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Expensive Patients, Reinsurance, and the Future of Health Care Reform

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EXPENSIVE PATIENTS, REINSURANCE, AND THE FUTURE OF HEALTH CARE REFORM

Govind Persad[*]

ABSTRACT

In 2017, Americans spent over $3.4 trillion—nearly 18% of gross domestic product—on health care. This spending is unevenly distributed: Almost a quarter is spent on the costliest 1% of patients, and almost half on the costliest 5%. Most of these patients soon return to a lower percentile, but many continue to incur health care costs in the top percentiles year after year. This Article focuses on the challenges that persistently expensive patients present for health law and policy, and how fairly dividing their medical costs among payers illuminates fundamental normative choices about the design and reform of health insurance. In doing so, this Article draws on bioethical and health policy analyses of the fair distribution of medical costs, and examines how legal doctrine shapes health systems' options for responding to expensive patients.

Part I of this Article discusses two real-world examples of expensive patients and the debate surrounding them, including the case of an Iowa teenager with hemophilia whose treatments cost more than $10 million per year. Part II then examines the normative question of how the costs of treating expensive patients' medical conditions should be shared and identifies three different dimensions of sharing: (1) scope, from narrow (plan members only) to broad (all of society); (2) boundedness, whether there are limits on the costs others can be asked to bear; and (3) progressivity, whether wealthier individuals are asked to bear more costs (similar to progressivity in tax). Part III then considers how health care reform choices could advance or hamper the adoption of broad, bounded, progressive sharing, with a focus on recent state-level reinsurance programs that legal scholarship has not yet analyzed in depth.

This Article contributes to the literature on health care reform in three interlocking ways. First, it develops a novel proposal for fairly sharing the cost of expensive patients' care that could usefully inform state- and federal-level policy discussions. Second, it provides a normative, rather than purely political

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or economic, analysis of existing and proposed options for sharing expensive patients' costs. Third, it bridges the disconnected literature on reinsurance, limit setting, and health care financing, identifying how proposals in these different areas intersect.

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INTRODUCTION

In 2018, Americans spent more than $3.6 trillion on health care—nearly 18% of gross domestic product (GDP).[1] This statistic conceals an underlying inequality: The top 5% most expensive patients incur more than half of health care costs, and the top 1% incur almost a quarter.[2] Most of these expensive patients do not remain expensive year after year.[3] Many have suffered one-off events—appendicitis, pregnancy, car accidents—and will soon return to a lower level of spending. But some incur high medical costs year after year. These patients—who might be called *chronic* rather than *acute* expensive patients—are the focus of this Article.

This Article's goal is not to scapegoat these patients as the cause of health system failures, but to consider how fairly sharing the cost of their care illuminates fundamental normative choices about the design and reform of health insurance. In doing so, this Article draws on work in bioethics and health policy on the fair distribution of medical costs and examines how legal doctrine channels the ways that health systems can respond to expensive patients.

Part I begins by discussing two real-world examples of expensive patients and the debate surrounding them, including the case of an Iowa teenager with hemophilia whose treatments cost more than $10 million per year.[4] Part II then considers the normative question of how the costs of treating expensive patients' medical conditions should be shared. This Article focuses on three axes along which conceptions of sharing might differ:

1. The *scope*, narrow to broad, of sharing. In narrow sharing, only certain social subgroups (e.g., employees of a firm, members of a plan, or residents of a U.S. state) share the cost of expensive patients' treatment. The narrower the sharing, the smaller the

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[1] Rabah Kamal et al., *How Has U.S. Spending on Healthcare Changed over Time?*, PETERSON-KFF HEALTH SYS. TRACKER (Dec. 20, 2019), https://www.healthsystemtracker.org/chart-collection/u-s-spending-healthcare-changed-time/#item-start.

[2] Bradley Sawyer & Gary Claxton, *How do Health Expenditures Vary Across the Population?*, PETERSON-KFF HEALTH SYS. TRACKER (Jan. 16, 2019), https://www.healthsystemtracker.org/chart-collection/health-expenditures-vary-across-population/#item-start.

[3] William C. Johnson et al., *Consistently High Turnover in the Group of Top Health Care Spenders*, NEJM CATALYST (Feb. 1, 2018), https://web.archive.org/web/20180202211922/https://catalyst.nejm.org/high-turnover-top-health-care-spenders/.

[4] *See* Tony Leys, *Iowa Teen's $1 Million-Per-Month Illness Is No Longer a Secret*, DES MOINES REG. (May 31, 2017, 5:53 PM), https://www.desmoinesregister.com/story/news/health/2017/05/31/hemophilia-patient-costing-iowa-insurer-1-million-per-month/356179001/ (describing treatments that cost $1 million per month).

subgroups. In contrast, under maximally broad sharing, everyone in society shares these costs.

2. The *boundedness* of sharing. Unbounded sharing sets no limits on the health care costs that others are asked to assume. Bounded sharing, in contrast, specifies that certain health care costs are not shared at all, or are not shared by some individuals.
3. The *progressivity* of sharing, similar to progressivity in tax. Some proposals for sharing expensive patients' costs are regressive in that they charge equal absolute amounts to everyone; others are analogous to a flat tax, asking individuals to pay a fixed percentage of their income. Still, others are progressive, taxing a higher percentage of wealthier contributors' economic holdings.

I argue that broad, bounded, progressive sharing—the opposite of the sharing that most private insurance facilitates—is the most normatively compelling.

Part III then considers how health care reform could further or stymie the adoption of broad, bounded, progressive sharing. It explores breadth by considering programs that socialize the costs of treating specific groups of expensive patients, such as Medicare's inclusion of patients with end-stage renal disease, and it also discusses the role of government-subsidized reinsurance in increasing the breadth of sharing. This Part then turns to boundedness, discussing how public and private insurers' use of health technology assessment could set cost-based limits on sharing and considering how such limits intersect with disability and antidiscrimination law. Lastly, it considers progressivity, contrasting financing through taxation with financing through insurance premiums. This Article concludes that broad, bounded, progressive sharing is the best way of distributing the costs of expensive patients' treatment. This strategy would achieve breadth and progressivity by funding treatments above a given cost through a tax that only falls on individuals whose income exceeds that cost, and would set boundaries by discouraging the development of interventions that would make patients expensive.

This Article contributes to the literature on health care reform in three interlocking ways. First, it develops a novel proposal for fairly sharing the cost of expensive patients that could usefully inform policy discussions at the state and national levels. Second, it provides a normative, rather than purely political or economic, analysis both of its proposal and of existing options for apportioning expensive patients' costs. Few commentators have analyzed the normative challenges that expensive patients present for health insurance design. Third, it bridges the disconnected literature on reinsurance, limit-setting, and

health care financing, identifying how proposals in these different areas intersect. Its discussion of reinsurance is particularly timely given the flurry of recent reinsurance proposals at the state level.[5]

I. EXPENSIVE PATIENTS: TWO VIGNETTES

That most health spending involves a small fraction of patients has prompted innovative health policy responses. Most of these responses focus on patients (often called "super-utilizers") who are expensive because of repeated emergency room visits and poor coordination of care.[6] While improving care for these patients is an important arena for health system innovation, it involves no fundamental ethical trade-offs. Successful innovation is likely to be both cost-saving for health systems and health-improving for patients. This Article, in contrast, focuses on patients whose persistently high costs cannot be addressed through improved coordination of care or other logistical fixes.

The first example this Article discusses is an Iowa teenager with hemophilia.[7] In 2016 and 2017, Iowa's largest Affordable Care Act (ACA) insurer, Wellmark, announced substantial premium increases and justified them by the need to offset the costs incurred by a single patient who required treatments costing $1 million per month.[8] The company's announcement led to a suit alleging that Wellmark violated this patient's privacy and unfairly discriminated against patients with hemophilia.[9] Wellmark left Iowa's ACA

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[5] *See infra* Part III.A. Legal scholarship has not yet analyzed these state reinsurance proposals: The last comprehensive analysis of health care reinsurance was Mark A. Hall, *Government-Sponsored Reinsurance*, 19 ANNALS HEALTH L. 465, 467 (2010). Though Hall's article is excellent, it does not examine the recent state proposals discussed in Part III.A.

[6] *E.g.*, Atul Gawande, *The Hot Spotters*, NEW YORKER (Jan. 17, 2011), http://www.newyorker.com/magazine/2011/01/24/the-hot-spotters; Kushal T. Kadakia et al., *Hot-Spotting North Carolina's Medicaid Transformation*, HEALTH AFF.: CONSIDERING HEALTH SPENDING (Nov. 5, 2019), https://www.healthaffairs.org/do/10.1377/hblog20191029.338902/full/.

[7] Hemophilia is a congenital bleeding disorder that leads to painful and dangerous bleeding episodes. *See* Sheh-Li Chen, *Economic Costs of Hemophilia and the Impact of Prophylactic Treatment on Patient Management*, 22 AM. J. MANAGED CARE S126, S129 (2016). Clotting factor concentrates are used to treat hemophilia. *Id.* Hemophilia is costly to treat, particularly in patients who have developed antibodies to clotting factor, for whom mean annual costs approach $700,000. *Id.*

[8] *See* Leys, *supra* note 4; *see also* MARK HALL, STABILIZING AND STRENGTHENING THE INDIVIDUAL HEALTH INSURANCE MARKET: A VIEW FROM TEN STATES 37 (2018) (discussing "the publicly-discussed presence of a single individual with a chronic genetic condition (hemophilia) that was costing Blue Cross several million dollars a year, which contributed to its decision to leave the market after just one year," and noting that "[o]bservers also thought that this single patient made other insurers reluctant to enter or remain in the market, knowing that this individual would likely transfer enrollment to one of them").

[9] *See* Administrative Complaint, Nat'l Hemophilia Found. v. Wellmark Inc. (Aug. 14, 2017), https://strategichealthcare.net/wp-content/uploads/2017/08/wellmark-complaint.pdf.

marketplace in 2018; when another insurer, Medica, entered, it set premiums even higher.[10]

In a *HuffPost* article, Jonathan Cohn argues that, contrary to Wellmark's assertions, the costly hemophilia treatments were not the cause of increased premiums:

> "I cried for two weeks," said Lisa, who agreed to talk to HuffPost on the condition that we not reveal the family's real names or identifying details. "Not only is he reading that he's the reason that people can't be insured, he's been reading people had to pay more money for insurance premiums just to take care of him. He's scared, and it's very upsetting." Eventually she and her husband—we'll call him Michael—sat down with Jacob, hoping to convey a simple message: "We just want[ed] to make sure he knows it's not his fault." It turns out they were right about that—in more ways than they probably realized.[11]

Cohn argues that Iowa's high premiums stem from mistakes and challenges in governance rather than from Jacob's medical costs.[12] The sparsely populated geography of rural Iowa means that many providers have effective monopolies.[13] The state's Republican governor failed to support exchange enrollment, and the Trump Administration cut risk-sharing payments to insurers who had expensive patients.[14] Many Iowans with individual health plans were grandfathered into noncompliant plans outside of the new ACA exchanges.[15] All of this led to a smaller and sicker pool of exchange enrollees.[16] Another commentator observes that the cost per participant for Jacob's treatment would have been much lower if Iowa had been able to spread costs across a larger pool of enrollees.[17] In any event, Cohn argues that premium increases to pay for Jacob's care would be justified: "The whole point of health insurance is to pay

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[10] Jonathan Cohn, *An Iowa Teenager Didn't Wreck His State's Health Care Market. Here's Who Did.*, HUFFPOST, https://www.huffpost.com/entry/iowa-teenager-obamacare-scapegoat_n_59f4715de4b077d8dfc9dd70 (last updated Oct. 29, 2017). "Jacob" and "Lisa" are pseudonyms.

[11] *Id.*

[12] *Id.*

[13] *See id.*

[14] *Id.*

[15] *Id.*

[16] *Id.*

[17] Erik Westlund, *The Story of the $1-Million-Per-Month Iowa Teen with Hemophilia Outed by a Health Insurance Executive: Reflections from a Hemophilia Parent*, MEDIUM (June 1, 2017), https://medium.com/@erikdbwestlund/the-story-of-the-1-million-per-month-iowa-teen-with-hemophilia-outed-by-a-health-insurance-cb47d6bd66a5.

for the medical expenses of the small number of people with the most serious health problems."[18]

Two core themes of Cohn's article, which repeat themselves in the next narrative that this Article discusses, are: (1) rejection of the claim that expensive patients are a cause of high costs by arguing that other actors are either the underlying or the intervening cause of these costs (i.e., the *no-causation* claim); and (2) rejection of the claim that limits should be placed on what society will pay to meet expensive patients' costs by arguing that the main purpose of health insurance is to meet these costs (i.e., the *no-limits* claim).

In 2012, Deanna Fei's daughter, Mila, was—like Jacob—singled out as an expensive patient.[19] Although Mila's medical costs will likely be only a fraction of Jacob's, her story has many parallels to his. Mila was born at twenty-five weeks; despite only one-in-three odds of avoiding death or serious disability, she survived months of intensive treatments to become a healthy toddler.[20] The next year, AOL CEO Tim Armstrong justified employee benefit cuts on the basis that "distressed babies that were born that we paid a million dollars each" had depleted the company's finances.[21] One of the babies Armstrong referenced was Mila.[22]

In an article in *Slate*, and later in a book, *Girl in Glass*, Fei offers an impressively nuanced reply to concerns about the cost of Mila's treatment.[23] She recognizes that, "in a country where so many are forced to do without basic health care, it's important to have a rational discussion about costs."[24] Fei acknowledges that whether a million dollars is a reasonable amount for society to pay to save a life is a matter of reasonable disagreement.[25] Instead, she zeroes in on how the apparent cost of Mila's care may inaccurately reflect its actual cost, given the difference between the sticker price of care and its discounted

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[18] Cohn, *supra* note 10.

[19] DEANNA FEI, GIRL IN GLASS 235 (2015).

[20] *Id.* at 4–6, 309–10.

[21] *Id.* at 235.

[22] *Id.*

[23] Deanna Fei, *My Baby and AOL's Bottom Line*, SLATE (Feb. 9, 2014, 10:27 AM), https://slate.com/human-interest/2014/02/tim-armstrong-blames-distressed-babies-for-aol-benefit-cuts-hes-talking-about-my-daughter.html; FEI, *supra* note 19, at 245.

[24] FEI, *supra* note 19, at 252.

[25] *Id.* at 273. Fei notes that an online commentator posted: "How much is too much? Is $1M to save a life worth it?" *Id.* at 270–71.

cost.[26] And—as in Jacob's case—she emphasizes the injustice and illegality of publicly identifying individuals who incur high health care costs.[27]

Fei, like Cohn, endorses the no-limits and no-causation claims. She suggests that "the whole point of health insurance" is to pay for very costly care, and later that "the fundamental purpose of [health] insurance" is to cover everyone in the event of a catastrophe.[28] In support of this understanding, Fei cites a health economist who reached out to her after Armstrong's comments, describing him as saying: "High-cost claims are what insurance is designed to cover . . . . If it's not for catastrophic claims, then what's it for? Nobody has a million dollars to pay for an event that everyone would want to have covered."[29] Similarly, Fei argues that Mila imposed no costs on AOL or other employees, instead blaming corporate greed and the flawed structure of employer-based insurance: "[I]f anyone is responsible for doing something 'high-risk' that cost AOL two million dollars, it's not the women who conceived the babies. It's the CEO and management team in charge of the company."[30] She contends that AOL could have easily protected itself from high costs via reinsurance coverage,[31] and that rather than cutting retirement benefits, Armstrong could have reduced his $12 million paycheck to cover the cost of Mila's care.[32] Even better, she suggests, would be separating health insurance from employment, thereby eliminating employers' and fellow employees' resentment of high-cost patients and removing incentives to fire employees with high health care costs.[33] These themes will resurface in Part III's discussion of breadth and progressivity in health insurance.

Jacob's and Mila's stories represent snapshots of a larger phenomenon. The number of patients with yearly claims over $1 million rose by 87% from 2014 to 2017.[34] A recent report noted two patients whose yearly treatment costs were $5 million or more (for hereditary angioedema and for hemophilia), and observed that the average yearly treatment cost in the database for hemophilia

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[26] *Id.* at 274–75.

[27] *Id.* at 252, 266.

[28] *Id.* at 245, 277.

[29] *Id.* at 277.

[30] *Id.* at 272.

[31] *Id.* at 276. Part III.A, *infra*, takes up the question of reinsurance.

[32] FEI, *supra* note 19, at 278–79.

[33] *See id.* at 282–83.

[34] Press Release, Sun Life Fin., Million-Dollar+ Medical Claims Increase 87 Percent from 2014–2017: Sun Life Report (July 16, 2018), https://www.sunlife.com/us/News+and+insights/Press+releases/2018/Million-dollar+medical+claims+increase+87+percent+from+2014-2017+Sun+Life+report?vgnLocale=en_CA.

was over $400,000.[35] A 2009 article observed that the rate of payouts over $1 million increased from less than one per million individuals in 2000 to a projected twenty-four to thirty-six per million in 2010.[36] This phenomenon has been a driver of reform proposals. One commenter on Alaska's insurance market stated: "You just need a couple of people with $1 million in claims, which these days is not unusual, . . . but say it's a $40 million market, . . . a couple of people with $2 million of claims just basically raises rates double-digits for the whole buying population."[37]

II. FAIR SHARING

Prior to the ACA, insurers could avoid paying some high-cost claims by refusing coverage to patients with preexisting conditions, or by capping annual or lifetime payouts.[38] While these strategies saddled families with medical costs that were frequently impossible to pay, they provided a ceiling on insurers' exposure.[39] The demise of these limiting strategies presents a normative question: Should others in society help meet these costs, and, if so, how should the costs be divided?

Both Cohn's discussion of Iowa's marketplace and Fei's criticism of AOL's insurance decisions suggest that treatment costs can be addressed through fundamentally technical fixes that require no difficult, normative trade-offs.[40] In contrast, this Part argues that fairly dividing the cost of treating expensive patients requires addressing three complex normative issues. The first involves *breadth:* whether expensive patients' medical costs should be shared primarily among individuals who are more closely connected to the expensive patient (such as those in the same insurance plan), or instead shared across society. The second is *boundedness*: whether there are limits on the costs others can be asked to pay for expensive patients' treatment, and how such limits could be justified. The last is *progressivity*: whether better-off individuals should assume a greater share of expensive patients' costs. Although breadth, boundedness, and progressivity are distinct concepts, they are also interconnected. Broader sharing, for instance, enables greater progressivity, because it allows costs to be

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35 SUN LIFE FIN., 2018 SUN LIFE STOP-LOSS RESEARCH REPORT 5, 19 (2018).

36 Maureen Glabman, *Million-Dollar Claim Club*, MANAGED CARE MAG. (Mar. 1, 2009), https://www.managedcaremag.com/archives/2009/3/million-dollar-claim-club.

37 HALL, *supra* note 8, at 35.

38 *See* Troy J. Oechsner & Magda Schaler-Haynes, *Keeping It Simple: Health Plan Benefit Standardization and Regulatory Choice Under the Affordable Care Act*, 74 ALB. L. REV. 241, 283, 294 (2010) (explaining several ACA reforms).

39 Thanks to Mark Hall for this point.

40 *See* Cohn, *supra* note 10; FEI, *supra* note 19, at 276.

shared among a pool that, because it is larger, is likely to include more wealthy households. And it allows the cost of expensive patients' care to be funded via taxation, which can be progressive, rather than by increasing premiums or out-of-pocket costs for other plan members, which is more difficult to make progressive.

Part II.A considers breadth and argues that broad sharing of costs is normatively preferable to narrow sharing. Part II.B argues that sharing should be bounded and identifies different bases for limits, including cost-effectiveness, past treatment use, and choice. Part II.C argues that there is a compelling case for progressive sharing, stronger than the general case for progressivity in taxation.

A. Breadth

In contrast to the United Kingdom's National Health Service and similar systems that fund all health care costs from tax revenues and therefore share those costs broadly across the population, the United States' health care system is characterized by narrow rather than broad sharing.[41] The narrowness of American sharing is reflected in the fact that Medicaid and ACA marketplace insurance pools only include residents of a single state (and the ACA pools are separated by insurer), and that more than half of the insured population is covered by employer-based insurance.[42]

Mila's and Jacob's expenses were shared relatively narrowly. As is typical in self-funded employer-based insurance, Mila's medical costs were initially shouldered by AOL, which passed them on to employees.[43] Jacob's expenses, similarly, were initially assumed by Wellmark (and later by Medica), who

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[41] *See, e.g.*, Rachel E. Sachs, *Prizing Insurance: Prescription Drug Insurance as Innovation Incentive*, 30 HARV. J.L. & TECH. 153, 184–85 (2016) (contrasting "countries like the UK, where nearly the entire market is defined by reference to their national insurance structure" with "the U.S., where our system is fragmented and defined by a number of separate insurance structures"). *See generally* Allison K. Hoffman, *Oil and Water: Mixing Individual Mandates, Fragmented Markets, and Health Reform*, 36 AM. J.L. & MED. 7 (2010) (discussing the factors that have produced a proliferation of separate insurance plans in the United States).

[42] *See* Hoffman, *supra* note 41, at 54 (observing that "each state has developed its own health insurance rules and market" and that "risk doesn't effectively pool across state lines for the most part," and also that more lenient regulation for self-funded insurance plans has "motivated many large employers to self-fund their health insurance plans and, in so doing, extract their employees into their own risk pool"); *Health Insurance Coverage of the Total Population*, KAISER FAM. FOUND., https://www.kff.org/other/state-indicator/total-population/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D#note-1 (last visited Mar. 3, 2020) (analyzing population in 2018).

[43] FEI, *supra* note 19, at 243–44.

passed them on to other insureds in the Iowa exchange.[44] Commentators on both cases identify narrow sharing as objectionable.[45] It is worth examining the normative problems with narrow sharing in detail.

One objection to narrow sharing is that it arbitrarily burdens those asked to share the cost of expensive patients' treatment. Alison Hoffman has argued that one major goal of health insurance is counteracting the effects of bad luck.[46] But even though narrow sharing cushions expensive patients from the financial consequences of their bad luck, it imposes arbitrary bad luck on those unlucky enough to end up as members of the same insurance plan, while allowing individuals outside that plan to enjoy arbitrary good luck. Broad sharing would eliminate this luck-based difference. Deborah Stone has similarly argued that health insurance should be organized around a principle of solidarity, in which individuals share one another's health care costs.[47] Although narrow sharing requires those in the same insurance pool to stand in solidarity with expensive patients, it requires no solidarity from individuals in other insurance pools. Broader sharing produces more consistent solidarity.

The burdens of narrow sharing can be severe as well as arbitrary. The $33 per month—nearly $400 per year—that it would cost to share Jacob's $12 million of yearly expenses evenly across a pool of thirty thousand insured households is a serious burden,[48] given that a $400 expense would be unaffordable for four in ten American households.[49] Narrow sharing, even while it helps keep expensive patients afloat, could drag many other families under, jeopardizing the financial security that Hoffman and others identify as a core goal of insurance.[50] As such, narrow sharing could be contrary to the goal of "reducing Americans' financial exposure to medical care costs,"[51] because it excessively exposes many American households to *others'* health care costs.

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[44] Cohn, *supra* note 10.

[45] FEI, *supra* note 19, at 35; Cohn, *supra* note 10.

[46] Allison K. Hoffman, *Three Models of Health Insurance: The Conceptual Pluralism of the Patient Protection and Affordable Care Act*, 159 U. PA. L. REV. 1873, 1922–32 (2011) (discussing the "brute luck" justification for health insurance).

[47] Deborah A. Stone, *The Struggle for the Soul of Health Insurance*, 18 J. HEALTH POL. POL'Y & L. 287, 290–91 (1993).

[48] *See* Westlund, *supra* note 17 (calculating the cost of sharing Jacob's expenses among a million households).

[49] BD. OF GOVERNORS OF THE FED. RESERVE SYS., REPORT ON THE ECONOMIC WELL-BEING OF U.S. HOUSEHOLDS IN 2017 1, 2 (2018).

[50] Hoffman, *supra* note 46, at 1908–22 (discussing a variety of policies that aim to "prevent the costs of medical care from causing financial insecurity" and reviewing the work of other scholars who conceptualize health insurance as reducing insecurity).

[51] *Id.* at 1921.

In contrast, broad sharing could mean that the cost of sharing expensive patients' treatment does not jeopardize financial security. The prevalence of expensive patients, however, means that broad sharing alone will not ensure financial security. For instance, while a hemophilia advocate observes that sharing the cost of Jacob's treatment across a million insured households would cost each only a dollar per month,[52] a pool of a million households is likely to include more than one very expensive patient. This suggests that fairly sharing the cost of expensive patients' treatment will require progressive and/or bounded, rather than simply broad, sharing. Broad sharing is nevertheless important to progressivity, because the small groups characteristic of narrow sharing are more likely to lack a sufficient number of wealthy members who could collectively bear the cost of paying for expensive patients' treatment without jeopardizing their own financial security.

Even if broad sharing is fairer than narrow sharing, is narrow sharing fairer than no sharing? It is unfair to place a crushing burden on the shoulders of expensive patients, but it is also unfair to transfer much of that burden to an arbitrarily selected group who are ill placed to assume it. Imagine the resentment and perceptions of unfairness that would follow the adoption of a no-fault insurance rule that required a person's neighbors, and only her neighbors, to share the cost of her accidental injuries.

Because broad sharing is normatively preferable to narrow sharing, expensive patients bear some responsibility for the costs that treating them imposes on others, via narrow sharing, in situations where broad sharing is unavailable due to logistical or political impediments. That expensive patients bear responsibility does not imply that they bear *sole*, or even *primary*, responsibility, or that they act wrongly, all things considered, in benefiting from narrow sharing. Commentators are right to note that other actors who prevent broad sharing or raise the cost of treatment—firms, CEOs, state lawmakers, pharmaceutical firms—also bear responsibility for the burdens narrow sharing imposes,[53] and that these actors are more morally culpable than expensive patients are. Yet, if expensive patients know that the cost of their treatment will end up unfairly burdening others because of unjust social arrangements, they too are responsible for this outcome. Such expensive patients are analogous to consumers who need to use electricity even though electricity generation

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[52] Westlund, *supra* note 17.

[53] *See* Cohn, *supra* note 10; Fei, *supra* note 23; Westlund, *supra* note 17 (contending that "[t]he market for expensive drugs is distorted by copay assistance programs" funded by manufacturers).

produces unjust environmental and climate harms.[54] While producers, not consumers, bear primary responsibility for environmental harm, the consumers who continue to purchase electricity also bear responsibility given that they know the real-world consequence of their choices.[55] The no-causation position discussed in Part I is therefore mistaken: Jacob—given existing unjust arrangements—genuinely is a cause of others' increased premiums, and his family should acknowledge rather than avoid that fact.[56] Expensive patients plausibly have a duty to advocate—as Fei and others have—for a shift toward broad sharing.[57]

It is worth considering whether narrow sharing between employees could be defended via a "common undertaking" argument that parallels the legal doctrine of liability for failure to rescue. Tort law recognizes that individuals pursuing a common undertaking have enforceable obligations to rescue one another.[58] However, employees are typically not understood as pursuing a common undertaking in this sense: Although *employers* have a duty to rescue employees in danger,[59] employees do not have a legally enforceable duty to one another,[60] and in any event Mila herself was not an AOL employee, but rather an employee's child. A common-undertaking argument likewise would not support narrow sharing in Jacob's case, because those asked to share his costs are not fellow employees but rather fellow participants in an ACA exchange.

B. Boundedness

The U.S. health care system is also characterized by unbounded sharing: There are few limits on the quantity or cost of approved treatments that insured patients can receive from a plan.[61] Setting limits on access to treatments is

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[54] *Cf.* Nathan Ostrander, *Consumer Liability for Harms Linked to Purchases*, 2 ARIZ. J. ENVTL. L. & POL'Y 111, 123 (2011).

[55] *Id.*

[56] *Cf.* Harry G. Frankfurt, *Freedom of the Will and the Concept of a Person*, 68 J. PHIL. 5, 20 n.10 (1971) (discussing situations where multiple individuals are causes of an outcome). *Contra* Cohn, *supra* note 10 (describing Jacob's parents' effort to assuage his concern that "people had to pay more money for insurance premiums just to take care of him").

[57] *Cf.* Stephanie Collins, *Filling Collective Duty Gaps*, 114 J. PHIL. 573, 577 (2017).

[58] *See* Farwell v. Keaton, 240 N.W.2d 217, 222 (Mich. 1976).

[59] *See e.g.*, Hanseatische Reederei Emil Offen & Co. v. Marine Terminals Corp., 590 F.2d 778, 783 (9th Cir. 1979) (discussing arguments regarding employer's "duty to rescue injured employees"); State v. Hunter, 911 P.2d 1121, 1124 (Kan. Ct. App. 1996) ("Special types of relationships, however, have been found to create a duty to render aid, such as . . . employer/employee . . . ." (citing RESTATEMENT (SECOND) OF TORTS § 314A (1964))).

[60] *See Hunter*, 911 P.2d at 1124 ("Generally, there is no legal duty to rescue or render aid to another in peril." (citing People v. Oliver, 210 Cal. App. 3d 138, 147 (1989))).

[61] *See* William M. Sage, *Managed Care's Crimea: Medical Necessity, Therapeutic Benefit, and the Goals*

among the most difficult normative problems in health system design, and is an even more difficult political problem.[62] For instance, despite popular concern about "death panels" that would limit access to treatment, the Affordable Care Act imposed no limits on access.[63] Rather, it did away with annual and lifetime dollar limits on health care.[64] While these limits placed serious burdens on expensive patients,[65] their removal exposes others to unlimited costs.

Many have argued that limit setting is unnecessary because expensive patients impose only de minimis burdens on others. Deborah Peel, for instance, argues in her discussion of Mila's case that while Americans "blame the sick people for being expensive, . . . the same sick people everywhere else—in the UK—. . . wouldn't be causing excess costs to the system."[66] Similarly, Cohn asserts, in reply to Jacob's father's plea that someone tell him "that [my son] will get his medicine," that:

> That's not a lot to ask—or, at least, it shouldn't be. The whole point of health insurance is to pay for the medical expenses of the small number of people with the most serious health problems. The way to do that is to have a large group of people that looks something like the population as a whole, with mostly healthy people, paying into a common system. Every other developed country in the world accomplishes this with some form of national health insurance.[67]

As Part II.A argued, while sharing the costs of expensive patients across a broader set of patients is necessary for fairness, it is not sufficient. Limit setting remains necessary even in a regime of broad sharing. What Peel and Cohn do not mention is that most countries with broad sharing set stricter limits on access than the United States does.[68] The UK's National Institute for Clinical

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of Administrative Process in Health Insurance, 53 DUKE L.J. 597, 640 (2003) ("Although the public thinks of managed care as cost-obsessed, virtually no health insurance policies explicitly refer to cost or cost-effectiveness in setting coverage standards or defining medical necessity.").

[62] *See* Govind Persad, *Priority Setting, Cost-Effectiveness, and the Affordable Care Act*, 41 AM. J.L. & MED. 119, 123 (2015); *see also* Peter D. Jacobson & Johanna R. Lauer, *Health Reform 2010: Incremental Advance or Radical Transformation?*, 42 ARIZ. ST. L.J. 1277, 1284–86 (2010) (reviewing political obstacles to limit-setting).

[63] *See* Persad, *supra* note 62, at 126.

[64] Hoffman, *supra* note 46, at 1918 (discussing the ACA's elimination of lifetime limits).

[65] *Id.* at 1919 ("These types of limits had previously created the potential for significant financial insecurity among a small, very sick population.").

[66] Jana Kasperkevic, *'We Blame the Sick for Being Expensive': The Mother Whose Baby Cost AOL $1m*, GUARDIAN (July 4, 2015, 7:00 AM), https://www.theguardian.com/us-news/2015/jul/04/deanna-fei-aol-distressed-baby-healthcare-privacy.

[67] Cohn, *supra* note 10.

[68] *See, e.g.*, Elizabeth H. Saindon, Book Review, 18 MD. J. INT'L L. & TRADE 237, 240 (1994) (reviewing LAURENE A. GRAIG, HEALTH OF NATIONS (2d ed. 1993)) ("[T]he United States has failed to set any limits on

Excellence (NICE), for instance, limits access to treatments that exceed specified cost-effectiveness thresholds.[69] Many other countries regulate pharmaceutical pricing tightly and do not offer certain expensive treatments.[70]

Boundedness need not involve setting hard limits on lifetime medical costs or receipt of treatment, as pre-ACA lifetime limits did. A better way of using lifetime limits is as a transition device between different payers, rather than as a hard stop on access to medical care. For instance, an expensive patient might not reasonably be able to ask other plan participants to absorb more than a limited amount of medical costs via premium increases, but costs beyond this limit would still be covered, albeit from a different source such as general public funds.[71]

Three plausible bases for establishing boundaries are *value*, *use*, and *choice*. Boundaries based on value consider the benefit that a given treatment provides in comparison to its cost and set limits on treatments that are not cost-effective. Boundaries based on use consider how much others have already contributed to a given expensive patient's costs and set limits on how much any individual can receive. Boundaries based on choice consider whether a patient's medical costs stem from choices about which people could reasonably disagree and set limits on how much others can be asked to bear the cost of these choices.

Pre-ACA lifetime limits served insurers' financial interests; they were not grounded in a principled normative rationale. In contrast, a compelling normative justification for limit-setting can be found in Ronald Dworkin's work on health insurance.[72] Dworkin proposes designing an insurance plan by

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health care expenditures. Other nations have been far more successful in keeping overall health care costs, as a percentage of gross domestic product, far lower than the U.S., mainly due to the stringent cost control measures that form central roles in their health care legislation.").

[69] *See* Persad, *supra* note 62, at 130; Christopher T. Robertson, *The Presumption Against Expensive Health Care Consumption*, 49 TULSA L. REV. 627, 629 n.15 (2014).

[70] *E.g.*, Yuting Zhang et al., *Comparing the Approval and Coverage Decisions of New Oncology Drugs in the United States and Other Selected Countries*, 23 J. MANAGED CARE & SPECIALTY PHARMACY 247, 252 (2017) (comparing approval and coverage decisions in the UK, France, Australia, and Canada).

[71] An example of a payment transition device is the eligibility of infants whose hospital stay exceeds thirty days for Medicaid (a federal program funded by tax revenues) regardless of their parents' income. *See, e.g.*, OHIO DEP'T OF HEALTH, FAMILY HANDBOOK FOR FAMILIES OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN OHIO 12 (2018). Because Medicaid serves as a secondary insurer, this policy does not shift costs borne by other insured individuals to the public, but does shift some costs from the parents to the public. Thanks to Timothy Jost for this example.

[72] *See* Ronald Dworkin, *Will Clinton's Plan Be Fair?*, N.Y. REV. BOOKS (Jan. 13, 1994), https://www.nybooks.com/articles/1994/01/13/will-clintons-plan-be-fair/ [hereinafter Dworkin, *Clinton's Plan*]; *see also* Ronald Dworkin, *Justice in the Distribution of Health Care*, 38 MCGILL L.J. 883, 890–92 (1993) [hereinafter Dworkin, *Distribution of Health Care*].

considering what society would spend on health care if the distribution of economic resources were fair and knowledge about the cost and benefit of medical procedures were open to all, but individuals and insurance companies were unaware of any particular person's specific risk of disease.[73] He argues that under these conditions, individuals would choose bounded rather than unbounded sharing.[74] In particular, they would accept limits on costly treatments for patients who are permanently unconscious or have advanced dementia, and on treatments that have poor chances of success or can only extend life briefly.[75] And he argues that individuals would select insurance plans that require a reasonable chance of success before providing life-saving treatment for seriously ill infants.[76]

Critics have challenged Dworkin by arguing that the hard choices he discusses will typically be resolved in favor of unbounded sharing in practice:

> What [Dworkin] does not speak to, however, is the case of heroic (and costly) treatments of probable value. It is precisely in this area that the decisions of the "prudent individual" might very well be in conflict with those of the society as a whole. Long-term renal dialysis for otherwise healthy patients is a classic example of a procedure that might be termed heroic but effective, as is bone marrow transplantation for certain forms of leukemia. Whereas a utilitarian perspective might argue that it is not prudent to provide insurance for such care, as it can consume considerable resources that might otherwise be used to benefit larger groups of individuals, it is likely that most individuals would want such treatments available to them. It seems to me that in instances in which medical intervention can prevent an early death and restore more or less normal functioning, most people probably do make decisions on the basis of a rescue principle, i.e., a willingness to bear any cost to save life and/or health.[77]

Dworkin's response is concessive: He admits that people would likely pay for treatments like dialysis or bone marrow transplantation, but that their willingness to pay reflects a willingness to accept high but bounded costs rather than an endorsement of the (unbounded) rescue principle.[78] He also observes

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[73] Dworkin, *Clinton's Plan*, *supra* note 72.

[74] *See id.* (arguing that a rational person would not choose "to buy insurance providing every form of treatment or care that might conceivably be beneficial for him under any circumstance").

[75] *See* Dworkin, *Distribution of Health Care*, *supra* note 72, at 892.

[76] Dworkin, *Clinton's Plan*, *supra* note 72.

[77] Bruce L. Smith & Jack G. Kleinman, *Would Clinton's Plan Be Fair?: An Exchange*, N.Y. REV. BOOKS (May 26, 1994), https://www.nybooks.com/articles/1994/05/26/would-clintons-plan-be-fair-an-exchange/.

[78] *See* Ronald Dworkin, Response, *Would Clinton's Plan Be Fair?: An Exchange*, N.Y. REV. BOOKS (May 26, 1994), https://www.nybooks.com/articles/1994/05/26/would-clintons-plan-be-fair-an-exchange/

that willingness to pay may be contextual—that "added life has an importance to people, one by one, that it does not have in familiar versions of aggregate cost-benefit calculations."[79]

Dworkin's comments point us toward two more compelling responses that Dworkin himself did not offer. The first is to consider how his proposal for insurance, which stipulates that people's economic shares are highly equal, would translate back into real-world circumstances of economic inequality. Dworkin argues that poorer people should not be required to pay higher premiums for a generous insurance package when they might reasonably prefer to spend their money on important goods other than health care.[80] Conversely, although Dworkin does not explore this, it might be appropriate to require wealthier people to pay high premiums for very generous insurance packages. Even if the opportunity costs of guaranteeing access to treatments that cost $12 million per year would make doing so imprudent for poor and middle-class patients, it might be prudent for a very wealthy person to accept these costs. And since it is only a matter of luck that Jacob, rather than a very wealthy person, is an expensive patient, it might be reasonable to ask a wealthy person to share the cost of Jacob's treatment even if it is not reasonable to ask a poor or middle-class person to do so. Rather than weakening boundedness in rescue cases, as Dworkin does, we can instead make the more modest concession that weaker boundedness is justified only in the presence of greater progressivity.

The second response reflects the fact that objections to limits on life-saving treatment may involve preferences that are different in (as Dworkin puts it) the "one by one"[81] context than at the societal level. Boundedness will be easier to achieve if limit-setting decisions are made at a societal level, in a way that eliminates the possibility of facing one-by-one decisions about individual access to lifesaving interventions. Confining limit setting to the societal level resembles a strategy for surmounting challenges that involve time-inconsistent or situationally inconsistent preferences—for instance, someone who avows moderation when she is at a safe distance from the cookie jar but knows that if she is in proximity to the cookies she will eat them all.[82] Precommitment can be an effective approach to inconsistent preferences about limit setting, just as it is to as with time and situational inconsistency. Ensuring that there are no cookies

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[hereinafter Dworkin, Response].

[79] *Id.*

[80] Dworkin, *Clinton's Plan*, *supra* note 72.

[81] Dworkin, Response, *supra* note 78.

[82] *Cf.* Lee Anne Fennell, *Willpower Taxes*, 99 GEO. L.J. 1371, 1378–79 (2011) (discussing an example of preference reversal).

in the house eliminates the risk of eating all the cookies, as well as the psychological cost of denying oneself cookies when they are nearby.[83] Similarly, ensuring that interventions that would make patients expensive are not developed or marketed can eliminate the psychological and ethical cost of failing to rescue someone with easily available means: By precommitting to make certain rescues impossible, society can avoid the burden of refusing to provide achievable but expensive rescues.

Precommitment might be less necessary where many treatments could keep a patient alive or maintain quality of life. For instance, providing access only to a lower-cost but reasonably effective treatment rather than to the most expensive drug available might be both politically feasible and ethically non-wrenching. Some European countries adopt this approach by using a more generous coverage threshold when a treatment is the only one available for a given condition, but a less generous one for new treatments for an already treatable condition.[84]

Dworkin's analysis also suggests that it can be legitimate to set limits based on choice:

> In my own view, fairness would not require universal coverage unless a substantial majority of prudent people would insure to provide it. If only a bare majority would do so, it would seem unfair to provide it for everyone, making almost half the population buy insurance that they did not want. (Though in such cases the additional coverage should of course be available as supplementary insurance at an additional premium.)[85]

Dworkin gives the case of "costly neo-natal treatment for extremely premature babies"—like Mila—as an example where "people would have sharply different opinions" about coverage.[86]

Dworkin's speculation that covering very premature neonates would be socially contested is borne out by recent debates over whether we should understand treating extremely premature babies as "saving" them or continuing their gestation.[87] It is also borne out by the debate Fei acknowledges regarding

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[83] *See id*. at 1417 (discussing various precommitment strategies, including "self-exclusion policies offered by casinos" and "agreements to forfeit money if [people] break their promises to themselves"); *id.* at 1389–90 (discussing the cost of exercising willpower).

[84] *See* Katherine Eve Young et al., *A Comparative Study of Orphan Drug Prices in Europe*, 5 J. MKT. ACCESS & HEALTH POL'Y 1, 4 (2017).

[85] *See* Dworkin, Response, *supra* note 78.

[86] *Id.*

[87] *See, e.g.*, Jeremy R. Garrett et al., *What We Do When We Resuscitate Extremely Preterm Infants*, AM.

Mila's treatment,[88] and by similar discussions elsewhere regarding the wisdom of treating very premature infants.[89] Progressivity also presents a solution to Dworkin's concern that making "almost half the population buy insurance that they did not want" is unfair.[90] While prudent members of a highly equal society might elect not to assume the cost of treating very expensive neonates, they would more likely choose access to such treatment if they were very rich. Requiring wealthy CEOs to fund treatment for very premature infants is normatively defensible in a way that requiring working-class households to do so might not be.[91]

Choice-based limits could also be achieved by discouraging the development or marketing of costly, socially contested treatments. Such an approach would avoid the ethical and psychic challenges that saying no to patients in one-on-one situations presents but would eliminate the possibility of allowing individuals who value those treatments to opt into access in advance.

C. Progressivity

Using insurance to divide the burden of expensive patients' care often produces arrangements that—if evaluated through a tax policy lens—would be described as regressive.[92] Covering expensive patients' costs by increasing the premiums of all insureds by the same amount, for instance, parallels a regressive user fee or head tax: It burdens the poor no less than the rich in absolute terms, and burdens the poor much more heavily as a percentage of income.[93] Yet

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J. BIOETHICS, Aug. 2017, at 1, 2; Dean Hayden & Dominic Wilkinson, *Asymmetrical Reasons, Newborn Infants, and Resource Allocation*, AM. J. BIOETHICS, Aug. 2017, at 13, 14; Travis N. Rieder, *Saving or Creating: Which Are We Doing When We Resuscitate Extremely Preterm Infants?*, AM. J. BIOETHICS, Aug. 2017, at 4, 10–11.

[88] *See* FEI, *supra* note 19, at 272–73.

[89] *E.g.*, Gautham K. Suresh, *In the 'Gray Zone,' a Doctor Faces Tough Decisions on Infant Resuscitation*, 32 HEALTH AFF. 1841, 1844 (2013).

[90] Dworkin, Response, *supra* note 78.

[91] *Cf.* FEI, *supra* note 19, at 279 (arguing that "[t]here is no inherent reason why health care spending and retirement contributions must be pitted against each other," and suggesting that "the real zero-sum game is between employee benefits and executive bonuses").

[92] Hoffman, *supra* note 41, at 33 ("[H]ealth redistribution can be regressive. Imagine a mandate requires every American to pay an equal amount for insurance, regardless of income. By doing so, it promotes horizontal equity (the notion that people with the same income should contribute equally) but simultaneously violates principles of vertical equity (the corollary that those with greater income should contribute more)."); *see also* Christopher T. Robertson, *Scaling Cost-Sharing to Wages: How Employers Can Reduce Health Spending and Provide Greater Economic Security*, 14 YALE J. HEALTH POL'Y L. & ETHICS 239, 244 (2014) (observing, regarding redistribution through insurance, that "[w]e would not tolerate this type of regressivity if the cost-sharing burdens were conceived as taxes").

[93] Clark C. Havighurst & Barak D. Richman, *Distributive Injustice(s) in American Health Care,* L. & CONTEMP. PROBS., Autumn 2006, at 7, 28 (analogizing insurance premiums to "a 'head tax,' which falls on individuals without appreciable correlation to wealth, income, or ability to pay").

"asking everyone to pay a little" to meet expensive patients' costs is commonly endorsed, as in the suggestion that Jacob's care could be funded through charging a dollar each to millions of insured households,[94] and has been used to defend the funding of other expensive procedures through raised insurance premiums.[95] Even scholars who emphasize concern for the poor endorse the imposition of small burdens on a large population via insurance without explicitly recognizing this approach's regressivity.[96]

Most defenses of funding expensive patients' care through insurance tacitly assume that imposing small costs on a large group is fundamentally preferable to imposing large burdens on a small one. In ethics, this is termed the "aggregation problem."[97] The imposition of small burdens on many in order to greatly help a few is contested in ethical theory, and the view that doing so is acceptable may rest on cognitive limitations in visualizing the magnitude of the population who experiences the small burden.[98] More seriously, in real-world cases, imposing putatively small costs on very large groups often will have the consequence of meaningfully harming a few within those groups. For instance, even if almost everyone could easily absorb an extra dollar per month in insurance premiums, a population of a million people is likely to contain some people for whom that dollar happens to be the difference between affording and not affording something important.[99]

The claim that financing expensive patients' treatment costs through insurance premiums redistributes from the healthy to the sick is similarly ubiquitous in health policy discussions.[100] Yet expensive patients are not reliably

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[94] Westlund, *supra* note 17.

[95] *E.g.*, Eugene Volokh, *Medical Self-Defense, Prohibited Experimental Therapies, and Payment for Organs*, 120 HARV. L. REV. 1813, 1840 (2007); *see also* Clio Sophia Koller, *The Luxturna Debate: Why Ethics Needs a Seat at the Drug Pricing Table*, BILL HEALTH (Jan. 2, 2019), https://blog.petrieflom.law.harvard.edu/2019/01/02/the-luxturna-debate-why-ethics-needs-a-seat-at-the-drug-pricing-table/ (reporting suggestion by one expert, regarding Luxturna's $850,000 price tag, that "sky-high pricing isn't a problem with insurance spreading the cost").

[96] Stone, *supra* note 47, at 292 ("[S]ubsidy from the vast majority of policyholders to a small minority is precisely what is supposed to happen in insurance. Such skewing is what people agree to when they join a social insurance risk pool . . . . [T]hey believe that sickness is one of those contingencies when society should rally around the individual.").

[97] Norman Daniels, *Four Unsolved Rationing Problems: A Challenge*, HASTINGS CTR. REP., July–Aug. 1994, at 27, 28.

[98] *See, e.g.*, Derek Parfit, *Justifiability to Each Person*, 16 RATIO 368, 375 (2003); John Broome, *A Comment on Temkin's Trade-Offs*, *in* DANIEL WIKLER & C.J.L. MURRAY, FAIRNESS AND GOODNESS IN HEALTH 56–58 (forthcoming), http://users.ox.ac.uk/~sfop0060/pdf/comment%20on%20temkins%20tradeoffs.pdf.

[99] *See, e.g.*, Oechsner & Schaler-Haynes, *supra* note 34, at 242 (noting that any increase in premium rates may result in individuals not being able to afford insurance).

[100] *See, e.g.*, Hoffman, *supra* note 41, at 32 (arguing that the ACA's design "compels the healthy to finance

sicker, understood in terms of shorter life expectancy, worse quality of life, or other plausible definitions,[101] than those with less costly conditions.[102] A patient with type 1 diabetes is not intrinsically healthier than Jacob—both require treatments to stay alive and maintain quality of life—but insulin is much cheaper than hemophilia prophylaxis.[103] Rather than redistributing from the *healthy* to the *sick*, meeting the cost of expensive patients' care by sharing it equally among all insureds redistributes from those who are *less expensive* (a group including both the healthy and the sick) to the *expensive*. Because many households are unable to comfortably absorb even small costs, making the broad group of sick but less expensive patients share the cost of expensive patients' care may worsen health outcomes for many poor and middle-class insured patients. For instance, raising co-payments for cheaper medications in order to cover the cost of expensive treatments could lead to sick patients skipping doses of medication,[104] and raising premiums could lead to these patients simply going uninsured.[105] This underscores that insurance needs progressivity to serve its goal of ensuring

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care for those sicker than themselves"); Theodore W. Ruger, *A New Deal in a World of Old Ones*, 42 ARIZ. ST. L.J. 1297, 1300 (2011) (arguing that the ACA redistributes resources "from the healthier to the sicker"); David A. Super, *The Modernization of American Public Law: Health Care Reform and Popular Constitutionalism*, 66 STAN. L. REV. 873, 947 (2014) (describing the ACA as a "massive redistribution of wealth from the healthy to the sick"); Elizabeth A. Pendo, Book Review, 29 J. LEGAL MED. 117, 122 (2008) (reviewing SUSAN STARR SERED & RUSHIKA FERNADOPULLE, UNINSURED IN AMERICA (2007)) ("[R]edistribution from the healthy to the sick is a necessary part of health insurance.").

[101] Health policy research defines the "sick" in a variety of ways. *See generally* Paula Diehr et al., *The Number of Sick Persons in a Cohort*, 29 RES. ON AGING 555, 557 (2007) (describing eight ways of defining "sick persons").

[102] This contradicts the typical conflation of the most expensive patients with the sickest. *E.g.*, John V. Jacobi, *Consumer-Directed Health Care and the Chronically Ill*, 38 U. MICH. J.L. REFORM 531, 533 (2005) ("Forty percent of health spending is attributable to the sickest 2 percent of the population, and 70 percent to the sickest 10 percent."); Christopher Smith, *It's a Mistake: Insurer Cost Cutting, Insurer Liability, and the Lack of ERISA Preemption Within the Individual Exchanges*, 62 CLEV. ST. L. REV. 75, 91 (2014) ("The individuals in state high-risk pools are, by definition, the sickest of the sick and the costliest of the costly.").

[103] *Compare* Danielle K. Roberts, *The Deadly Costs of Insulin*, AM. J. MANAGED CARE (June 10, 2019), https://www.ajmc.com/contributor/danielle-roberts/2019/06/the-deadly-costs-of-insulin (stating that the cost of insulin is typically between $300 and $800+ per month), *with* Chen, *supra* note 7 (observing that the mean direct medical cost for patients receiving prophylactic treatment is $292,525).

[104] *See* Sara R. Collins et al., *Too High a Price: Out-of-Pocket Health Care Costs in the United States*, COMMONWEALTH FUND, Nov. 2014, at 1, 6 ("Nearly half (46%) of insured adults with incomes under 200 percent of poverty said that because of their copayments or coinsurance, they had either not filled a prescription, not gone to the doctor when they were sick, skipped a medical test or follow-up visit recommended by a doctor, or not seen a specialist when they or their doctor thought they needed one . . . ."); *see also* Victor Laurion & Christopher Robertson, *Ideology Meets Reality: What Works and What Doesn't in Patient Exposure to Health Care Costs*, 15 IND. HEALTH L. REV. 43, 62 (2018).

[105] *See, e.g.*, Oechsner & Schaler-Haynes, *supra* note 99, at 242 ("For those without health insurance, premium rate increases have contributed to making many of them uninsured. Rate increases put affordable, quality coverage further out of reach for the uninsured.").

financial security: Without progressivity, insurance ensures the financial security of expensive patients at the expense of financial security for others.[106]

Rather than having fellow members of the same plan bear the entire cost of expensive patients' treatment, it would be preferable to cover this cost through progressive public financing. Such an approach aligns with Dworkin's framework: While prudent individuals might universally endorse covering the cost of common, moderate-cost treatments, making them appropriate for sharing through insurance, guaranteeing access to treatment like Jacob's would only be endorsed by individuals who know they will be wealthy. Part III will discuss how existing policy already moves certain expensive patients' costs off insurance onto public financing, and how policy innovations could serve to expand the scope of public financing.

III. IMPLEMENTING FAIR SHARING

A. Increasing Breadth Through Reinsurance

1. Private Reinsurance

Reinsurance is typically defined as an insurer's purchase of insurance against a risk it has taken on.[107] Commentators on both Mila's and Jacob's cases argue that if the firm responsible for paying claims—AOL (as self-insurer) or Wellmark—had been properly reinsured, its financial situation would not have been substantially disrupted.[108] Private reinsurance, however, is typically ineffective at spreading the costs of chronic, rather than one-off, expensive patients. This is because it normally includes a "lasering" provision, which excludes costs attributable to specific expensive patients from coverage in future years.[109] A policy that does not laser expensive patients is normally much

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[106] *Cf.* Hoffman, *supra* note 46, at 1921 (discussing how the Affordable Care Act aims to promote financial security).

[107] *See, e.g.*, Nat'l Am. Ins. Co. of Cal. v. Certain Underwriters at Lloyd's London, 93 F.3d 529, 532 n.4 (9th Cir. 1996) ("'Reinsurance' is a means by which insurance companies spread their exposure to risk."); Citizens Cas. Co. of N.Y. v. Am. Glass Co., 166 F.2d 91, 94–95 (7th Cir. 1948) ("Reinsurance is defined to be a contract that one insurer makes with another to protect the first insurer from a risk it has already assumed.").

[108] FEI, *supra* note 19, at 275–76 (describing private reinsurance as "a financial backstop if, say, an employee needs heart surgery, or gets hit by a car—or has an extremely premature baby" and arguing that AOL was either unaffected by the cost of Mila's treatment if reinsured or the victim of its own imprudence if not reinsured); Jacqueline Fox, *The Private Insurance Market: Not Very Big and Not Insuring Much, Either*, 46 J.L. MED. & ETHICS 877, 881 n.20 (2018) (arguing that Wellmark could, and likely did, protect against the cost of expensive patients like Jacob by purchasing a private reinsurance policy).

[109] *See, e.g.*, Myers v. Hog Slat, Inc., 55 F. Supp. 3d 1145, 1150 (N.D. Iowa 2014) (discussing the operation of a "laser" that excluded an expensive patient from private reinsurance coverage); s*ee also* Amy B. Monahan

costlier—so much so that the cost of reinsurance will substantially raise insurance premiums.[110] And even in the absence of lasering, the private reinsurer could still raise premiums to recoup the cost of expensive patients' treatment—negotiated "no-laser" policies still allow for 40% to 55% year-over-year premium increases.[111] All of this means that private reinsurance is unlikely to provide a technical fix for chronically expensive patients. While private reinsurance can spread unknown but potentially substantial risks, it does not address known high costs.[112]

Some states have prohibited lasering by law, just as the ACA prohibited preexisting condition exclusions. Currently, lasering is prohibited in certain markets in Utah, California, Colorado, Maryland, and the District of Columbia,[113] and lasering prohibitions have been proposed in Nevada.[114] But prohibitions on lasering do not prevent reinsurers from simply raising plan premiums for firms that have high claims,[115] in turn causing those firms to either drop reinsurance or pass on premium increases to employees; rather than broadening sharing, lasering prohibitions maintain the problems of narrow sharing. Public subsidies for reinsurance, discussed next, are likely a better solution than lasering prohibitions.

& Daniel Schwarcz, *Saving Small-Employer Health Insurance*, 98 IOWA L. REV. 1935, 1966 (2013) ("[S]top-loss insurers can apply a different attachment point to a particular employee or refuse to include that employee's costs in coverage at all, a phenomenon known as 'lasering.'").

110 *See Myers*, 55 F. Supp. 3d at 1151 (describing the premium increase of $100,000 required to eliminate a laser); *Time to Take Another Look at Stop-Loss Insurance*, BENEFITS COMPENSATION & HR CONSULTING (Segal Consulting), Jan. 2015, at 1, 3, https://archive.segalco.com/media/1321/jan2015.pdf ("Although it is possible to negotiate a no-laser contract, the economics must be reviewed with care. A no-laser contract will be more expensive . . . .").

111 MEDCOST BENEFIT SERVS., STOP LOSS COVERAGE WHITE PAPER: MAXIMIZING BENEFITS, LIMITING RISK 4 (2018).

112 HALL, *supra* note 8, at 37 ("[C]ommercial reinsurance will not cover high-cost patients that are already known.").

113 CAL. INS. CODE § 10752.1 (West 2019) ("A stop-loss insurer shall not exclude any employee or dependent on the basis of an actual or expected health status-related factor."); D.C. Code Ann. § 31-3822(c)(1) (West 2020) ("A stop-loss insurer shall not exclude any employee or dependent on the basis of an actual or expected health status-related factor."); UTAH CODE ANN. § 31A-43-301(2)(a) (West 2019) (prohibiting "lasering" in the small-employer market); AL REDMER, JR., MD. INS. ADMIN., FINAL REPORT ON THE USE OF MEDICAL STOP-LOSS INSURANCE IN SELF-FUNDED EMPLOYER HEALTH PLANS IN MARYLAND 13, 17 (2016) (describing lasering prohibitions in Colorado and Maryland).

114 *See* Requiring Certain Policies for Stop-Loss Insurance Relating to Group Health Plans to Satisfy Certain Standards and Include Certain Provisions and Information, LCB File No. R127-18, 2019 NV REG TEXT 493704 (proposed Feb. 7, 2019).

115 *See, e.g.*, Dave Kirby, *Texas Flood Doesn't Stop SIIA Members from Commenting on Draft Stop-Loss Regs*, SELF-INSURER, Dec. 2015, at 16, 16 (arguing that a lasering prohibition would lead to cost increases for employers).

2. State Reinsurance Programs

Reinsurance that spreads the cost of known high-cost patients is often offered through government-operated programs.[116] Although government-sponsored reinsurance has been discussed since the 1950s,[117] and is part of both the ACA and the Medicare Part D prescription drug benefit program,[118] recent cases involving expensive patients and concerns about unaffordable premiums have inspired increased interest, particularly at the state level. Alaska's program represents a paradigm case for this renewed government involvement in reinsurance. In 2016, Alaska faced a 42% increase in ACA exchange premiums, substantially driven by the costs of a few expensive patients.[119] It responded by passing legislation that covered medical costs associated with certain expensive conditions out of state general funds:

> Under Alaska's program, people who suffer from 33 relatively expensive conditions, like end-stage renal disease, hemophilia or cerebral palsy, would still buy their plan from the state's Blue Cross plan, Premera, and pay the same premiums as anyone else who relies on HealthCare.gov. But behind the scenes, their health care claims would be paid out of a $55 million state pool of reinsurance money, rather than Premera's own funds.[120]

The thirty-three conditions are defined by regulation,[121] although a recent proposed rule would "remove the list of covered conditions eligible for payment through the reinsurance program from the regulations for ease of updating them as needed or at least annually."[122]

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116 *See* Hall, *supra* note 5, at 470.

117 *Id.* at 465.

118 *See infra* Part III.A.3; *see also* HALL, *supra* note 8, at 34.

119 Erin Mershon, *Obamacare in Alaska: Cost-Control Plan Is Challenging but Working*, ROLL CALL (June 19, 2017, 5:00 AM), https://www.rollcall.com/2017/06/19/obamacare-in-alaska-cost-control-plan-is-challenging-but-working/; *see also* Timothy Jost, *Alaska Reinsurance Plan Could Be Model for ACA Reform, Plus Other ACA Developments*, HEALTH AFF.: FOLLOWING ACA (June 16, 2016), https://www.healthaffairs.org/do/10.1377/hblog20160616.055420/full/ (noting that approximately a quarter of the costs on Alaska's insurance exchange "came from just 37 cases").

120 Mershon, *supra* note 119; *see also* ALASKA ADMIN. CODE tit. 3, § 31.505(a) (2019) ("There is established within the Comprehensive Health Insurance Association a program to reinsure high risk residents of this state diagnosed with one or more . . . covered conditions under 3 AAC 31.540. The program will be referred to as the Alaska Reinsurance Program."); Lindsay F. Wiley, *Medicaid for All? State-Level Single-Payer Health Care*, 79 OHIO ST. L.J. 843, 864 (2018) (briefly noting Alaska's receipt of a federal waiver to fund its program); Sarah Kliff, *How Alaska Fixed Obamacare*, VOX (Apr. 13, 2017, 8:00 AM), https://www.vox.com/policy-and-politics/2017/4/13/15262614/obamacare-alaska-reinsurance.

121 tit. 3, § 31.540 (identifying conditions that define a high-risk resident).

122 Notice of Proposed Changes to the Alaska Comprehensive Health Insurance Association Reinsurance Program, 2018 AK REG TEXT 496721 (NS) (proposed June 29, 2018).

While Alaska's program was enacted at a state rather than a national level, the $55 million described as a "state pool" in fact currently comes largely from national tax revenues. This is because Alaska has received a § 1332 Medicaid waiver that allows the state to fund the reinsurance program using federal money that its residents would have received in premium tax credits if the cost of premiums had not been reduced due to the reinsurance program.[123] Although Alaska proposed to fund the program through a tax on insurers (including both health and non-health insurers), the waiver funds have funded most of the pool.[124] The use of federal funds via waiver further enlarges the breadth of sharing for Alaska's high-risk patients. It also increases progressivity, given that federal funds are obtained through progressive taxation.

By limiting premium increases, Alaska's program has enabled greater participation in the individual marketplace.[125] It does so by making insurance more attractive to the "relatively healthy people who face especially high premiums, because they are older, too wealthy to qualify for subsidies, or both—and who are bearing costs for sicker, more expensive enrollees."[126] Using sponsored reinsurance to cover the costs of the most expensive patients departs from Stone's dictum that plan members should collectively shoulder the costs of the most expensive patients,[127] but doing so also achieves greater financial security for households by lowering exorbitant premiums.[128]

Although commentaries on the Alaska program, as well as the statutory text itself, call the program "reinsurance," it and the similar programs discussed later in this subsection deviate from the classic definition of reinsurance. As discussed above, reinsurance typically protects *insurers* against having to make large, *unknown* payouts—it targets large payments, rather than expensive individuals.[129] Because the Alaska program to "reinsure high risk residents"[130]

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123 Timothy Jost, *ACA Round-Up: CMS Approves Alaska 1332 Reinsurance Waiver, Ceases Premium Outlier Reviews*, HEALTH AFF.: FOLLOWING ACA (July 12, 2017), https://www.healthaffairs.org/do/10.1377/hblog20170712.061031/full/ (noting that under the waiver, the "federal government will pass through funds to Alaska that it otherwise would have spent on premium tax credits had the benchmark premium not been reduced").

124 *Id.* ("HHS expects the program to cost $59 million for 2018, of which CMS will provide $48.4 million on a quarterly basis and Alaska the rest.").

125 *Id.* ("It is expected that because of the program premiums will be 20 percent lower in 2018 than they would otherwise be, and that 1,460 additional individuals will gain coverage.").

126 Mershon, *supra* note 119.

127 Stone, *supra* note 47, at 292.

128 Mershon, *supra* note 119 (discussing a household that saved almost $10,000 per year in premiums).

129 RANDALL R. BOVBJERG, MO. FOUND. FOR HEALTH, IMPLEMENTING REINSURANCE: HEALTH INSURANCE REFORM IN MISSOURI (2006).

130 ALASKA ADMIN. CODE tit. 3, § 31.505(a) (2019).

provides coverage for known expensive patients, it and similar programs, discussed in Table 1 below, are better understood as public insurance programs for expensive patients—some have termed them "invisible high-risk pool[s]."[131] However, the program likely benefits politically by being understood as a clever piece of "wonkish" insurance restructuring,[132] rather than as a new public insurance program that taxes and spends to pay for expensive patients (which might be unpopular on the right), or as a high-risk pool that relieves insurers and participants in Alaska's ACA exchange of the responsibility to collectively assume the costs of fellow participants in exchange insurance plans (which might be unpopular on the left).

As of November 2019, eleven other states, Colorado, Delaware, Maine, Maryland, Minnesota, Montana, North Dakota, New Jersey, Oregon, Rhode Island, and Wisconsin, have received waivers to develop reinsurance programs similar to Alaska's program.[133] Iowa and Oklahoma applied for waivers that included reinsurance as well as other changes, but ultimately withdrew them.[134] Arizona has adopted a reinsurance program confined to Medicaid enrollees, under which the state covers the costs of certain expensive treatments for Medicaid beneficiaries enrolled in managed care plans, as well as covering all costs over $650,000.[135] Connecticut and Wyoming have seen reinsurance proposals blocked in the legislative process, while several other states are in the process of initially developing these proposals.[136] Although these reinsurance proposals share a similar structure, there are also important differences between them, summarized in Table 1.[137]

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131 *See* Joel Allumbaugh et al., *Invisible High-Risk Pools: How Congress Can Lower Premiums and Deal with Pre-Existing Conditions*, HEALTH AFF.: FOLLOWING ACA (Mar. 2, 2017), https://www.healthaffairs.org/do/10.1377/hblog20170302.059003/full/.

132 *E.g.*, Mershon, *supra* note 119 (describing the Alaska program as a "plan to bring down those sky-high health insurance costs, or at least to keep them from spiking again, through the wonky idea of reinsurance"); *id*. ("The idea isn't nakedly partisan, like so many other health proposals, and doesn't alienate the hospitals, doctors or insurance companies that often fight changes to their business models.").

133 *See infra* note 137 and accompanying text.

134 *See Tracking Section 1332 State Innovation Waivers*, KAISER FAM. FOUND. (Jan. 7, 2020), https://www.kff.org/health-reform/fact-sheet/tracking-section-1332-state-innovation-waivers/ (providing an overview of state waiver applications, including applications for reinsurance waivers).

135 BRIGETTE COURTOT ET AL., URBAN INST., MEDICAID AND CHIP MANAGED CARE PAYMENT METHODS AND SPENDING IN 20 STATES 24 (2012) (describing the Arizona program).

136 *See infra* note 137 and accompanying text.

137 ALASKA DIV. OF INS., CMTY., & ECON. DEV., ALASKA 1332 WAIVER APPLICATION (2016) [hereinafter ALASKA 1332 WAIVER APPLICATION]; COURTOT ET AL., *supra* note 135; COLO. DIV. OF INS., COLORADO 1332 STATE INNOVATION WAIVER REQUEST APPLICATION TO DEVELOP A STATE REINSURANCE PROGRAM (2019) [hereinafter COLORADO 1332 WAIVER APPLICATION]; Jenna Carlesso, *Lamont: We'll Revisit Public Option Health Care Issue Next Year*, CT MIRROR (June 6, 2019), https://ctmirror.org/2019/06/06/lamont-vows-to-revive-public-option-health-care-issue-next-year/ (noting that Connecticut bill failed in state Senate); Christine

State	Eligible Claims	Portion of Claims Paid	Waiver Status	State Funding Source
AK	33 conditions	All	Approved, July 2017	Taxes on insurers
AZ	4 conditions and >$650,000 (Medicaid managed care only)	All	None needed	General revenues
CO	$30,000–$400,000	45–85%, depending on region within CO	Approved, July 2019	General revenues; fees on hospitals; potential taxes on insurers

Stuart, *Murphy Joins Call to End Trump's Cheap Health Plans*, STAMFORD ADVOCATE (Oct. 29, 2019, 3:34 PM), https://www.stamfordadvocate.com/local/article/Murphy-joins-call-to-end-Trump-s-cheap-health-14571837.php?src=sthpln (noting that Connecticut bill failed in state Senate); DEL. DEP'T OF HEALTH & SOC. SERVS., STATE OF DELAWARE 1332 STATE INNOVATION WAIVER APPLICATION TO ESTABLISH A STATE REINSURANCE PROGRAM (2019) [hereinafter DELAWARE 1332 WAIVER APPLICATION]; GEORGIA DRAFT SECTION 1332 WAIVER APPLICATION (2019); IOWA INS. DIV., IOWA STOPGAP MEASURE (2017) [hereinafter IOWA STOPGAP MEASURE]; IDAHO DEP'T OF INS., DRAFT FAIR ACCESS TO HEALTH COVERAGE WAIVER APPLICATION (2018); MD. HEALTH BENEFIT EXCH., MARYLAND 1332 STATE INNOVATION WAIVER APPLICATION TO ESTABLISH A STATE REINSURANCE PROGRAM (2018) [hereinafter MARYLAND 1332 WAIVER APPLICATION]; STATE OF MAINE EXECUTIVE SUMMARY AND APPLICATION FOR WAIVER UNDER SECTION 1332 OF THE PATIENT PROTECTION AND AFFORDABLE CARE ACT (2018) [hereinafter MAINE 1332 WAIVER APPLICATION]; MINN. DEP'T OF COMMERCE, MINNESOTA 1332 WAIVER APPLICATION (2017) [hereinafter MINNESOTA 1332 WAIVER APPLICATION]; MONT. GOVERNOR ET AL., MONTANA 1332 WAIVER APPLICATION (2019) [hereinafter MONTANA 1332 WAIVER APPLICATION]; N.D. INS. DEP'T, NORTH DAKOTA 1332 WAIVER APPLICATION (2019) [hereinafter NORTH DAKOTA 1332 WAIVER APPLICATION]; NEW HAMPSHIRE'S PROPOSAL TO WAIVE CERTAIN PROVISIONS OF THE PATIENT PROTECTION AND AFFORDABLE CARE ACT UNDER SECTION 1332 OF THE ACT, WAIVERS FOR STATE INNOVATION (2017); N.J. DEP'T OF BANKING & INS., NEW JERSEY 1332 WAIVER APPLICATION (2018) [hereinafter NEW JERSEY 1332 WAIVER APPLICATION]; SEC'Y OF HEALTH & HUMAN SERVS., 1332 STATE INNOVATION WAIVER APPLICATION FOR THE STATE OF OKLAHOMA (2017) [hereinafter OKLAHOMA 1332 WAIVER APPLICATION]; OR. DEP'T OF CONSUMER & BUS. SERVS., OREGON 1332 DRAFT WAIVER APPLICATION (2017) [hereinafter OREGON 1332 DRAFT WAIVER APPLICATION]; Pa. Pub. L. No. 2019-42, 40 PA. C. S. (2019); R.I. HEALTH INS. COMM'R, RHODE ISLAND'S 1332 WAIVER APPLICATION (2019) [hereinafter RHODE ISLAND 1332 WAIVER APPLICATION]; S.B. 845, 2018 Gen. Assemb., Reg. Sess. (Va. 2018); PREVENTION ALL., LEGISLATIVE BRIEF: HEALTH CARE ACCESS IN THE 2018 LEGISLATIVE SESSION (2018) (discussing the Washington proposed, but stalled, legislation); WIS. COMM'R OF INS., WISCONSIN 1332 WAIVER APPLICATION (2018) [hereinafter WISCONSIN 1332 WAIVER APPLICATION]; Seth Klamann, *Wyoming Senate Kills Bill that Would've Lowered Insurance Premiums for 3,500 Wyomingites*, CASPER STAR TRIB. (Feb. 15, 2019), https://trib.com/news/state-and-regional/govt-and-politics/health/wyoming-senate-kills-bill-that-would-ve-lowered-insurance-premiums/article_083ee350-b90c-5377-bd55-7cee8ebd268f.html (noting that Wyoming bill failed in state Senate); *see also Section 1332: State Innovation Waivers*, CTR. FOR MEDICARE & MEDICAID SERV., https://www.cms.gov/CCIIO/Programs-and-Initiatives/State-Innovation-Waivers/Section_1332_State_Innovation_Waivers- (last updated Feb. 25, 2020, 11:01 AM) (providing support for the waiver status of the following states: AK, CO, DE, GA, ID, IA, ME, MD, MN, MT, NJ, ND, OK, OR, RI, and WI).

State	Eligible Claims	Portion of Claims Paid	Waiver Status	State Funding Source
CT	TBD	TBD	Legislation failed in CT Senate	Taxes on insurers
DE	$65,000–$215,000	75%	Approved, August 2019	Taxes on insurers
GA	$20,000–$500,000	15–80%, depending on region within GA	Draft submitted for public comment, Nov. 2019	General revenues
ID	Regulator-developed list of conditions	All	Incomplete, Aug 2019	Taxes on insurers
IA	>$100,000	85% below $3M; none above	Withdrawn, Oct 2017	Taxes on insurers
MD	varies–$250,000	80%	Approved, August 2018	Taxes on insurers
ME	>$47,000	90% for claims under $77,000; all above	Approved, July 2018	Taxes on insurers
MN	$50,000–$250,000	80%	Approved, September 2017	General revenues; taxes on providers and insurers
MO	TBD	TBD	In progress	TBD
MT	$40,000–$101,750	60%	Approved, August 2019	Taxes on insurers
ND	$100,000–$1,000,000	75%	Approved, July 2019	General revenues (deductible tax on insurers)
NH	$45,000–$250,000	40%	Not submitted	Taxes on insurers
NJ	$40,000–$215,000	60%	Approved, August 2018	State individual mandate penalties; general revenues
OK	$15,000–$400,000	80%	Withdrawn, September 2017	Taxes on insurers

State	Eligible Claims	Portion of Claims Paid	Waiver Status	State Funding Source
OR	Varies–$1,000,000	50%	Approved, October 2017	Taxes on insurers; public insurance program fund balances
PA	TBD, delegated to Insurance Department	TBD, delegated to Insurance Department	Approved legislation (July 2019), waiver not yet submitted	Health insurance exchange fee on insurance premiums
RI	$40,000–$97,000	50%	Approved, August 2019	State individual mandate penalties
VA	$50,000–$250,000 (tentative)	80% for 2020; 50%–80% thereafter	Proposed legislation	Not specified
WA	$75,000–$1,000,000 (in development)	50%	Legislation stalled in committee	Not specified (Senate bill); taxes on insurers (House bill)
WI	$50,000–$250,000	50% for plan year 2019; 50%–80% thereafter	Approved, July 2018	General revenues
WY	TBD, delegated to commissioner	TBD, delegated to commissioner	Legislation failed in WY Senate	Taxes on insurers

In addition to the states listed in Table 1, reinsurance proposals have been examined for California by policy analysts,[138] by the state governments in South Dakota, Texas, Utah, and Vermont,[139] and supported by elected officials in West

[138] DENA B. MENDELSOHN, CONSUMERS UNION, CALIFORNIA STATE REINSURANCE: A PATH TO AFFORDABLE HEALTH INSURANCE? (2018).

[139] S.D. OFFICE OF PROCUREMENT MGMT., 1332 WAIVER AND MARKETPLACE ANALYSIS 2 (2018); SENATE COMM. ON BUS. & COMMERCE, TEXAS WAIVER OPTIONS AND IMPLEMENTATION ANALYSIS 1, 13 (2018); Kevin Caudill, *1332 Waivers and the Cost of Health Insurance for Texans*, CTR. FOR PUB. POL'Y PRIORITIES (Dec. 11, 2018), http://bettertexasblog.org/2018/12/1332-waivers-and-the-cost-of-health-insurance-for-texans/; Health Reform Task Force, *Balance Billing*, UTAH ST. LEGISLATURE (Dec. 11, 2018), https://le.utah.gov/av/committeeArchive.jsp?mtgID=15998&timelineID=124949; VT. AGENCY OF HUMAN SERVS., STATE-BASED REINSURANCE OPTIONS FOR VERMONT 2, 4 (2018).

Virginia.[140] These proposals have typically received strong support from individual state residents and from nonprofits that focus on specific diseases, such as the American Heart Association and American Cancer Society.[141]

Table 1 illustrates that states have made differing policy choices about reinsurance, including which claims are eligible for reinsurance; whether insurers remain responsible for some portion of eligible claims due to coinsurance; and how the reinsurance program is funded. These policy choices have economic implications, as spelled out in the actuarial analyses included in states' waiver requests. But they also have normative implications that have largely gone unexplored.

Most states use or propose "claims-based" eligibility criteria that define eligibility using the dollar amount of a claim.[142] Alaska and Idaho, in contrast, use "conditions-based" eligibility that provides reinsurance for specific health problems.[143] One recent report details the advantages and disadvantages of each approach.[144] Maine uses a hybrid approach that provides reinsurance for a

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[140] *Manchin Encourages West Virginia Insurance Commissioner to Prevent Healthcare Costs from Skyrocketing the Fall*, JOE MANCHIN (June 7, 2018), https://www.manchin.senate.gov/newsroom/press-releases/manchin-encourages-west-virginia-insurance-commissioner-to-prevent-healthcare-costs-from-skyrocketing-the-fall; *see also* Charles Gaba, *West Virginia: *Final* Avg. 2020 #ACA Premiums: 6.7% Increase. . .for the Highest Premiums in the Country*, ACASIGNUPS.NET (Oct. 31, 2019), https://acasignups.net/19/10/31/west-virginia-final-avg-2020-aca-premiums-67-increasefor-highest-premiums-country (discussing WV's failure to set up a reinsurance program).

[141] *See, e.g.*, COLORADO 1332 WAIVER APPLICATION, *supra* note 137 (showing endorsements from the Arthritis Foundation, Leukemia and Lymphoma Society, American Heart Association and American Stroke Association, and American Lung Association); DELAWARE 1332 WAIVER APPLICATION, *supra* note 137 (showing endorsements from the American Cancer Society Cancer Action Network, American Lung Association, American Heart Association and American Stroke Association, Cystic Fibrosis Foundation, and National Organization for Rare Disorders); MARYLAND 1332 WAIVER APPLICATION, *supra* note 137 (showing endorsements from the American Lung Association, National Multiple Sclerosis Society, and Epilepsy Foundation); MONTANA 1332 WAIVER APPLICATION, *supra* note 137, at 122, 124, 126 (showing endorsements from the American Lung Association, Cystic Fibrosis Foundation, and National Psoriasis Foundation); NORTH DAKOTA 1332 WAIVER APPLICATION, *supra* note 137, at 76–77, 80, 82, 83, 85, 87 (showing endorsements from the American Cancer Society Cancer Action Network, Arthritis Foundation, Leukemia and Lymphoma Society, American Heart Association and American Stroke Association, American Lung Association, and Cystic Fibrosis Foundation); RHODE ISLAND 1332 WAIVER APPLICATION, *supra* note 137 (showing endorsements from the American Lung Association, National Multiple Sclerosis Society, and New England Hemophilia Association/New England Bleeding Disorders Advocacy Coalition); WISCONSIN 1332 WAIVER APPLICATION, *supra* note 137 (showing endorsements from the American Cancer Society Cancer Action Network and National Multiple Sclerosis Society).

[142] CMTY. CATALYST, THE ADVOCATE'S GUIDE TO: REINSURANCE 3 (2019).

[143] *Id.* at 3–4 ("Alaska's state-run reinsurance program uses this [conditions-based] approach, covering the claims for individuals with 33 different high-cost conditions."). Claims-based and conditions-based eligibility each have advantages and disadvantages. *Id.*

[144] *Id.*

specified list of conditions and permits insurers to opt into reinsurance for other costly claims.[145] Most states also use coinsurance, which leaves the insurer responsible for some or all claims.[146] And many do not provide reinsurance for the portion of a claim that goes beyond a cap, paralleling the pre-ACA practice of imposing annual limits on individual insurance and also mimicking the transitional reinsurance program that was available through the ACA between 2014 and 2016, which capped reinsurance at $250,000.[147]

Dworkin's account of fairness in health insurance provides a useful framework for considering the normative implications of caps, coinsurance, and the choice between claims-based and condition-based reinsurance. As Dworkin notes, the case for providing treatments to expensive patients is different from the case for providing preventive care or lower-cost lifesaving treatments.[148] Spending millions of dollars to treat a small number of expensive patients is justifiable only in a society where some individuals have millions of dollars in income and wealth; whereas, spending a lesser sum of money to treat widespread health problems would be justifiable even in a highly equal society.[149] These fairness considerations favor reinsurance designs that do not cap the dollar amounts eligible for reinsurance, because caps shift the costs of the most expensive patients back onto the shoulders of a narrower pool. As discussed in the next subsection, the federal high-cost risk pooling program does meet some of the costs of patients whose bills exceed $1 million. It also favors reinsurance designs that, like Iowa's, have a high eligibility threshold,[150] or conditions-based insurance designs; these designs focus on patients whose conditions are costly enough to make narrower sharing normatively controversial. In contrast, reinsurance is harder to justify for fairly low-cost claims, which counts against designs like Oklahoma's that provide reinsurance for claims as low as $15,000.

The question of how states should fund reinsurance has presented the most serious political and normative disputes. The three most popular funding approaches are taxes on insurers, appropriations from the state's general fund,

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145 MAINE 1332 WAIVER APPLICATION, *supra* note 137, at 5–6; *see* CMTY. CATALYST, *supra* note 142, at 4.

146 IOWA STOPGAP MEASURE, *supra* note 137, at 23 (discussing the use of coinsurance for claims from $100,000 to $3 million, combined with complete reinsurance for claims above $3 million).

147 *E.g.*, WISCONSIN 1332 WAIVER APPLICATION, *supra* note 137, at 4 (establishing an attachment point of $50,000 and a reinsurance cap of $250,000); Timothy Jost, *CMS Expects to Reinsure 55.1 Percent of Claims Between $45,000 and $250,000*, HEALTH AFF.: FOLLOWING ACA (June 20, 2016), https://www.healthaffairs.org/do/10.1377/hblog20160620.055457/full/ (describing ACA transitional reinsurance).

148 *See supra* Part II.B.

149 *See* Dworkin, *Distribution of Health Care*, *supra* note 72, at 888.

150 IOWA STOPGAP MEASURE, *supra* note 137, at 23.

and proceeds from state individual mandates that require uninsured residents to make a payment to the state (just as the ACA's individual mandate required uninsured individuals to pay a tax to the federal government).[151] Each approach presents challenges. Taxes on insurers are politically popular and do not further stress already-strained state general funds, but they are typically passed on directly to insured patients. Objections from state legislators as well as insurer associations like America's Health Insurance Plans derailed efforts in Connecticut and Wyoming to fund reinsurance through taxes on insurers,[152] and may have led to New Jersey changing its funding source to general funds.[153] Objections to taxes on insurers are not unique to right-wing or elite advocacy: Several commenters on Oklahoma's proposal raised concerns about the burden that taxes on insurers would impose on tribal employers and members of tribes, without a corresponding benefit.[154]

The use of state general funds to pay for reinsurance, meanwhile, has been defended by insurers, but criticized from both the left and the right as an unfair bailout for insurers and a low-priority use of scarce funding.[155] Individual mandate funding is the least politically controversial, but produces a smaller and more variable revenue stream, and has been criticized for transferring resources from working-class households who make most of the individual mandate payments to middle-class and wealthy households who benefit most from reinsurance.[156] Problems with these prominent funding approaches have spurred

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[151] *See supra* note 137 and accompanying text.

[152] *See* Carlesso, *supra* note 137; Klamann, *supra* note 137; *see also* MAINE 1332 WAIVER APPLICATION, *supra* note 137 ("[W]e believe it is important that the funding source be broad-based, rather than an assessment on any health insurance market that would only serve to make coverage in those markets less affordable. Any premium or provider taxes simply result in higher premiums and serve to destabilize the markets being assessed.").

[153] *See* NEW JERSEY 1332 WAIVER APPLICATION, *supra* note 137, at app. attachment 8 (New Jersey Business & Industry Association letter dated June 29, 2018) (discussing amendment to remove tax on all individual and small-group health plans).

[154] OKLAHOMA 1332 WAIVER APPLICATION, *supra* note 137, at 127–28.

[155] CMTY. CATALYST, *supra* note 142, at 6 ("Within the advocacy community, reinsurance can be perceived as a 'bailout' to insurance companies. While the intent behind the program is to lower premiums for consumers, providing direct payments to insurers has drawn some criticism."); HALL, *supra* note 8, at 34 ("[S]ome critics continue to characterize reinsurance as little more than an insurer 'bail out . . . .'"); MINNESOTA 1332 WAIVER APPLICATION, *supra* note 137, at 63 ("Commenters mentioned that they view the MPSP as bailing out profitable insurance companies."); NEW JERSEY 1332 WAIVER APPLICATION, *supra* note 137, at app. attachment 7 (discussing hospitals' proposal to tax insurers rather than drawing on the general fund); Julie Rovner & Rachel Bluth, *5 Governors Press Congress for Fast Bucks to Secure Obamacare Market in 2018*, KAISER HEALTH NEWS (Sept. 7, 2017), https://khn.org/news/5-governors-press-congress-for-fast-bucks-to-secure-obamacare-market-in-2018/. *But see* Timothy Stoltzfus Jost, *Stabilizing Forces*, ACTUARY, Oct.–Nov. 2016, at 34, 37 (rejecting bailout critique).

[156] MENDELSOHN, *supra* note 138, at 12 ("[I]f a reinsurance program—which primarily benefits individuals earning over 400 percent of the federal poverty level, and the federal government—were funded by

some states to seek more innovative sources of funding, such as taxes on providers (in Colorado) or fees collected by operating a state-level ACA exchange rather than relying on the federal exchange (Pennsylvania); commenters on state proposals have also suggested "sin taxes" such as tobacco or alcohol taxes.[157]

The normative analysis also favors funding reinsurance through a source other than a tax on insurers. Taxes on insurers will be regressively passed through to insured individuals as premium increases,[158] as some opponents of Oklahoma's proposal noted in their response during the public comment period.[159] In contrast, funding from general revenues—which can be obtained through progressive taxation—could place more of the cost on better-off individuals. If funding from general revenues is impossible, however, it is fairer to tax all insurers than only private insurers, since taxing all insurers at least broadens sharing even if it does not make it more progressive.[160] Many critics have disagreed, however, arguing that it is unfair to raise costs for individuals with employer-based insurance in order to lower costs for purchasers in the individual marketplaces.[161] Another option that could avoid the problem of passing on the tax burden as a regressive premium increase would be to tax providers rather than insurers.[162]

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the individual mandate penalty, the effect would be that higher-income Californians would benefit from a program financed by their lower-income neighbors.").

[157] NEW JERSEY 1332 WAIVER APPLICATION, *supra* note 137, at app. attachment 7.

[158] *Cf.* Cynthia Goff, *An Individual Mandate to Have Health Care Coverage: How Minnesota Can Turn This Key to Health Care Reform*, 29 HAMLINE J. PUB. L. & POL'Y 85, 99 (2007) (discussing how Minnesota's high-risk pool is "funded by an assessment on all insurers in the State, which is then passed on to all insured people in the State through their premiums").

[159] *Public Comments on Waiver During Federal Comment Period*, CENTERS FOR MEDICARE & MEDICAID SERVICES, https://www.cms.gov/CCIIO/Programs-and-Initiatives/State-Innovation-Waivers/Downloads/Public-Comments-Federal-OK.pdf (last visited Apr. 5, 2020) (comprising the public comments on Oklahoma's application from the Self-Insurance Institute of America, ERISA Industry Committee, HR Policy Association, and National Association of Wholesaler-Distributors); *see also* MAINE 1332 WAIVER APPLICATION, *supra* note 137 (public comment from Anthem dated May 2, 2018) (discussing the argument that "premium or provider taxes simply result in higher premiums and serve to destabilize the markets being assessed").

[160] *Contra* MAINE 1332 WAIVER APPLICATION, *supra* note 137.

[161] MAINE 1332 WAIVER APPLICATION, *supra* note 137 (public comment from Anthem dated May 2, 2018) (reporting insurer's "concerns about an assessment on fully insured and self-funded accounts" because it "increases costs . . . without a corresponding benefit"); *id.* (public comment from Maine State Chamber of Commerce dated May 1, 2018) ("[A]ll employers are being asked to subsidize one segment of the insurance market by paying a substantial assessment, when they themselves are struggling to pay for their own polices [sic]."); OREGON 1332 DRAFT WAIVER APPLICATION, *supra* note 137, at 89–93; *cf.* DELAWARE 1332 WAIVER APPLICATION, *supra* note 137, at attachment 5 (Aflac letter dated June 14, 2019) (arguing that insurers "should not be included in the funding base for a program that does not impact or benefit them").

[162] *Cf.* COLORADO 1332 WAIVER APPLICATION, *supra* note 137, at 4 (funding reinsurance via tax on hospitals); MINNESOTA 1332 WAIVER APPLICATION, *supra* note 137, at 4 (proposing to fund program through a

Some states have attempted to bypass or obscure the challenges of funding insurance programs by framing taxes on insurers in ways that are at best shortsighted and at worst misleading. Many make the implausible assumption that taxing employer-based insurance will not affect the cost or benefit generosity of employer-based insurance,[163] or that taxes on insurers won't be passed down to individuals.[164] In the public presentation of their reinsurance plan, North Dakota claimed that it was funded by "assessments against North Dakota health insurance companies," omitting the fact that those assessments were deductible for insurers and that funding therefore ultimately came from general revenues.[165] It is more plausible that the taxes needed to fund reinsurance will have genuine but small effects.[166]

The complexity of reinsurance also obfuscates the winners and losers from the program. Consider the case of Alaska: Without the reinsurance program, premiums would have risen substantially in order to cover the costs of expensive patients; federal tax credits would have subsidized premiums for Alaskans under 400% of the poverty line, but better-off Alaskans would have been asked to shoulder the burdens of paying the rest of expensive patients' costs. The reinsurance program, coupled with the waiver, serves to redirect federal revenues to higher-income Alaskans who would not have received income-based ACA subsidies.[167] Commenters on several state reinsurance plans have

tax on providers); Coleman Drake et al., *Estimated Costs of a Reinsurance Program to Stabilize the Individual Health Insurance Market: National- and State-Level Estimates*, 56 J. HEALTH CARE ORG. PROVISION & FINANCING 1, 2 (2019).

163 *E.g.*, MAINE 1332 WAIVER APPLICATION, *supra* note 137, at 10 ("MGARA is not estimated to impact premium rates materially for employer-sponsored insurance."); MARYLAND 1332 WAIVER APPLICATION, *supra* note 137, at 3 ("Employer contributions and employee wages are not expected to be affected by the waiver."); OREGON 1332 DRAFT WAIVER APPLICATION, *supra* note 137, at 8 ("Although employer health plans will have a 0.3 percent assessment to fund the ORP, employer contributions and employee wages are not expected to be affected by the waiver.").

164 MONTANA 1332 WAIVER APPLICATION, *supra* note 137, at 127 ("Insurance companies have to pay a tax of 1.2% on premiums, not individuals.").

165 *See* NORTH DAKOTA 1332 WAIVER APPLICATION, *supra* note 137, at 3, 118.

166 *See* OKLAHOMA 1332 WAIVER APPLICATION, *supra* note 137, at 19, 23 ("Employers who offer commercial insurance that is subject to the assessment may see a slight increase in premiums due to the assessment. However, it is not anticipated that this assessment will impact employers' decision to offer coverage to their employees."); *cf.* DELAWARE 1332 WAIVER APPLICATION, *supra* note 137, at attachment 6 (email correspondence from IFS Benefits, LLC sent May 31, 2019) (providing commenter's question: "Am I correct that if the 1332 waiver program is implemented it will increase costs for employers due to the premium assessment fee that will be applied to health insurance companies. It would be expected that the health insurance companies would then pass this on to employers by increasing their premiums. Correct?").

167 *Cf.* OKLAHOMA 1332 WAIVER APPLICATION, *supra* note 137, at 7, 17 (predicting that nearly all households enrolling because of reinsurance will be those above 400% of the federal poverty line); WISCONSIN 1332 WAIVER APPLICATION, *supra* note 137, at attachment 5 (comments by Wisconsin Alliance for Women's Health and Kids Forward).

noted that the savings flow mainly to higher-income consumers, and have questioned the prioritization of reinsurance rather than efforts to assist lower-income buyers such as Medicaid expansion.[168] In describing the benefits of their programs, some states have skirted the fact that reinsurance almost exclusively benefits buyers with incomes above 400% of the poverty line: For instance, Alaska argues that the benefits of reinsurance "are shared by the entire individual health insurance market regardless of income, age, race and ethnic group, or any other demographic characteristic."[169] But, because the ACA's income-based subsidies mean that lower-income households typically do not pay list price for instance, these benefits are not shared equally "regardless of income."

That the benefits of reinsurance flow primarily to better-off households under the ACA's current subsidy structure indicates that reinsurance—even though it broadens sharing for expensive patients—replicates many of the same policy outcomes that can be achieved by directly subsidizing premiums for better-off households. The current structure of advance premium tax credits, which use tax revenues to cover all health insurance premiums for lower-income households that exceed a specified percentage of income, can be understood as creating broad, progressive sharing for the costs that expensive patients impose on these low-income buyers. California has extended premium subsidies to households over 400% to households below 600% of the poverty line, and proposals have been introduced at the federal level to provide all households with subsidies.[170] Some commenters have argued that simply subsidizing more-advantaged households would be more effective than reinsurance at increasing insurance enrollment,[171] and likely also more politically popular.[172] But reinsurance has the advantage of lowering costs for lower-income households that do not receive subsidies, such as families that fall into the Medicaid-expansion gap and—potentially—documented immigrants who decline available subsidies because of concerns about the "public charge" provision.[173]

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[168] OKLAHOMA 1332 WAIVER APPLICATION, *supra* note 137, at 120 (noting that "decreased premiums projected would benefit those above 400% FPL in the individual market" and asking whether steps are "being taken to provide coverage to those who are uninsured because of not expanding Medicaid").

[169] ALASKA 1332 WAIVER APPLICATION, *supra* note 137, at 5; *see also* MINNESOTA 1332 WAIVER APPLICATION, *supra* note 137, at 7 ("The benefits of an approved waiver will be shared by the entire non-grandfathered individual health insurance market, without regard to enrollees' income, age, health condition, tobacco status, area of residence, race, carrier selection, network selection, or metal level selection.").

[170] *See* Govind Persad, *Choosing Affordability in Health Insurance*, 88 GEO. WASH. L. REV. 819, 829-30 (2020).

[171] *See, e.g.*, HALL, *supra* note **8**, at 39–40; Charles Gaba, *Minnesota: #TeamReinsurance Dukes It Out with #TeamSubsidies*, ACASIGNUPS.NET (Mar. 22, 2019, 2:02 AM), http://acasignups.net/19/03/22/minnesota-teamreinsurance-dukes-it-out-teamsubsidies.

[172] *See* Gaba, *supra* note 171.

[173] *See* Jeanne Lambrew & Jen Mishory, *Closing the Medicaid Coverage Gap*, CENTURY FOUND. (July

Last, commenters on many of the state reinsurance proposals also note that reinsurance does not combat the high medical costs that make patients expensive in the first place, and advocate for efforts to address medical costs.[174] Part III.C discusses potential strategies for reining in high costs.

3. Federal-Level Reinsurance

The ACA incorporated publicly provided reinsurance as a transition program during its first two years.[175] The ACA's reinsurance structure, however, only covered expenses between $45,000 ($90,000 in 2016) and $250,000, with a variable coinsurance rate, and was phased out in 2016. Additionally, it was funded through a tax on insurers.[176] As discussed above, insurers simply pass these taxes through to their customers in the form of higher premiums. As such, the original ACA reinsurance program achieved greater breadth of sharing, but not greater progressivity: Each insured individual paid a similar amount in higher premiums in order to cover the costs of the most expensive patients. The ACA also currently includes a reinsurance program for patients with claims above $1 million, although this program covers only 60% of costs.[177]

Medicare's Part D prescription drug coverage also includes a reinsurance program, which currently covers 80% of the cost of drugs once a patient's spending crosses a specified threshold (currently just over $8,000 per year).[178] Part D reinsurance spending has been growing rapidly due to increasing drug prices, prompting the Medicare Payment Advisory Commission to recommend that reinsurance rates be reduced dramatically to cover only 20% of drug costs

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31, 2018), https://tcf.org/content/report/closing-medicaid-coverage-gap/; Sara Rosenbaum, *The New "Public Charge" Rule Affecting Immigrants Has Major Implications for Medicaid and Entire Communities*, COMMONWEALTH FUND (Aug. 15, 2019), https://www.commonwealthfund.org/blog/2019/new-public-charge-rule-affecting-immigrants-has-major-implications-medicaid-and-entire.

[174] *E.g.*, MENDELSOHN, *supra* note 138, at 3 ("Finally, reinsurance is an efficient mechanism for removing costly claims from rate setting, but it does not address the underlying healthcare costs that caused large bills in the first place."); NORTH DAKOTA 1332 WAIVER APPLICATION, *supra* note 137, at 90; OKLAHOMA 1332 WAIVER APPLICATION, *supra* note 137, at 120 ("Commenter had a concern that health care and health insurance are two separate issues. For example, health insurance has its own administrative complexity, which might potentially divert resources from needy people. Commenter would like the legislature to look at health care costs and ways to improve the health care system."); *id.* at 122 ("Insurance carriers can't reduce prices unless providers do. Where are they? Response: . . . We do acknowledge that we have to bend the health care cost curve."); *see also* HALL, *supra* note 8, at 36.

[175] *See* Jost, *supra* note 147.

[176] *See* HALL, *supra* note 8, at 33.

[177] Scott E. Harrington, *Stabilizing Individual Health Insurance Markets with Subsidized Reinsurance*, LDI ISSUE BRIEF, Sept. 2017, at 1, 6 n.7 (explaining the Federal High-Cost Risk Pooling Program in the ACA).

[178] MEDICARE PAYMENT ADVISORY COMM'N, REPORT TO THE CONGRESS: MEDICARE PAYMENT POLICY 390 tbl.14-1 (2019); *see also* Jost, supra note 155, at 37.

in order to give insurers an incentive to reduce drug spending.[179] An alternative to reducing reinsurance for drugs, discussed in Part III.C, would be to take other steps to reduce drug costs themselves in a systematic way. Most recently, several health reform proposals at the federal level have proposed the creation of a federal reinsurance program or federal grants to states to develop their own programs.[180]

Breadth and progressivity could both be improved by placing expensive patients onto a publicly funded insurance plan. This already happens for some categories of expensive patients. Nationally, patients with end-stage renal disease (ESRD) who require dialysis, regardless of age, are covered by Medicare.[181] Some have described the ESRD program as using Medicare as a "high-risk pool" for people with renal disease.[182] More generally, Medicare itself could be understood as a policy decision to move older and more expensive patients from private insurance onto a publicly funded program.[183]

4. Reimagining Reinsurance

As the Commonwealth Fund notes, "a more comprehensive national effort to help private insurers manage unpredictable risks in individual health insurance markets has enduring appeal."[184] The most normatively compelling design for a national reinsurance program would mix and match design features from various state plans. It would fund reinsurance via a broad-based, progressive tax, rather than an industry-specific tax that is passed on as a fee to insured individuals and would offer reinsurance to both exchange plans and employer-based plans. It would use modest coinsurance, to maintain incentives for insurers to control costs, but no cap on reinsurance. It would either have a

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[179] MEDICARE PAYMENT ADVISORY COMM'N, *supra* note 178, at 394–95; *see also* OFFICE OF INSPECTOR GEN., HIGH-PRICE DRUGS ARE INCREASING FEDERAL PAYMENTS FOR MEDICARE PART D CATASTROPHIC COVERAGE 3 (2017).

[180] *See generally* Jeanne Lambrew, *A Quick Look at Congress's Ideas to Improve Private Health Insurance*, CENTURY FOUND. (June 26, 2019), https://tcf.org/content/commentary/quick-look-congresss-ideas-improve-private-health-insurance/ (summarizing proposals).

[181] H. Bradley Southern, Note, *Medicare's End-Stage Renal Disease Program: Its Development and Implications for Health Care Policy*, 26 HARV. J. ON LEGIS. 225, 226 (1989) (observing that the ESRD program "is unique because it represents the first time a specific medical disease category has been isolated by the federal government for almost 100% federally-funded treatment").

[182] Sarah Kliff, *High-Risk Pools: The Newest Proposal to Fix the GOP's Health Plan, Explained*, VOX (May 3, 2017, 2:30 PM), https://www.vox.com/policy-and-politics/2017/5/3/15529428/republican-high-risk-pools.

[183] *See* KAREN DAVIS ET AL., COMMONWEALTH FUND, MEDICARE: 50 YEARS OF ENSURING COVERAGE AND CARE 22 (2015) ("[N]atural market forces cause private insurers to avoid those at highest risk.").

[184] Blumenthal et al., *supra* note 134.

claims-based structure with a reasonably high attachment point, or a hybrid conditions-based and claims-based structure, with the threshold for reinsurance varying by condition.

This national reinsurance program could also be structured as a national catastrophic-cost program that directly covers expensive patients rather than reimbursing insurers, akin to the ESRD program. Unlike beleaguered state risk pools, the national program could leverage the federal government's greater resources and financial flexibility to create a program that (like the ESRD program) has no caps, lifetime limits, or other issues that bedeviled state risk pools. It could also achieve cost savings by reimbursing at Medicare rates. As Part III.B argues, the most normatively appealing way of funding it would be via a highly progressive tax, akin to the ACA's Medicare tax.

The distinction between a national reinsurance program and a national high-risk pool program would largely be semantic, rather than substantive.[185] A recent normative critique of high-risk pools, which argues that "high-risk pools are unjust" regardless of their efficiency, might therefore apply to the state and national reinsurance programs discussed above or to a more comprehensive national reinsurance program.[186] This critique argues that high-risk pools are unjust because they (1) require high-risk individuals to pay more for their insurance, (2) deny high-cost patients procedural fairness by refusing to weigh their claims against those of lower-cost patients, and (3) segment the population on the basis of an unchosen characteristic.[187] While these objections are compelling for certain high-risk pool designs, they do not apply to most of the reinsurance programs discussed.

The first critique, that high-risk pools require high-cost patients to pay more, only applies to high-risk pools that are funded via premiums on expensive patients, not to "invisible" high-risk pools that are funded via taxation. The ESRD program, for instance, does not require ESRD patients to pay more for insurance than others do—in fact, they pay less for insurance because they pay

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185 *See* Allumbaugh et al., *supra* note 131 (describing government-sponsored reinsurance as a type of high-risk pool).

186 Jeremy Kingston Cynamon, *Normative Concerns with High-Risk Pools*, 46 J.L. MED. & ETHICS 766, 766 (2018); *see also id.* at 772 n.5 ("Many of the arguments here, though directed principally at high-risk pools, apply to other mechanisms for fragmenting solidarity in the health insurance market."). Reinsurance programs like Alaska's might also be understood as a mechanism for fragmenting solidarity, given that they are framed as protecting the "healthy people who face especially high premiums" from "bearing costs for sicker, more expensive enrollees." *See* Mershon, *supra* note 119.

187 Cynamon, *supra* note 186, at 771.

Medicare rates. The same is true for state reinsurance and for the national reinsurance program.[188]

Similarly, the second objection, that high-risk pools deny high-cost patients procedural fairness by refusing to weigh their claims against those of lower-cost patients, only applies if high-risk pools apply different criteria for access to interventions than other forms of insurance do. But uniform criteria for access can be applied without a "unitary risk pool."[189] As in the Alaska reinsurance program, a different source of payment for expensive patients could coexist with a uniform standard for treatment access for all patients.

The third objection, that high-risk pools segment the population on the basis of an unchosen characteristic, also applies to reinsurance. However, the objection is not compelling: Segmentation on the basis of unchosen characteristics is often justifiable, and appropriately designed high-risk pools will tend to ameliorate stigma rather than exacerbating it. First, fairness often requires treating unequals unequally, rather than treating everyone identically.[190] Unchosen inequalities can justify differential but fair treatment: For instance, the ESRD program segments the population on the basis of an unchosen characteristic in order to address the special needs of ESRD patients. Second, by making sharing broader and more progressive, a well-designed high-risk pool will reduce resentment of high-risk patients. The objection claims that whereas "in a society that does not make use of high-risk pools I might encounter Frank as my friendly neighbor who unfortunately suffers from a chronic illness," the use of high-risk pools makes me "more prone to encounter Frank as that high-risk person who lives in my building . . . and consumes more resources than he contributes."[191] It also claims that high-risk pools make a patient's illness, rather than the cost of treating it, salient, and inflict on high-cost patients a stigmatized "socio-legal identity" with "inferior benefits and privileges."[192] Both these claims are dubious. In Jacob's and Mila's cases, the *absence* of a high-risk pool led neighbors and coworkers to become resentful of the high costs they were

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188 *See, e.g.*, Mershon, *supra* note 119 (illustrating how those covered by a state reinsurance program pay the same premiums as others).

189 *But see* Cynamon, *supra* note 186, at 770.

190 *See, e.g.*, Knight v. State, 787 F. Supp. 1030, 1193 (N.D. Ala. 1991) (discussing "vertical equity which is the unequal treatment of unequals"), *aff'd in part, vacated in part, rev'd in part*, 14 F.3d 1534 (11th Cir. 1994); Lawrence O. Gostin & David P. Fidler, *Biosecurity Under the Rule of Law*, 38 CASE W. RES. J. INT'L L. 437, 462 (2007) ("Aristotle expressed the ideal of justice as the equal treatment of equals and the unequal treatment of unequals.").

191 Cynamon, *supra* note 186, at 768.

192 *Id.*

singled out to pay,[193] whereas the use of a broadly funded high-risk pool would have attenuated these costs and decreased resentment. And high-risk pools constructed like Alaska's program do not treat patients in an outwardly different way or impose inferior benefits and privileges. The ESRD program, in fact, arguably confers superior benefits on patients with kidney failure in response to their distinctive needs.

Rather than the critique's extension of philosophical theories of social recognition to claim that high-risk pools have deleterious "social-recognitional implications,"[194] a more apposite philosophical insight comes from work by John Rawls, Thomas Nagel, and others on the "division of moral labor" between individuals and social institutions.[195] Resentment is better mitigated by collectively supported institutions that meet needs without allowing those needs to excessively intrude on individuals' daily lives than by mandating direct, interpersonal mutual aid. As Nagel puts it,

> [I]t clearly is a desirable feature of a social order that within it, people should not be too constrained in the pursuit of their own lives by constant demands for impartial attention to the welfare of others. . . . But this is an adequate individual morality *only within the context of a societal framework that does much more* to satisfy the claims of impartial concern which other lives make on us.[196]

A broadly and progressively funded reinsurance program can serve as a crucial institutional element of a desirable societal framework by shielding poor and middle-class individuals from frequent and burdensome demands to contribute to the needs of expensive patients, while at the same time ensuring that those patients' needs are met.

B. Progressive Financing Through a Rescue Tax

Scholarship in tax defines a progressive tax system as "one in which the average tax rate—the proportion of income paid in taxes—increases with income."[197] The concept of progressivity has also been applied to the funding of

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[193] *See* FEI, *supra* note 19, at 269–71 (describing online reactions); *id.* at 250–51 (describing experience of another parent of a child who incurred high medical bills).

[194] Cynamon, *supra* note 186, at 766, 772 n.13 (proposing to evaluate high-risk pools using a theory of social recognition developed by G.W.F. Hegel, Axel Honneth, and others).

[195] *See* James D. Nelson, *The Trouble with Corporate Conscience*, 71 VAND. L. REV. 1655, 1665 & n.50 (2018) (collecting sources on the "division of moral labor").

[196] THOMAS NAGEL, EQUALITY AND PARTIALITY 83 (1991) (emphasis in original).

[197] David Kamin, Note, *What Is a Progressive Tax Change?: Unmasking Hidden Values in Distributional Debates*, 83 N.Y.U. L. REV. 241, 243 (2008).

social programs more generally.[198] For instance, while Medicare is partially funded by participant-paid premiums (a regressive fee), the greatest proportion of its funding comes from general tax revenues (financed through progressive taxation), and a substantial proportion also comes from payroll taxation, which has a flat structure.[199]

Public reinsurance programs have been funded in several ways, varying from more to less progressive. Fees are typically the least progressive funding strategy: Even though fees have the same absolute cost to all payers, their cost to the poor as a percentage of income is much greater than their cost to the rich.[200] Although reinsurance is typically not funded directly through fees, taxing insurers to fund reinsurance—as Alaska initially did and many other states currently do[201]—will ultimately have similar effects to a fee, because insurers will pass the tax through to customers without regard to customer wealth.[202] Taxing insurers to fund reinsurance may seem fair because reinsurance benefits insurers by protecting them from the cost of paying for expensive patients' treatment,[203] but insurers' ability to pass taxes through to customers makes the distributive impact of taxing insurers unattractive.

Other states have proposed to fund reinsurance via taxes on specific unhealthful products, such as tobacco.[204] While there are compelling policy

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198 *E.g.*, Tom Miller, *Measuring Distributive Injustice on a Different Scale,* LAW & CONTEMP. PROBS., Autumn 2006, at 231, 235 (analyzing the progressivity of Medicare).

199 *See* Theodore R. Marmor & Jacob S. Hacker, *Medicare Reform and Social Insurance: The Clashes of 2003 and Their Potential Fallout*, 5 YALE J. HEALTH POL'Y L. & ETHICS 475, 480 (2005) (describing Medicare's funding structure); Jill R. Horwitz, *The Virtues of Medicare*, 106 MICH. L. REV. 1001, 1010 (2008) (reviewing DAVID A. HYMAN, MEDICARE MEETS MEPHISTOPHELES (2006)) (similar).

200 *See* Stephanie R. Hoffer, *Redirecting Direct Democracy: Non-Essential Spending as Political Speech*, 95 MARQ. L. REV. 563, 614 n.211 (2012) ("Flat fees are regressive because they comprise a greater proportion of the income or wealth of taxpayers at the lower end of the economic spectrum.").

201 *See* Mershon, *supra* note 119.

202 *See* Arthur C. Graves, *Inherent Improprieties in the Income Tax Amendment to the Federal Constitution*, 19 YALE L.J. 505, 507 (1910) ("[A] tax . . . levied against the income of insurance companies derived in part from premiums on policies . . . fell ultimately, not upon the insurance company, but upon the policyholder, whose premium was proportionately increased by the amount of the tax levied."); Jonathan R. Macey & Geoffrey P. Miller, *The McCarran-Ferguson Act of 1945: Reconceiving the Federal Role in Insurance Regulation*, 68 N.Y.U. L. REV. 13, 73 (1993) (observing that insurance companies pass fees through to policyholders).

203 *See, e.g.*, MINNESOTA 1332 WAIVER APPLICATION, *supra* note 137, at 63 ("Commenters mentioned that they view the [reinsurance program] as bailing out profitable insurance companies.").

204 FAMILIES USA, REINSURANCE: A PRIMER 13 (2008) (suggesting tobacco tax revenues as a source for reinsurance funding); *see also* COLO. COMM'R OF INS., A REPORT REGARDING SB17-300: COLORADO HIGH-RISK HEALTH COVERAGE STUDY fig.6 (2017) (suggesting tobacco or marijuana tax revenues as a source for reinsurance funding); HEALTHSOURCE RI & OFFICE OF THE HEALTH INS. COMM'R STATE OF R.I., MARKET STABILITY WORKGROUP "2.0" (2018) (discussing use of tobacco tax revenue for reinsurance).

justifications for tobacco taxes, the link between tobacco and reinsurance is weak, given that most expensive patients' medical costs are not attributable to tobacco use. Raising revenue via Pigouvian (i.e., behavior-modifying) taxes, such as tobacco taxes, also has the recognized flaw that Pigouvian taxes raise less revenue as they become more effective at disincentivizing socially undesirable behavior.[205] It is also challenging to design Pigouvian taxes to be progressive.[206] Some have criticized tobacco taxes, for instance, as regressive, although their health benefits for poor consumers makes that charge dubious.[207]

Still other states fund reinsurance out of general revenues.[208] The progressivity of this strategy depends on the progressivity of the tax system used to collect those revenues. Taking a broader view, it also depends on where the revenues would otherwise have been spent. In Wisconsin, state-funded subsidies for reinsurance—which typically lower the premiums for middle-class patients who are too well off to receive ACA tax credits—have been criticized for potentially taking money from Medicaid funding and other programs that help lower-income residents.[209]

Part II's discussion suggests that there is a distinctive case for progressivity in funding expensive patients' care, one that goes beyond the typical case for progressivity in taxation. Typically, progressive taxation is justified on the basis that better-off individuals experience fewer utility losses from paying taxes than worse-off ones do, or that economically worse-off individuals have a fundamentally stronger claim to resources.[210] But taxation to fund expensive

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[205] *See* Nadav Shoked, *Cities Taxing New Sins: The Judicial Embrace of Local Excise Taxation*, 79 OHIO ST. L.J. 801, 811 (2018) ("Consider the local cigarette tax. If the tax effectively promotes the alleged goal of depressing the consumption of the product deemed harmful . . . , then the number of cigarettes purchased will decline, and the revenue raised through the tax . . . will decrease.").

[206] *See* Henry Ordower et al., *Out of Ferguson: Misdemeanors, Municipal Courts, Tax Distribution, and Constitutional Limitations*, 61 HOW. L.J. 113, 133 (2017) (discussing regressive effects of tobacco taxes).

[207] *Cf.* Lauren Kaplin, *A National Strategy to Combat the Childhood Obesity Epidemic*, 15 U.C. DAVIS J. JUV. L. & POL'Y 347, 391 (2011) (arguing that tobacco taxes increase overall utility for lower-income consumers); April Schweitzer, *Soda Taxes: A Missed Opportunity or an Untested Tactic?*, 20 ANNALS HEALTH L. ADVANCE DIRECTIVE 112, 118 (2011), https://www.luc.edu/media/lucedu/law/centers/healthlaw/pdfs/advancedirective/pdfs/issue6/schweitzer.pdf (similar).

[208] COLORADO 1332 WAIVER APPLICATION, *supra* note 137, at 4; GEORGIA DRAFT SECTION 1332 WAIVER APPLICATION, *supra* note 137, at 5–6; MINNESOTA 1332 WAIVER APPLICATION, *supra* note 137, at 4; NORTH DAKOTA 1332 WAIVER APPLICATION, *supra* note 137, at 2–3; RHODE ISLAND MARKET STABILITY WORKGROUP, *supra* note 204; WISCONSIN 1332 WAIVER APPLICATION, *supra* note 137, at 3.

[209] *See Public Comments on Waiver During Federal Comment Period*, CENTERS FOR MEDICARE & MEDICAID SERVICES, https://www.cms.gov/CCIIO/Programs-and-Initiatives/State-Innovation-Waivers/Downloads/WI-Federal-Public-Comments-Merged.PDF (last visited Apr. 5, 2020) (listing public comments on Wisconsin's application from Katie Pope, Abby Hammes, and ABC for Health).

[210] *See* Kamin, *supra* note 197, at 269–71.

patients' care can also draw on Dworkin's account of insurance, which supports the idea that individuals who are much wealthier than they would be in an ideal society can be asked to contribute more money to expensive patients' treatment.[211] Put another way, there is no single answer to the often-asked question of how much "we" should pay to assist an expensive patient; rather, the answer changes depending on who in society is paying.[212]

Dworkin's approach supports funding reinsurance through a dedicated progressive tax. One such option would be a "rescue tax" that pays for very costly interventions by taxing only households whose yearly income exceeds the cost of the intervention. So, for instance, the cost of Jacob's hemophilia treatment would be covered by a tax only on households who make $12 million or more per year. The rationale for the rescue tax is that: (1) only brute luck separates very wealthy individuals from being in the same position as Jacob, and (2) it would be rational for very wealthy individuals, unlike average-income or poor individuals, to pay high premiums to insure against the risk of needing very high-cost treatment. Although a rescue tax would face political challenges, there is real-world precedent for progressive taxation to fund health care: The ACA increased Medicare funding via taxes on high earners and on wealthy households' investments.[213]

One consequence of the rescue tax approach is that, in a poor or a highly equal society, very costly treatments would not be publicly subsidized. This outcome makes normative sense—a poor society should not be required to pay for very expensive medicines that would bankrupt the health care system.[214] And we see in practice that more equal societies are less willing to pay unlimited prices for costly medicines.[215]

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[211] *See* Dworkin, *Distribution of Health Care*, *supra* note 72, at 888.

[212] *Cf.* Emma Court, *More and More Health Care Bills Are Over $1 Million—and Expensive Drugs Are Playing a Major Role*, MARKETWATCH (July 22, 2018, 10:53 AM), https://www.marketwatch.com/story/million-dollar-health-bills-have-spiked-and-expensive-drugs-are-playing-a-major-role-2018-07-16 ("What is the level of expense that we think is appropriate to pay for breakthrough drugs? . . . We will have to get to a point where we ask, 'Is a $23 million drug something we want to pay for as a society?'"); Glabman, *supra* note 36 ("If a single patient can increase health care costs for all and perhaps become a burden to society, what is the responsibility of the many to provide health care to the few? Whom should we keep alive? How much should we pay for it?").

[213] *See* Linda Sugin, *Payroll Taxes, Mythology, and Fairness*, 51 HARV. J. ON LEGIS. 113, 162–63 (2014).

[214] *Cf.* Govind Persad, *The Medical Cost Pandemic: Why Limiting Access to Cost-Effective Treatments Hurts the Global Poor*, 15 CHI. J. INT'L L. 559, 562 (2015).

[215] *See* Margaret K. Kyle, *Competition Law, Intellectual Property, and the Pharmaceutical Sector*, 81 ANTITRUST L.J. 1, 20 (2016).

C. Setting Boundaries

As critics of reinsurance note and reinsurance proponents concede, reinsurance does not combat the high medical costs that necessitate its use.[216] Financing reinsurance progressively mitigates this concern but does not eliminate it. Even if treatment for expensive patients were entirely funded by taxes on the wealthy, these taxes would still have opportunity costs: The revenues raised could have been used to fund other important goals, such as ameliorating pollution and other upstream causes of ill health, and the taxes themselves create some degree of economic drag.[217] Coupling reinsurance with efforts to limit costs is therefore attractive. This Section discusses three ways of limiting high costs: (1) discouraging the development of interventions that make patients costly to treat; (2) giving patients the option to opt out of costly treatments; and (3) requiring expensive patients to bear more of their own treatment costs. The first option is the most normatively justified and likely to be the most politically viable.

1. Advance Discouragement of Expensive Treatments

Jacob's medical treatments are expensive because the drugs he takes are very costly. But drugmakers' ability to charge these high prices is a result of a policy choice not to set limits on what society is willing to pay for treatment. Unlike most other countries, the United States neither regulates drug pricing nor considers costs at the stage of drug approval.[218]

What would be a fair way of regulating prices for very expensive drugs? Some have suggested that society's willingness to pay high amounts for rescue in individual situations indicates that it must attach a very high value to expensive drugs.[219] This analysis overlooks the fact that time- and situationally

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[216] *See, e.g.*, MENDELSOHN, *supra* note 138, at 3 ("Finally, reinsurance is an efficient mechanism for removing costly claims from rate setting, but it does not address the underlying healthcare costs that caused large bills in the first place."); NORTH DAKOTA 1332 WAIVER APPLICATION, *supra* note 137; OKLAHOMA 1332 WAIVER APPLICATION, *supra* note 137, at 120 ("Commenter had a concern that health care and health insurance are two separate issues. For example, health insurance has its own administrative complexity, which might potentially divert resources from needy people. Commenter would like the legislature to look at health care costs and ways to improve the health care system."); *id.* at 122 ("Insurance carriers can't reduce prices unless providers do. Where are they? Response: . . . We do acknowledge that we have to bend the health care cost curve."); *see also* HALL, *supra* note 8, at 37.

[217] *See* Kamin, *supra* note 197, at 271 (discussing inefficiency produced by taxation).

[218] *See* Eric M. Katz, *Europe's Centralized New Drug Procedures: Is the United States Prepared to Keep Pace?*, 48 FOOD & DRUG L.J. 577, 585 (1993).

[219] *See* Michelle M. Mello, *What Makes Ensuring Access to Affordable Prescription Drugs the Hardest Problem in Health Policy?*, 102 MINN. L. REV. 2273, 2282 & n.41 (2018).

inconsistent preferences (as discussed in Part II) make the value of a drug dependent on context. Society may rightly regard itself as ethically obligated to absorb very high costs to save someone once the means of saving them are close at hand, but not to absorb the same costs to ensure that the relevant means are close at hand.[220] The socially justified cost to ensure the availability of expensive drugs may therefore be different from the socially justified cost of providing those drugs once they exist. This difference means that preventing the development of certain costly drugs can generate better outcomes by forestalling the existence of expensive societal obligations.

Preventing the development and sale of expensive drugs could be achieved through a variety of precommitment strategies. One strategy would be to decrease incentives to produce treatments that are likely to be very expensive in comparison to the benefits they provide, because they help only a few patients or have only small benefits.[221] Another would be to impose taxes or price regulations (potentially based on economic evaluations) on expensive treatments, which could encourage companies to channel resources into developing treatments that can be profitably sold at a lower cost.[222] Yet another would be allowing insurers to exclude these treatments from coverage or formularies.[223] Of these strategies, price caps and limits on research are likely to be most effective, because their preventive effect is furthest upstream and least likely to be criticized as denying rescue. Legally empowering insurers to refuse coverage would still expose them to public pressure to pay for expensive treatments.[224]

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[220] *Cf.* F. M. KAMM, INTRICATE ETHICS 371 (2007) (arguing that individuals may have an obligation to sacrifice their current possessions in order to rescue others, but no obligation to acquire possessions in order to rescue others).

[221] *See* Tito Fojo & Christine Grady, *How Much Is Life Worth: Cetuximab, Non-Small Cell Lung Cancer, and the $440 Billion Question*, 101 J. NAT'L CANCER INST. 1044, 1045 (2009); Govind Persad, *Should Research Ethics Encourage the Production of Cost-Effective Interventions?*, *in* ETHICS AND GOVERNANCE OF BIOMEDICAL RESEARCH 13, 16 (Daniel Strech & Marcel Mertz eds., 2016).

[222] The use of price regulation to incentivize lower-cost drug development would parallel the use of taxes on high-cost insurance plans to incentivize lower-cost care. *See* Kathryn L. Moore, *The Future of Employment-Based Health Insurance After the Patient Protection and Affordable Care Act*, 89 NEB. L. REV. 885, 919 (2011) (discussing how employers planned to respond to a tax on high-cost health plans by seeking to improve cost-efficiency and manage care more closely). For an example of price regulation for pharmaceuticals, see Emma Cosh et al., *Investing in New Medical Technologies: A Decision Framework*, 13 J. COM. BIOTECHNOLOGY 263, 267 (2007) (arguing that "[i]f there is little or no chance that the technology could be marketed at a price" below the cost-effectiveness threshold, "then the technology should not attract further investment," and devising a system for manufacturers to assess at an early stage whether to invest).

[223] *See* Ed Silverman, *CVS and the $100,000 QALY*, MANAGED CARE MAG. (Nov. 24, 2018), https://www.managedcaremag.com/archives/2018/12/cvs-and-100000-qaly.

[224] *E.g.*, *id.* (discussing critical responses to refusal of coverage for costly pharmaceuticals).

Price caps are likely to be a politically attractive solution because they could also garner support from current patients like Jacob. One commentator on Jacob's case, for instance, recognizes that hemophilia drugs' high prices reflect strategic decisions by pharmaceutical firms.[225] Price caps would lower costs in the short term and thereby protect many patients from becoming expensive in the first place. We might still worry about a purported bad consequence of capping drug prices—reduced investment in research and development.[226] But, where treatments are so expensive that they have little or no positive social value, the long-term reduction in investment in these treatments that price caps on pharmaceuticals would produce is in fact socially desirable.[227] So is the incentive that such caps would generate to research and develop treatments whose cost would fall under the cap. It is not socially valuable for drug companies to invest in developing treatments that make patients tremendously expensive to treat.[228] These investments, in fact, arguably do societal harm because they turn unpreventable tragedies into costly tragic choices.[229] Although none of the state waiver or reinsurance proposals to date have incorporated price caps or other efforts to discourage the development of expensive treatments, coupling reinsurance with price regulation would help to fill the cost-control gap in current reinsurance efforts.

Another way of discouraging the development of treatments that make patients expensive is to restructure subsidies for drug development. The Orphan Drug Act financially subsidizes the development of "orphan" drugs that will treat only a few patients.[230] This subsidy is normatively difficult to justify. Patients with rare diseases are neither more nor less worthy of treatment than others, yet the Orphan Drug Act creates an incentive to prioritize saving fewer lives over saving more.[231] It is misguided to incentivize the development of drugs that will help only a few patients at a time when research into new antibiotics, vaccines, and pain medications is urgently needed. Instead of

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225 Westlund, *supra* note 17.

226 *Id.*

227 *See* Govind Persad, *Pricing Drugs Fairly*, 62 WM. & MARY L. REV. (forthcoming 2020).

228 *Id.* at 25.

229 *Cf.* Paul J. Zwier, *High Prices in the U.S. for Life-Saving Drugs: Collective Bargaining Through Tort Law?*, 17 MARQ. BENEFITS & SOC. WELFARE L. REV. 203, 209 (2016) (arguing that pharmaceutical companies who charge excessive prices for lifesaving treatments commit the tort of intentional infliction of emotional distress).

230 Orphan Drug Act, Pub. L. No. 97-414, 96 Stat. 2049 (1983); *see* Baker Norton Pharm., Inc. v. U.S. Food & Drug Admin., 132 F. Supp. 2d 30, 31 (D.D.C. 2001) (describing the Orphan Drug Act).

231 *See* Niklas Juth, *For the Sake of Justice: Should We Prioritize Rare Diseases?*, 25 HEALTH CARE ANALYSIS 1, 7 (2017) (discussing arguments based on principles of need); Emily A. Largent & Steven D. Pearson, *Which Orphans Will Find a Home? The Rule of Rescue in Resource Allocation for Rare Diseases*, HASTINGS CTR. REP., Jan.–Feb. 2012, at 27, 29 (discussing ethical dilemmas presented by orphan drug funding).

subsidizing "orphan" drugs, governments would do better to offer prizes for drugs that address urgent and broadly harmful problems, such as antibiotic resistance, dementia, and obesity, or to increase scientific funding in these areas.[232]

Changes to subsidies and drug prices might have meant that Mila's and Jacob's conditions were untreatable, rather than treatable at high cost. Fei describes her obstetrician telling her that "[t]wenty years ago, this would have been a miscarriage."[233] And a commentator on Jacob's case asserts that "synthetic factor has been something like a miracle for the hemophilia community," enabling longer life spans and better daily life.[234] From a societal perspective, however, we can question whether these outcomes are "miracles," or instead what Lewis Thomas calls "halfway technologies" that allow patients to stay alive at tremendous cost.[235] It is difficult to say no to providing these technologies once they exist, but their cost means that we may be better off keeping them out of our own reach.[236]

2. Opting Out of Treatment

Yet another way of limiting costs posed by expensive patients is to allow patients to choose to decline expensive treatments in advance. One strategy for doing this, which Arti Rai calls "rationing through choice," involves offering patients the option of committing in advance to refuse certain expensive treatments.[237] Rationing through choice presents two difficult ethical issues, one involving distributive fairness and one involving the revocability of waiving one's rights. The issue of distributive fairness is whether individuals who know they will not develop certain expensive conditions should be able to profit from this knowledge. Declining the option to receive expensive treatment for hemophilia presents a way for people who do not have hemophilia to avoid paying the cost of hemophilia treatment, regardless of whether they would have

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[232] *See* Amy Kapczynski, *The Cost of Price: Why and How to Get Beyond Intellectual Property Internalism*, 59 UCLA L. REV. 970, 1019 (2012) (discussing "[p]rizes for vaccines or antibiotics"); Aaron S. Kesselheim & Kevin Outterson, *Improving Antibiotic Markets for Long Term Sustainability*, 11 YALE J. HEALTH POL'Y L. & ETHICS 101, 150–51 (2011); W. Nicholson Price II, *Grants*, 34 BERKELEY TECH. L.J. 1, 6, 49–50 (2019).

[233] FEI, *supra* note 19, at 6.

[234] Westlund, *supra* note 17.

[235] Lewis Thomas, *Notes of a Biology-Watcher: The Technology of Medicine*, 285 NEW ENG. J. MED. 1366, 1367 (1971).

[236] *Id.* at 1368.

[237] Arti Kaur Rai, *Rationing Through Choice: A New Approach to Cost-Effectiveness Analysis in Health Care*, 72 IND. L.J. 1015, 1018 (1997); *see also* Persad, *supra* note 170, at 17.

selected expensive treatment if they had a chance of having hemophilia.[238] This differs from the example of declining expensive treatment for late-life cancer, which will typically be purchased by people who are uncertain of their odds of developing cancer. Choosing such a plan can be understood as expressing a normative commitment to receiving more resources now in exchange for receiving fewer under certain specified circumstances later, rather than as profiting from one's own better health.

The waivability issue arises if someone opts out of access to a treatment, but then wants to opt back in once ill.[239] Denying access to treatment, even based on an agreed-to past commitment, may be psychologically wrenching. Imagine, for instance, if Mila's parents had opted out of access to expensive treatment before knowing they would have a very premature infant—we might want to give them the opportunity to reconsider, even though permitting such reconsideration vitiates the idea of a binding precommitment.[240] People may also feel that they are better informed once they have become ill, although establishing whether the ill present or the healthy past should be the more privileged perspective for informed decision-making is difficult.[241]

Another strategy for advance opt-out, which Christopher Robertson has called the "split benefit," would allow ill patients to waive their right to expensive treatment in exchange for receiving a portion of the money that would otherwise have been spent on treating them.[242] This approach avoids the problem of advantaging the healthy, since only ill patients will be offered this option. But the problem of waivability remains. Imagine that Jacob chooses (for instance) to receive a million dollars rather than a year of treatment. Once he is on death's door, it will be difficult to enforce his bargain against him. The split benefit also has the problem of recurring eligibility: Opting to receive the split benefit rather

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238 Rai discusses the problem of a choice-based system making it impossible to purchase insurance that will cover the problems of known expensive patients, but does not grapple with the problem of whether it is fair to profit from one's own better health, as opposed to one's health care preferences. *See* Rai, *supra* note 237, at 1042–45.

239 *Id.* at 1038.

240 Although Rai recognizes this problem, she has difficulty addressing it: She suggests that "ex ante rationing choices that contemplated very serious and irreversible deprivations of liberty might be disallowed," and that choices that bound individuals for more than a three- to five-year period would also be nonbinding. *Id.* at 1038–39. This exception would swallow the rule, because it would prohibit rationing that refuses lifesaving treatment, given that death is a serious and irreversible deprivation of liberty, and would also prohibit choices that have long-term serious health implications.

241 *See* Samuel R. Bagenstos & Margo Schlanger, *Hedonic Damages, Hedonic Adaptation, and Disability*, 60 VAND. L. REV. 745, 776 (2007).

242 Christopher Robertson, *The Split Benefit: The Painless Way to Put Skin Back in the Health Care Game*, 98 CORNELL L. REV. 921, 945 (2013).

than an expensive treatment could lead someone to become even sicker and then to be eligible for a different expensive treatment. For the split benefit to avoid the problem of recurring eligibility, it would have to involve permanently waiving access to any treatment that arises out of a given condition, or waiving access to any treatment above a certain cost.

3. Undue Hardship and Cost-Sharing

If advance discouragement and opt-out fail, society faces the difficult question of when, if ever, expensive patients can be asked to pay for treatment out of pocket. This question is particularly difficult because out-of-pocket payment for expensive patients—unlike for cheaper treatments—is likely to mean de facto denial, or reliance on charity or crowdfunding.[243]

The most compelling justification for setting boundaries on sharing involves the burdens that sharing imposes on others. One way of considering these burdens is the undue hardship framework used in disability accommodation law.[244] Undue hardship doctrine establishes that a person with a disability is not entitled to an accommodation, even a very beneficial one, if the accommodation would impose an excessive burden on others. Importantly, assessing whether an accommodation imposes undue hardship involves considering the financial position of the actor who is being asked to absorb the accommodation's cost: An accommodation may impose an undue hardship on a struggling employer, but not a wealthy firm.[245] Or it may impose an undue hardship on other employees who are overwhelmed, even if it would be reasonable to ask employees with ample time to take up some of the slack.[246]

An undue hardship framework would support bounding support for expensive patients at the point that funding this support imposes undue hardship on others. Such a framework would make boundedness dependent on breadth and progressivity. The broader or more progressive the cost-sharing structure is, the slower boundaries would be reached. Importantly, because undue hardship

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[243] *See* Hoffman, *supra* note 46, at 1920 n.207 (noting that few households can absorb very high costs).

[244] *See* US Airways, Inc. v. Barnett, 535 U.S. 391, 400 (2002); *see also* Gregory S. Crespi, *Efficiency Rejected: Evaluating "Undue Hardship" Claims Under the Americans with Disabilities Act*, 26 TULSA L.J. 1, 2, 8 (1990); Jeffrey O. Cooper, Comment, *Overcoming Barriers to Employment: The Meaning of Reasonable Accommodation and Undue Hardship in the Americans with Disabilities Act*, 139 U. PA. L. REV. 1423, 1432 (1991).

[245] *See* Crespi, *supra* note 244, at 14.

[246] *See, e.g.*, Kazmierski v. Bonafide Safe & Lock, Inc., 223 F. Supp. 3d 838, 852 n.10 (E.D. Wis. 2016) ("Employers . . . may be able to show undue hardship where provision of a reasonable accommodation would be unduly disruptive to other employees' ability to work.").

analysis is distinct from a cost-benefit trade-off, sharing the cost of expensive patients' care could be an undue hardship even if the costs that expensive patients impose are less than the total benefit they receive. The undue hardship framework is more analogous to the view that sacrifices can only be expected from others until those others must give up something of moral importance.[247] Once something of importance is at stake, individuals can legitimately be excused from further assistance even if the benefits of assistance, judged from a social perspective, outweigh its costs.

Rather than asking expensive patients to pay the entire cost of treatments that impose an undue hardship out of pocket, expensive patients could instead be asked to assume a greater proportion of cost sharing. This departs from the typical justification for cost-sharing, which rests on the discouragement of moral hazard,[248] by grounding cost sharing in a fairness, rather than an efficiency, justification. Although this type of cost-sharing is sometimes seen, as with brand-name drugs under value-based insurance, cost-sharing is ill-suited to setting limits on the sharing of expensive patients' costs. This is because the treatments used by expensive patients are so costly that almost no household would be able to afford any significant amount of cost-sharing.[249]

Ultimately, cost-sharing, like an advance opt-out, is difficult to implement in a context where expensive lifesaving technology exists.[250] It is hard to hold individuals to a promise to die when (expensive) treatment is close at hand, or to deny individuals this treatment if they are unable to pay. This indicates that the upstream strategies discussed in Part III.A may be more effective at preventing patients from becoming expensive. By strictly regulating prices or refusing to approve or research expensive drugs, health policy can prevent tragic choices from arising—it can prevent the existence of costly treatment for unidentifiable expensive patients, rather than waiting for these patients to become identifiable and then denying them access to treatment.

CONCLUSION

This Article has argued that fairly distributing the cost of expensive patients' care requires considering three values: increasing the *breadth* of sharing, setting

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[247] *Cf.* Peter Singer, *Famine, Affluence, and Morality*, 1 PHIL. & PUB. AFF. 229, 241 (1972) (discussing the proposal "that we should prevent bad occurrences unless, to do so, we had to sacrifice something morally significant").

[248] *See, e.g.*, Robertson, *supra* note 242, at 939.

[249] Hoffman, *supra* note 46, at 1920 n.207.

[250] *See* Robertson, *supra* note 242, at 941.

defensible *boundaries* on sharing, and increasing the *progressivity* of sharing. These values are most effectively operationalized by creating a reinsurance program to handle expensive patients' costs; funding this program through a progressive tax that requires only wealthy individuals to pay for very expensive patients; and combining this tax-funded program with efforts to reduce the development and provision of treatments that would render patients very expensive. While this suite of policy prescriptions is the most likely to be effective and politically palatable, this Article has also discussed alternative ways of trying to increase breadth, set boundaries, and improve progressivity.

As the next wave of healthcare reform proposals appear, recognizing the fact that so much of healthcare spending is directed toward expensive patients is crucial. Because so much medical spending is directed to expensive patients, limiting and fairly distributing the cost of their treatment will be an essential part of any successful healthcare reform that controls and fairly divides costs. This Article has provided a framework that can help enable health reform plans to achieve these goals.