Note

Coerced into Health: Workplace Wellness Programs and Their Threat to Genetic Privacy

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"It's Official: Employee Wellness Is a 'Scam.'"[1] "Workplace Wellness Programs May Cost More than They're Worth."[2] "Workplace Wellness Programs Are a Sham."[3] These are just a few of many headlines suggesting a backlash against the workplace wellness programs that have proliferated under the Affordable Care Act (ACA). Now, it is not uncommon for employers of all sizes to ask workers to undergo health assessments and incentivize healthy eating and exercise through rewards like gift cards, discounted gym memberships, and health insurance reductions. These programs are certainly attractive in theory: What employer would *not* want to have a healthier, more productive workforce, lower healthcare costs, and play a role in solving this country's persistent obesity epidemic? And what employee would not want a significant reduction in their health insurance premiums and other rewards in exchange for staying healthy? After all, the ACA's encouragement of these programs

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1. Al Lewis, *It's Official: Employee Wellness Is a "Scam,"* HUFFINGTON POST (Apr. 17, 2015), https://www.huffingtonpost.com/al-lewis/its-official-employee-wel_b_7046652.html.

2. Brianna Ehley, *Workplace Wellness Programs May Cost More than They're Worth*, FISCAL TIMES (Dec. 16, 2014), http://www.thefiscaltimes.com/2014/12/16/Workplace-Wellness-Programs-May-Cost-More-They-re-Worth.

3. L.V. Anderson, *Workplace Wellness Programs Are a Sham*, SLATE (Sept. 1, 2016), http://www.slate.com/articles/health_and_science/the_ladder/2016/09/workplace_wellness_programs_are_a_sham.html.

was one of the few provisions of the incredibly polarizing law that garnered bipartisan support.[4]

However, seven years have passed since Congress enacted the ACA, and results are not so promising. Workplace wellness programs have generally proven to be ineffective at both making employees healthier and saving on healthcare costs.[5] Perhaps even more troubling, though, are the opportunities these programs present for disturbing invasions of privacy. Few employees would probably welcome their employer's knowledge of their weight fluctuations, cholesterol levels, and blood pressure. When hundreds or even thousands of dollars of annual savings on health premiums are at stake, however, many employees might find these programs hard to turn down.

Particularly problematic is the potential for employers to gain access to genetic testing results and family medical history of employees, and even their spouses, who are on the same company-sponsored health plan. This risk brings wellness programs under the purview of the Genetic Information Nondiscrimination Act (GINA) of 2008,[6] which Senator Edward Kennedy praised as "the first civil rights bill of the new century of life sciences."[7] While responding to the United States' legacy of a racist conception of genetics and the appalling practices accompanying it,[8] GINA was a forward-looking law. It defines genetic information to include both results of genetic tests and family medical history,[9] which can reveal much about a person's predisposition to diseases without any testing at all.[10] Foreseeing dramatic advances in medicine and technology, it anticipated the risks such innovation could mean for employees and patients. Not only did

4. *See* Julia Belluz, *A New Bill Would Allow Employers to See Your Genetic Information—Unless You Pay a Fine*, VOX (Mar. 13, 2017), https://www.vox.com/policy-and-politics/2017/3/13/14907250/hr1313-bill-genetic-information.

5. *See* Anderson, *supra* note 3.

6. Pub. L. No. 110-233, 122 Stat. 881 (2008) (codified in scattered sections of 26, 29, and 42 U.S.C.).

7. David H. Kaye, *GINA's Genotypes*, 108 MICH. L. REV. FIRST IMPRESSIONS 51, 51 (2010).

8. *See generally* Peter Blanck & Aisling de Paor, *US Legislative and Policy Response: Some Historical Context to GINA*, *in* GENETIC DISCRIMINATION: TRANSATLANTIC PERSPECTIVES ON THE CASE FOR A EUROPEAN-LEVEL LEGAL RESPONSE 97 (Gerard Quinn et al. eds., 2015) (detailing the social, cultural, and historical background of genetic discrimination in the United States).

9. 42 U.S.C. § 2000ff(4) (2012).

10. *Cf.* Kerry Abrams & Brandon L. Garrett, *DNA and Distrust*, 91 NOTRE DAME L. REV. 757, 767 (2015) (describing how genetic testing can identify a "person's likely health or medical predispositions").

GINA join the important federal employment antidiscrimination statutes by outlawing the kind of genetic discrimination described above, but it also represented a significant step in privacy law by prohibiting employers from even *accessing* employees' genetic data in the first place.[11] GINA similarly applies in the health insurance context to prevent discriminatory practices by insurers.[12]

But what happens when well-intentioned wellness programs request genetic tests or family medical histories as part of their baseline Health Risk Assessments (HRA)? Just as employers offer perks like gift cards and subsidized gym memberships in exchange for wellness program participation, they have also incentivized disclosing this sensitive information through discounts on employees' health premiums. The assumption behind this practice is that knowledge of one's genetic information can help predict risks of future illness and encourage appropriate preventative behavior.[13] Congress and government agencies, notably the Equal Employment Opportunity Commission (EEOC), have decided that GINA's privacy concerns should, to some degree, give way to the needs of voluntary wellness programs. To this end, the EEOC recently tried to decide by regulation at what point an incentive for lower health insurance premiums in exchange for such information crosses the line from voluntary to coercive. The agency concluded that any discount amounting to less than thirty percent of the employee's premiums kept a program within the definition of "voluntary."[14] The rules also tried to make the complex regulatory framework involving GINA, the ACA, the American with Disabilities Act (ADA), the Employee Retirement Income Security Act (ERISA), and the Health Insurance Portability and Accountability Act (HIPAA) more consistent, with mixed results.

11. *See* Abigail Lauren Purdue, *Justifying GINA*, 78 TENN. L. REV. 1051, 1068 (2011) (noting GINA's broad definition of "requests" of genetic information).

12. 42 U.S.C. § 300 gg-53 (2012).

13. *See* Jennifer S. Bard, *When Public Health and Genetic Privacy Collide: Positive and Normative Theories Explaining How ACA's Expansion of Corporate Wellness Programs Conflicts with GINA's Privacy Rules*, 39 J.L. MED. & ETHICS 469, 480 (2011). Scientific studies, however, have not necessarily supported this conventional wisdom. *Id.* at 480–81; *see also infra* notes 168–70 and accompanying text.

14. 29 C.F.R. § 1635.8(b)(2)(iii) (2017).

There is both vigorous opposition to the EEOC rules and arguments these rules did not go far enough. Employee and privacy rights advocates believe even a thirty percent incentive level is too coercive, while business and wellness program industry interests suggest a rule like this one hinders employers' freedom in crafting these programs.[15] In fact, members of Congress have voted a bill out of committee that would expand these statutes' exceptions to encourage wellness program participation.[16] In December of 2017, a federal district judge ordered the rules vacated effective January 1, 2019. The judge reasoned that there appeared to be a real risk of coercion and the EEOC had not explained why it had set the maximum at thirty percent.[17] With these divergent positions and the agency now back to the drawing board, the issue of incentives, wellness programs, and genetic information is far from settled.

This Note explores whether some wellness programs' genetic information-sharing requirements conflict with the purpose of GINA. Part I describes the problem of genetic discrimination, how GINA addresses it, and whether it is successful in doing so. Part II then examines wellness programs, both what they are and how they are regulated, especially in relation to how they must comply with GINA. Part II analyzes how financial incentives for disclosing genetic information amount to coercion and render such a practice involuntary. Part III proposes that a zero-incentive rule would better advance GINA's purpose and address the concerns that motivated this legislation. Ultimately, financial incentives at any level amount to impermissible coercion because of the unique nature of genetics and intangible risks related to genetic privacy. Instead, opportunities for genetic testing should be strictly optional, untethered from even minor reductions in health insurance costs. This new rule might even lead to more successful wellness program outcomes and would offer certainty to employers seeking clarity in this area of law. Since privacy is an important tool for antidiscrimination law[18] and genetic privacy specifically deserves strong protec-

15. *See infra* Part I.C.2.

16. *See infra* Part I.C.2.

17. AARP v. EEOC, 292 F. Supp. 3d 238, 243 (D.D.C. 2017).

18. Jessica L. Roberts, *Protecting Privacy to Prevent Discrimination*, 56 WM. & MARY L. REV. 2097, 2102 (2015) [hereinafter Roberts, *Protecting Privacy*] ("Antidiscrimination law prohibits discriminatory actions by outlawing certain types of conduct, but privacy law renders the offensive conduct practically impossible by impeding access to the information necessary for the unfavorable

tions, incentivizing these disclosures would substantially infringe on GINA's purpose.

I. EVOLUTION OF GINA AND WORKPLACE WELLNESS PROGRAMS

GINA and wellness programs have separate and distinct backgrounds, but they become closely intertwined where wellness programs raise privacy concerns. To understand why wellness programs are highly problematic in this context, it is necessary to understand GINA's background, purpose, and how workplace wellness programs operate. This Part first details the history of genetic testing in the United States, the forces culminating in GINA's enactment in 2008, the statutory provision related to employment, and what makes the law unique. This Part then describes the development of wellness programs, the various laws they implicate, and the attempt at regulating their use of financial incentives for obtaining information protected by GINA.

A. THE GENETIC INFORMATION NONDISCRIMINATION ACT

1. Historical Background of Genetic Testing

The United States has had a long, complicated, racist history of genetic discrimination. The idea of Social Darwinism helped give rise to the eugenics movement in the early 20th century.[19] Theories of biological worthiness and assumptions about undesirable traits like race and disabilities being passed on coincided with the sharp influx of immigrants into the United States.[20] In 1927, the Supreme Court infamously gave its stamp of approval to the eugenics movement when it authorized forced sterilizations.[21] Between 1907 and 1937, thirty-two states passed forced sterilization laws to control populations of "genetically undesirable individuals."[22]

differentiation.").

19. *See* Blanck & de Paor, *supra* note 8, at 98–100; *see also* MARK TAYLOR, GENETIC DATA AND THE LAW: A CRITICAL PERSPECTIVE ON PRIVACY PROTECTION 4 (2012) (noting how the use of genetics for ill purposes is not limited in the West to the obvious example of Nazi Germany).

20. *See* Blanck & de Paor, *supra* note 8, at 98–100.

21. Buck v. Bell, 274 U.S. 200 (1927). Interestingly, *Buck* has never been expressly overturned and is still good law.

22. Blanck & de Paor, *supra* note 8, at 99.

More recently, genetic discrimination and race have been closely linked since the discovery of African Americans' genetic predisposition to sickle cell anemia in the 1970s.[23] African Americans were barred from jobs, educational opportunities, and even insurance coverage if they carried a sickle cell gene mutation.[24] In fact, some states even passed laws requiring sickle cell testing, and such tests could be a condition to obtain a marriage license or attend public school.[25] The only genetic discrimination case to reach a federal court of appeals—both pre- and post-GINA—concerned sickle cell testing. In *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, plaintiffs challenged their employer's policy that new hires undergo medical exams, including blood and urine samples.[26] Without their knowledge, the plaintiffs were tested for the sickle cell gene, in addition to syphilis and pregnancy.[27] The Ninth Circuit reversed summary judgment for the employer and remanded to the district court, finding that there was at least a triable issue on the plaintiffs' federal constitutional privacy claims.[28] It suggested in dicta that this gross invasion of privacy violated the Fourth Amendment's protection against unlawful searches.[29] In fact, *Norman-Bloodsaw* and the racist history of genetic discrimination figured prominently in the congressional findings preceding GINA.[30] This case prompted the House of Representatives to state in its

23. *Id.* at 100.

24. Louise M. Slaughter, *The Genetic Information Nondiscrimination Act: Why Your Personal Genetics Are Still Vulnerable to Discrimination*, 88 SURGICAL CLINICS N. AM. 723, 726 (2008).

25. *See* Bradley A. Areheart, *GINA, Privacy, and Antisubordination*, 46 GA. L. REV. 705, 716 (2012); Philip R. Reilly, *Laws to Regulate the Use of Genetic Information*, *in* GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 369, 371 (Mark A. Rothstein ed., 1997); Bahrad A. Sokhansanj, Note, *Beyond Protecting Genetic Privacy: Understanding Genetic Discrimination Through Its Disparate Impact on Racial Minorities*, 2 COLUM. J. RACE & L. 279, 290 (2012).

26. 135 F.3d 1260, 1265 (9th Cir. 1998).

27. *Id.*

28. *Id.* at 1270. The case settled before it could go to trial. Elizabeth Pendo, *Race, Sex and Genes at Work: Uncovering the Lessons of* Norman-Bloodsaw, 10 HOUS. J. HEALTH L. & POL'Y 227, 246 (2010).

29. *Norman-Bloodsaw*, 135 F.3d at 1269 ("[I]t goes without saying that the *most basic* violation possible involves the performance of unauthorized tests . . . [which] may also be viewed as searches in violation of Fourth Amendment rights that require Fourth Amendment scrutiny.").

30. H.R. REP. NO. 110-28, pt. 1, at 2 (2007).

report on GINA, "Congress clearly has a compelling public interest in relieving the fear of discrimination and in prohibiting its actual practice in employment and health insurance."[31]

2. Motivations for Enacting GINA

Prior to GINA and in addition to a patchwork of genetic nondiscrimination state laws,[32] the Americans with Disabilities Act (ADA) came closest to a federal prohibition on genetic discrimination.[33] The employment provision of the ADA, administered by the EEOC, offered some protection against employers' inquiries about disabilities which might include medical exams. In *EEOC v. Burlington Northern & Santa Fe Railway Co.*, the agency sued on behalf of employees filing for worker's compensation who were required either to undergo medical tests that tested for genetic markers of carpal tunnel syndrome, or face disciplinary action if they refused.[34] The EEOC settled for $2.2 million but noted "that the mere gathering of an employee's DNA may constitute a violation of the ADA."[35]

EEOC v. Burlington Northern & Santa Fe Railway Co. highlighted a major blind spot of the ADA. The BNSF employees won because the test was for a specific disability that could have affected their ability to work, thus falling under the purview of the ADA.[36] By contrast, it was unclear whether the ADA could similarly protect a plaintiff who was "denied employment based on a gene *associated* with risks of cancer or a future heart condition,

31. *Id.* at 883.

32. At the time of GINA's enactment, over thirty states had some kind of law related to genetic discrimination, but GINA would provide a "federal 'floor.'" Slaughter, *supra* note 24, at 735. Most of these state laws were much less expansive than GINA, protecting only against, for example, employment discrimination against those with a sickle cell trait or not including family medical history under the definition of "genetic information." *See* Mark A. Rothstein, *Genetic Secrets: A Policy Framework*, *in* GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA, *supra* note 25, at 451, 476.

33. *See* Blanck & de Paor, *supra* note 8, at 105–06.

34. Agreed Order Settling the Lawsuit, No. 02-C-0456, 2002 WL 32155386, at *1 (E.D. Wis. May 8, 2002).

35. Press Release, Equal Emp't Opportunity Comm'n, EEOC and BNSF Settle Genetic Testing Case Under Americans with Disabilities Act, (May 8, 2002), https://www.eeoc.gov/eeoc/newsroom/release/5-8-02.cfm.

36. KEN LEFEBVRE, GENETIC DISCRIMINATION LAW IN THE UNITED STATES: A SOCIOETHICAL & LEGAL ANALYSIS OF THE GENETIC INFORMATION NONDISCRIMINATION ACT (GINA), SCH. OF PUB. POLICY CAPSTONES, UNIV. OF MASS. AMHERST 14–15 (2015), http://scholarworks.umass.edu/cgi/viewcontent.cgi?article=1039&context=cppa_capstones.

rather than a more specific disability."[37] In fact, prior to the settlement with BNSF, the Commissioner of the EEOC acknowledged this gap, imploring Congress to pass federal genetic antidiscrimination legislation.[38]

Rapidly advancing technology—notably the Human Genome Project—only exacerbated the concern that existing statutory protections were inadequate. Specifically, Congress worried that the ADA was insufficient and that protection against genetic discrimination itself should be codified.[39] DNA tests were becoming cheaper, easier to conduct, and available to consumers by mail or through the internet.[40] Moreover, this accessibility and sophisticated technology would improve exponentially with the lucrative financial rewards for companies engaged in this industry.[41]

The concern was that "while these scientific advancements might alter the way in which we understand and treat disease, they would also create new ways to discriminate."[42] Surveys of Americans at this time revealed widespread fears about genetic testing. In 2006, two-thirds of survey respondents expressed "concerns about how their genetic information would be stored and who would have access to it."[43] About the same number worried about health insurers having unauthorized access to this information and slightly fewer feared their employers accessing it.[44] Seventy-two percent believed there should be laws to protect genetic privacy, and even more agreed that employers would discriminate in the absence of such legislation.[45] With the increasing complexity of the modern healthcare system, these fears were understandable even if they were not borne out, given that so many parties—insurers, specialists, and staff across hospitals—typically have access to patients' health information.[46]

37. *Id.* at 15.

38. *See* Blanck & de Paor, *supra* note 8, at 105–06.

39. *Id.*

40. *See* TAYLOR, *supra* note 19, at 58.

41. *See id.* at 59.

42. Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 439, 443 (2010) [hereinafter Roberts, *Preempting Discrimination*].

43. Slaughter, *supra* note 24, at 726–27.

44. *Id.* at 727.

45. *Id.*

46. *See generally* Aaron Varner, *Title II of the Genetic Information Nondiscrimination Act and Its Promulgating Regulations: Analyzing Employer Acquisition of Employee Genetic Information in the Context of Fairness and Privacy*, 62 LAB. L.J. 202, 205–06 (2011) (describing the complexities of the healthcare

These concerns can deter people from undergoing genetic testing and benefiting from early medical screenings and thus from successful treatment, particularly for cancer.[47] Others have admitted to seeking out genetic testing through use of false names and addresses.[48] While there are some measures researchers and institutions can take to anonymize the information, such efforts can only go so far.[49] This reluctance among the public regarding genetic testing was also a concern for scientists.[50] Potentially life-saving research depends on the public's participation in scientific studies and clinical trials, so avoiding these tests could hold back scientific progress.[51] Consequently, GINA was also meant to encourage public participation in clinical research by assuaging fears about data sharing.[52]

system and why federal laws are needed to protect patient and employee privacy).

47. *See* Slaughter, *supra* note 24, at 727. For example, the House of Representatives report regarding GINA cites a study from 2003 of almost 500 people with a family history of colorectal cancer showing that almost half were very concerned about genetic discrimination and thus were reluctant to undergo genetic testing or even to discuss it with their doctor. H.R. REP. NO. 110-28, pt. 1, at 28 (2007) (citing Donald W. Hadley et al., *Genetic Counseling and Testing in Families with Hereditary Nonpolyposis Colorectal Cancer*, 163 ARCHIVE INTERNAL MED. 573, 579 (2003)).

48. Slaughter, *supra* note 24, at 726.

49. *See generally* Sokhansanj, *supra* note 25, at 285–86 (discussing the different ways to prevent genetic data from being linked to specific individuals and these methods' downsides).

50. *See, e.g.*, *Appropriations for Fiscal Year 2008: Hearing Before the Subcomm. on Labor, Health & Human Servs., Educ., & Related Agencies of the S. Comm. on Appropriations*, 110th Cong. 409 (2007) (statement of Dr. Francis S. Collins, Director, National Human Genome Research Institute, Department of Health and Human Services) ("[The National Human Genome Research Institute] remains concerned about the impact of potential genetic discrimination on research and clinical practice.").

51. *See* H.R. REP. NO. 110-28, pt. 1, at 31 (2007) ("Fewer participants in genetic research lead to slower development of treatments, beneficial drugs, and cures."); *cf*. Peter Aldhous, *US Outlaws Genetic Discrimination*, NEW SCIENTIST (Apr. 28, 2008), https://www.newscientist.com/article/dn13785-us-outlaws-genetic-discrimination ("With the passage of GINA, researchers and clinicians can actively encourage Americans to participate in clinical trials and appropriate genetic testing." (quoting the president of the American Society of Human Genetics)).

52. *See, e.g.*, H.R. REP. NO. 110-28, pt. 1, at 2 (2007); Varner, *supra* note 46, at 206.

3. Provisions of GINA

After a thirteen-year road through Congress,[53] GINA was finally enacted almost unanimously in 2008.[54] There are two provisions of the law, one prohibiting genetic discrimination in health insurance and the other in employment.[55] GINA addresses both of these contexts because Congress recognized that the majority of Americans receive health insurance through their employer.[56] Title I of the statute prohibits health insurers from collecting or requesting genetic information and making coverage determinations based on that data.[57] HIPAA, enacted in 1996, already addressed this concern, but only in a limited way, so GINA significantly broadened HIPAA's protections.[58] Title II makes it unlawful for employers to "request, require, or purchase genetic information with respect to an employee or a family member of the employee" and from using it in employment decisions such as hiring, firing, and promotions.[59] This provision requires plaintiffs to exhaust administrative remedies through the EEOC just like the ADA and Title VII of the Civil Rights Act of 1964.[60] The statute's definition of genetic information includes both genetic testing results of the individual and their family members as well as the individual's family medical history.[61]

GINA addressed some of the concerns arising after *EEOC v. BNSF*, which had made clear that the ADA's scope of protection was not broad enough to cover genetic privacy.[62] While the ADA restricts employers' ability to inquire about employees' observable, existing health conditions, GINA prohibits questions related

53. Blanck & de Paor, *supra* note 8, at 104.

54. The bill passed the Senate 95-0 and the House 414-1, with Representative Ron Paul as the only dissenter. Jessica L. Roberts, *The Genetic Information Nondiscrimination Act as an Antidiscrimination Law*, 86 NOTRE DAME L. REV. 597, 599 n.2 (2011) [hereinafter Roberts, *Genetic Information*].

55. GINA is codified in scattered sections of 26, 29, and 42 U.S.C.

56. Slaughter, *supra* note 24, at 729 ("[W]hat good is ensuring that insurers cannot discriminate if people can lose their jobs, and consequently their insurance coverage, because of the results of genetic testing?").

57. 29 U.S.C. § 1182 (2012).

58. EMP. BENEFITS SEC. ADMIN., U.S. DEP'T OF LABOR, FREQUENTLY ASKED QUESTIONS REGARDING THE GENETIC INFORMATION NONDISCRIMINATION ACT (2010), https://www.dol.gov/sites/default/files/ebsa/about-ebsa/our-activities/resource-center/faqs/gina.pdf.

59. 42 U.S.C. § 2000ff-1 (2012).

60. *Id.* § 2000ff-6(a); *see* Purdue, *supra* note 11, at 1073.

61. § 2000ff(4)(A).

62. *See supra* notes 34–37 and accompanying text.

to conditions the employee might not actually have and might never even develop.[63] GINA closed a more specific gap in the ADA as well. The ADA allows employers to request medical examinations after a job offer has been made as a condition to starting work, and it allows the examinations to gather information not related to the job.[64] This provision is why the plaintiffs in *Norman-Bloodsaw* lost their ADA claims, which would have likely been successful today under GINA.[65]

4. GINA's Uniqueness as an Antidiscrimination Law

GINA is unique from other antidiscrimination laws in two important ways. First, GINA uses a privacy approach by prohibiting even *acquiring* the protected information. In other words, an employer could violate GINA simply by asking for the results of a genetic test, even if it never acted on that information.[66] In contrast, Title VII prohibits adverse employment actions based on a protected category.[67] Being a woman, for example, is typically not information an employer could avoid knowing about an employee who identifies as female. It is only when the employer takes some adverse action because of that characteristic that it has violated Title VII.[68] Under GINA, the employer's inquiry into whether the female employee has a gene predisposing her to breast cancer is enough for liability.[69] This example shows why privacy protections can be instrumental to preventing discrimination: employers cannot discriminate if they do not possess this information.[70]

Second, GINA is a forward-looking antidiscrimination law that aims to prevent future violations, unlike Title VII, for example, which meant to curtail already-pervasive discriminatory practices.[71] While not approaching the vast scale of discrimina-

63. *See* Varner, *supra* note 46, at 205.

64. 42 U.S.C. § 12112(d)(3).

65. *See* Pendo, *supra* note 28, at 248.

66. 42 U.S.C. § 2000ff-1(b); *see* Roberts, *Protecting Privacy*, *supra* note 18, at 2130, 2136.

67. § 2000e-2(a).

68. Roberts, *Protecting Privacy*, *supra* note 18, at 2130.

69. The statute makes an exception for employers who "inadvertently" acquire this information. *See* 42 U.S.C. § 2000ff-1(b)(1).

70. *See supra* note 18 and accompanying text.

71. *See* Roberts, *Preempting Discrimination*, *supra* note 42, at 440–41 (discussing the "preemptive" nature of GINA and the implications of this aspect of the law).

tion against African Americans and women in the mid-20th century, there is evidence that genetic discrimination was a real problem that could only grow worse because of advancing and cheaper technology. Leading up to GINA's passage, Louise Slaughter, the long-serving congresswoman and former microbiologist who sponsored the bill, highlighted specific stories of genetic discrimination against employees that came out in congressional testimony.[72] To prove that it was a widespread issue, Slaughter also pointed to the growing prevalence of advertisements for genetic testing, an organization devoted to testing young Hasidic Jews, and statistics on employers' use of genetic information about their employees.[73] In a 2001 survey, about one percent of companies tested employees for sickle cell anemia and used those results in hiring, firing, and promotion decisions.[74] A fifth of companies inquired about family medical history and about a quarter of those relied on that information in taking employment actions.[75] In addition, a survey of Massachusetts residents in 2000 found almost 600 people who said they "had been turned down for jobs because of 'flaws' discovered in their genes," and a 1996 survey found that thirteen percent of Americans reported they or a family member had lost their jobs because of genetic conditions such as risk of heart disease or mental problems.[76]

However, prior to GINA's passage, some members of Congress called the bill "a solution in search of a problem."[77] These skeptics might be justified based on the number of GINA claims filed with the EEOC since the statute went into effect. From 2010 to 2016, the EEOC received around 200 or 300 charges a year under GINA, and typically at least half result in a finding of "no reasonable cause."[78] By comparison, in 2016 there were over 32,000 race-based charges[79] and almost 27,000 sex-based

72. For example, a high-performing social worker was fired when her employer discovered her family's history of Huntington's disease. Slaughter, *supra* note 24, at 725–26.

73. *Id.*

74. *Id.*

75. *Id.*

76. Ifeoma Ajunwa, *Genetic Data and Civil Rights*, 51 HARV. C.R.-C.L. L. REV. 75, 87 (2016) [hereinafter Ajunwa, *Genetic Data*].

77. Slaughter, *supra* note 24, at 725.

78. *Genetic Information Non-Discrimination Act Charges*, EEOC, https://www.eeoc.gov/eeoc/statistics/enforcement/genetic.cfm (last visited Nov. 2, 2018).

79. *Race-Based Charges*, EEOC, https://www.eeoc.gov/eeoc/statistics/enforcement/race.cfm (last visited Nov. 2, 2018).

charges.[80] The EEOC did not even file its first lawsuit under GINA until 2013.[81] Of course, it is virtually impossible to know whether the low number of GINA claims is because there is low public awareness of the law,[82] the law is successfully preventing genetic discrimination, or there are simply few incidents of this problem in the first place.

Nevertheless, some scholars argue that there is substantial anecdotal evidence of genetic discrimination, enough to render it a problem that needs addressing.[83] According to the EEOC, a complainant often does not allege a GINA violation until "after the investigation of an ADA charge uncovered evidence that an employer had asked about an employee's family [medical] history."[84] Given that GINA is a relatively new law and employment practices and technology are constantly evolving, its impact is difficult to evaluate. Looking at the number of EEOC claims by themselves, it is clear that the risks of genetic discrimination are real and can negatively impact individuals.[85] Just because the number of charges under Title VII dwarf those under GINA does not mean that GINA serves little purpose. By anticipating the greater risks that more advanced technology presents, GINA is just as much about prevention as it is about providing remedies for statutory violations.[86] After all, genetic testing is still becoming much cheaper and more accessible.[87] Because prevention is

80. *Sex-Based Charges*, EEOC, https://www.eeoc.gov/eeoc/statistics/enforcement/sex.cfm (last visited Nov. 2, 2018).

81. *See* Press Release, Equal Emp't Opportunity Comm'n, Fabricut to Pay $50,000 to Settle EEOC Disability and Genetic Information Discrimination Lawsuit, (May 7, 2013), https://www.eeoc.gov/eeoc/newsroom/release/5-7-13b.cfm.

82. Alicia A. Parkman et al., *Public Awareness of Genetic Nondiscrimination Laws in Four States and Perceived Importance of Life Insurance Protections*, 24 J. GENETIC COUNSELING 512, 515 (stating that less than twenty percent of adult survey respondents are even aware there are genetic nondiscrimination laws).

83. *See* Pendo, *supra* note 28, at 246.

84. Robert C. Green et al., *GINA, Genetic Discrimination, and Genomic Medicine*, 372 NEW ENG. J. MED. 397, 398 (2015).

85. When it is a company-wide employment policy, such practices can affect many people. In *Norman-Bloodsaw*, for example, "the class of employees and job applicants affected by the settlement . . . 'stretched back 27 years to 1972 and involve[d] as many as 8,000 people.'" Pendo, *supra* note 28, at 247.

86. *Cf. id.* at 247 ("It is fair to say that the risk of genetic discrimination increases as genetic tests become more available, and genetic information is more commonly included in medical records.").

87. *See* LEFEBVRE, *supra* note 36, at 7, 8.

difficult if not impossible to quantify, measuring GINA's impact is that much harder.

B. WORKPLACE WELLNESS PROGRAMS

Contemporary workplace wellness programs are only the latest instance of employers collecting medical information from employees. After World War II, companies required widespread medical testing for both diagnostic and predictive purposes, understanding that it was in their financial interest to have healthy employees.[88] By the 1980s, almost all employers with over 500 employees required pre-employment medical tests.[89] At the same time, healthcare costs began rising substantially, so these exams' role shifted to screening out potential employees who would increase a company's health insurance costs.[90] While today the ADA, HIPAA, and GINA provide significant protection against this intrusive practice, the same kind of testing and inquiry remains in wellness programs.

By now, these programs are ubiquitous and take almost infinite forms. Generally, they reward employees for working toward certain health goals or engaging in healthy activities. Although there is no single definition of such programs, they all aim to further employers' shared goals: to lower health insurance costs and have healthier, more productive employees.[91] It is easy to understand why wellness programs are so attractive to employers. Around two-thirds of American adults are overweight or obese[92] and chronic conditions that cause seventy percent of adult deaths—such as hypertension and diabetes—are both costly and usually preventable.[93] Not only does chronic disease increase the costs of health insurance for employers, but it also

88. Mark A. Rothstein, *The Law of Medical and Genetic Privacy in the Workplace*, *in* GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA, *supra* note 25, at 281–82.

89. *Id.* at 282.

90. *Id.*

91. Bahaudin G. Mujtaba & Frank J. Cavico, *Corporate Wellness Programs: Implementation Challenges in the Modern American Workplace*, 1 INT'L J. HEALTH POL'Y & MGMT. 193, 194 (2013).

92. Steven C. Sizemore, Comment, *A Fatter Butt Equals a Skinnier Wallet: Why Workplace Wellness Programs Discriminate Against the Obese and Violate Federal Employment Law*, 11 WYO. L. REV. 639, 642 (2011).

93. Adrianna McIntyre et al., *The Dubious Empirical and Legal Foundations of Workplace Wellness Programs*, 27 HEALTH MATRIX: J. L.-MED. 59, 61 (2017).

reduces productivity due to employees missing work and working while sick.[94]

Workplace wellness programs come in a variety of forms, and they can be mandatory or voluntary. Penalties under mandatory programs to ensure compliance can be severe: "increasing employee health-related contributions, garnishing wages, and even restricting employee access to the workplace itself."[95] Many employers also include spouses, children, and even retirees in their programs.[96] Initial screening activities are the most common feature and serve as an entry point for further interventions.[97] This screening often consists of a detailed questionnaire called a Health Risk Assessment (HRA) and then might be followed by biometric testing, which may involve obtaining employees' medical histories, taking blood tests for cholesterol, and recording employees' heights and weights.[98] This baseline information can then be used both to incentivize employees to maintain healthy habits and measure their progress in improving certain health markers and also to penalize employees for failing to meet certain health standards.[99] These incentives and penalties often take the forms of reimbursement for health care spending and reductions or increases in health insurance premiums.[100] As technology has evolved, constant fitness monitoring of employees has become increasingly common.[101] A market re-

94. *Id.* at 62.

95. Daniel Charles Rubenstein, Comment, *The Emergence of Mandatory Wellness Programs in the United States: Welcoming, or Worrisome?*, 12 J. HEALTH CARE L. & POL'Y 99, 101 (2009). Some scholars have also argued that today's wellness programs are both "more intensive and coercive than earlier models." Gordon Hull & Frank Pasquale, *Toward a Critical Theory of Corporate Wellness*, 13 BIOSOCIETIES 190, 200 (2018).

96. *Employer Wellness Programs: Better Health Outcomes and Lower Costs: Hearing Before the S. Comm. on Health, Educ., Labor & Pensions*, 114th Cong. 23 (2015) (statement of Catherine Baase, Chief Medical Officer, The Dow Chemical Company) [hereinafter *Employer Wellness Programs: Better Health Outcomes and Lower Costs*].

97. McIntyre et al., *supra* note 93, at 60.

98. Mujtaba & Cavico, *supra* note 91, at 193–94; Sizemore, *supra* note 92, at 646.

99. For a comprehensive discussion of incentives and penalties, see Mujtaba & Cavico, *supra* note 91, at 194–96.

100. *See, e.g.*, Ifeoma Ajunwa et al., *Health and Big Data: An Ethical Framework for Health Information Collection by Corporate Wellness Programs*, 44 J.L. MED. & ETHICS 474, 476 (2016).

101. *See id.* at 478; *Corporate Wellness Is a 13 Million Unit Wearable Wireless Device Opportunity*, ABI RES. (Sept. 25, 2013), https://www.abiresearch.com/press/corporate-wellness-is-a-13-million-unit-wearable-w [hereinafter

search firm estimates that by 2018 over 13 million wearable fitness tracking devices will be integrated into workplace wellness programs.[102] Programs also encourage preventative measures such as gym membership discounts, immunizations, and healthy cafeteria food.[103] They may involve an educational component that can include nutrition counseling, stress management programs, or medical education through classes and online resources.[104]

Workplace wellness programs are, by now, ubiquitous. Between one-half and two-thirds of employers, and virtually all employers with more than 200 employees, have some kind of program.[105] Wellness programs have flourished under the ACA, which aimed to reduce the nation's health care spending in addition to insuring more people.[106] The ACA encouraged employers to implement wellness programs to bring down health care costs. Workplace wellness programs garnered such broad support that this part of the law is considered one of the only ACA provisions with bipartisan support.[107] The workplace wellness industry is also big business. Over half of large employers offer incentive-based programs, usually managed by third-party vendors, "which increasingly include health-contingent programs that reward employees for remedying identified risks."[108] It is estimated that by 2020 corporate wellness vendors will be a $12 billion industry.[109]

Corporate Wellness].

102. *Corporate Wellness*, *supra* note 101.

103. *Employer Wellness Programs: Better Health Outcomes and Lower Costs*, *supra* note 96.

104. Mujtaba & Cavico, *supra* note 91.

105. Ajunwa et al., *supra* note 100.

106. *See* Dennis G. Shea & Dennis Scanlon, *Moving Beyond "Wellness Does Not Work,"* 27 HEALTH MATRIX: J.L.-MED. 125, 128 (2017).

107. *See* Belluz, *supra* note 4.

108. Jill R. Horwitz et al., *Wellness Incentives in the Workplace: Cost Savings Through Cost Shifting to Unhealthy Workers*, 32 HEALTH AFF. 468, 469 (2013); *see also* Julie Appleby, *New Wellness Program Rules Elicit Mixed Reactions*, GOVERNING (May 18, 2016), http://www.governing.com/topics/health-human-services/khn-eeoc-wellness-rules.html.

109. Jay Hancock, *Workplace Wellness Programs Put Employee Privacy at Risk*, CNN (Oct. 2, 2015), http://www.cnn.com/2015/09/28/health/workplace-wellness-privacy-risk-exclusive/index.html.

C. REGULATING WORKPLACE WELLNESS PROGRAMS

1. Statutes and Agency Rules

Workplace wellness programs have long been subject to federal regulation. These statutes and regulations are concerned with the inherently discriminatory nature of health-contingent wellness programs, which by definition treat employees differently based on health status.[110] Originally, this kind of discrimination would have violated HIPAA, so Congress created "an exception that allowed employers to condition up to twenty percent of the cost of coverage upon successfully meeting wellness standards."[111] Provisions addressing wellness programs were also added in ERISA, the Internal Revenue Code, and the Public Health Service Act—laws that prohibited insurers from discriminating based on health in eligibility, benefits or premiums.[112] The ADA also addresses workplace wellness programs out of concern for privacy and implications for people with disabilities. The ADA's more significant limitations include strict confidentiality requirements for health-related information and "requiring alternatives for individuals who are able to perform the essential functions of their job but, because of disability, unable to achieve a health factor requirement under a mandatory wellness plan."[113]

The ACA encouraged participation in wellness programs mostly by increasing the amount employees could be reimbursed. The law allows employer-sponsored health plans to include wellness programs that are voluntary and "reasonably designed,"[114] and it raised the incentive limit to a thirty percent reduction in coverage costs and fifty percent for smokers.[115] The ACA allows for considerable discretion in how employers craft their wellness programs. A "reasonably designed" program does not have to be based on empirical evidence or collect information on the impacts of the program on employees' health.[116] The ACA

110. McIntyre et al., *supra* note 93, at 64.

111. *Id.*

112. *Employer Wellness Programs: Better Health Outcomes and Lower Costs*, *supra* note 96, at 24.

113. Kristin N. Stone, *Emerging Voices: Limitations & Legal Implications of Employee Wellness Programs*, 63 LAB. L.J., 72, 74 (2012).

114. Kathy L. Hudson & Karen Pollitz, *Undermining Genetic Privacy? Employee Wellness Programs and the Law*, 37 NEW ENG. J. MED. 1, 1 (2017).

115. Kristin Madison et al., *Smoking, Obesity, Health Insurance, and Health Incentives in the Affordable Care Act*, 310 J. AM. MED. ASS'N 143, 143 (2013).

116. Hudson & Pollitz, *supra* note 114, at 1–2.

also incorporated wellness program incentives into Medicaid and Medicare.[117]

Finally, GINA contains an exception for workplace wellness programs. It allows employers to obtain genetic data and family medical history about employees and their family members *voluntarily* as part of these programs.[118] The EEOC's first rulemaking concerning GINA and wellness programs in 2010—pre-ACA—explicitly barred employers from offering any incentives for employees to provide genetic information as part of a wellness program.[119] This regulation was significant, given that over three quarters of companies included questions about family medical history in their HRAs "or use[d] such histories to link an employee's participation in these types of risk assessments to wellness rewards or penalties."[120] A case from 2014—before the EEOC proposed new rules on this issue—illustrates the tension between the ACA's encouragement of wellness programs and GINA's antidiscrimination and privacy protections. To participate in one of its health insurance programs, Honeywell required employees to undergo tests and provide medical information about a spouse, otherwise employees would be subject to financial surcharges and would not be eligible for a Health Savings Account.[121] The EEOC sued, claiming the incentives "made participation non-voluntary under the ADA and GINA *even if* the incentives complied with the ACA and its implementing regulations."[122] A federal judge denied the agency's motion for a preliminary injunction in part because of confusion around this area of law.[123]

In May 2016, the EEOC issued a final rule that clarified the statute's exception and moved away from its original position

117. Madison et al., *supra* note 115.

118. 42 U.S.C. § 2000ff-2(b)(2)(B) (2012) (stating that the employee must give "prior, knowing, voluntary, and written authorization").

119. 75 Fed. Reg. 68,912, 68,935 (Nov. 9, 2010) (to be codified at 29 C.F.R. pt. 1635).

120. Bard, *supra* note 13, at 480.

121. EEOC v. Honeywell Int'l, Inc., No. 14-4517 ADM/TNL, 2014 WL 5795481, at *1–2 (D. Minn. Nov. 6, 2014).

122. Paul H. Kehoe, *A Proposed Fix for Wellness Plans*, SEYFARTH SHAW LLP: EMP. L. LOOKOUT (Mar. 4, 2015), http://www.laborandemploymentlaw counsel.com/2015/03/a-proposed-fix-for-wellness-plans.

123. *Honeywell Int'l, Inc.*, 2014 WL 5795481, at *5–6 (noting the "great uncertainty" in how GINA interacts with the ACA and that Honeywell's program appears to comply with the ACA, but more clarity is needed). For a detailed review of wellness program case law, see Elizabeth A. Brown, *Workplace Wellness: Social Injustice*, 20 N.Y.U. J. LEGIS. & PUB. POL'Y 191, 231–40 (2017).

that no incentives were acceptable. With this post-ACA rulemaking, the EEOC had wanted to "harmonize" GINA and the ADA with the antidiscrimination protections of HIPAA and the wellness programs provisions of the ACA.[124] The rule specified what level of inducement qualifies as "voluntary" and when it applies.[125] It allowed employers to offer an inducement to an employee for their spouse to share genetic information and undergo testing as part of the wellness program.[126] The inducement cannot exceed thirty percent of the employee's cost for self-only health insurance coverage under the employer's group health plan.[127] Incentivizing the acquisition of the employee's children's genetic data was still prohibited because it is possible to learn genetic information about an employee from the genetics of their children but not their spouse.[128]

Although the EEOC attempted to reconcile GINA and the ADA with workplace wellness programs in this recent rulemaking, swift litigation has revealed the conflict between these laws and programs in terms of incentives. Arguing that the rules negatively affect its members, the AARP prevailed on its summary judgment motion in August 2017, when a federal district judge in Washington D.C. found that the rules should not receive *Chevron* deference because the EEOC failed to provide a reasoned explanation for the thirty percent incentive level.[129] However, the judge left the rule in place and remanded to the agency for reconsideration rather than vacating the rule, which would be too disruptive to employers already relying on it.[130] Then in December 2017, on the AARP's motion to amend the judgment, the judge overruled his earlier opinion because leaving the "arbitrary and capricious" rules in place until the agency issues new

124. *See, e.g.*, AARP v. EEOC, 267 F. Supp. 3d 14, 29 (D.D.C. 2017) ("[The EEOC] argues principally that it adopted this new interpretation to harmonize its regulations with the HIPAA regulations governing wellness programs and to induce more individuals to participate in wellness programs, as that was the goal expressed by Congress in the ACA.").

125. *EEOC's Final Rule on Employer Wellness Programs and the Genetic Information Nondiscrimination Act*, EEOC, https://www.eeoc.gov/laws/regulations/qanda-gina-wellness-final-rule.cfm (last visited Nov. 2, 2018) [hereinafter *EEOC's Final Rule*].

126. *Id.*

127. 29 C.F.R. § 1635.8(b)(2)(iii) (2017).

128. *EEOC's Final Rule*, *supra* note 125.

129. *AARP*, 267 F. Supp. 3d at 37. For a detailed explanation of how the EEOC appears to have settled on the thirty percent level, see Brown, *supra* note 123, at 230–31.

130. *AARP*, 267 F. Supp. 3d at 38.

final rules—three years later, at the earliest—would be "unacceptable."[131] Still concerned with immediate disruptive consequences of vacating the rules on wellness program policies, he instead ordered a vacatur to take effect on January 1, 2019, leaving in place 2018 plans.[132]

2. Proposed Legislation

This regulation was not expansive enough for some policymakers. House Republicans have recently proposed a bill, the "Preserving Employee Wellness Programs Act" (PEWPA) that would override any agency rules.[133] Supported by the American Benefits Council, a lobbying organization that represents employers, the bill was voted out of committee on party lines in March 2017.[134] The sponsors did not think the EEOC rules went far enough and would actually discourage employers' wellness programs by setting incentives too low to influence employees' behavior.[135] PEWPA would allow employers to offer greater incentives—up to thirty percent of the cost of coverage of an entire family, rather than the cost of covering only the employee—without running afoul of GINA and the ADA.[136] It would tie this incentive to the ACA's allowance of reducing health insurance up

131. AARP v. EEOC, 292 F. Supp. 3d 238, 245 (D.D.C. 2017) ("If left to its own devices, then, EEOC will not have a new rule ready to take effect for over three years—not what the Court envisioned when it assumed that the Commission could address its errors 'in a timely manner.'").

132. *Id.* at 241.

133. H.R. 1313, 115th Cong. (2017).

134. Editorial, *A House Bill Poses a Threat to Worker Privacy*, WASH. POST (Mar. 31, 2017), https://www.washingtonpost.com/opinions/a-house-bill-poses-a-threat-to-worker-privacy/2017/03/31/654ca80a-0f53-11e7-9d5a-a83e627dc120_story.html; Lena H. Sun, *Employees Who Decline Genetic Testing Could Face Penalties Under Proposed Bill*, WASH. POST (Mar. 11, 2017), https://www.washingtonpost.com/news/to-your-health/wp/2017/03/11/employees-who-decline-genetic-testing-could-face-penalities-under-proposed-bill.

135. *See* Harold Bishop, *Notes on: Are Employer Wellness Programs Under Attack by the EEOC?*, 67 LAB. L.J. 556, 559 (2016); *see also* Gary Loveman, *BRT Comment Letter to EEOC on Wellness Programs*, BUS. ROUNDTABLE (June 19, 2015), http://businessroundtable.org/resources/brt-comment-letter-eeoc-wellness-programs. The sponsor of the bill argued that employers faced contradictory regulations as if confronted with conflicting road signs: "Although both turns seem permitted, no matter which decision drivers make, they could still be punished." Virginia Foxx, *Preserving Employee Wellness Programs*, WASH. POST (Apr. 18, 2017), https://www.washingtontimes.com/news/2017/apr/18/employee-wellness-programs-should-be-preserved.

136. Reed Abelson, *How Healthy Are You? G.O.P. Bill Would Help Employers Find Out*, N.Y. TIMES (Mar. 10, 2017), https://www.nytimes.com/2017/03/10/health/workplace-wellness-programs-health-genetic-data.html.

to thirty percent to generally incentivize wellness program participation rather than have specific rules for when employers seek genetic information.[137] In other words, under PEWPA, if a program complies with ACA standards, then it would also comply with GINA and the ADA.[138]

The bill has been met with substantial criticism. Over seventy groups including the AARP and American Academy of Pediatrics signed a letter to the House committee arguing that the bill would weaken GINA's and the ADA's privacy protections.[139] The American Society of Human Genetics has publicly opposed the bill, claiming it would coerce employees to give up private information.[140] Some scholars contend that the bill fundamentally misunderstands the relationship between these laws and that they actually do not conflict at all.[141] The controversy over this bill is emblematic of how the important privacy concerns of GINA interact with wellness programs' complex statutory and regulatory framework. The next Part explains why these criticisms about genetic privacy and lack of voluntariness have merit with regard to any financial incentive at all.

II. PRIVACY AND COERCION WHERE GINA AND WELLNESS PROGRAM INCENTIVES MEET

As Part I described, there is obvious tension between GINA and wellness programs wherever there is disclosure of statutorily protected genetic information. Because this information is often central to programs' assessments of employees' health, all parties involved have a great interest in the regulation of this practice.[142] Attempts to define an incentive that maintains a program's voluntary nature confront a complicated statutory and regulatory landscape as well as competing interests, with corporations on one side and consumer advocates on the other. This

137. Hudson & Pollitz, *supra* note 114, at 2–3.

138. *Id.* at 3.

139. Sun, *supra* note 134.

140. *ASHG Opposes H.R. 1313, the Preserving Employee Wellness Programs Act*, AM. SOC'Y HUM. GENETICS (Mar. 8, 2017), http://www.ashg.org/press/201703-HR1313.html.

141. *See* Hudson & Pollitz, *supra* note 114, at 2–3 (2017); *see also* Editorial, *supra* note 134 ("According to advocates, the bill was never meant to threaten employees' privacy, yet by painting their act in sloppy strokes, that is what its authors have done.").

142. *See* Bard, *supra* note 13, at 482 ("Disclosing family health history, however, is at the core of most Wellness Programs because it is the starting point of assessing what particular risks an individual employee faces.").

Part argues that any financial incentive at all for disclosing personal genetic information renders a wellness program involuntary and thus in violation of GINA. As Samuel R. Bagenstos writes, "as a matter of privacy and social equality, employers should not be permitted to leverage their economic power over employees as a means of controlling the aspects of workers' out-of-work lives that wellness programs affect."[143] Applied in this context, such leverage amounts to coercion and strikes at the ideals envisaged for GINA when Congress passed this law. This Part describes the problems this practice presents, beginning with an examination of how the law treats the idea of coercion and, applied to this specific wellness program context, how such a legal framework suggests that financial incentives for providing genetic information is unacceptably coercive. To illustrate why this practice in particular is coercive, this Part contrasts it with the related but distinguishable example of incentives for participating in scientific research. Next, this Part explains the practical economic impact of this incentive scheme on lower-income workers, for whom any discount on premiums may be difficult to turn down. Finally, this Part shows how both the public's poor understanding of genetic science and the data privacy concerns involved in the information gathered by wellness programs exacerbate the coercion problem and create greater risks of genetic discrimination.

A. VOLUNTARINESS, COERCION, AND FINANCIAL INCENTIVES FOR GENETIC INFORMATION

Interpreting "voluntary" to allow financial incentives for any amount or kind of genetic information would render them impermissibly coercive. The idea of voluntariness and coercion are ill-defined concepts in the law because they are heavily context-dependent.[144] Bagenstos advocates a standard for this voluntariness requirement that would prohibit employers from offering incentives that give an employee "no fair choice" in participating.[145] Similarly, the philosopher John Hodson proposes that the unifying principle for legal coercion involves the

143. Samuel R. Bagenstos, *The EEOC, the ADA, and Workplace Wellness Programs*, 27 HEALTH MATRIX: J.L.-MED. 81, 82 (2017).

144. *See, e.g.*, *id.* at 87.

145. *See id.* at 91. For in-depth arguments in favor of no financial incentives for information protected under the ADA specifically—not GINA—see generally *id.*; Stefanie Brody, *Working Well(ness): The Impact of the ADA Final Rule on Wellness Program Regulation and a Proposal for a Zero-Incentive Rule*, 11 ST. LOUIS U. J. HEALTH L. & POL'Y 209 (2017).

recognition "of each person's having control over his or her own life in accordance with his or her own unencumbered choices."[146] While it is widely accepted that some level of coercion is necessary for a functioning democratic society,[147] the law has also found certain policies to be unacceptably coercive.[148] Kristin M. Madison et al. cite an inclusive definition: "the intentional use of a credible and severe threat of harm or force to control another or to compel him or her to do something."[149] David A. Reidy and Walter J. Riker point out common examples of legal coercion as "clubs and other voluntary organizations . . . coerc[ing] members to insure [sic] fidelity to organizational norms and ends," and "officials sanction[ing] and sometimes dissolv[ing] corporations."[150] More broadly, the law itself is coercive in that it seeks to shape people's behavior according to the legislature's commands.[151] The theory of "universal coercionism" even asserts that "every exchange, even in a competitive market, is coerced."[152] In her discussion of the doctrine of unconstitutional conditions,[153] Kathleen Sullivan advocates for a broad view of coercion that can exist "even in the absence of force or fraud, and even in an apparently consensual bargain."[154]

146. JOHN D. HODSON, THE ETHICS OF LEGAL COERCION 129 (1983).

147. DAVID A. REIDY & WALTER J. RIKER, COERCION AND THE STATE 1, 2 (David A. Reidy & Walter J. Riker eds., 2008) ("Coercion is . . . "an ubiquitous feature of our institutional, political world."); *Coercion*, STAN. ENCYCLOPEDIA PHIL., https://plato.stanford.edu/entries/coercion (last updated Oct. 27, 2011) ("A state's legitimacy and sovereignty is sometimes thought to depend on its ability to use coercion effectively and to monopolize its use within its territory against competitors, both internal and external.").

148. Tenth Amendment jurisprudence, which concerns whether the federal government has coerced states into taking a certain action, is a paradigmatic example. *See, e.g.*, Nat'l Fed'n of Indep. Bus. v. Sebelius, 567 U.S. 519, 583 (2012) (striking down the ACA's Medicaid expansion provision on the ground that it was unconstitutionally coercive).

149. Kristin M. Madison et al., *The Law, Policy, and Ethics of Employers' Use of Financial Incentives to Improve Health*, 39 J.L. MED. & ETHICS 450, 459 (2011).

150. REIDY & RIKER, *supra* note 147.

151. *See id.*

152. Kathleen M. Sullivan, *Unconstitutional Conditions*, 102 HARV. L. REV. 1413, 1446–47 (1989) (citing the work of Robert Hale).

153. *See id.* at 1425 ("An unconstitutional conditions challenge asks whether government's offer of a benefit on condition demands stronger justification than the minimally rational basis that would support the government's unconditional offer or wholesale denial of the same benefit.").

154. *Id.* at 1420.

While it can be difficult to define when a law is too coercive, weighing considerations such as utility can be useful. For example, coercion "does not always deliver, indeed, does not always promise, significant utility gains," and it "sometimes so offends against freedom, equality, independence, respect or some other value affirmed by those acting within the relevant institutional or political context that it cannot be morally redeemed by utility gains, even if they are significant gains."[155] Sullivan describes coercion as "depend[ing] on underlying theories of autonomy, utility, fairness, or desert."[156]

Under this pseudo-balancing framework, genetic information's minimal utility does not outweigh privacy concerns, thus rendering this "apparently consensual" practice impermissibly coercive. One justification for violating the principle of unencumbered choice is what Hodson calls "the welfare principle," which "require[s] persons to aid others, provided that *what is required is (or is quite likely to be) vital to the personal functioning . . . of those aided*."[157] This idea highlights why financial incentives in this context are coercive: there is no clear benefit to employees—or even to employers—of disclosing this information as part of a wellness program. While it is true employees would save some money on their health insurance, they would do so after facing an unfair choice. Moreover, the fact that genetics is such a unique concept burdened with risks and nonmonetary value further distorts the equation.[158] These significant but intangible harms related to privacy and DNA's role in conceptions of identity make these incentives too coercive because these policies "involve a departure from some baseline of 'the normal or natural or expected course of events' that makes the recipient worse off."[159]

It is worth noting that the way one views an incentive—as financial rewards or penalties—does not have bearing on whether it could be considered coercive or not. Because coercion is an "inescapably normative" concept,[160] it is tempting to consider such a policy differently depending on how it is framed. For example, people overwhelmingly support the idea of discounts

155. REIDY & RIKER, *supra* note 147.

156. Sullivan, *supra* note 152, at 1443.

157. HODSON, *supra* note 146, at 130 (emphasis added).

158. *See infra* Part III.A.1 (describing the significance of genetics to one's identity and how privacy relates to genetics).

159. Sullivan, *supra* note 152, at 1448 n.142.

160. *Id.* at 1446, 1450.

on health insurance for participation in a weight management program—a reward—but overwhelmingly disapprove of mandating a higher premium for those who do not participate in such a program.[161] The reality is that these designs can very well be identical; how employees view it depends on the employer's presentation.[162] For lower-income employees "for whom 'the only way to obtain affordable insurance is to meet the targets,' incentive programs' voluntariness can become dubious and 'programs that are offered as carrots may feel more like sticks,'"[163] or, as one scholar calls it, a "privacy tax."[164] The EEOC enforcement guidance regarding the ADA and disability-related inquiries from 2000 stated, "A wellness program is 'voluntary' as long as an employer neither requires participation nor penalizes employees who do not participate."[165] Since an incentive could just as well be a penalty depending on one's perspective, framing the incentive as a reward does not mean that it is not coercive.[166]

Even the pro-incentives business interests and politicians who support PEWPA do not articulate a reason for why a wellness program should be free to collect the family medical history of employees and their family members.[167] The common assumption is that this information is useful in evaluating future health

161. Madison et al., *supra* note 149, at 458.

162. *See id.* at 459 ("[I]t is not clear that all carrots are created equally, as they can often be reframed easily as sticks.").

163. *Id.* (quoting Harald Schmidt et al., *Carrots, Sticks and Health Care Reform—Problems with Wellness Incentives*, 362 NEW ENG. J. MED. e3(1), e3(3) (2010)); *see also* Bagenstos, *supra* note 143, at 88–90.

164. Robert Sprague, *Survey of (Mostly Outdated and Often Ineffective) Laws Affecting Work-Related Monitoring*, 93 CHI.-KENT L. REV. 221, 250 (2018) (citing Mark A. Rothstein & Heather L. Harrell, *Health Risk Reduction Programs in Employer-Sponsored Health Plans: Part I—Efficacy*, 51 J. OCCUPATIONAL & ENVTL. MED. 943, 944 (2009)).

165. U.S. EQUAL EMP'T OPPORTUNITY COMM'N, No. 915.002, ENFORCEMENT GUIDANCE: DISABILITY-RELATED INQUIRIES AND MEDICAL EXAMINATIONS OF EMPLOYEES UNDER THE AMERICANS WITH DISABILITIES ACT (ADA) (2000), https://www.eeoc.gov/policy/docs/guidance-inquiries.html.

166. *See* Madison et al., *supra* note 149, at 460; *see also* Sullivan, *supra* note 152, at 1436, 1440 (explaining how the baseline from which the Supreme Court views a law influences whether the Court upholds it).

167. Rather, their advocating of enshrining incentives in the law is usually articulated as a reining in of the EEOC's wellness program litigation and excessive government regulation that is burdensome to employers. *See, e.g.*, COMM. ON EDUC. & THE WORKFORCE, FACT SHEET: PRESERVING EMPLOYEE WELLNESS PROGRAMS ACT (2017), https://edworkforce.house.gov/uploadedfiles/preserving_employee_wellness_programs_act.pdf; Sun, *supra* note 134; *see also* Foxx, *supra* note 135.

risks and taking steps to prevent illness.[168] One wellness program vendor executive even complained that GINA's ban on collecting this information would "hamstring companies' ability to collect more extensive information to help design wellness programs."[169] However, research has not found that this information actually promotes better health among employees.[170] In fact, this specific practice fits into the larger picture of wellness programs' ineffectiveness overall at improving workers' health and lowering health care costs.[171] As one writer put it, "the answer is always to eat better and exercise more regardless of your genes,"[172] so incentivizing GINA-protected information is just not useful enough to justify the invasion of privacy.

1. Distinguishing Between an Example of Legal Coercion: Human Subject Research

A closely related but distinguishable example of legal coercion is financially incentivizing human subject research in the sciences. Bioethicist Ezekiel J. Emanuel has argued that inducing participation in clinical trials, even with high monetary rewards, is ethical because the institutional review boards (IRBs) that evaluate research proposals only approve trials that will not

168. *See* Bard, *supra* note 13, at 480.

169. *See id.*

170. *See id.* at 481 (quoting the president of the American Heart Association, who pointed out the absence of data "suggest[ing] that knowing family history per se affects the success of a wellness program").

171. *See, e.g.*, Brody, *supra* note 145, at 214; Horwitz et al., *supra* note 108, at 469 (explaining that any cost savings an employer experiences "may come from making workers with health risks pay more for their health care than workers without health risks do"); Jessica L. Roberts & Leah R. Fowler, *How Assuming Autonomy May Undermine Wellness Programs*, 27 HEALTH MATRIX: J. L.-MED. 101, 111–12 (2017) (citing a study of ten years' worth of data finding that the return on investment was only fifty cents for every dollar spent on the wellness program). Nearly all of the studies highlighting wellness program success stories have been conducted by wellness vendors themselves using non-rigorous, flawed methods. *See, e.g.*, Michael Hiltzik, *A Federal Judge Takes Aim at 'Voluntary' Company Wellness Programs that Invade Your Privacy*, L.A. TIMES (Dec. 27, 2017), http://www.latimes.com/business/hiltzik/la-fi-hiltzik-wellness-20171227-story.html; Al Lewis, *Genetic Testing: The New Frontier of Wellness Madness*, HEALTH CARE BLOG (Dec. 16, 2015), http://thehealthcareblog.com/blog/2015/12/16/genetic-testing-the-new-frontier-of-wellness-madness/.

172. Al Lewis, *Your Employer's Wellness Program Can Demand Your DNA*, HUFFINGTON POST (May 14, 2016), https://www.huffingtonpost.com/al-lewis/should-your-employers-wellness-program-can-demand-your-dna_b_7249684.html.

be excessively risky or painful.[173] Thus, even if participants enroll in a study out of poor judgment and a high incentive, they will not become worse off because of the safeguards of the IRB process.[174] A critique of Emanuel's view is that it focuses too much on the risk of such participation and not enough on the context of the offer, namely that there are special concerns for people in vulnerable populations or circumstances.[175] A critical difference between human subject research and wellness programs is that in the latter, there is an employer-employee relationship where the employer has the upper hand and the employee depends upon continued employment and health insurance.[176] This power imbalance "alters the options available."[177]

The coercive nature of offering financial incentives for disclosing genetic information may not be immediately obvious, especially since analogizing it with voluntary human subject research seems at least superficially reasonable. If one views coercion as a high standard requiring serious threats and significant harm,[178] simply paying thirty percent more in health premiums might not seem to rise to this level. Under Emanuel's framework, the purported benefits of disclosing genetic information in a wellness program—greater awareness of one's health risks and better health—could make this practice acceptable.[179] However, Title II of GINA is an employment antidiscrimination law, which "put[s] all workers, when compared across the forbidden axes of discrimination, on the same footing in dealing with their employers."[180] If financial incentives give some—wealthier—employees a fair choice and not others, then GINA is not putting employees on the same footing. Moreover,

173. *See generally* Ezekiel J. Emanuel, *Ending Concerns About Undue Inducement*, 32 J.L. MED. & ETHICS 100 (2004) (arguing that worries about undue inducement are displacements of other ethical concerns).

174. *See id.* at 104.

175. *See generally* Joan McGregor, *Undue Influence as Coercive Offers in Clinical Trials*, *in* COERCION AND THE STATE, *supra* note 147, at 45 (suggesting that, with sufficiently vulnerable populations, coercion may be accomplished by offer instead of requiring a threat).

176. Bagenstos, *supra* note 143, at 91 ("[W]orkers are, in general, asymmetrically vulnerable in the employment relationship . . . it is generally much easier for an employer to find another worker than it is for an employee to find another job.").

177. *See* McGregor, *supra* note 175, at 50.

178. *But see id.* at 45.

179. *See* Madison et al., *supra* note 149, at 461.

180. Bagenstos, *supra* note 143, at 92.

the importance of health insurance in this scenario should not be overlooked. Unlike in scientific research where participation is not essential to the research subjects, employees in the wellness program context are coming from a place of needing health insurance. Foregoing an incentive would still be altering such a fundamental benefit, even if it is not entirely taken away. The unique and changing nature of health care costs also complicates this equation, as thirty percent of self-only coverage could represent a much higher dollar amount in five or ten years given how costs only keep increasing.[181]

2. Coercion and Disparate Economic Impact on Lower-Income Employees

While the Sections above outlined how the very theory of financial incentives for providing genetic information is coercive, such a policy can, in practice, adversely impact vulnerable populations. Financial incentives at any level—and particularly as high as thirty percent—can really function as penalties, not "incentives,"[182] which are theoretically allowed by GINA's exception for "voluntary" programs. Instead, they create inequality between poorer and wealthier people in terms of privacy rights; only employees with more resources have a true *option* of keeping this personal information private if they wish, while lower-income workers might find the incentive hard to resist.

Statistics on average income and health insurance costs illustrate just how coercive such a regulatory scheme can be. In 2015, for example, self-only coverage cost, on average, $6,251 per year.[183] Since forty percent of American households earn less than $42,000 annually, saving $1,875—thirty percent of the coverage cost—in exchange for disclosing this information could be too significant to pass up.[184] These savings are not trivial. It

181. *See* Brody, *supra* note 145, at 228 ("As health insurance costs continue to rise—when considering not just premiums but increasingly high deductibles, without equitable gains in income—the amount of money represented by thirty percent of self-only coverage becomes larger and larger, thus becoming more and more burdensome.").

182. *See supra* notes 160–66 and accompanying text.

183. Bagenstos, *supra* note 143, at 96.

184. *Id.* Even $1875 can understate the amount of savings, given substantial differences in benefits costs based on geography and other factors. In fact, almost a fifth of workers pay over $7500 in self-only coverage, making the penalty they would pay for keeping information private *at least* $2250. *Id.*

could pay for two months' rent, two months of childcare, or several months' worth of the average family's groceries.[185] Significantly, the GINA rule clarified that the incentive under that rule could be in *addition* to the parallel ADA incentive, with the potential cumulative effect "that the combined total inducement will be no more than twice the cost of 30 percent of self-only coverage."[186] Thirty percent of this amount is $5,100, which could be extremely consequential savings for the many households earning less than $42,000 a year. PEWPA, as a statute, would adopt this limit and supersede any agency rules.[187]

In addition to this financial impact, this incentive structure may have a particularly negative effect on older and less healthy people's access to medical care. Perversely, a penalty for choosing not to share genetic information with an employer could, in theory, backfire on the goals of a wellness program by "actually [limiting] people's access to the medications and primary and preventive care they need to get and stay healthy" because they now have less money in their pocket to spend on these important items.[188] As an official from the American Heart Association says, "When penalties become that high, it really is a deterrent to affordable, quality health care."[189] This was the concern in many comments the EEOC received before issuing the final rules. The agency refrained from addressing this issue, which the judge in the AARP case cited as a factor in his decision to vacate the rules.[190] In bringing the suit on behalf of its members, the AARP was especially concerned with financial incentives' effect on older employees as well. In a statement after the rules were issued, the organization said:

> Older workers, in particular, are more likely to have the very types of less visible medical conditions and disabilities—such as diabetes, heart disease, and cancer—that are at risk of disclosure by wellness ques-

185. AARP v. EEOC, 267 F. Supp. 3d 14, 32–33 (D.D.C. 2017).

186. GINA Rule, 81 Fed. Reg. 31,143, 31,146 (May 17, 2016) (to be codified at 29 C.F.R. pt. 1635).

187. *See* Sun, *supra* note 134.

188. Michelle Andrews, *EEOC Takes Aim at Wellness Programs Increasingly Offered by Employers*, KAISER HEALTH NEWS (Dec. 2, 2014), https://khn.org/news/eeoc-takes-aim-at-wellness-programs-increasingly-offered-by-employers.

189. *Id.*

190. *AARP*, 267 F. Supp. at 33 ("The possibility that the ADA rule could disproportionately harm the group the ADA is designed to protect would appear to pose a 'significant problem.'").

> tionnaires and exams. . . . By financially coercing employees into surrendering their personal health information, these rules will weaken medical privacy and civil rights protections.[191]

So not only would employees with less financial resources be disclosing private information not entirely willingly, they are also left with less money in their pocket to potentially spend on improving or maintaining their health. This impact is unfortunate because wellness programs' primary targeted population is the sickest workers, who also tend to be the poorest.[192]

B. ADDITIONAL ISSUES THAT ALTER PERCEPTION OF RISK AND HEIGHTEN PRIVACY CONCERNS

While the Section above discusses how this incentive structure itself is coercive, there are two outside factors that exacerbate the unfairness of the "choice" employees make when faced with the decision to disclose genetic information. First, laypeople's poor understanding of genetics creates greater risks of discrimination, and second, data privacy concerns mean that employees' information might be much less secure than they think it is.

1. Misunderstanding of Genetic Science

A problematic aspect of the coercion balancing framework is that because of common misunderstandings of genetic science, employees cannot fairly evaluate the risks and benefits of disclosing genetic information. The common belief in genetic determinism—that genetics is responsible for almost everything about a person—can lead wellness program vendors and employers, if they obtain access to the information, to place too much significance on medical history and genes when evaluating employees. This view can thus overemphasize the perceived utility of this information in wellness programs[193] and even result in discriminatory attitudes:

> A focus on genetics emphasizes racial and ethnic differences, a very sensitive matter both now and possibly in the future. Stressing the genetics of race has the potential to intensify those divisions, while reinforcing the view that perceived differences are not mere accidents of

191. Appleby, *supra* note 108.

192. Horwitz et al., *supra* note 108, at 473.

193. *See* GRAEME LAURIE, GENETIC PRIVACY: A CHALLENGE TO MEDICO-LEGAL NORMS 97 (2002) ("Such a reductionist view sets too much store by the influence of genetics in the determination of human the condition . . . .").

> culture and circumstance but are grounded in biology, which is itself seen as somehow fundamental and unalterable.[194]

The problem is that genetics predict far less about a person's health risks than is commonly thought.[195] For example, social conditions often predict health outcomes better than genetic data, and can even alter genetic expression.[196] And yet, "the phenomenon of the lay public acquiescing to an over-reliance on genetic information without fully comprehending its complexity" can lead to the incorrect belief that genetics determines everything, creating risks of genetic discrimination.[197] Without the right expert guidance on interpreting this information, genetic tests results can even be dangerous.[198] As Louise Slaughter, who spearheaded GINA through Congress, said, "Expecting human resources professionals to interpret a genetic test accurately is about as realistic as asking them to predict the weather for a particular city a year from that date."[199] This is especially troublesome given the speed at which this field of technology is advancing,[200] making it even more difficult to interpret this information accurately according to current science.

194. Thomas H. Murray, *Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different from Other Medical Information?*, *in* GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA, *supra* note 25, at 60, 63.

195. Thomas H. Murray & Ross S. White, *Genetic Privacy in the United States: Genetic Exceptionalism, GINA, and the Future of Genetic Testing*, *in* GENETIC PRIVACY: AN EVALUATION OF THE ETHICAL AND LEGAL LANDSCAPE 253, 256 (Terry Sheung-Hung Kaan & Calvin Wal-Loon Ho eds., 2013) ("Recent studies suggest that information from multiple genetic variants does not necessarily provide a better prediction of diabetes risk than well-known risk factors such as age, body mass index, and sex, and is less predictive of coronary heart disease and cardiovascular events than factors such as age, blood pressure, triglycerides, cigarette use, and diabetes.").

196. *See* Ajunwa, *Genetic Data*, *supra* note 76, at 81; *see also* Craig Konnoth, *Health Information Equity*, 165 U. PA. L. REV. 1317, 1360–61 (2017).

197. Ajunwa, *Genetic Data*, *supra* note 76, at 81.

198. Murray & White, *supra* note 195, at 257, 263 (describing studies of direct-to-consumer genetics testing that reach incorrect and contradictory interpretations about the same genes); *see also* Ajunwa, *Genetic Data*, *supra* note 76, at 84 ("Given the established sociological phenomena of genetic essentialism, genetic determinism, and genetic coercion, the government must intervene with stronger protections against genetic discrimination.").

199. Slaughter, *supra* note 24, at 734.

200. The current Director of the National Institutes of Health—himself a physician-geneticist—stated that the field of genetics "is moving so quickly that any genetic risk predictions based on today's understanding will need to be revised in the context of new discoveries tomorrow." Abrams & Garrett, *supra* note 10, at 767; *Biographical Sketch of Francis S. Collins, M.D., Ph.D.*, NAT'L

Some scholars have argued that genetic information should not receive special protection for the very reason that genes say little about individuals compared to environmental and behavioral factors.[201] However, the common assumption of "immutable genetic risks" can be far from "obsolete" even when the science shows otherwise.[202] In fact, while this assumption may have been even more dominant in the years leading up to GINA's passage,[203] PEWPA's incentivizing disclosure, which "reeks of genetic determinism,"[204] shows that this notion is still prevalent. It is this very misunderstanding about how genetics works that should make lawmakers especially wary of financial incentives making employees susceptible to coercion,[205] and is why PEWPA threatens to dramatically undercut GINA's protections.[206]

2. Data Privacy

These concerns are exacerbated by the risk of private genetic data falling into the wrong hands. The current rules do require employers to tell employees who has access to disclosed medical information, which in many cases is a third-party vendor.[207] They also mandate that a vendor share only aggregated data with the employer to avoid identifying individual employees.[208] However, it seems far from guaranteed that the information an employee discloses remains under lock and key that only a designated entity has access to—and even if it were, it would not be without concerns. Instead, most information today is susceptible to data breaches, and employees probably do not

INSTS. HEALTH (June 27, 2017), https://www.nih.gov/about-nih/who-we-are/nih-director/biographical-sketch-francis-s-collins-md-phd.

201. Green et al., *supra* note 84, at 399; Murray, *supra* note 194, at 67.

202. *See* Green et al., *supra* note 84, at 399.

203. *Id.*

204. Ricki Lewis, *Saving GINA: Is Genetic Privacy Imperiled?*, PLOS BLOGS: DNA SCI. BLOG (Mar. 9, 2017), https://blogs.plos.org/dnascience/2017/03/09/saving-gina-is-genetic-privacy-imperiled.

205. *See* McGregor, *supra* note 175, at 45 ("This model of coercion that focuses only on the notion of threats does not go far enough to capture cases where the victim's vulnerability is taken advantage of to accomplish the coercion."). *See generally* Lewis, *supra* note 204 (illustrating the problematic risks that a misunderstanding of genetic science poses in the context of wellness programs).

206. *See* Hudson & Pollitz, *supra* note 114, at 3 ("H.R. 1313 undermines the principle that genetic information needs the highest level of protection so that people can make decisions about obtaining their own information without fearing that it might be used against them.").

207. Appleby, *supra* note 108.

208. *Id.*

know how many unknown parties can lawfully access their wellness program data even when there is no breach.[209] The reliance on third-party vendors "introduces an additional layer of regulatory complexity as vendors must coordinate their compliance efforts with their employer-clients,"[210] and with more complexity might come more opportunity for mistakes. This concern came out in the congressional testimony about the bill by Representative Sheila Jackson-Lee:

> While some of my colleagues are focused that GINA will provide further incentives and additional opportunities for litigation against employers, they seem to forget the very real concern of individual protections. In an age where electronic databases are easily tampered with and private information is passed around like a bad cold, we must focus on the rights of individuals and their families when dealing with such a complex and contentious issue.[211]

In the decade since this testimony, the amount of American lives that resides online can only have increased, arguably presenting an even greater risk since GINA's passage. In fact, "[c]onsumer and patient advocates note that wellness programs routinely obtain passive authorization from participants to access further information about them, including claims and medical records data, and share it with their business partners."[212] Even if vendors do not sell or share collected information, there is still a risk of data breaches.

Unfortunately, research shows that "large databases containing health information are an attractive target for hackers."[213] One wellness vendor admits in the small print of its website that it stores the data it gathers and can reuse it to perform research or sell it for profit, and that a number of different kinds

209. *See generally* Julie Brill, Comm'r, Fed. Trade Comm'n, Big Data and Consumer Privacy: Identifying Challenges, Finding Solutions, Address at Woodrow Wilson School of Public and International Affairs, Princeton, University (Feb. 20, 2014) (describing the vast extent of consumers' information online and who has access to it, and the troubling implications this situation poses).

210. Alden J. Bianchi, *The Emerging Contours of the Rules Governing Wellness Programs*, 63 PRAC. L. 43, 44 (2017).

211. 154 CONG. REC. 5935, 7486 (2008) (statement of Rep. Sheila Jackson-Lee).

212. Hudson & Pollitz, *supra* note 114, at 2.

213. Ifeoma Ajunwa, *Workplace Wellness Programs Could Be Putting Your Health Data at Risk*, HARV. BUS. REV. (Jan. 19, 2017), https://hbr.org/2017/01/workplace-wellness-programs-could-be-putting-your-health-data-at-risk. For example, "[s]ixty million Anthem policyholders were breached, a large wellness company called Staywell had a breach, and there have been 2.3 million reported instances of medical identify theft." Lewis, *supra* note 172.

of people can have access to it.[214] Even though the data is purportedly anonymized, such a solution is not foolproof because "DNA can and has been re-identified," according to a privacy expert.[215] Allowing employers and wellness program vendors to access such sensitive information legally might erode any confidence employees have in the protection of their information because the law is failing to protect something it is supposed to protect, which in turn could deter positive wellness program outcomes.[216] Moreover, genetic testing can both help advance medical technology and lead to better individual health outcomes,[217] so practices that discourage such testing are in no one's best interests.[218]

The significance imputed to genetic information and today's widespread data privacy risks are more evidence that financial incentives can impermissibly distort the decision-making autonomy employees should have in this situation. Employees might not realize the dangers of data breaches their disclosures pose,[219] which would in fact increase the negative risks in Emanuel's "undue inducement" equation.[220] Other unknowns that are difficult to quantify but might make employees apprehensive about sharing genetic information concern the future risks and uses of this data that today is only speculative. Nancy Yue Liu refers to this possibility as "function creep."[221] In other words, genetic data could be used for purposes beyond that which it was intended in the wellness program context. These speculative

214. Lewis, *supra* note 172.

215. *Id.*

216. *See* Brill, *supra* note 209.

217. *See* Roberts, *Genetic Information*, *supra* note 54, at 605.

218. *Cf.* Steven Greenhouse, *Ex-Worker Says Her Firing Was Based on Genetic Test*, N.Y. TIMES (Apr. 30, 2010), https://www.nytimes.com/2010/05/01/us/01gene.html (recounting how, if a woman claiming her firing was because she had a gene for breast cancer lost her case, her lawyers believe "it could discourage other workers from going for genetic testing about particular illnesses and from having surgery in response to such testing—steps that are good for their health").

219. *See* discussion *supra* Part II.B.1.

220. *See supra* note 173 and accompanying text.

221. NANCY YUE LIU, BIO-PRIVACY: PRIVACY REGULATIONS AND THE CHALLENGE OF BIOMETRICS 66 (2012) ("[T]he potential of biometric data cannot be restricted by the purposes for which they are/were originally used."); *see also* TAYLOR, *supra* note 19, at 4 ("It is this *interpretive potential* of genetic data that helps to demonstrate the limitations of the current regulatory system as well as to understanding the multitude of different preferences that might be expressed regarding its access and use.").

harms might be difficult to grasp,[222] so when there is a financial reward hinging on disclosure, these risks can also be easy to ignore or underestimate.[223] They suggest coercion because they "[undermine] the freedom of the [employee] and [render] his or her consent invalid."[224] All of these problems indicate the lack of voluntariness involved in this incentive structure, which is directly contrary to GINA's wellness program exception and points to the need for a new rulemaking to prohibit financial rewards of any amount.

III. THE AGENCY AND CONGRESS SHOULD READ GINA'S "VOLUNTARY" EXCEPTION AS FORECLOSING ANY FINANCIAL INCENTIVES

Given the problems outlined above, this Part recommends that a financial incentive of any kind is inappropriate for employees' disclosure of genetic information. While, in theory, a ten percent level is more acceptable than a thirty percent level, the very idea of a monetary reward—or penalty, depending on one's view—linked with such fundamentally private information as genetics is antithetical to the spirit of GINA and today's significant concerns about data privacy.[225] Now that the EEOC's rules have been vacated, it should issue a new rule that expressly prohibits any kind of financial incentive for employees to disclose genetic information through wellness programs, as it originally did in 2010. The agency should read GINA's text strictly to allow "voluntary" disclosures, uncompromised by offering financial incentives. First, financial incentives are incompatible with the statute's intent to promote genetic privacy. While a categorical prohibition on such incentives may seem far-reaching, this solution is consistent with the expansive privacy and antidiscrimination protection that GINA represents, as well as with the ACA's purpose of broadening access to healthcare. This breadth

222. Barbara Sandfuchs, *Privacy Nudges: An Introduction*, *in* PROTECTING THE GENETIC SELF FROM BIOMETRIC THREATS: AUTONOMY, IDENTITY, AND GENETIC PRIVACY 256, 259 (Christina M. Akrivopoulou ed., 2015) ("Citizens may find the complexity of the consequences self-disclosure of genetic data can cause difficult or impossible to understand.").

223. *See id.* at 261 ("People suffer from optimism-bias . . . . [I]f a harm is hard to imagine people underestimate the probability of its occurrence.").

224. *See* McGregor, *supra* note 175, at 49.

225. This argument is limited only to *financial* incentives, which typically constitute reductions on health insurance. While also arguably financial, smaller tokens such as gift cards or gym membership discounts are outside the scope of this Note, which attempts to analyze only what has been controversial under GINA and applicable regulations.

is also necessary in order to avoid the problems arising under the 2016 rule's application to the genetic information of employees' spouses. Next, the practical effect of making these disclosures strictly optional under a zero-incentive rule could actually make wellness programs more successful in improving employee health. Finally, this solution would lead to much needed legal certainty in this area for employers because of the EEOC's ambiguous position after the recent AARP ruling.

A. GENETIC INFORMATION, PRIVACY, AND STATUTORY PURPOSE

Perhaps just as problematic as the discriminatory *use* of genetic data is simply the idea that an employer could have access to an employee's genetic test results or spouse's family medical history. Congress recognized this concern in formulating GINA as a hybrid antidiscrimination *and* privacy law. Prohibiting financial incentives would be in keeping with legal theories of privacy as applied to genetics and would advance GINA's broad purpose.

1. Financial Incentives' Inconsistency with Genetic Privacy

Even though genes predict far less than many people assume, they are still intimately tied to our conceptions of ourselves.[226] The very idea of DNA is thought to be fundamental to one's identity, forms connections to family members and long-ago ancestors, and simply "helps us conceptualize the person as a person."[227] Anita Allen describes genetic privacy as connected to all four kinds of privacy the law is concerned with: informational privacy (access to personal information), physical privacy (one's physical bodily integrity), decisional privacy (the interference of government and third parties with individual decision-making), and proprietary privacy (the possession and rights of the "owner" of information).[228] Traditionally, physical privacy has been most fraught in search and seizure law related to invasive procedures such as drug testing and body cavity searches, as well as in mandatory immunizations laws.[229] By now though,

226. *See, e.g.*, LAURIE, *supra* note 193, at 90 ("Exposure to [knowledge of one's genetics] can alter self-perception and challenge notions of identity.").

227. *See* Konnoth, *supra* note 196, at 1341–42 ("Indeed, genetic data is popularly framed as the essence of personhood.").

228. Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, *in* GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA, *supra* note 25, at 31, 33–34.

229. LIU, *supra* note 221, at 72.

"DNA is an emerging area in this field," indicating that society's view of genetics is so fundamental as to "[transcend] the physical" and encompass "the dignity of the human person."[230] "[T]he idea of the human body as an inviolate entity is now common in the laws of Western states," so DNA fits neatly in with these values.[231]

It is true that the meaning of one's genetics and the desire for privacy might vary tremendously from person to person. Like coercion, privacy is thus an inherently normative concept, which makes evaluating whether an offer is truly voluntary more complicated.[232] One employee may be comfortable broadcasting their entire family medical history to managers at work and all over social media, while a colleague would prefer to not even learn about their own genetics let alone tell others this information. Disconnecting any financial reward from this practice would respect everyone's diverse tolerances for privacy. As Mark Taylor states:

> Privacy protection is about maintaining these highly variable norms: both protecting the states of separation they represent *and* enabling the access that they expect. When there are different norms in play, then regulation must seek to account reasonably for them all in a process that determines which has priority in any case of conflict.[233]

Here, the law should prioritize the privacy concern because the benefit of the alternative—the wellness program having access to genetic information—is not worth the cost in lost privacy.[234] This normative nature of privacy also relates to the desire *not* to discover one's genetic information. Right or wrong, it is easy to attach special significance to inherited diseases; learning one's genetic predisposition can have negative effects on all aspects of a person's life.[235] Because of the intensely personal and high-stakes nature of genetic test results, learning about this information through a wellness program should be strictly voluntary and free of financial influence.[236] These complicating factors

230. *Id.*

231. LAURIE, *supra* note 193, at 190.

232. *See* McGregor, *supra* note 175, at 50 ("The threshold between voluntary and nonvoluntary actions depends on the context, normative and otherwise.").

233. TAYLOR, *supra* note 19, at 202.

234. *See supra* note 155 and accompanying discussion of the utility—or lack thereof—of genetic information in wellness programs.

235. Elsa Supiot & Margo Bernelin, *Genetic Privacy: A European Design or Default?*, *in* PROTECTING THE GENETIC SELF FROM BIOMETRIC THREATS: AUTONOMY, IDENTITY, AND GENETIC PRIVACY 198, 202 (Christina M. Akrivopoulou ed., 2015).

236. *See, e.g.*, Pagan Kennedy, *What if You Knew Alzheimer's Was Coming*

make even a middle-ground incentive model that one scholar proposes inadequate. Elizabeth Brown suggests that "regulators instead might compare the cost of the incentive to the employee's net income" instead of to the cost of overall coverage.[237] While this solution might be less harmful on its face in terms of economic impact on employees, these privacy concerns are still present and problematic.

This Note does not attempt to argue in favor of genetic exceptionalism, which proposes that genetics is so different from other health-related information that it should receive more protection.[238] It would be unfair and overly simplistic to view an employer knowing or acting upon an employee's family medical history as categorically worse than doing so based on an employee's manifested disease or disability. As Murray and White point out, why should a predictive medical test—such as cholesterol evaluation—be treated differently than a test for a gene suggesting a higher risk of breast cancer?[239] While there are compelling arguments that federal law should protect employees against *medical* discrimination beyond what the ADA covers,[240] such concerns are outside the scope of this Note. Instead, this Note simply seeks to show that genetic information's unique challenges regarding privacy in the employment context are sufficient to prohibit any financial incentives in exchange for this data.

2. Consistency with GINA's Broad Purpose

Interpreting "voluntary" to prohibit financial incentives would be consistent with Congress's intent to ensure genetic privacy, assuage the public's fears, and further scientific research by enacting GINA. As Mark Taylor explains, "It is important

for You, N.Y. TIMES (Nov. 17, 2017), https://www.nytimes.com/interactive/2017/11/17/opinion/sunday/What-if-You-Knew-Alzheimers-Was-Coming-for-You.html; *Learning About Huntington's Disease*, NIH NAT'L HUMAN GENOME RES. INST., https://www.genome.gov/10001215/learning-about-huntingtons-disease (last updated Nov. 17, 2011); Dustin W. Massie, *23, My Employer & Me: On Genetic Testing, Privacy, and Employment*, BENCH & B. MINN. (Dec. 1, 2017), http://mnbenchbar.com/2017/12/genetic-testing.

237. Brown, *supra* note 123, at 243.

238. *See* Murray, *supra* note 194, at 61.

239. Murray & White, *supra* note 195, at 269 ("While knowledge obtained from genetic tests, such as greater susceptibilities to disease, can cause psychological stresses and anxiety, it would be unreasonable to assume that non-genetic discoveries could not be as discouraging for a patient or individual.").

240. *See, e.g.*, Green et al., *supra* note 84, at 399; Anya E.R. Prince & Benjamin E. Berkman, *When Does an Illness Begin: Genetic Discrimination and Disease Manifestation*, 40 J. L. MED. & ETHICS 655, 657 (2012).

that genetic data is *seen to be* subject to appropriate privacy protection for the sake of those who rely upon participants' trust in the security and integrity of the research process."[241] The understanding that this kind of information receives sufficient protection could provide benefits on an individual level—by not discouraging people to undergo potentially helpful genetic tests—as well as on a macro level through advancing scientific research.[242] Alleviating fear about who can access this sensitive information was a central reason for enacting GINA,[243] so chipping away at the federal floor of protection GINA offers is harmful. In fact, only forty-one percent of employees agree to disclose health information to large employers who have health-contingent wellness plans because they fear a lack of privacy, discrimination, and sharing of information with unauthorized parties.[244]

A broad reading of GINA's "voluntary" language to foreclose any financial incentives would also be consistent with the significance of the statute at the time of its enactment. Until 2008, while many states did have some kind of genetic privacy or antidiscrimination laws, their scope of protection was comparatively minimal. Most were limited to the health insurance—not employment—context, and only applied to genetic test results, not family medical histories.[245] Some were so narrow as to only concern the sickle-cell gene.[246] While European countries were, and still are, grappling with similar questions about how to protect genetic privacy, the need for an inclusive federal law in the U.S. was particularly great because Americans receive health insurance from their employers.[247] While there are multiple ways to

241. TAYLOR, *supra* note 19, at 5.

242. Madison Powers, *Justice and Genetics: Privacy Protection and the Moral Basis of Public Policy*, *in* GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA, *supra* note 25, at 355, 359–60.

243. *See supra* notes 43–50 and accompanying text; Roberts, *Genetic Information*, *supra* note 54, at 603. Around the time of enactment, "ninety percent of Americans expressed concern regarding the misuse of their genetic information." *Id.*

244. Hudson & Pollitz, *supra* note 114, at 2.

245. *See* Reilly, *supra* note 25, at 387.

246. *See* Rothstein, *supra* note 32, at 476.

247. LAURIE, *supra* note 193, at 150–51, 158. Canada, in fact, only passed its genetic antidiscrimination law in 2017, and it is already being challenged in court as unconstitutional. Brandie Weikle, *Door Will Open to Genetic Discrimination if Act Protecting Canadians Is Overturned, Genomics Expert Says*, CBC NEWS (May 14, 2018), https://www.cbc.ca/news/health/genetic-non-discrimination-act-challenge-quebec-1.4658432.

define genetic information, GINA took the broadest approach by including family medical history.[248] GINA was evidently meant to signify a substantial step forward in the law of genetic privacy and discrimination, so PEWPA's codification and expansion of the "voluntary" exception would represent a major step back.

A zero-incentive rule would not only be consistent with GINA's purpose but also with the spirit of the ACA. Because the ACA was meant to level the playing field in terms of access to healthcare, making employees pay more for coverage in exchange for keeping information related to their family's genetics and health private creates inequality in terms of privacy rights. President Obama himself, champion of the ACA, has recognized the importance of "an autonomy-based ownership understanding of information," stating, "[O]nce you understand [that the data is] yours, . . . you have agency in the process."[249] It should not be the case that affluent workers can choose more privacy because they find paying more in premiums acceptable, while it is much harder for lower-income people to maintain that same privacy when the financial reward would make a meaningful difference in their budget.[250] A zero-incentive rule would actually grant employees agency over this information.

That the EEOC's 2016 rule only applied to manifested diseases in employees' spouses[251] does not make such an incentive scheme acceptable and illustrates why a categorical prohibition on financial incentives is the solution that is more consistent with GINA's intent. The reasoning for the rule's narrow scope is that because employees and their spouses do not share genetic information, "the spouse's disease history is unlikely to enable discrimination against the employee on the basis of her genetic information."[252] In addition, employers do have a stake in

248. *See* Supiot & Bernelin, *supra* note 235, at 203–04 (drawing a contrast with the European Union's definition that only includes genetic test results). *But see* TAYLOR, *supra* note 19, at 191–92 (describing GINA's limitations).

249. Konnoth, *supra* note 196, at 1341. In fact, one scholar has compellingly framed the problem of wellness programs, genetic data and incentives under Michel Foucault's theory of "biopower," where, through government condoning of workplace wellness programs, the government becomes a third party who wields power over our bodies. *See* Ajunwa, *Genetic Data*, *supra* note 76, at 83–84.

250. *See* Reed Abelson, *Employee Wellness Programs Use Carrots and, Increasingly, Sticks*, N.Y. TIMES (Jan. 24, 2016), https://www.nytimes.com/2016/01/25/business/employee-wellness-programs-use-carrots-and-increasingly-sticks.html; *ASHG Opposes H.R.1313*, *supra* note 140.

251. *See* 29 C.F.R. § 1635.8(b)(2)(iii) (2017).

252. McIntyre et al., *supra* note 93, at 75.

spouses' health when spouses are covered by the employer's health plan.[253] However, this "clarification" seems to contradict both the text and purpose of GINA.[254] The purpose of including a spouse's information in GINA's definition of "genetic information" was to prevent increased health insurance costs based on the status of any dependents on the plan—even though an employee and their spouse do not share the same genetic information.[255] Moreover, the line between manifested diseases and pure genetic information that GINA attempts to draw is not always clear, so knowing a spouse's medical history could actually be the same as knowing their genetic information.[256]

This limitation is not harmless. The genetic background of an employee's spouse—which may be disclosed—would typically also reveal genetic information about the employee's children—whose disclosure of information is *not* allowed.[257] As Bahrad Sokhansanj writes, "Most critically, compromises to genetic privacy affect family members as much as they do the individual who has either consented to the release of their genetic information or participated in a study that releases genetic information."[258] Some of the comments to the proposed 2016 rule even noted that allowing this disclosure could lead to conflict within families when an employee and spouse disagree about whether to avoid a penalty by providing the spouse's genetic information.[259] This situation cannot be dismissed on the basis of being too narrow and theoretical. In fact, one study found that three quarters of employers who offer health assessment and management programs include spouses in their plans.[260] More specifically, in the AARP case, the judge's finding of standing was partly based on one of the plaintiffs' spouses being affected by the employer's new wellness plan.[261] More broadly, allowing

253. *Id.*

254. *See* 42 U.S.C. 2000ff(3) (2012).

255. AARP v. EEOC, 267 F. Supp. 3d 14, 34–35 (D.D.C. 2017).

256. Ajunwa, *Genetic Data*, *supra* note 76, at 94 ("[S]ome diseases are strictly genetic in nature or have strong genetic correlations, such that a manifested condition is evidence of the presence of a mutated gene.").

257. McIntyre et al., *supra* note 93, at 76.

258. Sokhansanj, *supra* note 25, at 309.

259. Genetic Information Nondiscrimination Act, 81 Fed. Reg. 31,143, 31,153 (May 17, 2016) (to be codified at 29 C.F.R. pt. 1635).

260. Barbara J. Zabawa, *The* AARP v. EEOC *Case and GINA*, WELLNESS COUNCIL AM. (Mar. 21, 2018), https://www.welcoa.org/blog/aarp-v-eeoc-case-gina.

261. AARP v. EEOC, 267 F. Supp. 3d 14, 23–26 (D.D.C. 2017).

the employee to disclose their non-employee spouse's information not only seems to insert troubling questions into a couple's private relationship but also contradicts the spirit of GINA to provide broad genetic privacy protections in health insurance and employment, contexts in which this situation squarely falls.

B. A STRICT READING OF "VOLUNTARY" MIGHT INCREASE WELLNESS PROGRAMS' EFFECTIVENESS

Prohibiting financial incentives for genetic information would far from doom employers' well-intentioned wellness programs. In fact, a rule that interprets "voluntary" strictly might actually be a positive development for both employees and employers, especially in the midst of bleak research about wellness programs' low success rates.[262] To effectively carry out the ACA's mandate of improving employee health and decreasing healthcare costs, wellness programs need to focus on engaging employees.[263] Awareness of certain risks from learning one's genetic information could be used to tie health outcomes to financial incentives, which "reframes health and bodily integrity as an obligation owed from the worker to the employer."[264] In contrast, meaningfully engaging with the possible implications of genetic test results might be more likely—and thus more likely to lead to better health outcomes—if employees volunteered to learn about this information free of any monetary reward.[265] It would still be unlawful for employers to make decisions based on this volunteered data, as GINA prohibits such discriminatory actions even when they are based on information lawfully acquired through one of the statute's enumerated exceptions.[266] GINA's confidentiality provisions would still apply to this data as well.[267]

Making this testing fully optional would not necessarily mean that no employee would participate. In fact, one study found that healthy people were more likely to obtain long-term

262. *See supra* note 171 and accompanying text.

263. *See, e.g.*, Rubstein, *supra* note 95, at 114–15; *see also* Hull & Pasquale, *supra* note 95, at 206 ("If health nannyism is necessary, it should be democratically developed and controlled.").

264. *See* Hull & Pasquale, *supra* note 95, at 204.

265. *See id.* ("It is also not clear that nudging individual behaviors is the right strategy at all, as public health initiatives also demonstrate that environmental factors, features of the built environment, and corporate product promotions can have profound effects on the health of individuals.").

266. *See* 42 U.S.C. § 2000ff-1(c) (2012).

267. *See id.* § 2000ff-5(a)–(b).

care insurance if their genetic tests revealed higher-risk results,[268] suggesting that people could be genuinely interested in learning and acting upon this information. However, the burden should be on the employer—or wellness program vendor—to explain the value of this opportunity. As the American Heart Association's director of policy research said, "The incentives are meant to engage employees . . . but they're not the comprehensive programming we'd like to see employers offer."[269] From this perspective, whether an employee can receive a five or fifty percent discount is irrelevant—the incentive does not actually solve anything.[270] Strictly voluntary participation in a genetic component of a program could play an important role in giving employees autonomy and making them feel as if wellness programming is "done *for* employees" rather than "done *to* [them]."[271]

C. LOOKING AHEAD: A ZERO-INCENTIVE RULE AND LEGAL CLARITY

Finally, a rule clarifying that GINA's "voluntary" requirement prohibits any kind of financial incentive would have the advantage of bringing legal certainty to this area for employers. Because part of the impetus for the 2016 EEOC rules was to clarify what kind of incentives GINA allowed, their impending vacatur will likely cause some confusion until the agency can finalize new rules,[272] especially for those employers with "mid-year plans" that started on July 1 rather than January 1.[273] In its March 2018 status report submitted to the court, the EEOC took a position that provided no real guidance. The agency stated it

268. Green et al., *supra* note 84, at 399.

269. Andrews, *supra* note 188.

270. *See* Bagenstos, *supra* note 143, at 92 ("It is the structure of the incentive, not the size, that matters.").

271. *See* Lewis, *supra* note 1 (emphasis added); *see also* Hull & Pasquale, *supra* note 95, at 200 (stating that wellness programs "present an exercise of power of employer over employee, one that attempts to push a rebranding of the reluctant").

272. Ice Miller Employee Benefits Team, *Court Ruling Creates New Incentive for Wellness Programs*, COLUMBUS BUS. FIRST (Mar. 7, 2018), https://www.bizjournals.com/columbus/news/2018/03/07/court-ruling-creates-new-uncertainties-for.html. For legal opinions illustrating just how ambiguous this situation is for employers, see *Legal Alert: EEOC's Status Report in* AARP v. EEOC *Creates Uncertainty for Wellness Programs*, JA COUNTER (Apr. 17, 2018), https://jacounter.com/legal-alert-eeocs-status-report-aarp-v-eeoc-creates-uncertainty-wellness-programs; Barbara J. Zabawa, *Tips for Employers with Mid-Year Plans Post* AARP v. EEOC, WELLNESS COUNCIL AM. (May 16, 2018), https://www.welcoa.org/blog/tips-employers-mid-year-plans-post-aarp-v-eeoc.

273. Zabawa, *supra* note 260.

had no plans to issue a Notice of Proposed Rulemaking soon, "but it also has not ruled out the possibility that it may issue such a Notice in the future."[274] The upside to this uncertainty is that it might push employers away from the model of financial incentives for health assessments, and toward offerings based around health education that do not involve inquiries into personal information like genetic background.[275]

Even if the agency did issue a Notice soon, it is unlikely the new rules would be finalized until late 2019, and would not go into effect until one or two years later.[276] When proposing new rules, the EEOC would ideally heed the judge's implicit warning in his opinion vacating the rules. When reconsidering the remedy for his earlier ruling that found the rules arbitrary and capricious under *Chevron* but nevertheless left them in place, he implied that once the agency reevaluates the question of an acceptable incentive level, "it is far from clear that the EEOC will view a 30% incentive level as sufficiently voluntary," and its decision "may very well be different on remand."[277] It is not necessary to go as far as amending GINA itself, which does not say anything about incentive levels at all. On its face, there is nothing wrong with the statute's exception for employers to acquire the genetic information of employees who "voluntary[ily]" authorize it as part of a wellness program.[278] Given that the purpose of such a rulemaking would simply clarify a statutory term and PEWPA has indicated Congress's inclination to move in the other direction, a regulation promulgated by the EEOC would be sufficient. Because of the significant coercion and privacy concerns outlined above, the agency should issue a new proposed rule soon that would expressly forbid any kind of financial incentive for GINA-protected information.

274. Defendant's Status Report at 1, AARP v. EEOC, No. 1:16-cv-02113 (JDB) (D.D.C. Mar. 30, 2018). The agency cites as one reason for this lack of guidance the two pending nominations to the EEOC, one of which is for the position of Chair. *Id.*

275. *See* Michael Popke, *The EEOC Isn't Taking Action on Wellness Regulations, but Employers Certainly Can*, BENEFITSPRO (June 28, 2018), https://www.benefitspro.com/2018/06/28/the-eeoc-isnt-taking-action-on-wellness-regulation.

276. Ice Miller Employee Benefits Team, *supra* note 272.

277. AARP v. EEOC, 292 F. Supp. 3d 238, 244 (D.D.C. 2017).

278. *See* 42 U.S.C. § 2000ff-1(b)(2)(A)–(B) (2012).

CONCLUSION

The problem of genetic privacy in wellness programs is at the intersection of many issues: the legacy of the history of genetic discrimination, a unique preemptive antidiscrimination law, the incredibly complex regulation of healthcare, socioeconomic inequality, workers' rights, and corporate and political interests. While genetic information gathering is admittedly a small aspect of wellness programs, it raises significant privacy concerns. Even if it is not common practice that employers ask workers about their family medical histories and try to reward them for such disclosures, a prohibition on these incentives are at least an important preventative step, just as GINA was for the phenomenon of genetic discrimination. Tightening privacy rights in this narrow context could even represent a significant step toward progress in heightening privacy protection in wellness programs generally.[279] Given the powerful forces representing business interests and supporting PEWPA that oppose heightened regulations and advocate greater freedom for employers, the timeliness of resolving this issue is high. Absent PEWPA's enactment and thus stripping of the EEOC's enforcement power, the agency now has an opportunity in the wake of the AARP ruling to take a firm stance against financial incentives for disclosing GINA-protected information. Such a position might be the beginning of a needed shift in wellness program policy.

279. *C.f.* Ajunwa et al., *supra* note 100, at 478 ("[T]he current state of the law is such that there is no check against wellness programs trawling for health information that the employee has not volunteered.").