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# Saving Money on Health Insurance Just Got a lot Easier . . . Or Did It?: The Preserving Employee Wellness Programs Act and its Impact on the Future of Employee Health

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# Saving Money on Health Insurance Just Got a lot Easier . . . Or Did It?: The Preserving Employee Wellness Programs Act and its Impact on the Future of Employee Health

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ABSTRACT

*This Note addresses the growing use of employer-sponsored wellness programs in the American workplace and the concomitant harms and risks these programs impose on employee privacy and insurance costs. Specifically, this Note analyzes the Preserving Employee Wellness Programs Act (PEWPA)—a proposed law that would allow employers to require employees to disclose genetic information to qualify for an employer-sponsored wellness program (and the program's associated insurance premium benefits). This Note ultimately argues that employees and employee advocacy groups must work to thwart PEWPA to preserve employee privacy in the face of mounting corporate pressure to alter the structure of employer-sponsored health insurance.*

## INTRODUCTION

Employer-sponsored wellness programs have secured a comfortable position in corporate America since Congress and President Barack Obama enacted the Patient Protection and Affordable Care Act (ACA) in 2010. The ACA amended the Public Health Services Act (PHSA) and the Employee Retirement Income Security Act (ERISA) to permit employers to offer wellness incentives as part of group health plans.[1] The success of wellness programs, in large part, rests on employers' presumptions that wellness programs decrease employer-borne health insurance costs, bolster employee health through weight management regimens and smoking cessation programs, and lead to a more productive workforce.[2] Employers deem the programs an opportunity for employees to receive an insurance premium deduction of up to thirty percent—an opportunity few employees have good reason to reject.[3] Legal and social sciences scholars have written much on the efficacy of wellness programs and whether the enormous incentive to participate in (or penalty to abstain from) them truly provides employees with a voluntary choice. Most scholars argue that the programs do not.[4]

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1. Alfred Lewis, Vikram Khanna & Shana Montrose, *Employers Should Disband Employee Weight Control Programs*, 21 AM. J. MANAGED CARE e91 (2015).

2. *Id.* at e91.

3. *Id.*

4. *See, e.g.,* Matt Lamkin, *Health Care Reform, Wellness Programs and the Erosion of Informed Consent*, 101 KY L.J. 435, 437 (2013) (arguing that conditioning insurance premium reductions on employee participation in wellness programs ironically reduces employee

Around the same time wellness programs garnered popularity, direct-to-consumer ("DTC") genetic testing companies, such as 23andMe and Color Genomics, determinedly launched themselves into the consumer health arena.[5] DTC companies provide services allowing consumers to trace their genealogy and genetic history and to examine whether they are genetically predisposed to adverse health conditions, such as cancer or heart disease.[6] While DTC testing services enjoy largescale consumer participation, legal scholars criticize DTC companies for inadequately disclosing to consumers how their genetic information may be used, especially when consumers choose to analyze their genetic predisposition to disease.[7] Put differently, critics argue that DTC companies do not secure the type of informed consent from consumers that the Health Insurance Portability and Accountability Act (HIPAA) requires when doctors and patients engage in genetic testing. DTC genetic testing companies do not provide results from the tests to a consumer's doctor, but they do warn consumers that insurers may use information consumers receive from the tests against them via enlarged premiums.[8] Indeed, healthcare lawyers and medical professionals are particularly concerned that consumers who learn they are predisposed to disease will provide their test results to doctors,[9] and insurance providers might increase premiums.[10]

Wellness programs and DTC genetic testing are two separate phenomena. Wellness programs allow employees to reduce health insurance costs through pledges to exercise, quit smoking, and live more active and healthy lifestyles.[11] DTC genetic testing, on the other hand, allow consumers to dig into their ancestral history

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health). *But see* Ron Z. Goetzel, et al., *Do Workplace Health Promotion (Wellness) Programs Work?*, 56 J. ENVTL. & OCCUPATIONAL MED. 927 (2014) (maintaining that workplace wellness programs increase employee health).

5. *See, e.g.,* Erika Check Hayden, *The Rise, Fall and Rise Again of 23andMe*, 550 NATURE 174, 176 (2017) (describing 23andMe's 2009 resurgence into DTC genetic testing for disease predisposition).

6. *Id.* at 177.

7. *See, e.g.,* Erica Che, Note, *Workplace Wellness Programs and the Interplay Between the ADA's Prohibition on Disability-Related Inquiries and Insurance Safe Harbor*, 2017 COLUM. BUS. L. REV 280, 302–03 (2017) (arguing that employees do not receive proper disclosure from employers about how their medical information can be used in workplace wellness programs).

8. *See* Linsey Jones, *FDA Regulation Defines Business Strategy in Direct-to-Consumer Genetic Testing*, BIOTECH CONNECTION (Oct. 30, 2017), https://biotechconnectionbay.org/view-points/fda-regulation-defines-business-strategy-in-direct-to-consumer-genetic-testing/ [https://perma.cc/K8EU-TMZU].

9. *Id.* In theory, providing information from a genetic test to a doctor would be a good thing because doctors are able to screen for specific diseases. However, the fear is that insurance companies will receive the genetic information before the disease is covered, thus inflating premiums. *See id.*

10. *See* Julia Ries, *There's a Catch that Comes with Taking a 23AndMe Test*, HUFFINGTON POST (Dec. 3, 2018), https://www.huffpost.com/entry/23andme-warnings-at-home-genetic-test_n_5c01b108e4b0606a15b54dae [https://perma.cc/8CF6-A2JR] (discussing how GINA often does not apply to life insurance, "meaning that these premiums could very well fluctuate based on your test results.").

11. Lewis, Khanna & Montrose, *supra* note 1, at e91.

and discover whether they are predisposed to genetic health issues.[12] Nevertheless, congressional concern that employers could use employee genetic information as a weapon against employees prompted Congress to enact the Genetic Information Nondiscrimination Act (GINA).[13] GINA prohibits employers from requesting employee genetic information and from using employee genetic information against them. As of now, GINA bars employers from factoring employee genetic information into whether employees qualify for wellness programs.[14]

Congress is currently considering the Preserving Employee Wellness Programs Act (PEWPA).[15] The Act, which passed through committee on partisan lines, would permit employers to require employees to submit to genetic testing to qualify for an employer-sponsored wellness program—and thus to qualify for the insurance premium deductions attached to the wellness program.[16] In light of the safeguards Congress enacted to protect employee genetic information and employee autonomy, Congress should strike down PEWPA and enact measures to bolster employee choice and autonomy regarding the use of their genetic information. What is more, Congress must ensure that if an employee provides genetic information they do so voluntarily.

Part I of this Note will analyze the Act in light of literature and litigation regarding wellness programs and DTC genetic testing. Part II contemplates PEWPA's legality in light litigation stemming from the EEOC's recently promulgated rules permitting employers to require an employee's spouse to provide genetic information to qualify for a wellness program. Part III proscribes a plan to respond to the Act and its implications, whether Congress enacts it or not.

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12. Hayden, *supra* note 5, at 175–76.

13. Genetic Information Nondiscrimination Act of 2008, 42 U.S.C. §2000ff-1(b)(2) (2018).

14. *Id.*

15. Preserving Employee Wellness Programs Act, H.R. 1313, 115th Cong. (2017); *see also* Michael R. Dohn, *Personal Genomics and Genetic Discrimination: Is Increased Access a Good Thing*, 45 W. ST. L. REV. 107, 124–25 (2018) (discussing how PEWPA would erode GINA protections).

16. While the Act passed committee on partisan lines, with all Republicans voting for the Act and all Democrats against it, President Obama, a democrat, sparked genetic data pooling with the Precision Medicine Initiative—which has since evolved into the National Institute of Health's *All of Us* research program. *All of Us* works to solve America's current healthcare crisis through precision medicine—a medical technique that works to cure a specific patients or groups of patients by using their genetic code to search for medical predispositions. *See* SEAN RILEY, PRESERVING EMPLOYEE WELLNESS PROGRAMS ACT (HR 1313, 115TH CONGRESS), DUKE SCI. POL. 2 (2017); Sy Mukherjee, *It Might Soon Be Legal for Employers to Force You Into a Genetic Test*, FORTUNE (Mar. 10, 2017), http://fortune.com/2017/03/10/genetic-testing-workplace-wellness-bill/ [https://perma.cc/8WEA-92CQ].

## I. EMPLOYER-SPONSORED WELLNESS PROGRAMS AND GENETICS: PARTICIPATION FACTORS, COERCION, & THE EEOC

This Part discusses the coercive role employer-sponsored wellness programs play in the American workplace. Section A analyzes relevant statutes and litigation in the employer-sponsored wellness program sphere and their potential impact on employees. Section B places DTC genetic testing within the context of GINA and relevant informed consent standards and fleshes out why DTC genetic testing should be subject to informed consent standards to preserve GINA's purpose.

### *A. Wellness Programs: The Path Towards Employer-Mandated Compulsion of Genetic Information*

The term "wellness program" typically refers to employer-sponsored health promotion and disease prevention programs offered to employees. Some wellness programs are part of an employer-sponsored group health plan, while others are not; this Note will focus on the former. Wellness programs generally ask employees to answer questions on a health risk assessment (HRA), undergo biometric screenings for risk factors (such as high blood pressure or cholesterol), or partake in nutrition classes and weight loss and smoking cessation programs.[17] Some employers encourage employee spouses to participate in wellness programs, especially when the employee is part of a group health plan.[18]

Before Congress enacted the ACA, employers offered small-scale incentives, like gift cards or additional vacation days, to employees who participated in wellness programs.[19] But these incentives proved ineffective at reducing health costs. They did not motivate employees to make substantial changes to their lifestyles.[20] To make wellness programs worth employer time and effort, Congress raised the ceiling on employer-sponsored, health-conditioned insurance premium deductions to thirty percent—meaning that employees participating in employee-only health insurance plans could see nearly $1,800 per year deducted from their insurance premiums.[21]

Studies show that most employees participate in employer-sponsored wellness programs because they believe the programs offer a convenient method to bolster their health.[22] The potential to save money on health insurance premiums and copays increase employee desire to take advantage of wellness programs, leading many

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17. *Id.* at 3.

18. *Id.*

19. *See* Lamkin, *supra* note 4, at 450.

20. *See* Lewis, Khanna & Montrose, *supra* note 1, at e91.

21. *Id. See also* U.S. EQUAL EMP'T OPPORTUNITY COMM'N, EEOC'S FINAL RULE ON EMPLOYER WELLNESS PROGRAMS AND THE GENETIC INFORMATION NONDISCRIMINATION ACT 2 (2016) (finding that under employee-only plans with a self-option premium of $6,000, employees participating in wellness programs could save up to $1,800 via the ACA's thirty percent insurance premium deduction scheme).

22. *See* Alan Kohll, *Why More Employees Don't Embrace Wellness Programs, and How to Fix It*, FORBES (June 22, 2017), https://www.forbes.com/sites/alankohll/2017/06/22/why-more-employees-dont-embrace-wellness-programs-and-how-to-fix-it/#2d07acf01d95 [https://perma.cc/5SZ9-T73T].

employees not to question the terms of the contract they enter into with their employer.[23] To qualify, many employees simply check a box pledging they will work out, eat healthier, and refrain from smoking.[24] From an employee perspective, how could a regime designed to save you money and make you healthier harm you? None of *these* requirements are subjectively or objectively bad, and they will only foster a healthier population.[25]

Comparing employer-sponsored wellness programs to adhesion contracts, which they might well be, may help shed additional light on why employees participate in wellness programs. Most consumers never read the terms and conditions of contracts that will cost them substantial sums of money because they know that, if they disagree with the terms, they cannot use the product or service.[26] This is true for powerful companies like Amazon and Apple that present customers with lengthy electronic disclosures that they can easily pass over by clicking a button. It would not be surprising, then, if employees never read the terms of their employer-sponsored wellness contract. After all, why read something that is supposed to make you healthier and save you money if you never read the terms for something for which you are spending money? It might be that "innocuous" programs encouraging you to exercise and not smoke would not trigger protective instincts.

On their face, wellness programs attached to large insurance premium deductions *should* encourage healthy behaviors, decrease employee risk to injury and disease, and suppress employer susceptibility to increased healthcare costs.[27] However, studies on whether employer-sponsored wellness programs have actually cultivated healthier workforces and decreased employer-borne healthcare expenses have yielded largely negative results.[28] In fact, wellness programs with such large

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23. Angela Lashbrook, *Your Boss Wants You Healthy for All the Wrong Reasons*, THE OUTLINE (Nov. 29, 2018), https://theoutline.com/post/6714/your-boss-wants-you-healthy-for-all-the-wrong-reasons?zd=1&zi=has5yfeh [https://perma.cc/S2DS-4P75].

24. *Id.*

25. *Id.*

26. David Greene, *Do You Read the Terms of Service Contracts? Not Many Do, Research Shows*, NPR (Aug. 23, 2016), https://www.npr.org/2016/08/23/491024846/do-you-read-terms-of-service-contracts-not-many-do-research-shows [https://perma.cc/5AMN-47ZF].

27. *See* Sharon Begley, *Do Workplace Wellness Programs Improve Employees' Health?*, STAT NEWS (Feb. 19, 2016) https://www.statnews.com/2016/02/19/workplace-wellness-programs-employee-health/ [https://perma.cc/L9SQ-TWFM]; Austin Frakt & Aaron E. Carroll, *Do Workplace Wellness Programs Work? Usually Not*, N.Y. TIMES (Sept. 11, 2014), https://www.nytimes.com/2014/09/12/upshot/do-workplace-wellness-programs-work-usually-not.html [https://perma.cc/KP3G-Z5VC].

28. *See* SOEREN MATTKE, HANGSHENG LIU, JOHN P. CALOYERAS, CHRISTINA Y. HUANG, KRISTIN R. VAN BUSUM, DMITRY KHODYAKOV & VICTORIA SHIER, RAND HEALTH, WORKPLACE WELLNESS PROGRAMS STUDY: FINAL REPORT 45-46 (2013) (finding smoking cessation to be the only health behavior where achieving the health goal earned a greater reward than participating in the program); Sharon Begley, *Exclusive: 'Workplace Wellness' Fails Bottom Line, Waistlines – RAND*, REUTERS (May 24, 2013), https://www.reuters.com/article/us-wellness/exclusive-workplace-wellness-fails-bottom-line-waistlines-rand-idUSBRE94N0XX20130524 [https://perma.cc/T2HN-ZDC9] (reporting that participants in wellness programs lose an average of one pound every three years and that participating does not yield significant reduction in cholesterol levels). *See also* Ann Hendrix

insurance premium deductions may actually harm employee health, coerce patients, and impair their autonomy.[29]

The question of whether wellness programs unduly coerce employees has garnered much attention in corporate, employment, and healthcare law circles.[30] In 2017, the American Association of Retired Persons (AARP) won a court battle against the Equal Employment Opportunity Commission (EEOC) regarding EEOC rules permitting employers to charge or penalize employees choosing not to participate in health screenings or provide health information related to employer-sponsored wellness programs.[31] The EEOC's rule would have authorized employers to impose insurance premium rates up to two or three times the rate imposed on employees who did provide requested information and engage in health checks.[32] The District Court for the District of Columbia vacated the EEOC rule, holding that a thirty percent insurance premium hike on employees who chose not to participate in a wellness program was considered involuntary.[33]

AARP's strategy of framing the issue as a penalty imposed on employees for failing to participate in wellness programs, rather than as an incentive to partake in them, proved key to why AARP won the lawsuit and shed light on employer motives in the wellness and insurance industries.[34] The court's decision was somewhat novel. Many courts and scholars who sympathize with corporate and employer interests have refused to call the insurance premium deductions "penalties" but instead label them "incentives" for employees to provide employers with sought-after information.[35] But while the court handed employees and patients a win, it also

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& Josh Buck, *Employer-Sponsored Wellness Programs: Should Your Employer Be the Boss of More than Your Work?*, 38 SW L. REV. 465, 466–67 (2009) (urging employers to recognize employee concerns regarding discrimination based on genetic information).

29. *See* Lamkin, *supra* note 4, at 466 (finding that financial incentives attached to wellness programs may harm patient health by forcing patients to partake in aggressive medical procedures they would otherwise not participate in).

30. *Compare* Press Release, American Benefits Counsel, Consistent Federal Policy and Regulatory Framework Vital for Workplace Wellness Programs 1 (Mar. 1, 2017) (asserting that wellness programs are beneficial to employers and employees, have been successful, Congress must streamline legislation to ensure wellness programs remain a valuable tool for employers), *with* David Frank, *Workers Score Court Victory on Workplace Wellness Rules*, AARP (Aug. 14, 2017) (encouraging lawmakers to restrict incentives attached to wellness programs and ensure employees are not penalized for not participating in programs that do not have a strong record of success).

31. AARP v. United States Equal EMP'T OPPORTUNITY COMM'N, 292 F. Supp. 3d 238 (D.D.C. 2017). Dara Smith, lead attorney for the AARP Foundation Litigation, praised the court's ruling, claiming "[i]t means two fewer years of coercive penalties imposed on employees who exercise their civil right to keep private health-related information private in the workplace." David Frank, *AARP Wins Victory for Worker's Civil Rights*, AARP (Dec. 22, 2017), https://www.aarp.org/politics-society/advocacy/info-2017/eeoc-workers-rights-fd.html [https://perma.cc/H9XU-354Y].

32. Frank, *supra* note 31.

33. AARP, 292 F. Supp. 3d at 244–45.

34. Frank, *supra* note 31.

35. While the 2017 AARP case dealt primarily with procedural issues, the court did not cite to a single case discussing why the EEOC's thirty percent premium hike was not

punted on key provisions of the EEOC rule that permit employers to require an employee's spouse to produce genetic information to participate in a wellness program. If an employee's spouse refuses to provide the information, the employee does not receive the insurance premium deduction because their spouse cannot participate in the wellness program.[36] The court's decision not to address the genetic component has proved crucial to the PEWPA's fate.

Some scholars suggest wellness programs can coerce employees if the programs diminish an employee's right to informed consent.[37] Informed consent ensures that patients understand the benefits and risks of medical procedures and voluntarily consent to or refuse them.[38] Not all wellness programs should be considered "medical procedures."[39] For example, a wellness program that requires an employee to exercise or participate in a smoking cessation program would not be considered a medical procedure because it does not require the employee to establish a doctor-patient relationship. However, wellness programs that require patients to receive medical treatment, such as taking medication or undergoing medical tests, should be considered "medical procedures" governed by informed consent because they do require patients to establish a doctor-patient relationship.[40] And full disclosure applies in contexts outside of medical procedures as well. Thus, whether a wellness program violates a patient's right to informed consent should center on the nature of the plan, including the treatment regimen and whether the patient's choice to participate in that regimen is voluntary.

Whether a decision is truly voluntary centers on whether the patient is substantially free from external influence.[41] Faden and Beauchamp, two influential ethics scholars, maintain that outside influence weakens voluntariness if the patient cannot resist the stimulus.[42] Threats to penalize patients for not partaking in certain actions, as well as incentives inviting them to participate, can violate a patient's right to informed consent if the patient finds the penalty or incentive difficult to resist.[43] And while employers can no longer "penalize" employees for not participating in wellness programs, they can still offer "incentives" for participating. In the realm of insurance premium deductions, drawing the line between a "penalty" and an "incentive" is virtually impossible; deducting money from an employee's premium and requiring an employee to pay additional money are two sides of the same coin. Thus, it follows that wellness programs that induce patients to make choices regarding medical procedures they would not have made but for the "incentive" violate patients' rights to informed consent.

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voluntary. AARP, 292 F. Supp. 3d at 243. *See* Lamkin, *supra* note 4 at 441-42 (noting that wellness programs can be framed as either penalties or incentives and, thus, determining when something is one of the other is quite hard to do).

36. AARP, 292 F. Supp. 3d at 244–45.

37. Lamkin, *supra* note 4, at 446-47.

38. Ruth R. Faden & Tom L. Beauchamp, A HISTORY AND THEORY OF INFORMED CONSENT 8 (1986).

39. *Id.* at 358.

*40. See Id.*

41. *Id.*

42. *Id.* at 256.

43. *Id.* at 261–62.

While the ACA amended the PSHA and ERISA to permit employers to offer wellness programs, it did not amend key provisions of the PSHA, ERISA or the ADA barring insurance companies from discriminating against employees based on their participation in a wellness program.[44] Nevertheless, insurance companies quickly took advantage of the amendments and pitched employers with plans centered on reducing healthcare costs via wellness programs. For example, Blue Care Network of Michigan began offering employers a group health plan called "Healthy Blue Living."[45] Employees participating in Healthy Blue Living received enhanced benefits, like decreased deductibles for ninety days. After ninety days, employees have to visit their primary physician to begin a wellness program. Blue Care requires physicians to fill out a form confirming employee participation in the plan. If employees refuse to participate, they lose their enhanced benefits and have to pay higher copays and deductibles.[46]

BeniComp Advantage offers a similar program but reverses the order in which employees see decreased healthcare costs. BeniComp starts by increasing employee deductibles. Only once employees agree to comply with wellness program conditions, including provisions requiring them to take prescribed medications, do deductibles and premiums decrease.[47] Most employees know that wellness programs will require them to exercise or quit smoking, but they often do not know that they will have to take prescribed medication or undergo medical tests. These deductions are not de minimus, and large discounts are much more likely to coerce employees to participate in employer-sponsored wellness programs, even if it means consuming unwanted medication or enduring invasive tests.[48]

For Lamkin, this Hobson's choice vitiates informed consent.[49] Lamkin argues that incentivizing employees to participate in wellness programs can vitiate informed consent because the programs may require employees to participate in healthcare regimens they would not adopt but for the financial penalty for not doing so.[50] If wellness incentives become too large, it is reasonable to assume that they influence employees to make decisions against their values, thereby rendering the incentive a "penalty."[51] When wellness program mandates shift from nothing at all to smoking cessation and weight-loss regimens to requiring participants to take certain medications, the informed consent waters become increasingly murky.[52] Encouraging people to quit smoking or hit the gym through incentive programs does not violate informed consent. But cloaking a "penalty" as an "incentive" and coercing patients into deciding based on a financial inducement does.[53]

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44. Incentives for Nondiscriminatory Wellness Programs in Group Health Plans, 78 Fed. Reg. 33158 (June 3, 2013) (to be codified at C.F.R. pts. 146 & 147).
45. Lamkin, *supra* note 4, at 449.
46. *Id.* at 449–50.
47. *Id.* at 449–51.
48. *Id.*
49. *See id.* at 457.
50. *Id.*
51. *Id.* at 450.
52. *Id.*
53. *See id.* at 450–57.

Persad discounts Lamkin's argument, claiming that wellness programs cannot harm employees because encouraging better health and wellness cannot place employees in a position worse than what they were in prior to participating in the program.[54] Persad compares a potential wellness requirement pressuring a patient to consume certain medications with a taxi driver's requirement to go to the eye doctor to retain her license. He suggests that, because requiring a taxi driver to go to the doctor and receive new glasses does not vitiate informed consent simply because it requires the taxi driver to make a decision based on financial incentives, it is not coercive to require an individual to take medicine to qualify for an insurance premium deduction.[55]

### *B. Employer-Compelled Genetic Testing: GINA, 23andMe & their Turbulent Relationship with Informed Consent in Consumer Settings*

Section B.1 discusses the history and purpose of GINA, as well as the role that employers and insurance companies play in undermining GINA's goals. Section B.2 examines the lack of an informed consent standard in the DTC genetic testing realm. Specifically, Section B.2 warns consumers about the potential harms of providing DTC genetic testing companies sensitive medical information that is not subject to a confidential patient-physician relationship.

#### 1. GINA and Safeguarding Patient Genetic Information

GINA stemmed, in part, from congressional concern that employers would try to take advantage of massive technological advances in genetic information processing to obtain employee genetic information and use it to make cost-related decisions.[56] Passed with almost unanimous support, GINA bars insurance companies from denying coverage or charging larger premiums to healthy individuals purely because of their genetic predisposition to developing a disease.[57] GINA also prohibits employers from making hiring, firing, or promotion decisions based on an individual's genetic makeup.[58]

When Democrats enacted the ACA in 2010, they also invested billions of dollars into precision medicine.[59] Precision medicine is an approach to patient care where doctors ask patients to participate in genetic tests, the results of which help formulate a personalized patient-treatment plan centered on the individual's genetic makeup. Doctors use precision medicine most often when treating cancerous tumors, because patient genetics allow doctors to understand the disease better and to develop

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54. Govind Persad, *Paying Patients: Legal and Ethical Dimensions*, 20 YALE J.L. & TECH 177, 228–29 (2018).

55. *Id.*

56. *See* Riley, *supra* note 16, at 2.

57. Genetic Information Nondiscrimination Act of 2008, 42 U.S.C. §2000ff-1(b)(2) (2018).

58. *Id.*

59. *See* Riley, *supra* note 16, at 2.

personalized treatment regimens unique to a specific disease and patient.[60] Patients must voluntarily provide their genetic information and must consent to doctors using it before undergoing any medical procedures.[61]

The law provides special protection to genetic information, especially in the medical realm.[62] Currently, Title II of GINA undoubtedly provides the strongest protections. Title II bars employers and insurance companies from requesting employee genetic information, and thus encourages patients to provide genetic information for medical procedures, especially precision medicine.[63] GINA works to quell patient concern that insurers and employers will penalize them for their genetic makeup and predisposition to disease.[64] But insurance companies skirted ACA provisions barring them from discriminating against employees based on their participation in wellness programs by inducing employers to do the work for them via insurance premium deductions.[65] Now, insurers are attempting to do the same with genetic information.[66]

### 2. 23andMe and Direct-to-Consumer Genetic Testing: Consumer Foray into Dangerous Waters

Consumers remain fascinated with genealogy and genetic makeup.[67] Genetics and genealogy are mysterious to most people, yet they control who we are as humans—more than almost anything else.[68] Aside from information passed on from relatives, it is hard to tell where we really come from in the world. And even if our relatives possess insight on our genealogy, they cannot provide information about our genetic predisposition to disease. Many families have an idea if they are predisposed to heart disease or diabetes based on struggles their relatives have had with those ailments. But simply knowing your familial track record for disease does not provide insight into why genetics predispose us to certain diseases and whether we carry those traits. Past experiences leave us anxious and wanting more. DTC genetic testing companies allow consumers to delve into their genetic code and have helped consumers solve some of the enigmatic issues about their lineage, their familial risk for cancer, and how they can plan a safer pregnancy and optimize their diet and fitness regimens.[69]

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60. *See Precision Genomics*, IND. UNIV. HEALTH, https://iuhealth.org/find-medical-services/precision-genomics [https://perma.cc/2LPC-J8HU].

61. *See Precision Medicine in Cancer Treatment*, NAT'L CANCER INST., https://www.cancer.gov/about-cancer/treatment/types/precision-medicine [https://perma.cc/K5XB-9JW8].

62. Genetic Information Nondiscrimination Act of 2008, 42 U.S.C. §2000ff-1(b)(2).

63. *Id.*

64. *See* Riley, *supra* note 16, at 3.

65. *See* Lamkin, *supra* note 4, at 449.

66. *See* Riley, *supra* note 16, at 2.

67. *See* Karen Norrgard, *DTC Genetic Testing for Diabetes, Breast Cancer, Heart Disease, and Paternity*, NATURE EDUCATION (Sept. 23, 2018), https://www.nature.com/scitable/topicpage/dtc-genetic-testing-for-diabetes-breast-cancer-698/ [https://perma.cc/PDP5-TTVS] (discussing the various congenital health benefits associated with DTC genetic testing).

68. *Id.*

69. *Id.*

While DTC genetic testing companies assert that they do not diagnose consumers, this contention is highly debatable, especially when considering their recent foray into genetic health risk (GHR) reports, which approximate a user's risk for developing a disease.[70]

As an *in vitro* test, the Food and Drug Administration (FDA) classifies DTC genetic tests as medical devises.[71] Unlike laboratory-developed tests (LDTs), physicians do not order DTC genetic tests. Consequently, DTC genetic tests do not require a physician or trained expert to explain the results of the test, though the FDA regulates DTC genetic testing companies and requires them prove that they are accurately and safely relaying information to consumers.[72]

Experts estimate that twelve million Americans participated in DTC genetic tests in 2017, meaning that one in twenty-five American adults possess access to personal genetic data.[73] The DTC genetic testing industry reached almost $100 million in sales in 2017, with experts predicting the industry's value to skyrocket to upwards of $350 million by 2022.[74] Consumer interest in genetic literacy will persist—at least for the near future—and on many levels, that is remarkable. But as the adage goes: "With great power, comes great responsibility."[75] Genetic information is immensely powerful. Consumers now have the ability to trace their ancestry—something most people never fathomed could happen.[76] What most consumers do not know, however, is how this powerful, enlightening tool can be wielded against them—especially by insurance companies.[77]

GINA bars insurance companies from requiring individuals to provide them information they receive from genetic testing companies.[78] However, if a person receives disheartening information from a DTC test and provides that information to their doctor, who then diagnoses the patient with a disorder or prescribes treatments tailored to specific ailments, insurance agencies can become privy to that information.[79] For example, 23andMe outlines in their terms and conditions that "[g]enetic [i]nformation that you choose to share with your physician or other health care providers may become part of your medical record and through that route be accessible to other health care providers and/or insurance companies in the future."[80] The terms provide that if an individual receives information about adverse health

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70. *See* Jones, *supra* note 8.
71. *Id.*
72. *Id.*
73. *Id.*
74. *Id.*
75. *See* SPIDER-MAN (Marvel Comics 2010).
76. *See* Matloff, *supra* note 67.
77. *See generally* Deepthy Kishore, *Test at Your Own Risk: Your Genetic Report Card and the Direct-to-Consumer Duty to Secure Informed Consent*, 59 EMORY L.J. 1553, 1584–85 (2010) (discussing how consumers must be informed via the reasonable patient standard because they likely do not understand the effects of DTC genetic testing).
78. Genetic Information Nondiscrimination Act of 2008, 42 U.S.C. §2000ff-1(b)(2) (2018).
79. Dustin W. Massie, *23, My Employer & Me: On Genetic Testing, Privacy and Employment*, 74 BENCH & B. MINN. , 12 (2017).
80. *Terms of Service*, 23ANDME, https://www.23andme.com/about/tos/ [https://perma.cc/N5FX-8Q5T].

conditions and does not disclose the information to their insurance provider when asked to do so, they may be committing a fraud.[81] For the average consumer with scarce knowledge of insurance contracts and disclosure requirements for avoiding fraud, these terms are likely terrifying . . . if consumers read them.

As with terms regarding employer-sponsored wellness programs (and most other contracts), consumers likely do not read the terms and conditions associated with their DTC genetic testing kit.[82] What is more, unlike employer-sponsored wellness programs, where an employer or human resources specialist *could* spell out the terms of the wellness program contract to the employee, no one is helping the consumer interpret or understand the gravity of participating in a DTC genetic testing service.[83] After all, that is a key feature of DTC genetic testing: no doctors, no geneticists, no testing specialists. For many people, this is a perk—but it is a perk with consequences they hardly understand.[84] It may be annoying and costlier to go to a doctor or a lab to undergo genetic tests to see if you are predisposed to disease. But at least if you go to the doctor, you are subject to informed consent and covered by a doctor-patient relationship.[85] What is more, you get an expert, in-person opinion on what your genetic information means and how your genetics could adversely impact your health.[86] DTC genetic testing services provide none of these safeguards.[87] By using these services, you embark on your genetic journey alone.

Scholars, including Kishore, agree almost unanimously that consumers using DTC genetic testing services should receive some variation of informed consent—whether it is actually called informed consent or not.[88] While informed consent traditionally is only required where there is a physician-patient relationship, the nature of DTC genetic testing is largely medical, especially when consumers test for predisposition to disease.[89] Indeed, if the sort of testing that DTC genetic testing companies provide were performed by a doctor, informed consent would be required.[90] Logically, then, it makes sense to require DTC genetic companies to provide some variation of informed consent to ensure consumers receive some form of risk disclosure.

Courts have applied two informed consent standards to determine what qualifies as adequate disclosure to a patient: the reasonable physician standard and the reasonable patient standard.[91] The reasonable physician standard places a premium

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81. *Id.*
82. *See* Greene, *supra* note 26.
83. *See* Jones, *supra* note 8.
84. *See generally* Kishore, *supra* note 77, at 1589 (discussing how consumers rarely understand the terms of their DTC genetic test).
85. *See* Jones, *supra* note 8; *See also* Kishore, *supra* note 77 (arguing that regulators should require DTC genetic testing companies to provide consumers with adequate information regarding their DTC genetic test—akin to the requirements for testing done in labs or by physicians).
86. Kishore, *supra* note 77, at 1585–87, 1589.
87. *Id.*
88. *Id.* at 1584–85.
89. *Id.*
90. *Id.*; *see also* Jones, *supra* note 8.
91. Kishore, *supra* note 77, at 1584–85.

on patient welfare but sacrifices patient autonomy by allowing physicians to choose what is best for the patient.[92] Under this standard, physicians only have to disclose what the reasonable physician in their situation would disclose to a patient, not what the reasonable patient would want to hear. The reasonable physician standard also permits doctors to invoke the "therapeutic privilege" if they believe disclosing information to their patient will harm their welfare.[93]

The reasonable patient standard, which courts impose only in a minority of jurisdictions, emphasizes patient autonomy more than the reasonable physician standard.[94] This standard seems to be ideal in consumer settings in general and the DTC genetic testing setting in particular because patients will receive information about their predisposition to disease regardless of the harm and trauma that may result.[95] DTC genetic testing companies cannot evade the potential trauma consumers may feel from their results. They cannot invoke the therapeutic privilege, because if they did, their services would be futile. What is more, allowing DTC genetic testing companies to use the reasonable physician standard could pose a financial conflict of interest, as companies may refrain from disclosing information about genetic testing out of fears that results or consequences from the tests may discourage consumer participation.[96] According to Kishore, the reasonable patient standard is the most pragmatic informed consent standard available in the DTC genetic testing arena.[97]

As DTC genetic testing companies delve further into GHR reporting and continue to develop diagnostic services that incur upon doctor's medical opinions, consumers should be aware of what they are signing up for.[98] This is especially true as PEWPA looms in Congress. As this paper will discuss in Part III, DTC genetic test results that spur a visit to the doctor could drastically affect a patient's wellness program requirements and insurance liabilities. What was a seemingly innocuous attempt to trace patient genetic predisposition to disease could lead patients down an invasive and expensive battle with employers and insurers steadfast on curbing medical costs.

## II. JUDICIAL GLOSS . . . OR LACK THEREOF: THE PRESERVING EMPLOYEE WELLNESS PROGRAMS ACT IN LIGHT OF EEOC LITIGATION

On its face, PEWPA smacks of illegality—primarily because it flies in the face of GINA. GINA specifically bars insurers and employers from discriminating against employees based on genetic information or from requiring them to provide genetic information involuntarily. PEWPA encourages the latter and makes it easier to accomplish the former. A hallmark of GINA is that it only permits employers and insurers to see employee healthcare information in aggregate form. PEWPA would drastically weaken GINA, allowing employers, for the first time, to see genetic

92. *Id.*
93. *Id.*
94. *Id.*
95. *Id.*
96. *Id.*
97. *Id.*
98. *See* Jones, *supra* note 8.

information of specific individuals. Nevertheless, judicial hesitance to address the issue casts doubt on whether a court would strike down PEWPA.

In 2017, AARP provided the court an opportunity to strike down an EEOC rule permitting employers to require spouses of employees to submit to genetic testing to qualify for a wellness program and its concomitant insurance premium deduction.[99] The District Court for the District of Columbia handed down a major win to employee advocates but punted on the genetic testing issue—holding only that the thirty percent insurance premium hike on employees who choose not to participate in an employer-sponsored wellness program was involuntary and thus violated GINA.[100]

The court's reluctance to address the genetic testing requirement in the EEOC's rules, even in dicta, suggests that the court either does not know how it would rule on the issue or that it does not a see a blatant problem with the requirement.[101] While AARP did not ask the court to strike down the genetic testing provision, the court's decision to strike down the insurance premium rate as an involuntary penalty was groundbreaking.[102] Thus, it is somewhat surprising that a progressive bench did not even mention the genetic testing requirement. The court's silence speaks even louder considering PEWPA passed the committees on Commerce, Energy, and Ways and Means unchanged and on partisan grounds just five days before the court issued its opinion.[103] While proper judicial etiquette would counsel against discussing PEWPA, courts often seize on opportunities to address controversial issues. What is more, although PEWPA was not ripe for review, the EEOC rules permitting employers to require employee spouses to submit to genetic testing were. Thus, the court could have addressed the genetic testing issue in the EEOC rules in its 2017 opinion, but it did not.[104]

The EEOC Rules and PEWPA appear different in one key aspect: to whom they apply.[105] Specifically, the EEOC rules only permit employers to require the spouse of an employee to submit to genetic testing. The EEOC rules do not allow employers to require an employee or an employee's children to submit to genetic testing,

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99. *Compare* Preserving Employee Wellness Programs Act, H.R. 1313, 115th Cong. (2017), *with* Genetic Information Nondiscrimination Act of 2008, 42 U.S.C. §2000ff-1(b)(2) (2018). *See also* Mark A. Rothstein, Jessica Roberts & Tee L. Guidotti, *Limiting Occupational Medical Evaluations Under the Americans with Disabilities Act and the Genetic Information Nondiscrimination Act*, 41 AM. J.L. & MED. 523, 564 (2015) (arguing that because PEWPA, on its own terms, claims not to violate GINA, employers should enjoy an added layer of protection against employee genetic discrimination claims).

100. AARP v. United States Equal EMP'T OPPORTUNITY COMM'N, 292 F. Supp. 3d 238, 245 (D.D.C. 2017).

101. *See id.* However, it would be very hard for them to not see the problem, considering GINA directly prohibits insurers and employers from requiring employees to involuntarily provide them with their genetic information.

102. *See* Frank, *supra* note 31.

103. Preserving Employee Wellness Programs Act, H.R. 1313, 115th Cong. (2017).

104. *Id. See also* AARP, 292 F. Supp. 3d at 238.

105. *See* Preserving Employee Wellness Programs Act, H.R. 1313, 115th Cong. (2017); Genetic Information Nondiscrimination Act of 2008 42 U.S.C. §2000ff-1(b)(2) (2018).

whereas PEWPA would.[106] The EEOC justified its rule on the basis that employee spouses do not share similar genes with an employee, unlike children, who would share similar genes to the employee.[107] Thus, the EEOC contends that requiring employee spouses to submit to genetic testing does not foster an environment for employers to discriminate against an employee based on their genes.[108] This logic is shaky on two grounds.

First, under group health plans that cover employee spouses, employers have just as much of an incentive to discriminate against spouses based on genetic information and health abnormalities as they do with employees. In cost and coverage terms, employees and employee spouses are the same since employers cover them both. So, while employees may not face discrimination from their employer at the office, there is nothing stopping them from facing discrimination via an insurance premium hike if their spouse does not participate in the genetic testing. Such an effect on an employee's pocketbook could easily spill over into a workplace dispute—consequently leading to the discrimination that the EEOC said was unlikely to happen. [109] The EEOC is using employee spouses as test subjects and as a means to eventually test employees—only testing employees will come with a congressional blessing.

Second, GINA adopts ERISA's definition of "employee," which includes an employee of an employer and the employee's spouse and children.[110] The EEOC claims that, because spouses do not have a similar genetic makeup and predisposition to disease as their spouses, employees and their spouses face minimal risks of discrimination.[111] Whether this rationale is true is debatable at best. But even if it is true, it almost certainly violates GINA—especially when analyzing the text of the statute.[112] While the letter and spirit of legislative policy goals are important, the text of GINA clearly bars the EEOC rules as written. And because PEWPA takes the EEOC rules one step further and permits employers to require employees and their children to submit to genetic testing, PEWPA should be struck down as well if passed. Thus, while the EEOC rules and PEWPA appear distinct, they are actually very similar. Judicial analysis of either the EEOC rules or PEWPA should yield the same result: eradication of the genetic testing requirement.

The EEOC has remained in the dark about their next moves—most likely waiting to see how Congress responds to PEWPA. If PEWPA passes, the EEOC's job—at least as it pertains to their court order to promulgate new rules—would likely be finished because PEWPA would encompass its work. For PEWPA to pass judicial muster and not violate GINA, the EEOC, or whichever scheme and entity Congress charges to regulate employee genetic testing, will have to ensure that any genetic information employees provide to employers for wellness programs will be provided voluntarily. But what the court considers "voluntary" is largely elusive. Are twenty-

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106. Preserving Employee Wellness Programs Act; Genetic Information Nondiscrimination Act of 2008 §2000ff-1(b)(2).

107. *See* Equal EMP'T OPPORTUNITY COMM'N , *supra* note 21, at 3.

108. *Id.*

109. *See id.*

110. Genetic Information Nondiscrimination Act of 2008 §2000ff-1(b)(2).

111. *See* Equal EMP'T OPPORTUNITY COMM'N, *supra* note 21, at 3.

112. *See* Genetic Information Nondiscrimination Act of 2008 §2000ff-1(b)(2).

rive percent penalties for nonparticipation voluntary? Must the penalty dip under twenty percent? Fifteen percent? Or, more realistically, should the degree of voluntariness reflect an individual's financial capacity? Some employees can stomach a thirty percent penalty. Others could not take on a five percent hit. Perspective matters, and whatever choice Congress and administrative regulators make, they must keep that in mind.

## III. MOVING FORWARD: PEWPA'S FATE & RESPONDING TO ITS AFTERMATH—REGARDLESS OF THE OUTCOME

In its 2017 opinion striking down the EEOC's wellness programs insurance premium hike as involuntary, the court ordered the EEOC to promulgate new rules by August 2018 to make the incentives voluntary.[113] In a May 2018 status update, the EEOC stated that it does not plan on updating its rules in time for the August 2019 deadline.[114] Insurance and employment experts suggest the EEOC's defiance rests in large part on a belief that President Trump will appoint a new EEOC commissioner.[115] With Republicans gaining additional seats in the Senate, this hunch becomes ever more likely. If the Trump administration turns its eye towards PEWPA and employer access to employee genetic information, one could only guess at what the administration would seek to accomplish.[116] The fact that Democrats spurred the wellness program rush via the ACA will likely only fuel Republicans to push insurance premium deductions conditioned on wellness program participation to their outermost bounds.

With the current political climate and slate of Supreme Court justices in mind, employee advocates and policymakers need to develop a plan to address PEWPA if it passes and if it fails. If PEWPA passes, employee advocates need to develop a mechanism to make the current wellness programs more effective—to the point where employers have faith that they do not need to require employees to submit to genetic testing to qualify. And if PEWPA fails, either in Congress or if the judiciary strikes it down, employee advocates need to develop a plan to counteract PEWPA 2.0. Otherwise the win will be short-lived. This paper will offer my opinions regarding both scenarios below.

### *A. Living in a World with PEWPA and Mitigating its Aftermath*

The worst-case scenario for employees is if Congress approves PEWPA in its current state. As written, PEWPA would permit employers to condition employer-sponsored wellness programs—and the insurance premium deductions associated with them—on whether employees submit to genetic testing. While most bills do not

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113. AARP, 292 F. Supp. 3d at 245. Unsurprisingly, the court did not hint as to what "voluntary" means.

114. Anu Gogna & Ben Lupin, *EEOC Wellness Update and Planning for 2019*, WILLIS TOWERS WATSON (May 9, 2018), https://www.willistowerswatson.com/en-US/Insights/2018/05/eeoc-wellness-update-and-planning-for-2019 [https://perma.cc/2TBG-WYSV].

115. *Id.*

116. *Id.*

make it through Congress unaltered, most bills do not make it through Ways and Means either.[117] Given that Democrats just regained control of the House of Representatives, it is unlikely they would vote to approve PEWPA as currently written. Nevertheless, it is not hard to envision a world with PEWPA, especially if Republicans can convince Democrats tied to the ACA and big business to bend in their favor. If Congress approves PEWPA, employee advocates need to ensure that insurance premium deductions stemming from PEWPA do not coerce employees to make involuntary decisions.

Whether Congress approves PEWPA or not, one thing is certain: big business wants to require employees to submit to genetic testing to qualify for wellness programs and their concomitant insurance premium deductions.[118] The American Benefits Counsel, which advocates on behalf of Fortune 500 companies like AT&T, ExxonMobile, CBS, and MetLife, has penned multiple memos urging Congress to bolster its efforts to improve employer-sponsored wellness programs via genetic testing requirements.[119] With this type of money and pressure backing PEWPA, it is imperative that employee advocates pressure the EEOC to promulgate regulations with penalties significantly below the thirty percent mark that the court struck down in 2017. Presenting the issue to employers in the context of informed consent could help.

Framing employer-sponsored wellness programs in the context of informed consent would humanize them—especially if employers require employees to submit to genetic testing. After all, few things define human health as much as our genetic makeup.[120] While a court has found a thirty percent penalty for not participating in a wellness program to be involuntary, coercive, and in violation of GINA, employee advocates need to push this logic further and persuade the judiciary to apply it as a modified informed consent standard for employees.[121] That is, the court and Congress need to require employers to disclose the nature of wellness programs to their employees to ensure that employees understand (or, at least, understand better) the potential physiological and financial impact that the testing could bring about. To date, PEWPA is the most ideal vehicle to accomplish this task.

Courts have been hesitant to apply informed consent outside of the physician-patient relationship, particularly because the physician-patient relationship differs from almost all other fiduciary relationships. However, requiring employees to submit to genetic testing could qualify as a medical procedure, and thus fall within the bounds of informed consent, because it treads on diagnosing patients. This paper

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117. *See generally*, Ezra Klein, *Almost None of the Bills Introduced into Congress Ever Becomes a Law*, WASH. POST (Jan. 16, 2014), https://www.washingtonpost.com/news/wonk/wp/2014/01/16/almost-none-of-the-bills-introduced-into-congress-ever-becomes-a-law/?noredirect=on&utm_term=.04a8b76e4361 [https://perma.cc/D8G4-3Z4Y].

118. *See* Brief for the American Benefits Council, p. 1, The Preserving Employee Wellness Program Act (2015).

119. *See About Us,* AM. BENEFITS COUNCIL, https://www.americanbenefitscouncil.org/about-the-council/about-us/ [https://perma.cc/QML7-KED7] (last visited Oct. 15, 2019).

120. *See* Hayden, *supra* note 5, at 176.

121. AARP v. United States Equal EMP'T OPPORTUNITY COMM'N, 292 F. Supp. 3d 238, 243-45 (D.D.C. 2017)

argues that Congress (but more realistically, courts) should require employers to provide employees an informed consent-like disclosure regarding how their genetic information will be used in their employer-sponsored wellness program because these requirements require employees to undergo medical procedures.[122] Just as DTC genetic testing providers *should* be required to employ the reasonable-patient standard under Kishore's analysis, Congress should require employers and DTC genetic testing companies to provide employees with information that the reasonable employee would find relevant to a wellness program because employees are submitting to tests that, if conducted, could harm them financially and jeopardize their ability to get future insurance.[123] Because wellness programs are designed to prevent disease and ailments, employees do not find themselves in a position that would warrant the therapeutic exception.[124] Thus, the reasonable-patient standard is the ideal standard for genetic testing in the wellness programs context because this standard will provide employees with a framework to view their predisposition to disease and to help prevent developing illnesses.[125] The reasonable physician standard is ill-equipped to deal with this issue, just like it would inadequately protect consumers in the DTC genetic testing context, because employers would find themselves with an inherent conflict of interest.[126] While employees are not consumers in the same sense that DTC genetic test users are, ideally, they will make their decision whether to participate in the program voluntarily, like consumers.

To skirt informed consent, wellness program providers will likely require employees to submit to a form of DTC genetic testing and provide those results to the wellness programs provider to develop their personalized program. If wellness program providers pursued employee genetic information via this route, they would be doing exactly what DTC genetic testing companies warn against: providing genetic information to medical professionals who, in turn, would use your genetic information in a way that may alter your insurance costs. If Congress approves PEWPA, employee advocates could press for regulations requiring doctors or certified lab technicians to conduct the genetic tests. This way, employees will receive at least some form of informed consent regarding their genetic information and will enter a physician-patient relationship with binding ethical duties. However, by providing genetic information to a medical professional, a patient will be more likely to be diagnosed with an ailment[127]—and thus face steeper insurance costs—than if she used a DTC genetic testing service. Neither option is perfect, so analyzing the best way to protect employee interests will be key to developing a strategy to combat PEWPA.

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122. I say "informed consent-like" because the FDA, Congress, courts, and other regulators have not extended informed consent to other genetic testing procedures not conducted by doctors, with DTC genetic testing serving as the prime example.

123. Kishore, *supra* note 77 at 1584–85.

124. *Id.*

125. *Id.*

126. *Id.*

127. Again, being diagnosed with an ailment, while not good, is better than its alternative in most contexts because patients will have the opportunity to receive treatment. I present it as a negative because the diagnosis would provide the opposite goal of requiring patients to go to doctors to receive testing. *See generally* Lamkin, *supra* note 4, at 438.

If Congress approves PEWPA, it should direct the EEOC to establish baseline disclosure subjects that employers must provide to employees. Employers should have to disclose how employee genetic information may cause their insurance rates to increase if their genetic tests result in them being diagnosed with an ailment. Further, should employees choose not to provide their genetic information, employers should comprehensively explain how their insurance costs will increase. Employers must emphasize that employees will not face discrimination in the workplace based on their genetic predisposition to disease or on their decision whether to participate in a wellness program. Most importantly, employers should underscore to employees that employee health trumps cost savings. PEWPA will likely polarize employers and employees if enacted. Cutting costs on employee health insurance plans only works if an employer has employees.

The American Benefits Council and employers will likely protest congressional mandates to provide informed consent-like disclosure to employees because employers do not have a physician-patient relationship with employees.[128] Moreover, they will likely argue that employees will have already received informed consent from the doctor or lab technician who conducts their genetic test or from the terms and conditions of the DTC genetic testing kit they use. Employers could also adopt Persad's argument that informed consent is not necessary in the wellness program context because to qualify for employment, all employees must make healthcare decisions that cut against their autonomy.[129] However, Persad missed the mark when he compared requiring an employee to ingest medication to qualify for a wellness program to requiring a taxi driver to pass an eye exam to qualify for a job.

Persad conflates a requirement to protect the welfare of others (passing an eye exam so you can see the road and not hit citizens and/or crash your car and harm your customers) with a mandate to take medication that, if not ingested, likely would not affect third parties.[130] Individuals have a right to informed consent, but that right cannot infringe on the rights of others, especially if that infringement can result in public harm.[131] Requiring a patient to choose between taking a medication (a form of medical procedure) or risk losing a $1,500 insurance premium deduction does not implicate third parties, and neither do genetic tests (which, if performed by a doctor, are medical procedures) to determine an employee's predisposition to disease. Persad correctly identifies that the law will always require employees to meet certain medical benchmarks to qualify for a job.[132] But the law must place these requirements on a spectrum and not as binary choices. Expect employers to advance this argument in the beginning to gauge how much they must give to attain their interests.

With the 2017 *AARP* decision in mind, employers should be conscious to not impose coercive insurance premium penalties (or provide insurance premium incentives—they are the distinctions without differences) on employees who do not

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128. *See* Press Release, American Benefits Counsel, *supra* note 30.

129. *See* Persad, *supra* note 54, at 229.

130. *Id.*

131. *See, e.g.,* K.H. Satyanarayana Rao, *Informed Consent: An Ethical Obligation or Legal Compulsion?*, 1 J. CUTANEOUS AESTHETIC SURGERY 33, 34 (2008) (asserting that one's right to informed consent "cannot impinge the rights of others").

132. *See* Persad, *supra* note 54, at 229.

participate. Although the District Court for the District of Columbia did not strike down the EEOC's rules pertaining to genetic testing requirements, it indicated its displeasure with the EEOC's push to allow employers to penalize employees who do not participate in wellness programs.[133] It would be wise for the EEOC to alter its penalty/incentive thresholds well below thirty percent. Further, to withhold judicial scrutiny, the EEOC should require employers to disclose how genetic testing will impact employee insurance costs. If Congress passes PEWPA (or a variation of it), transparency will be key to fostering trust between employers and employees and truly bolstering employee well-being.

### *B. What Doesn't Kill Congress (and Big Business) Makes it Stronger: Fighting PEWPA 2.0*

If PEWPA fails in Congress, or if a court strikes it down, it would be naïve to think that this will be the last we hear from wellness programs centered on genetic testing requirements. The American Benefits Council vehemently supports this bill, and its members will likely continue funding legislation designed to decrease employer-borne healthcare costs.[134] And they should. But employee advocates must make every effort to convince employers that compelled genetic testing is not the answer.

It is easy to see why employers—and more importantly, insurers—would want to require employees to submit to genetic testing to qualify for insurance premium deductions. Precision medicine has worked remarkably well—almost entirely because patients provide their genetic information for doctors to develop a treatment plan based on their genetic makeup.[135] On the other hand, wellness programs have failed to save employers and insurers money and have failed to create a healthier workforce.[136] One possible explanation for their failure could be based on the lack of employee genetic information provided to tailor employee-specific workout programs, diet plans, and medical treatment regimens. If employees provided their genetic information to help create a program personalized to their genetic needs, there is a good chance it would work. But for many generations currently using employer-sponsored wellness programs, especially older ones, it is probably too late.

While employer-sponsored wellness programs have been prevalent since 2010, the ACA incentivized medical professionals to implement them to help prevent early-onset diseases.[137] The goal of wellness programs is to prevent chronic ailments, such as heart disease and obesity, from developing in the first place. But many of the employees currently suffering from illnesses that wellness programs were designed to prevent began developing the illnesses long before they participated in their first wellness program.[138] It is hard to determine how accurate a disease prevention

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133. AARP v. United States Equal EMP'T OPPORTUNITY COMM'N, 292 F. Supp. 3d 238, 243-45 (D.D.C. 2017).

134. *See* Press Release, American Benefits Counsel, *supra* note 30.

135. *See* Precision Medicine in Cancer Treatment, *supra* note 61.

136. *See* Lewis, Khanna & Montrose, *supra* note 1, at e91.

137. *Id.*

138. *See* Elizabeth Heubeck, *Workplace Wellness Programs Work Best when Bosses Buy Into Them*, WASH. POST (Nov. 27, 2018),

mechanism is on a group of people who developed unhealthy habits and ailments early on in their lives. For participants with heart disease or clogged arteries, a wellness program will not cure them—and it is not supposed to. Rather, wellness programs work to prevent these issues from ever starting.[139] The public should scrutinize any government-sponsored initiative meticulously, especially when consumers direct billions of dollars into it. However, well-intentioned initiatives deserve a fair shot. Wellness programs have not received a fair shot yet. Employers should remain keen on providing insurance premium deductions conditioned on participation in a wellness program, but they should also familiarize themselves with how they are supposed to work.

To help see better results without coercing employees to submit to genetic testing, employers should implement stronger quality-assurance measures to ensure employees are actually making good on their promise to *participate* in a wellness program. Many employees see wellness programs as an annoying cost-saver, rather than an opportunity to improve their health.[140] Employees with this mindset thus often do not carry out the goals their wellness program provider designed for them.[141] For example, some male employees have admitted that they lied about receiving a mammogram solely to receive enough points to qualify for insurance premium deductions conditioned on their participation in wellness programs.[142] Another employee stated that the nicotine tests in her program are easy to cheat. She said "Two people on my team smoke cigars and chew tobacco . . . . They know how long it takes for nicotine to clear from their system to test negative, so they stop long enough just for the test, then fire right back up again."[143] While not all employees try to game the system, the fact that it is easy to certainly does not give employers a strong impression of the programs they help pay for.[144] Employee advocates need to find a way to resolve these problems. Otherwise, why would employers not resort to genetic testing, especially since it has worked wonders in the medical world?

## CONCLUSION

PEWPA presents Congress with an opportunity to make a lasting difference in the healthcare and employment law sectors. Whether Congress approves PEWPA or not, one thing is for certain: employers will continue working to make wellness programs, and the concomitant insurance premium deductions attached to them, worth their money. And they should. It is up to employee advocates, legal scholars, and medical professionals to find a way to improve wellness programs without requiring employees to submit to involuntary genetic testing to qualify for a wellness program. Money talks, and it is clear which way the money is moving. Finding a way to push

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https://www.washingtonpost.com/lifestyle/wellness/workplace-wellness-programs-work-best-when-bosses-buy-into-them-studies-show/2018/11/26/c273339a-e775-11e8-a939-9469f1166f9d_story.html?utm_term=.870537b30f54 [https://perma.cc/8NT3-HCUL].

139. *Id.*
140. Kohll, *supra* note 22.
141. *Id.*
142. *See* Lashbrook, *supra* note 23.
143. *Id.*
144. *Id.*

PEWPA off track is imperative to preserving the integrity of GINA and placing employee rights above the bottom line.