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THE STRUGGLE TO BURY PRE-EXISTING CONDITION CONSIDERATION

SALLIE THIEME SANFORD*

I. INTRODUCTION

As of January 1, 2014, applicants for comprehensive health insurance do not face questions about their health history. The Affordable Care Act (ACA) prohibits health insurers from considering an individual's health history in determining whether to sell that person a comprehensive health insurance policy, the policy's price, or its coverage terms.¹ Pre-existing condition (PEC) consideration is, in this crucial context, dead. Few will mourn its passing. This legislative milestone marks a significant step towards the goal of a healthier population.

While celebrating this achievement, however, we ought to recall the context of PEC consideration, its practical application, and its continuing potential to infect other aspects of health care coverage. The "struggle for the soul of health insurance" continues.² With the ACA's reliance on private insurance, albeit under a much different regulatory framework, competitive pressures to favor the healthy will persist. Moreover, enforcement of the new regulatory framework will be hampered by the ACA's complex and contentious federalism dance. Vigilance will be required to ensure that those made vulnerable by illness or injury are not further disadvantaged by other key aspects of insurance, such as coverage exclusions, benefit decisions, and provider networks. Access to health insurance is only the beginning.

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¹ Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010), *amended by* Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029 (codified as amended in scattered sections of 26 and 42 U.S.C.). *See also* Katie Keith, Kevin Lucia, & Christine Monahan, *Nondiscrimination Under the Affordable Care Act*, CENTER ON HEALTH INSURANCE REFORMS, GEORGETOWN U. HEALTH POL'Y INST., at 8-9 (July 2013), http://chir.georgetown.edu/pdfs/NondiscriminationUndertheACA_GeorgetownCHIR.pdf (discussing a number of the ACA's other nondiscrimination provisions relating to health insurance such as mandated essential health benefits coverage requirements, elimination of lifetime coverage limits and expanded civil rights protections).

² Deborah A. Stone, *The Struggle for the Soul of Health Insurance*, 18 J. HEALTH POL. POL'Y & L. 287 (1993).

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II. THE HISTORIC TENSION BETWEEN ACTUARIAL FAIRNESS AND SOLIDARITY

Insurance access has historically included barriers for those with a variety of medical conditions. As Deborah Stone details in her seminal 1993 article *The Struggle for the Soul of Health Insurance*, the logic of “actuarial fairness” — people paying for their own risk — developed as an inherent part of the competitive markets for health insurance.³ It also resonates with social divisions and individualistic philosophies that remain prominent in American society. Its practical application involved medical underwriting, including in some markets, individual questionnaires to find “the best and most desirable insureds.”⁴

Stone contrasts this with the “solidarity principle” that accepts sickness as “a condition that should trigger mutual aid” and presumes risk pooling within the community as broadly conceived.⁵ Although at the end of the last century there was increasing political pressure to restrain underwriting, Stone concludes that the embedded nature of actuarial fairness will make it extremely hard to eradicate.⁶

In terms of what constituted a PEC for purposes of health insurance, varied definitions have been propounded over the years in statutes and insurance contracts. Under one type of definitional framework, coverage could be denied for medical conditions for which a person had actually received a diagnosis or treatment prior to applying for coverage. Another framework allowed consideration of undiagnosed conditions that caused symptoms for which a prudent person would have sought treatment.⁷

³ *Id.* at 292–300.

⁴ *Id.* at 294 (internal citation omitted).

⁵ *Id.* at 290–92.

⁶ *Id.* at 290. See also Timothy Stoltzfus Jost, *The Regulation of Private Health Insurance*, NAT'L ACAD. OF SOC. INS., at 1-5 (Jan. 2009), http://www.nasi.org/usr_doc/The_Regulation_of_Private_Health_Insurance.pdf (discussing particular challenges and structural tensions in the health insurance context, including its market dynamics).

⁷ See Jennifer M. Franco, *Undermining the Protection of Health Insurance: The Preexisting Condition Clause*, 30 New Eng. L. Rev. 883 (1996) (citing Robert Lowe, *Genetic Testing and Insurance: Apocalypse Now?*, 40 Drake L.

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The ACA's PEC protections did not spring up *sui generis* in the 111th Congress. There has long been legislative concern regarding the perversity of health insurance being denied to some precisely because they are likely to need it. States, the traditional regulators of insurance, particularly on the individual market, addressed pieces of the problem, with significant variation among the states.⁸ For example, some states allowed insurers to permanently exclude coverage for a PEC; others limited the exclusion timeframe to a matter of months or years. Some states limited how much more someone could be charged based on a PEC or other factors such as age or tobacco use; others created high risk pools for those denied coverage, and defined the PEC circumstances that could land a person there.

Federal laws addressed pieces of the problem. The federal Health Insurance Portability and Accessibility Act (HIPAA) of 1996, for example, reduced the applicability of PEC consideration in the employer-provided insurance context.⁹ It also provided some protection from PEC exclusions on the individual market — but only for those who had had qualifying group coverage and then “COBRA’ed” it for as long as allowed. Depending on the state, the offered coverage might be within a high risk pool, typically an expensive option.¹⁰ Another

Rev. 507, 521 (1991). *See also Health Insurance Market Reforms: Pre-Existing Condition Exclusions*, HENRY J. KAISER FAMILY FOUND., at 3-5 (Sep. 2012), <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8356.pdf>.

⁸ *Health Insurance Market Reforms: Pre-Existing Condition Exclusions*, HENRY J. KAISER FAMILY FOUND. (Sep. 2012), <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8356.pdf> (3-5) (summarizing state approaches to PEC exclusions). *See also* Jost, *supra* note 6 (discussing historic and evolving roles of state and federal regulation in health insurance).

⁹ Health Insurance Portability and Accountability Act, Pub. L. No. 104-191 (1996) (codified at 42 U.S.C. §§ 300gg, 1320d et seq., 29 U.S.C. § 1181 et seq.).

¹⁰ *See* Jessica Roberts, “Healthism”: A Critique of the Antidiscrimination Approach to Health Insurance and Health-Care Reform, 2012 U. Ill. L. Rev. 1159, 1180–82 (2012) (discussing HIPAA’s significant practical limitations). The federal law popularly known as COBRA requires most, but not all group plans to provide a temporary continuation of health insurance coverage that would otherwise be lost due to certain events (such as job lost or divorce). The length of coverage varies between 18 – 36 months and the beneficiary may be charged up to 102% of the total premium cost, a prohibitive amount for many, particularly those who are eligible precisely because they have lost their jobs. *See* Consolidated Omnibus Budget Reconciliation Act of 1985, Pub. L. No. 99-272, 100 Stat. 82 (codified as amended in scattered sections of 29 U.S.C.); *Fact Sheet, Consolidated Omnibus Budget Reconciliation Act (COBRA)*, U.S. DEP’T OF LABOR, <http://www.dol.gov/ebsa/newsroom/fscobra.html> (last visited January 27, 2014).

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federal law, the Genetic Information Non-Discrimination Act, expands HIPAA's prohibition on using genetic information in medical underwriting; it does not prohibit consideration of manifest genetically linked conditions.¹¹

This patchwork of federal and state laws left many dangling between the threads, unable to get a policy or offered policies with key coverage exclusions or prohibitively high cost.¹² And it did not impact only those with serious illnesses and injuries; relatively benign conditions could lead to exclusions and extra costs. A substantial portion of Americans faced the risk of being unable to secure adequate insurance if they lost or never had employer-provided coverage.¹³ As a concrete example of the how PEC consideration functioned, it is worth recalling recent history in a state with comparatively protective laws in this area.

III. A QUESTIONNAIRE: PEC CONSIDERATION IN ACTION

If you are wondering what can go wrong with a body, the Washington State Health Insurance Questionnaire is a good place to look. It was introduced as part of a 2000 legislative package that attempted to revive the individual market after piecemeal evisceration of comprehensive reform had left it in tatters.¹⁴ As part of the package, insurers could impose a nine-month waiting period for PEC coverage on the individual market, faced few rate

¹¹ Genetic Information Nondiscrimination Act, Pub. L. No. 110-233, 122 Stat. 881 (codified as amended in scattered sections of 29 USC and 42 USC) (2008). *See also* Roberts, *supra* note 11, at 1184–85 (citing Genetic Information Nondiscrimination Act, Pub. L. No. 110-233, §§101(a)(3)(A), 101(b)(c)(1), 122 Stat. 881, 883-905 (amending ERISA §702(b))).

¹² *See* Sara Rosenbaum, *Insurance Discrimination on the Basis of Health Status: An Overview of Discrimination Practices, Federal Law, and Federal Reform Options*, ROBERT WOOD JOHNSON FOUND., at 2, (2009), <http://www.rwjf.org/content/dam/farm/reports/reports/2009/rwjf36943> (arguing that these and other laws, while laudable, provide “relatively limited protections.”).

¹³ *Kaiser Health Tracking Poll: June 2013*, HENRY J. KAISER FAMILY FOUND. (June 19, 2013), <http://kff.org/health-reform/poll-finding/kaiser-health-tracking-poll-june-2013/> (In 2013 survey, 49 percent of adults under age 65 say they or someone in their household has a pre-existing condition, and many of them report problems related to getting and keeping insurance).

¹⁴ *See* Adele M. Kirk, *Riding the Bull: Experience with Individual Market Reform in Washington, Kentucky, and Massachusetts*, 25 J. HEALTH POL., POL'Y & L. 133, 133-37 (2000) and Sallie Thieme Sanford, *Mind the Gap: Basic Health along the ACA's Coverage Continuum*, MD. J. HEALTH CARE L. & POL'Y (forthcoming 2014) (describing Washington State's comprehensive health reform efforts in the early 1990s).

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limitations, and could exclude entirely the most expensive patients. Rejected applicants were then entitled to coverage within the state's high-risk pool, which, though subsidized, came with high premiums and high cost-sharing in addition to waiting periods for PEC coverage.¹⁵ As with the medical underwriting examples from the early 1990s provided in Stone's article, this tool provides a concrete description of one form of risk consideration in the health insurance marketplace.

The questionnaire, which remained substantially the same through 2013, was designed to identify the most expensive patients, the roughly eight percent of individual insurance applicants the companies could reject entirely.¹⁶ Those who were "HIPAA-eligible" — basically those who were covered under an employer-sponsored plan that they continued for the maximum allowed time under COBRA — and some others¹⁷ were exempt from the questionnaire and the prospect of individual insurance denial. All others who wanted individual insurance in the state had to fill out the questionnaire. Those whose scores reached a certain number could be — and would be — denied coverage and allowed to join the state's high-risk pool.¹⁸

The questionnaire exceeded 25 pages, with more than 200 medical conditions grouped within 11 categories (circulatory problems, digestive issues, skeletal malfunctions and more). Each medical condition had a point value attached, and the total score determined eligibility for individual insurance. The scoring sheet was available online, and the threshold score number was set for some time at 325.

¹⁵ Act of March 23, 2000, ch. 79, 2000 Wash. Sess. Laws 413, 425 (codified as amended in scattered sections the WASH. REV. CODE).

¹⁶ WASH. REV. CODE § 48.41.060 (2010).

¹⁷ WASH. REV. CODE. § 48.43.018 (2010), *amended by* S.B. 6412, 62nd Leg., Reg. Sess. (Wash. 2012).

¹⁸ WASH. REV. CODE. § 48.41.100 (2010); *Standard Health Questionnaire for Washington State*, WASH. STATE HEALTH INS. POOL, <https://www.wship.org/Docs/SHQ%20Revised%2004%203%202012%20Final%20Post.pdf> (last revised March 2012). For rules, *see* WASH. ADMIN. CODE §§ 182-23-010, 182-23-020, 182-23-060, 284-43-975, 284-43-985.

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Each of the 36 conditions listed on the first two pages was scored at 325. The questionnaire did not explicitly say that, but it did allow that if you had checked any of them you “may choose to answer” the remaining sections or may simply skip to the end.¹⁹ Included in this alphabetically listed group were AIDS, cystic fibrosis, necrotizing fasciitis, and pulmonary heart disease. There were also 325-pointers scattered throughout the other sections; this group included many malignancies.²⁰

The automatically disqualifying conditions changed over time as treatments evolved. For example, the inclusion of multiple sclerosis was tied to the availability of medications that slow the disease’s progression and that come with a wholesale price of as much as \$48,000 a year.²¹ The questionnaire’s lowest-scoring condition, coming in at one point, was having had jaundice as an infant (last 12 months). This part of the questionnaire faded away in 2010, as the ACA’s prohibition on PEC for children’s health insurance coverage went into effect.

As a parlor game, one could try to amass a collection of relatively common and benign conditions to see if the score can reach 325. Nasal polyp (last 12 months), eczema, insomnia, depression (last 5 years), flu (treated by physician), food allergies, erectile dysfunction (if mental), and high cholesterol add up to 325.²² A recent history of tennis elbow, migraine headache, kidney stones, yeast infection, and restless leg syndrome would also suffice.

IV. THE CHALLENGES OF BURYING PEC CONSIDERATION

As of January 1, 2014, applicants for health insurance do not have to fill out this questionnaire. The ACA forbids it. Whether applying for health insurance coverage through

¹⁹ *Standard Health Questionnaire for Washington State*, *supra* note 19, at 9.

²⁰ *Scoring for the Standard Health Questionnaire for Washington State, Use for Individual Coverage Beginning On or After October 1, 2009*, WASH. STATE HEALTH INS. POOL, <https://www.wship.org/Docs/SHQ%20Point%20Scores%20Final%20%20Condition%20Numbers.pdf> (last revised May 12, 2009).

²¹ K. Noyes, et al., *Cost-effectiveness of disease-modifying therapy for multiple sclerosis: A population-based study*, 77 NEUROLOGY 355 (2011).

²² *Scoring for the Standard Health Questionnaire for Washington State*, *supra* note 21.

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individual or group markets, people cannot be denied coverage or charged more because of their health status. The currently healthy do not get the advantage of paying less in premiums and the currently sick do not face the disadvantage of paying more.²³

In this sense, the individual market comes closer to the operation of the employer-provided insurance market. In addition, the package of “essential health benefits” to be offered includes coverage — such as maternity care and mental health treatment — that has not been readily available on the individual market and that targets conditions with distinct societal impacts. Where allowed by state law, rates can vary on the individual market based on tobacco use (with tobacco users charged up to fifty percent more than non-users) and age (with older people charged up to three times as much as young people).²⁴ While these provisions certainly reflect consideration of actuarial fairness and an effort to maintain financial viability of the private market, the ACA’s overall approach moves the country decisively towards the solidarity principle of insurance.²⁵

Among those who know about them, the ACA’s PEC prohibitions are among its most popular aspects. A March 2012 New York Times/CBS poll found eighty-five percent approved of the “provision in the 2010 health care law that requires health insurance companies to cover those who may have an existing medical condition or prior illness.”²⁶²⁷ In an expression of the

²³ Of course, those with greater health care needs are likely to end up paying more in out-of-pocket costs. Additionally, of course, the overall rates paid by a covered group are impacted by the health care expenses of those who make up the group.

²⁴ Patient Protection and Affordable Care Act § 1201, adding Public Health Service Act (PHSA) § 2701 (codified at § 42 U.S.C. 300gg). *See also Overview: Final Rule for Health Insurance Market Reforms*, CTR FOR MEDICARE AND MEDICAID SERVICES (Feb. 27, 2013), <http://www.cms.gov/CCIIO/Resources/Files/Downloads/market-rules-technical-summary-2-27-2013.pdf>

²⁵ Jessica Roberts argues that these and other aspects of the ACA approximate health status, and thus continue disadvantaging the same populations as the prior system. “Thus, while the Affordable Care Act may end health-status discrimination on its face it will not in its effect.” Jessica L. Roberts, “*Healthism*”: A Critique of the Antidiscrimination Approach to Health Insurance and American Health-Care Reform, 2012 U. ILL. L. REV. 1159, 1160 (2012).

²⁶ *Poll (field date Mar. 21-25, 2012)*, N.Y. TIMES/CBS NEWS at 4, (Mar. 27, 2012), http://www.nytimes.com/interactive/2012/03/27/us/03272012_polling_doc.html.

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tension highlighted by Deborah Stone decades ago, however, this coverage requirement is also increasingly cited as unfair to the young and healthy. An anti-ACA advertisement aimed at young people, for example, argues that the young will unfairly pay higher premiums: "Sure, you work out, stay healthy. But, come on bro, someone's got to pay for people who smoke, drink 85 ounce sodas, and live in Barcaloungers."²⁸ Key questions for the insurance exchanges going forward will be the claims status of their risk pools and the resulting costs of unsubsidized insurance. This is a primary reason why reports on enrollment numbers break down the enrollees by age group, as a proxy for health status.²⁹

The ACA's insurance reforms aim not only to increase coverage but also, by facilitating apples-to-apples comparison, to encourage competition on quality and price. Given the reality of price competition, though, market pressures to favor the healthy are likely to persist. Those pressures could play out in other key aspects of insurance.³⁰

An area of concern relates to the networks of providers (including particularly physicians and hospitals) offered by the health insurance plans on the new Exchanges or Marketplaces. In 2014, they seem to be generally narrow, or limited, compared to the broader networks typically

²⁷ A January 2014 Kaiser Foundation poll found that about half of those surveyed did not know whether the ACA "[p]rohibit[s] insurance companies from denying coverage because of a person's medical history." *Kaiser Health Tracking Poll: January 2014*, HENRY J. KAISER FAMILY FOUND. (Jan. 30, 2014), <http://kff.org/health-reform/poll-finding/kaiser-health-tracking-poll-january-2014/> (finding that the public generally views the ACA unfavorably).

²⁸ CrossroadsGPS, *Crossroads GPS: Propaganda*, YOUTUBE (August 26, 2013), <http://www.youtube.com/watch?v=hfP6LmJiSec&list=UUZtZuLHzPSeodii1DhtQzWA&feature=c4-overview>; see also Stone, *supra* note 2, at 287 (discussing health insurance ad that includes the statement "If you don't take risks, why should you pay for someone else's?").

²⁹ See *Health Insurance Marketplace: January Enrollment Report*, DEP'T OF HEALTH AND HUMAN SERVS., OFFICE OF THE ASSISTANT SEC'Y FOR PLANNING AND EVALUATION (January 13, 2014), http://aspe.hhs.gov/health/reports/2014/MarketPlaceEnrollment/Jan2014/ib_2014jan_enrollment.pdf.

³⁰ See Keith, Lucia & Monahan, *supra* note 1 (detailing areas of potential concern, the challenges of defining, monitoring and enforcing the ACA's nondiscrimination standards). See also Sara Rosenbaum, *Insurance Discrimination on the Basis of Health Status: An Overview of Discrimination Practices, Federal Law, and Federal Reform Options*, ROBERT WOOD JOHNSON FOUND., at 2, (2009), <http://www.rwjf.org/content/dam/farm/reports/reports/2009/rwjf36943> (written prior to the ACA's passage, setting out areas of concern and how they might be addressed under various reform proposals).

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offered by employer-sponsored plans.³¹ Narrow networks can hold down costs, and thus premiums, supporting the goal of affordability. They could also deter selection by those who need care for serious or chronic conditions, disadvantaging the unhealthy. How will regulators approach a situation in which, for example, a child is born with a congenital heart disease but the network does not include a pediatric cardiologist?³² As the Marketplaces evolve over time, regulators will need to monitor network adequacy, not only in terms of numbers of providers, but also types of providers.

Another area of potential concern relates to coverage exclusions and delays for medical treatment and also for medications. One reason for this concern is that the Marketplace plans are based on “benchmark plans” sold in the state prior to the ACA’s enactment. Updating a benchmark plan to include the required ten essential benefits is relatively straightforward compared to addressing the “gray areas” of benefit design such as exclusions and visit limits.³³

Utilization review practices also hold a potential for inappropriate discrimination. Utilization review is a process by which insurers decide on a case-by-case basis whether to cover, or continue to cover, a particular treatment. While the ACA creates more standardized independent review options for these decisions, the burden of challenging a utilization review decision rests largely with the patient, or the patient’s family.³⁴ The new appeal rights are extremely valuable but might not be the best way to identify problematic practices on a systemic basis.

³¹ Robert Pear, *Lower Health Insurance Premiums to Come at Cost of Fewer Choices*, N.Y. TIMES (Sep. 22, 2013), http://www.nytimes.com/2013/09/23/health/lower-health-insurance-premiums-to-come-at-cost-of-fewer-choices.html?pagewanted=all&_r=0.

³² This example is included in the Georgetown report based on interviews with regulators and advocates. See Keith, Lucia & Monahan, *supra* note 1 at 11.

³³ *Id.* at 13 -14 (reflecting statements of interviewed regulators).

³⁴ *Id.* at 15 (discussing practical challenges to bringing an appeal).

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Vigilance will be required to ensure that those made vulnerable by illness or injury are not further disadvantaged by these and other aspects of insurance coverage. Enforcement and monitoring of the ACA's health insurance reforms will be complicated, however. There is as of yet little federal guidance on the practical meaning of the ACA's nondiscrimination requirements.³⁵ What benefit design features perpetuate discrimination now disallowed by the ACA? How can regulators and others identify them?

In addition, this is one of the many areas of the law that involves a complex and contentious federalism dance.³⁶ The regulation of health insurers and of commercial insurance has historically been a state function. The ACA presumed that most states would run their own insurance Marketplaces. Most have declined to do so, at least for the first year, and deferred to the fallback position of a federally facilitated exchange. If states fail to monitor compliance with the ACA's insurance regulation, or actively decline to enforce them, will the federal government have the resources and expertise to do so? Will advocacy groups take up the challenge? These are some of the many ACA implementation questions highlighted by the ongoing political opposition to the law.

PEC consideration in health insurance issuance is gone. This and other aspects of the ACA's insurance reforms take a decisive and much needed step away from the logic of actuarial fairness and toward the principle of social solidarity. That principle will be tested, however, by the ACA's allowable rating features and by market pressures to favor the healthy in other aspects

³⁵ *Id.* at 15 -16 (discussing possible forms of guidance and issues to be addressed).

³⁶ Another key area, of course, is in the ACA's expansion of the joint federal-state Medicaid programs to cover citizens with incomes below 138% of the Federal Poverty Level. As written, the ACA presumes that all states would do so; following the Supreme Court's decision making this expansion optional, many have declined to do so, at least beginning in 2014. *See generally Status of State Action on the Medicaid Expansion Decision, 2014*, HENRY J. KAISER FAMILY FOUND., <http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/> (last visited Jan. 27, 2014); *National Federation of Independent Business v. Sebelius*, 132 S.Ct. 2566 (2012); *A Guide to the Supreme Court's Decision on the ACA's Medicaid Expansion*, HENRY J. KAISER FAMILY FOUND. (August 2012), <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8347.pdf>.

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of coverage. It will also be tested by the ACA's complex overlap of federal and state authority.

The struggle for the soul of health insurance continues, as does the overarching struggle to ensure robust access to health care for all.