently-asked-questions-about-fda-drug-approval-process (Feb 7, 2017).

[128] CMS has never had the ability to consider cost when making coverage decisions, being bound by statutory language that limits it to considering what is "reasonable and necessary" for treatment. Changing this would allow CMS to keep up with private

less likely to be examined than its use by a large government agency would be.

Finally, a deeply problematic way of using CER is to refuse or delay coverage for treatments because they are expensive, even in circumstances where a patient and their provider have sufficient reasons for seeking the coverage. This contract reserves the right to do this, and in fact, expressly does this in its coverage of prescription drugs. While the cost sharing arrangements for prescriptions are described in the body of the contract, the Definitions section contains a definition for "Step Therapy" within its definition of "Prescription Medication or Drug" which states:

> **Step Therapy**[129]—the process of trying another proven, cost-effective medication before coverage may be available for the drug included in the Step Therapy program. Many Brand Name drugs have a less-expensive Generic or Brand Name alternative that might be an option. There must be documented evidence that another eligible medication in the same or different drug class has been tried before the Step Therapy medication will be paid under Outpatient Prescription Medication or Drug benefit.[130]

Reading this section closely, the insurer is reserving the right to refuse a patient access to a medication prescribed by the treating physician unless the patient first uses a different medication chosen by the insurer. The key phrase triggering this requirement is "proven, cost-effective," which is not

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insurers, but it would also offer a significant counterbalance to misapplied comparative effectiveness research that may be distorting people's access to beneficial care in private plans. If comparative effectiveness claims are being made by insurers to deny care or shift costs to patients in questionable circumstances, it might be worth CMS revisiting its role.

[129] Step therapy is wide-spread and well researched in health policy. It is widely known to be problematic. *See, e.g.*, Rahul K. Nayak & Steven D. Pearson, *The Ethics of 'Fail First': Guidelines and Practical Scenarios for Step Therapy Coverage Policies*, 33 Health Affs. 1779–80 (2014). For additional perspectives by care providers and health advocates who are concerned about the negative impact of step therapy, see also David K. Karp & Ann M. Palmer, *Step Therapy Hurts America's Sickest Patients—Reasonable Parameters Are Needed Now*, MSN (May 25, 2021), https://www.msn.com/en-ca/news/newspolitics/step-therapy-hurts-americas-sickest-patients-—-reasonable-parameters-are-needed-now/ar-AAKnuFg, and Brandon M. Macsata, *Why Managed Care's Fail First Requirements are A "Step" in the Wrong Direction*, My Patient Rights: Stay Informed Blog (June 15, 2021), https://mypatientrights.org/stay-informed/why-managed-cares-fail-first-requirements-are-a-step-in-the-wrong-direction/. The issue relevant here is its role in the patient experience of insurance and the strange use of CER as a justification for it, but it appears step therapy also has a measurable negative effect on health outcomes.

[130] This language can be found in the Definitions section of a Silver Plan offered in 2021 which could be purchased on the exchange from Blue Cross Blue Shield of North Dakota.

defined anywhere in the contract. A different BCBS plan, in Michigan, offers this explanation of step therapy for their members:

> [BCBS] may require prior authorization or step therapy for drugs that:
>
> Have dangerous side effects or can be harmful when combined with other drugs
>
> Should only be used for certain health conditions
> Can be misused or abused
>
> Are prescribed when there are preferred drugs available that are *just as effective*[.][131]

The first three conditions apply to most prescription medications, reserving a wide scope of power to the insurer to potentially require preauthorization for anything they choose to. The fourth condition contains the phrase "just as effective" which is meaningless, from a medical or legal perspective, as the word "just" has no clear definition and "as effective" implies a certitude in the results of CER that does not occur. The other conditions where step therapy or prior authorization may be required are also problematic, though the dangerous side effects/harmful in condition one is arguably protective in case the prescribing provider and pharmacy do not have complete information about other medications the patient is taking or fail to solicit informed consent with proper warnings. The clause "should only be used for certain health conditions" is written in a somewhat cagey and undefined manner, leaving the phrase "certain" to carry a lot of water and not giving guidance as to who determines which ones are considered, but can work to push back against drug company marketing, providing a counterweight to protect patients from, for example, unnecessary wide spectrum antibiotic prescribing.

The crux of the matter is that there are health problems where the best treatment is expensive and where there are less expensive alternatives that treat a similar diagnosis in other people but may not perform well in the patient seeking coverage. For people with experience in treating their own conditions and working closely with physicians who also have this knowledge and trust in the patient's reporting, this type of clause leads to delays in treatment, poorer outcomes, and a persistent sense of stress and devaluing

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[131] *Prior Authorization and Step Therapy Coverage Criteria*, Blue Cross Blue Shield Care Network Mich., https://www.bcbsm.com/content/dam/public/Consumer/Documents/help/documents-forms/pharmacy/prior-authorization-and-step-therapy-guidelines.pdf (Apr. 1, 2022) (emphasis added).

of the patient's knowledge of themselves.[132] There are myriad examples of this, including medications for psoriasis,[133] psychiatric conditions,[134] and diabetes, all of which are impacted by formulary restrictions which may include step therapy.[135]

The use of vague claims of comparative effectiveness as a basis for this type of decision, coupled with facially unprovable criteria, such as "just as effective," is a weak ground for insurers to stand on, particularly in a case with even minimal evidence that a patient requires immediate access to the more expensive drug. In other words, a denial of coverage or a requirement for step therapy would often be difficult to justify in litigation and would also likely fail in an appeal conducted by an attorney. An examination of the complexity of true CER, especially related to any one specific claim about it, coupled with a contract's promise to cover prescription drugs (absent an actual exclusion of the one in question), would lead to any one drug being covered for any specific patient.

But returning to the lived experience of patients, the contract rights and access to process are rendered almost meaningless in this context. Insurers have appropriated the language of CER to create a structure where patients are routinely deprived of timely access to care that would help them.[136] This language, devoid of the rigorous research and careful recommendations CER was meant to consist of, is coupled with programs such as step therapy, staking out broad turf in health care. Doctors accept it as a routine aspect of practicing medicine[137] and patients are counseled that

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[132] Jennifer Snow et al., *The Impact of Step-Therapy Policies on Patients*, Xcenda AmerisourceBergen, https://www.xcenda.com/-/media/assets/xcenda/english/content-assets/white-papers-issue-briefs-studies-pdf/impact-of-step-therapy-on-patients_final_1019.pdf?la=en&hash=A7BB3FA4DAC189D9240CF8B724B435A8942E91DF (last visited Aug. 1, 2021).

[133] Jessica Burgy & Mark G. Lebwohl, *To Limit the Harms of Step Therapy, Implement Robust Standards and Protect Physician Autonomy*, Health Affs. Blog (Dec. 22, 2020), https://www.healthaffairs.org/do/10.1377/hblog20201221.255119/full/.

[134] Sharona Hoffman, *Step Therapy: Legal, Ethical, and Policy Implications of a Cost-Cutting Measure*, 73 Food & Drug L.J. 38, 42, 47 (2018).

[135] *See* Rashad I. Carlton et al., *Review of Outcomes Associated with Formulary Restrictions: Focus on Step Therapy*, 2 Am. J. Pharmacy Benefits (2010).

[136] Sharona Hoffman has a thorough analysis of this problem in her law review article, *supra* note 134. Even as she recounts numerous stories of successful appeals, she also describes the health and financial costs of the delays that the patients suffered before getting access to the care they needed. She notes that major problems with step therapy include: "[L]ack of transparency, inflexibility that may disregard emerging evidence from precision medicine and other research initiatives, and discrimination." Hoffman, *supra* note 134, at 41.

[137] *See, e.g.*, *Mitigating the Negative Impact of Step Therapy Policies and Nonmedical Switching of Prescription Drugs on Patient Safety*, Am. Coll. Physicians (2020), https://www.acponline.

drugs the doctor believes are less efficacious or even likely to cause harmful side effects simply have to be tried first, with symptoms and bad outcomes endured,[138] even as every single person involved in that patient's care know it is not the best decision.[139]

i. Recommendations

CER language, absent the rigorous of true CER, appears to have been adopted by insurers. This has created a significant risk of a widespread impact on the quality of care patients are receiving, with often questionable results.[140] The responsibility of conducting and interpreting CER, as well as formulating recommendations from those findings, in all but the most straightforward of scenarios[141] ought to be removed from insurers so that proper CER is conducted and disseminated. PCORI[142] already does this, bound by rigorous standards that have been subject to extensive public debate, making this private undertaking that adheres to none of the PCORI standards particularly vulnerable to criticism. Furthermore, putting CER in the hands of publicly funded researchers who will disseminate their findings is more efficient than requiring each insurer to conduct its own research.

Improper medical necessity determinations, couched in the language of CER, can have broad reaching, problematic effects on how care is provided. We risk providers conflating inaccurate CER conclusions with actual quality standards. This lets short sighted, cost-based rationing drive how medical care is provided without even requiring that these rationing decisions be justified with evidence of improved outcomes and overall reductions in spending.

CER, no matter its source, can lead to decisions about how care ought to be provided. These decisions impact all care, provided for all

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org/acp_policy/policies/step_therapy_nonmedical_switching_prescription_drugs_policy_2020.pdf.

[138] *What Is Step Therapy and What Does It Mean for Patients?*, PFIZER, https://www.pfizer.com/news/hot-topics/what_is_step_therapy_and_what_does_it_mean_for_patients; *Mitigating the Negative Impact of Step Therapy Policies and Nonmedical Switching of Prescription Drugs on Patient Safety*, *supra* note 137.

[139] *Mitigating the Negative Impact of Step Therapy Policies and Nonmedical Switching of Prescription Drugs on Patient Safety*, *supra* note 137.

[140] *See* Nayak & Pearson, *supra* note 129.

[141] An example of this type of scenario would be a clearly equivalent generic drug being reimbursed at a higher rate than the name-brand one.

[142] PCORI describes itself as an independent nonprofit founded for the purpose of providing trustworthy information to help guide truly complex decisions where there are multiple possible ways of treating a problem. *About PCORI*, PCORI, https://www.pcori.org/about/about-pcori (last visited Apr. 1, 2022).

persons. Those debating its use, while seeking methods for doing it properly, recognize the importance of transparency, peer review, and stakeholder perspectives. The insurance contracts discussed above do not require any of the safeguards that protect the quality of the research, and the decisions being made by the insurance companies purporting to be based on CER are risking the quality of all care in the country.

Furthermore, step therapy must be constrained. If it is to be allowed at all, it ought to be based on proper CER and it cannot be implemented merely due to insurance preferences arising from shifting costs of specific medications, as described in more detail below. It ought not be implemented based solely on the patient's experience with that insurer or during a singular course of an illness but must, instead, consider the individual patient's entire medical history, so that a patient is not required to undergo step therapy using a medication that has already failed or under circumstances where the treating physician has a reasonable belief that it is contra-indicated.

For those with chronic conditions, the application of step therapy requirements can be particularly inappropriate and inefficient. Assuming an insurer's decision to utilize step therapy is motivated by something other than rapaciousness, a procedure for protecting patients with lengthy medical histories from being forced to use a drug that they know does not work would, logically, constrain waste and improve outcomes. For example, an advocate within the insurance company, who is familiar with the patient and the condition, can be empowered to determine that step therapy is not necessary. This ensures that the value of the patient's prior experience with their care is incorporated into the insurer's decision-making process.[143]

C. *Prescription Drug Coverage*

i. The Contract

Insured people's interactions with prescription drug coverage help to illustrate how the system creates hurdles for people without sophisticated research capacity, internet access, and access to means of travel. Issues of cost, problematic insurance behaviors, and patient lack of medical or legal knowledge are also present here, as they are in the other examples in this Article. These problems can be present for those with the means to cover copayments and deductibles, though are logically going to be worse

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[143] This proposal builds on the model of case management that insurers experimented with in the 1980s. Mary G. Henderson et al., *Private Sector Initiatives in Case Management*, Health Care Fin. Rev. (Supp. 1988), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4195124/pdf/hcfr-88-supp-089.pdf.

for those who do not have those means, since less money is associated with less control over one's time[144], no or lower quality internet,[145] and fewer transportation options.[146] Given that close to half of all people in the country use prescription drugs in any one month,[147] problems with prescription drug coverage are also important absent any implications these problems might have for insurance more generally.

The cost of the same drug can vary widely depending on the method for payment and the place a person buys it.[148] Payment and reimbursement rates for drugs are set against a backdrop of a system of procurement and provision that stymies even sophisticated professionals who work in the field, and the cost savings from negotiating this system well can be substantial. For example, the chart below is from a study that maps the flow of money through the industry and demonstrates the various participants in the prescription drug marketplace.[149]

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[144] For a nuanced study of work, social class, race, gender, etc. and how this relates to control over one's schedule, see Naomi Gerstel & Dan Clawson, *Control Over Time: Employers, Workers, and Families Shaping Work Schedules*, 44 ANN. REV. SOCIO., 77 (2018), https://www.annualreviews.org/doi/10.1146/annurev-soc-073117-041400.

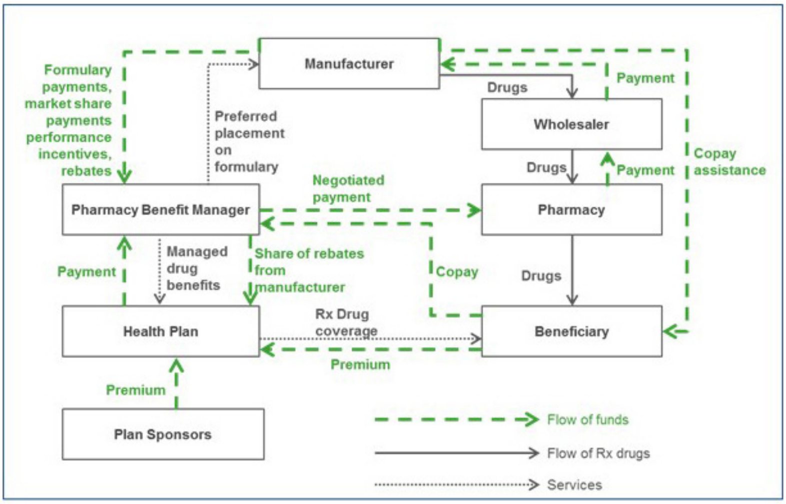
[145] Kendall Swenson & Robin Ghertner, *People in Law-Income Households Have Less Access to Internet Services*, U.S. DEP'T HEALTH & HUM. SERVS. (Apr. 2020), https://aspe.hhs.gov/sites/default/files/private/pdf/263601/Internet_Access_Among_Low_Income.pdf.

[146] Wesley Jenkins, *The Unequal Commute*, URB. INST. (Oct. 6, 2020), https://www.urban.org/features/unequal-commute.

[147] The CDC has found that between 2015 and 2018, 48.6% of people in the country use prescription drugs in any given 30-day period. *Therapeutic Drug Use*, CTRS. FOR DISEASE CONTROL & PREVENTION (Oct. 20, 2021), https://www.cdc.gov/nchs/fastats/drug-use-therapeutic.htm.

[148] *See* Kevin Fiscella et al., *A Practical Approach to Reducing Patients' Prescription Costs*, FAM. PRAC. MGMT., May–June 2019, at 5, 7, https://www.aafp.org/fpm/2019/0500/p5.html?cmpid=em_FPM_20190515 (stating how websites such as that from GoodRx can provide comparative costs between pharmacies and coupons for drugs, and because one study found nearly one quarter of filled prescriptions, patient copayments exceeded the reimbursement pharmacies receive from insurance, "shopping around could help" (citing Karen Van Nuys et al., *Overpaying for Prescription Drugs: The Copay Clawback Phenomenon*, USC SCHAEFFER CTR. FOR HEALTH POL'Y & ECON., at 1 (Mar. 2018), https://healthpolicy.usc.edu/wp-content/uploads/2018/03/2018.03_Overpaying20for20Prescription20Drugs_White20Paper_v.1-2.pdf).

[149] Neeraj Sood et al., *Flow of Money Through the Pharmaceutical Distribution System*, USC SCHAEFFER CTR. FOR HEALTH POL'Y & ECON., at 2 (June 6, 2017), https://healthpolicy.usc.edu/wp-content/uploads/2017/06/USC_Flow-of-MoneyWhitePaper_Final_Spreads.pdf.



It is important for the patient to engage with the complexity because the potential cost savings are important. From an outcome perspective, cost is a significant component of patient non-compliance with medications, so navigating the payment system well can lead to better outcomes overall by reducing cost impediments.[150]

Insurance plans often sort drugs into tiers of coverage, with lower numbered tiers costing patients less in copayments than higher tiers do. Problems arise across the tiers. Generally, inexpensive generic drugs are in the first tier. Oddly, these can be so inexpensive as to cost less than the copayment, allowing the insurance company to claw back any excess that remains from the patient's copayment and profit from the patient filling the prescription, as discussed in more detail below. For higher tiers, many of the tier assignments are justified with reference to CER (as discussed in the prior section) but often the assignments appear to reflect little more than immediate costs to insurers.[151] Patients can have a need for a medication with no tier one options, with no choice beyond paying high potential costs or foregoing the medication. To further complicate this, some expensive drugs are both in higher tiers and require patients to use step therapy, undergoing a course of a drug that is different from what their physician initially prescribes and prove that drug fails to work or has unendurable negative effects on the

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[150] Fiscella et al., *supra* note 148, at 5.

[151] For example, looking at the chart in Sood et al., *supra* note 149, the pharmacy benefit manager negotiates with manufactures and pharmacies, and these negotiations result in regular changes to formularies. Different brands of insulin, for example, can move among tiers depending on these contracts.

patient's health. Only then can they gain coverage for the more expensive, higher tier drug, which they then pay more for because that tier has a higher patient copayment.

The calculations need to begin once a patient is aware that a prescription is forthcoming because most prescriptions are transmitted electronically to a specific place, and prices can vary among pharmacies. It is time-consuming for a patient to direct their care provider to issue a new prescription to a different pharmacy after the patient has left, as many offices have systems that can take between one and three workdays to issue prescriptions once a patient has left the office. This could delay the patient's access to necessary medications. A patient can also ask for a paper prescription, which will increase the time they have to do research. The research generally requires access to the internet, generally by cellular phone if it happens in the doctor's office. A person can research some options by visiting different stores, though this is much more burdensome and may not give them access to all cost saving options.

First, a patient must calculate how much their insurance plan will cover and how much the patient must pay under the terms of the contract. The next step is to research if the drug is available at a reduced rate without any insurance at any pharmacy they have access to, such as a Target or Walmart.[152] Both of these chains have many common prescriptions available for $4 a month.[153] It may seem, initially, that the best approach is to go to a pharmacy that accepts one's insurance, pay the copayment and any deductibles, and then take the medicine, but these pharmacy prices are generally less than the copayments would be, even for Tier one drugs.

Purchasing prescription drugs is common. The average person in their fifties fills approximately twenty prescriptions a year.[154] For those with chronic conditions, the number of prescriptions filled every year can be much higher.[155] Once the number of prescriptions begins to climb, patients must consider the need to save money on individual prescriptions, by choosing the lower cost option at the pharmacy, versus paying a higher cost and having that money go towards their coinsurance responsibilities. For example, in the

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[152] These are usually posted on the store websites. *See, e.g.*, *$4 and $10 Generic Medication List*, TARGET PHARMACY (Nov. 2010), https://tgtfiles.target.com/pharmacy/WCMP02-032536_RxGenericsList_NM7.pdf, and *$4 Prescriptions*, WALMART, https://www.walmart.com/cp/4-prescriptions/1078664 (last visited Mar. 31, 2022).

[153] *Supra* note 152.

[154] Statista Research Department, *Prescriptions Per Capita in the United States by Age Group*, STATISTA, https://www.statista.com/statistics/315476/prescriptions-in-us-per-capita-by-age-group/.

[155] *Prescription Drugs*, GEO. U., https://hpi.georgetown.edu/rxdrugs (last visited Mar. 31, 2022).

South Carolina insurance plan for state employees, a Tier one copayment is \$9.[156] If a person has twenty prescriptions a year, a \$4 prescription will cost \$80, whereas using their insurance, the same prescriptions will cost \$180, with the bulk of that likely going to the insurer. For people with chronic conditions who use multiple drugs a month, the amounts can be much higher. If a person is likely to meet their out-of-pocket maximum in a year, paying higher drug costs and funding the insurance claw backs to reach that maximum faster may be a sound decision.

Claw backs seem problematic. The scenarios described above show that the cost of drugs is fluid and that some drugs are inexpensive for pharmacies to purchase. These inexpensive drugs, in turn, create the opportunity for insurers to take money from their members because the cost is less than the copayment. It seems almost inconceivable that insurers are profiting from some prescriptions that they are, in theory, "covering," because the actual price is lower than what the patient is paying. Yet they definitely do, most often with generic drugs, and especially with the most commonly prescribed ones. A study conducted in 2013 found that these claw backs occurred in twenty three percent of pharmacy prescriptions, where patient copayments exceeded the average reimbursement paid by the insurer by more than \$2.[157]

The very idea of a claw back is startling, as the reason a person purchases health insurance is to have help offsetting the costs of medical care. The contract, and the educational materials that patients receive, couch the patient's responsibility in terms that appear to be clear, that there are costs that must be borne, and the plan has divided those costs between the patient and the insurer. A claw back violates the core of this agreement, as the implication created by the language of the contract is of co-responsibility for fixed costs, not of patients paying a bonus to the insurer for access to medicine supplied by other parties.

The cost differences between different drugs can be substantial, leading doctors to attempt to prescribe medications at the lowest tier they can, or to counsel their patients about discount options.[158] When it appears that a higher tier drug is the best option, the patient risks spending far more money than they need to for that drug if they lack the sophistication and

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[156] *2021 Insurance Benefits Guide*, S.C. PEBA S.C. RET. SYS. & STATE HEALTH PLAN 80 (2021), https://www.peba.sc.gov/sites/default/files/2021_ibg.pdf.

[157] Van Nuys et al., *supra* note 148.

[158] *See* Fiscella et al., *supra* note 148. For a detailed study of tiers and cost sharing in the United States, see GARY CLAXTON ET AL., KAISER FAM. FOUND., EMPLOYER HEALTH BENEFITS 2019 ANNUAL SURVEY (2019), https://files.kff.org/attachment/Report-Employer-Health-Benefits-Annual-Survey-2019.

resources to find bargains.

For more expensive or unusual medications, then, the next step is checking various coupon companies that offer discounted prescription medications.[159] This can be useful when a person's deductible has not been satisfied or when the final payment, after the coupon, is less than the patient's co-payment would be for a drug in a high tier. Drugs purchased with coupons likely do not count towards deductibles or copayments, however.[160]

A popular coupon company is GoodRx.[161] As an example of how this works, consider a patient who is told to use PrEP, also known as Descovy or Truvada,[162] in June of 2021. PrEP is a prescription medication that can protect a person from contracting HIV, even if they are exposed.[163] Insurance companies have covered PrEP but historically have covered it in the highest tier, with the highest level of patient cost sharing.[164] Because it has proven to be an excellent preventive measure, it has been found to be preventive care under the ACA, and so should be available under many insurance plans with no copayments and without satisfying the deductible.[165] Private insurers

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[159] These coupons sometimes have common drugs at prices that are lower than the $4 lists.

[160] Emma Ryan & Emily Fitts, *The Hidden Costs of Discount Cards: Understanding Copay Accumulator Adjustment*, diaTribe (Mar. 22, 2019), https://diatribe.org/hidden-costs-discount-cards-understanding-copay-accumulator-adjustment.

[161] GoodRx has an interesting FAQ about whether the amount a patient pays using their coupons goes towards satisfying their deductibles or can count as an out of network cost that satisfies out of pocket caps. In effect, it says the company has tried to get clear answers about this from insurance companies and has failed. Sometimes it happens, sometimes it does not, and they have no clear reason for either result. *Insurance and GoodRx*, GoodRx, https://www.goodrx.com/insurance/goodrx (last visited Mar. 31, 2022).

[162] *See* Hope Chang, *Truvada vs. Descovy for PrEP*, GoodRx (Sept. 17, 2021), https://www.goodrx.com/conditions/hiv/descovy-vs-truvada (noting that PrEP medications include Truvada and Descovy).

[163] *Deciding to Take PrEP*, Ctrs. For Disease Control & Prevention, https://www.cdc.gov/hiv/basics/prep/prep-decision.html (last visited Mar. 31, 2022). PrEP is very effective but the choice to use it comes with stigma, making any cost impediments particularly problematic, as they could tip the balance away from using it. For an excellent discussion of PrEP stigma, see Doron Dorfman, *The PrEP Penalty*, 63 B.C. L. Rev. (forthcoming 2022), https://lawdigitalcommons.bc.edu/bclr/vol63/iss3/3/?utm_source=lawdigitalcommons.bc.edu/bclr/vol63/iss3/3&utm_medium=PDF&utm_campaign=PDFCoverPages.

[164] *See* Emma Sophia Kay & Rogério M. Pinto, *Is Insurance a Barrier to HIV Preexposure Prophylaxis? Clarifying the Issue*, 110 Am. J. Pub. Health 61, 61 (2020).

[165] Landon Myers & Sean Bland, *Most U.S. Health Plans Must Now Cover the Full Cost of PrEP, but More than the Medication Is Needed for HIV Prevention,* O'Neill Inst. Nat'l & Glob. Health L. (Jan. 19, 2021) https://oneill.law.georgetown.edu/most-u-s-health-plans-must-now-cover-the-full-cost-of-prep-but-more-than-the-medication-is-needed-for-hiv-prevention/. In June 2019, PrEP was determined to be a preventive service

have been slow to implement this coverage, even with robust evidence of cost effectiveness and efficacy, even months after it should have been provided at no cost.[166] For people in plans that have not yet shifted to full coverage or those in grandfathered plans,[167] the cost sharing is substantial. PrEP costs roughly $2,000 a month without insurance.[168] A typical insurance cost sharing for PrEP is 30% after satisfying any deductibles,[169] leaving roughly $600 a month as a copayment. As of February 2022, GoodRx had coupons available for PrEP brand Truvada varying from a cost to patients of $38.32 for a month at Publix[170] to $719.13 at Walmart.[171] For one month of medicine, using a coupon at Publix would offer savings. However, if a patient is in a plan with an unmet deductible or an unmet out-of-pocket cap, especially if the coupon savings are not as dramatic as with Publix, it may make more sense to pay the insurance price, even though it is inflated. Each dollar paid towards the prescription through insurance would reduce any future medical costs once out of pocket maximums were met, so eventually the patient would not have to pay anything more for healthcare during that calendar year, whereas if they purchased PrEP with a coupon, the full deductible and out of pocket

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of value. *Id.*; *see also Final Recommendation Statement: Prevention of Human Immunodeficiency Virus (HIV) Infection: Preexposure Prophylaxis*, U.S. PREVENTIVE SERVS. TASK FORCE (June 11, 2019), https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/prevention-of-human-immunodeficiency-virus-hiv-infection-pre-exposure-prophylaxis. This finding means it will be covered by non-grandfathered private plans without co-payments or deductibles. Coverage of Certain Preventative Services Under the Affordable Care Act, 80 Fed. Reg. 41317, 41320 (July 14, 2015) (to be codified at 26 C.F.R. pt. 54; 29 C.F.R. pts. 2510, 2590; 45 C.F.R. pt. 147). However, ancillary care associated with using the drug, such as necessary blood work, will be subject to regular insurance cost sharing. *See, e.g.*, Jas Florentino & Julia Zigman, *PrEP Ancillary Support Services Now Allowable Use of CDC HIV Funding*, NAT'L ASS'N CNTY. & CITY HEALTH OFFS.: VOICE (Jan. 3, 2022), https://www.naccho.org/blog/articles/cdc-release-guidance-that-up-to-15-of-a-state-city-awards-can-be-used-for-prep-ancillary-service (discussing how the CDC will allow domestic HIV prevention funding to go to PrEP ancillary services, such as laboratory test costs).

[166] Sarah Varney, *HIV Preventative Care Is Supposed to Be Free in the US. So, Why Are Some Patients Still Paying?*, KAISER FAM. FOUND. (Mar. 3, 2022), https://khn.org/news/article/prep-hiv-prevention-costs-covered-problems-insurance/.

[167] *See* ME. REV. STAT. tit. 24-A, § 4320-G (West 2021).

[168] The listed prices at large pharmacies range from $1,282 to $2,100. *Truvada*, GOODRX, https://www.goodrx.com/truvada (last visited Apr. 12, 2022).

[169] *See, e.g.*, BLUE CROSS BLUE SHIELD S.C., 2021 INDIVIDUAL AND FAMILY PLANS 7 (2021) https://www.southcarolinablues.com/web/public/resources/cf4defd9-ef95-4821-81c9-96b584e03af3/GRIN_212491_20_2021+BlueEssentials+Brochure+Individual+and+Family+Plans+-+FINAL.pdf?MOD=AJPERES&CVID=njuWUAw.

[170] *Save with Our Truvada Rx Pharmacy Coupons at Publix*, RXGO, https://www.rxgo.com/pharmacy/publix/truvada (last visited Apr. 1, 2022).

[171] *Truvada*, *supra* note 168.

costs would remain.[172]

Some pharmacies have created programs to assist patients in finding coupons or other discounts, but they can be misleading, as they exclude information about the difference in cost that the same coupon can yield at different stores. CVS has such a program called "Free RX Savings Review," that can be done by the pharmacist or by the patient on a computer once they have sent a prescription to CVS.[173] In the example above for PrEP, Truvada is $574.15 a month at CVS with a coupon from GoodRx as of February 2022.[174] A patient who relies on "Free RX Savings Review" could be spending much more than they would if they used the same coupon at Publix and not realize it.

The patient then needs to research various copayment assistance plans that are available from drug manufacturers. It is common with expensive medications for manufacturers to offer some assistance to some patients to offset copayments. PrEP has extensive ones. These have annual limits on how much the manufacturer will cover. The limits matter because if the funds available are insufficient to cover copayments for a year and, importantly, if the manufacturer copayments go towards the patient's deductible and out of pocket caps, the patient may have less to pay once the coupon is not available. If the copayments do not go towards satisfying self-insurance obligations, the patient may have large out of pocket costs for medication that suddenly appear, a significant problem for a medication like PrEP, which must be taken every day to function properly.[175]

Unfortunately, there is confusion as to whether these copayment assistance programs count towards a patient's deductibles or out of pocket caps.[176] The United States Department of Health and Human Services (HHS) has clarified that insurers may use these payments in this manner, but HHS does not require them to do so.[177] Some patients may find themselves

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[172] The author would like to thank Mathew Turk, J.D., for his research on insurance coverage of PrEP while he was a student of hers, which has informed this analysis.

[173] *Free RX Savings Review*, CVS, https://www.cvs.com/content/prescription-savings (last visited Jan. 15, 2022).

[174] *Truvada*, *supra* note 168.

[175] *Pre-Exposure Prophylaxis*, HIV.gov, https://www.hiv.gov/hiv-basics/hiv-prevention/using-hiv-medication-to-reduce-risk/pre-exposure-prophylaxis (Jan. 7, 2022).

[176] *See* Joyce Friedman, *Copay Assistance Programs Help Patients but Confuse Them Too*, MedPage Today (Jan. 13, 2021), https://www.medpagetoday.com/publichealthpolicy/healthpolicy/90688. In response to comments, HHS said "there was confusion about whether the HHS policy finalized in the 2020 Payment Notice required plans and issuers to count the value of drug manufacturers' coupons toward the annual limitation on cost sharing." 85 Fed. Reg. 29164, 29233 (May 14, 2020) (to be codified in 45 C.F.R. pts. 146, 149, 155, 156, 158).

[177] This is somewhat of an oversimplification, but useful for the scenario described here.

swept into "copay accumulator" programs created by insurance companies to maximize the value from industry coupons and then subtract industry copayment assistance plans from patients' deductibles and out of pocket responsibilities.[178]

Finally, patients may have problems getting any coverage for the medication their doctor prescribes because of step therapy, as described earlier.[179]

The problems described here are particularly complex for people with diabetes, where insurers are aggressive in policing the type of insulin, the type of pump, and all other supplies that people use.[180] Leaving aside the omnipresent problem of underinsurance and burdensome patient financial responsibilities, people with diabetes routinely have insurers changing the coverage or reimbursement levels of their medications due to shifting contracts with drug suppliers.[181] This is not a flaw in the system but is part of how it is designed to function.

A study of the insulin marketplace found that "[pharmacy benefits managers] attempt to keep medication costs down by moving market share between competing products, and their market power is directly related to their ability to provide exclusive formulary coverage for particular brands of medications."[182] The structure of this market creates an incentive for changes to coverage of different medications as the pharmacy benefit managers angle for market power and try to attract large group plans to

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There are still potential problems with counting these manufacturer copayment offsetting programs as coming from the individual patient within certain high deductible health plans coupled with healthcare savings accounts because of IRS rules about what counts as an actual individual expense. *See* Friedman, *supra* note 176.

[178] Erin Atkins & Stephanie Trunk, *HHS Clarifies Position on Copay Accumulators? Or Does It?*, JD SUPRA (May 29, 2020), https://www.jdsupra.com/legalnews/hhs-clarifies-position-on-copay-19750/. For a good discussion of copayment accumulator plans, see John S. Linehan, *Copay Accumulator and Maximizers*, MANAGED CARE (2019), https://lsc-pagepro.mydigitalpublication.com/publication/frame.php?i=565820&p=&pn=&ver=html5&view=articleBrowser&article_id=3300095.

[179] *See supra* Section IV.B.

[180] Bram Sable-Smith, *It's Not Just Insulin: Diabetes Patients Struggle to Get Crucial Supplies*, NPR (Sept. 18, 2019), https://www.npr.org/sections/health-shots/2019/09/18/744117217/its-not-just-insulin-diabetes-patients-struggle-to-get-crucial-supplies.

[181] *See* Richard Dolinar et al., *The Non-Medical Switching of Prescription Medications*, 131 POSTGRADUATE. MED. 335, 355 (2019) (discussing how non-medical switching may increase overall costs for patients); *see also The True Costs of Non-Medical Switching*, U.S. PAIN FOUND., https://uspainfoundation.org/wp-content/uploads/2016/01/costs-of-non-medical-switching-infographic.pdf (last visited Aug. 1, 2021) (discussing how these changes are both expensive for patients and damaging to patient health).

[182] William T. Cefalu et al., *Insulin Access and Affordability Working Group: Conclusions and Recommendations*, 41 DIABETES CARE 1299, 1304 (2018).

work with them.

Furthermore, if a patient switches insurance plans, the coverage can also be different,[183] many times leading to patients again being required to use step therapy to show the insurer the product they need is necessary.[184] This can have devastating effects on people with diabetes, with changes in medication and delivery systems being a significant driver of emergency hospital treatment for this population.[185] The system as it is currently constructed leads to a constant grappling with struggles to obtain the ideal or even any necessary medications. As evidence of the confusion and unmet needs for clear guidance, there are online communities for people with diabetes that function almost entirely as places for people to help each other navigate this complicated system.[186]

ii. Recommendations

Drug prices need to be rationalized and the market must be stabilized so it becomes less chaotic and labor intensive for patients to negotiate. This market developed in such a manner as to be highly irrational from a patient perspective, with multiple participants having managed to construct systems that leach large amounts of money out of the system through methods such as claw backs without that money helping offset costs for patients' care.[187] What may have initially offered opportunities for using market share to negotiate lower drug costs has, instead, turned into a system that shifts both costs and

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[183] It is difficult to find specific numbers for how often this happens, but even pre-COVID, tens of millions of people change or lose jobs every year, their employers change the coverage that is offered, or people change the policy they purchase on the exchange, so the number is likely substantial.

[184] *See* Snow et al., *supra* note 132, at 14 (noting that when patients change jobs or plans, they are often "whipsawed" in step therapy between various medications).

[185] *See* Sarah Gantz, *Where Insurers Drop Medications for Cheap Alternatives, the Effects Can Be Devastating for Some Patients*, PHILA. INQUIRER (July 18, 2018), https://www.inquirer.com/philly/health/health-costs/step-therapy-formulary-changes-affect-patients-20180718.html-2; *see also* Yuexin Tang et al., *The Effects of a Sitagliptin Formulary Restriction Program on Diabetes Medication Use*, 10 AM. HEALTH & DRUG BENEFITS 456, 456 (2017) (finding that step therapy patients changed how they used sitagliptin and other anti-diabetes drugs, with some patients stopping sitagliptin treatment without replacement).

[186] See, for example, the JDRF Type1 Nation forum for Healthcare and Insurance, which has dozens of separate posts since it started in August of 2017 asking for help with insurance or accessing supplies, with hundreds or thousands of people reading the discussions. *Forum: Healthcare & Insuran*ce, JDRF TYPEONENATION, https://forum.jdrf.org/c/healthcare-insurance/33?_ga=2.146258742.385039400.16251935611734477104.16251931 (last visited Apr. 1, 2022).

[187] *See* Michael Stensland et al., *An Examination of Costs, Charges, and Payments for Inpatient Psychiatric Treatment in Community Hospitals*, 63 PSYCHIATRIC SERVS. 666, 668 (2012).

the burden of changing treatments to patients while allowing insurers to interfere in patient's care to a degree that is causing harm. Setting prices will stop much of this from occurring. Claw backs by insurance companies need to be made illegal and all contracts should allow copayments to be reduced proportionately if the price of the drug is lower than the original copayment is. The system ought to function in a manner that is transparent, easily navigable, and ethically justifiable. The current system fails to do this.

D. *Psychiatric and Addiction Treatment*

i. The Contract and State Laws

As is well known, insurance coverage for treatment of SUD and severe mental health crises are not good enough.[188] Furthermore, it appears from anecdotal information that insurers often reflexively deny coverage for in-patient treatment.[189] A patient has the right to appeal this, and would likely win such an appeal, but asking a person in withdrawal from an addiction or who is suffering from a debilitating mental health problem to handle a complex appeal is problematic on its face.

The weaknesses in the current system are revealed by examining situations where a person has both a mental health problem and a substance problem and is having a crisis. Many patients with mental health problems also have SUD.[190] People who suffer from mental health disorders may need

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[188] Mental health and substance problem coverage is meant to be the same as coverage for other medical issues. *See* Amber Gayle Thalmayer et al., *The Mental Health Parity and Addiction Equity Act (MHPAEA) Evaluation Study: Impact on Quantitative Treatment Limits*, 68 Psychiatric Servs. 435 (2017). However, even with the passage of laws that claim to mandate parity, insurance coverage for these issues is still far more problematic than for more tradition "medical" problems. Nathaniel Counts et al., *What's Confusing Us About Mental Health Parity*, Health Affs. (Dec. 22, 2016), https://www.healthaffairs.org/do/10.1377/hblog20161222.058059/full/.

[189] For an excellent discussion of insurance denial patterns in mental health cases, see Neiloy Sircar, *Your Claim Has Been Denied: Mental Health and Medical Necessity*, 11 Health L. & Pol'y Brief 1 (2017), https://digitalcommons.wcl.american.edu/cgi/viewcontent.cgi?article=1147&context=hlp.

[190] While reasons for this have been hypothesized, understanding the "why" is not important here. It is the prevalence of the cross-over that is relevant for an insurance analysis. The exact numbers are hard to track. A call for research proposals in 2019 asserted that, even with incomplete data, "[i]n 2017, an estimated 35.4 million adults (14.3 percent) in U.S. households had mental illness in the past year and 18.7 million had a substance use disorder while 8.5 million had both a mental and substance use disorder (co-occurring disorders)." *Notice of Funding Opportunity (NOFO): Mental and Substance Use Disorders Relevance Study*, SAMHSA: Substance Abuse & Mental Health Servs. Admin., https://www.samhsa.gov/grants/grant-announcements/fg-19-003

changes to, or the introduction of, medications.[191] Both of these issues, the combination of SUD and mental health problems and changes to medication during a crisis, are complicated to manage.[192] Patients need to be closely monitored during treatment[193] and the close monitoring is expensive,[194] thus likely to trigger conflict with insurers. Problems with accessing insurance coverage add complications to these already medically and emotionally complex scenarios.

An example of this type of problem is coverage for treatment of bipolar episodes coupled with SUD.[195] This is a particularly useful example because this is a problem where modern medicine has an ability to effect substantial, positive change[196] if the patient can get access to appropriate care.[197] These patients often present in substantial emotional pain, while also presenting a risk of harm if not treated appropriately.[198] The treatment protocols are complex and currently require intensive clinical work and close monitoring to be done properly.[199] Patients generally present to the emergency department, and then require transfer, many times to other

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(Apr. 29, 2020).

[191] Substance Abuse & Mental Health Servs. Admin., Substance Use Disorder Treatment for People with Co-Occurring Disorders—Treatment Improvement Protocol TIP 42, at 77 (2020) [hereinafter TIP 42], https://store.samhsa.gov/sites/default/files/SAMHSA _Digital_Download/PEP20-02-01-004_Final_508.pdf.

[192] *See, e.g.*, Rakesh Jain, *Managing Bipolar Disorder from Urgent Situations to Maintenance Therapy*, 68 J. Clinical Psychiatry 367, 372 (2008) [hereinafter *Managing Bipolar Disorder*] (discussing bipolar disorder and how substance use is a compounding element to medical outlook for patients with bipolar disorder); *see also* Murdoch Leeies et al., *The Use of Alcohol and Drugs to Self-Medicate Symptoms of Posttraumatic Stress Disorder*, 27 Depression & Anxiety 731, 731 (2010).

[193] David Fariello & Susan Scheidt, *Clinical Case Management of the Dually Diagnosed Patient*, 40 Psychiatric Servs. 1065, 1065 (1989).

[194] *See* Zeynal Karaca & Brian J. Moore, *Costs of Emergency Department Visits for Mental and Substance Use Disorders in the United States, 2017*, Agency for Healthcare Rsch. & Quality, https://www.ahrq.gov/news/hcup-statistical-brief.html (Oct. 2020).

[195] This is a phenomenon known as a dual diagnosis, which is very difficult to diagnose and treat. *See* George Woody, *The Challenge of Dual Diagnosis*, 20 Alcohol Health & Rsch. World 76, 76, 78 (1996). "Among individuals with substance use disorders (SUDs), comorbidity with other psychiatric disorders is common and often noted as the rule rather than the exception." Dawn E. Sugarman et al., *Technology-Based Interventions for Substance Use and Comorbid Disorders: An Examination of the Emerging Literature*, 25 Harv. Rev. Psychiatry 123, 123 (2017). For an excellent discussion of diagnosis and treatment for substance and bipolar problems, see *Managing Bipolar Disorder*, *supra* note 192.

[196] *Managing Bipolar Disorder*, *supra* note 192, at 370.

[197] Sugarman et al., *supra* note 195, at 123.

[198] TIP 42, *supra* note 191.

[199] *Managing Bipolar Disorder*, *supra* note 192, at 374.

facilities.[200] It is often difficult to find psychiatric facilities that can handle a complex borderline episode coupled with the physical and mental issues around withdrawal.[201]

Each step of this process involves satisfying the requirements of insurers, with the concurrent risk of the patient losing access to the effective care they desperately need at that moment. Many insurers also have contracts with mental health benefit management companies that handle psychiatric and substance problems,[202] so patients may also have to negotiate different systems with the two separate companies as they switch from the emergency department to a psychiatric facility, further complicating the process.

Finally, insurers in many states have a legislatively enacted financial incentive to deny treatment in some circumstances due to Alcohol Exclusion laws. These laws[203] allow insurers to deny payment for medical care springing from any accident or injury that happens to a patient while they are impaired by alcohol or on any medication that is not prescribed by a physician.[204] State laws vary greatly not only in the mandates they impose on insurance coverage but also in what they allow plans to include that can reduce benefits, and many states have legislation specifically allowing these exclusions to be included in insurance contracts. People with a dual diagnosis of bipolar and SUD who are in distress are at a very high risk of being injured[205] which, absent these laws, might give insurers an incentive to ensure they receive treatment, as the insurer otherwise would have to pay for any subsequent care that is required because the patient suffers physical harm.

In states with Alcohol Exclusion laws, however, rather than facing

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[200] *See, e.g.*, *An Introduction to Bipolar Disorders and Co-Occurring Substance Use Disorder*, SAMSHA Advisory No. 2, 2016, at 4–7 (describing the different treatments patients suffering from bipolar disorder and substance use disorders may need, from screenings to different therapies).

[201] *See, e.g.*, TIP 42, *supra* note 191, at 10.

[202] *See* Deborah W. Garnick et al., *Private Health Plans' Contracts with Managed Behavioral Healthcare Organizations*, J. Behav. Health Servs. & Rsch. 1–2 (2017), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4754164/pdf/nihms716196.pdf (describing the role managed behavioral health organizations have played in delivering behavioral health services to patients).

[203] There is a patchwork of laws that combine to require these appeals be included in all insurance contracts. For employer-sponsored plans, rights to appeal are provided by federal laws and regulations, most importantly, 29 C.F.R. § 2560.503-1 (2020).

[204] *Traffic Safety Facts: Alcohol Exclusion Laws*, Nat'l Highway Traffic Safety Admin. (Jan. 2008), https://www.nhtsa.gov/sites/nhtsa.gov/files/810885.pdf. South Carolina allowed this type of clause up until recently, allowing insurance policies to include exclusions for "INTOXICANTS AND NARCOTICS: The company is not liable for any loss resulting from the insured being drunk or under the influence of any narcotic unless taken on the advice of a physician." S.C. Code Ann. § 38-71-370 (2013).

[205] TIP 42, *supra* note 191, at 77.

higher costs due to denying coverage, insurers can deny coverage for inpatient care and not pay for subsequent and foreseeable care related to any injuries the patient may suffer because they did not receive appropriate care in the first place.

This is an exceptionally problematic insurance exclusion when paired with legal requirements to provide treatment for SUD. The financial incentives of these two clauses are in conflict. If a person seeks admission for substance abuse, the insurance company can refuse coverage even if it is medically necessary, knowing that if subsequent health problems arise due to substance abuse, the insurer will not have to pay for any care related to those injuries. An example of this would be a person seeking inpatient treatment for alcoholism who is refused coverage, then drives while intoxicated, suffering injuries as a result. If treatment for injuries sustained while intoxicated were covered by the health insurance plan, it would have an incentive to provide early treatment that could prevent the subsequent injury. Here, given the Alcohol Exclusion clause, it has an incentive to deny that early treatment. If the patient has health insurance coverage through an ERISA plan, with no damages available for wrongful denials of coverage, the incentives are even more skewed.

State laws that allow insurance companies to deny coverage of injuries that occur when a patient is intoxicated or using illegal drugs are not logical or proper from a health policy perspective, as they function simply to shift costs to patients or healthcare providers who do not have the capacity to anticipate the costs or spread the risk across a pool. The EMTALA requires hospitals to treat these patients[206] and the patients have been paying into a pool for the purpose of paying for care when it is necessary. If these laws spring from an idea of punishing people for drinking to excess or using illegal drugs, shifting costs to hospitals and physicians is an irrational outcome. If a patient is injured doing something such as driving while intoxicated when they are injured, there is already a system in place to punish them for the behavior,[207] making these provisions seem even less justified.

ii. Recommendations

Alcohol Exclusion laws as they are currently written are problematic and should be repealed. Given how common SUDs are[208] and that insurers

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[206] 42 U.S.C. § 1395dd (examination and treatment for emergency medical conditions and women in labor).

[207] *Drunk Driving*, Nat'l Highway Traffic Safety Admin., https://www.nhtsa.gov/risky-driving/drunk-driving (last visited Apr. 10, 2022).

[208] *10 Percent of US Adults Have Drug Use Disorder at Some Point in Their Lives*, Nat'l Inst.

must cover treatment for these problems,[209] allowing insurers to escape financial responsibility if a person is harmed while using these substances seems unwise. While repealing these laws is best, amending them so that they do not apply to people diagnosed with SUD would also be helpful, serving to ensuring the negative effects are reserved for a narrower subset of injuries, ones that do not occur in those who are actively seeking treatment.

For all patients seeking behavioral, psychiatric, and SUD care, any denial by an insurance company ought to trigger an immediate appeal without requiring the patient to ask for it. In practice, these denials should be promptly reviewed internally by someone with a high level of relevant training who can assess the situation and reach out to the treating physician and/or facility so any problems with the initial request for coverage can be addressed efficiently. This builds on the appeals process envisioned by the Department of Labor in its ERISA appeals regulations[210] and so should not be unduly burdensome to the insurers.

This case study exemplifies the vulnerabilities to denials that patients often have when sick or injured. Proactive, baked-in appeals assistance is likely necessary in other situations where patients are impaired or particularly vulnerable to not having the wherewithal to exercise appeals rights they may be entitled to.

Conclusion

In the years since the ACA was passed, much has improved in the healthcare system. As with any large-scale change to a system, these years have also revealed some problems. People are carrying too much of a financial burden. Insurers, faced with a new set of incentives, have developed new methods of gaming the system. The specifics of these types of problems need to be identified and corrected.

The process of seeking to identify and examine these problems quickly reveals a separate, related, underlying flaw. People need to be at the center of the design and reform of the healthcare financing system. The case studies in this Article reveal numerous instances where the system

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Health (Nov. 18, 2015), https://www.nih.gov/news-events/news-releases/10-percent-us-adults-have-drug-use-disorder-some-point-their-lives.

[209] *Mental Health & Substance Abuse Coverage*, HealthCare.gov https://www.healthcare.gov/coverage/mental-health-substance-abuse-coverage (last visited Mar. 31, 2022); *What Marketplace Health Insurance Plans Cover*, Healthcare.gov, https://www.healthcare.gov/coverage/what-marketplace-plans-cover/ (last visited Mar. 31, 2022).

[210] Internal Claims and Appeals and External Review Processes, 45 C.F.R. § 147.136 (2021).

would not look the way it does if we designed it from the perspective of the people who must use it. The most obvious example of this is that, given the small amount of savings and discretionary income most people have, large deductibles and co-insurance make no sense for much of the population. Similarly, given the number of prescriptions many people have, the byzantine drug pricing system makes no sense, requiring cash-strapped people to go on a time-intensive, arbitrary, and often fruitless search for the best price for their medications.

Healthcare reform needs sophisticated experts to continuously maximize quality, access, and choice, while also minimizing cost, doing all of this in a rapidly changing environment. The work of these experts must always be informed by the perspective of those they seek to help. The way the healthcare financing system functions in people's nonideal lives is the true measurement of its effectiveness, and we ought to remember this, value it, and plan with it in mind.