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2019

GINA, Big Data, and the Future of Employee Privacy

Brad Areheart, *University of Tennessee College of Law*



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THE YALE LAW JOURNAL

BRADLEY A. AREHEART & JESSICA L. ROBERTS

GINA, Big Data, and the Future of Employee Privacy

ABSTRACT. Threats to privacy abound in modern society, but individuals currently enjoy little meaningful legal protection for their privacy interests. We argue that the Genetic Information Nondiscrimination Act (GINA) offers a blueprint for preventing employers from breaching employee privacy. GINA has faced significant criticism since its enactment in 2008: commentators have dismissed the law as ill-conceived, unnecessary, and ineffective. While we concede that GINA may have failed to alleviate anxieties about medical genetic testing, we assert that it has unappreciated value as an employee-privacy statute. In the era of big data, protections for employee privacy are more pressing than protections against genetic discrimination. Instead of failed legislation, GINA could represent the future of employment law.

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INTRODUCTION

Workers of the future may enjoy little to no privacy on the job. A recent article in the *Economist* describes Humanyze, a data-analytics firm that is using its algorithmic approach to human resources on its own employees.¹ Workers at Humanyze wear identification badges that monitor their every move. The devices include microphones that pick up conversations, Bluetooth and infrared sensors that track location, and an accelerometer that records movement.² That data is cross-referenced with employees' calendars, emails, and other personal information.³ The reports generated from this data include a surprisingly intimate amount of detail, including how much time an employee spends with members of the same sex, her level of physical activity, and the amount of time she spends speaking versus listening.⁴

The head of Humanyze sees these practices as smart business. He explains, “[e]very aspect of business is becoming more data-driven. There’s no reason the people side of business shouldn’t be the same.”⁵ However, employees may not share that sentiment. One employee of the software firm Workday, which also offers predictive data, quipped, “[t]his company knows much more about me than my family does.”⁶ This sentiment is increasingly common among workers. A recent study in the United Kingdom revealed that most respondents believed that their bosses were spying on them, and two-thirds thought that the increasing amount of worker surveillance made possible by technology would lead to distrust and discrimination.⁷

Stories like these give people more reason to be concerned with their privacy than ever before. New technology, sometimes called “big data,” offers the opportunity to aggregate and cross-reference information to gain access to some of our most intimate secrets, including our disease risks, our reproductive choices,

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1. See *There Will Be Little Privacy in the Workplace of the Future*, *ECONOMIST* (Mar. 28, 2018) [hereinafter *There Will Be Little Privacy*], <https://www.economist.com/special-report/2018/03/28/there-will-be-little-privacy-in-the-workplace-of-the-future> [https://perma.cc/343W-P69Y].
 2. See *id.*
 3. See *id.*
 4. See *id.*
 5. *Id.*
 6. *Id.*
 7. Ben Chapman, *More than Half of Employees Believe Their Boss Is Spying on Them at Work*, *INDEPENDENT* (Aug. 17, 2018, 9:15 AM), <https://www.independent.co.uk/news/business/news/workplace-surveillance-employees-boss-spying-on-workers-tuc-survey-a8495651.html> [https://perma.cc/KV6R-S3D4].

and information regarding our personal relationships. Employers might be particularly interested in snooping into their employees' private lives. Data analytics could reveal which employees are more likely to get sick, which employees are more likely to take parental leave, and which employees are more likely to be under stress at home. At present, the law offers few legal protections against this kind of prying. We propose that the Genetic Information Nondiscrimination Act (GINA),⁸ an idiosyncratic federal antidiscrimination law, might provide an unexpected pathway for navigating the growing challenges presented by big data.

In this Feature, we argue that one decade after its passage, GINA, which Congress intended primarily as a safeguard against discrimination based on genetic-test results, is better understood as a much-needed protection for employee privacy. In so arguing, we offer three novel contributions. First, we provide an empirical account of all the available cases decided under GINA. Systematically examining all the cases and quantifying both the recurring factual scenarios and the legal issues that have arisen in GINA's first decade allows us to say exactly what the statute is – and is not – accomplishing in the courts.

Second, we use that original case research to establish that in GINA's first ten years, there have been no successful claims filed for discrimination based on genetic-test results. Instead, most of the successful cases under GINA have involved impermissible requests for protected data. GINA, in practical terms, has functioned more as a protection against invasions of privacy than as a protection against discrimination.

While GINA's role as a privacy law is unexpected, it could hardly be better timed. The genetic-testing market has ballooned in recent years because of the FDA's increasing openness to genetic tests that allow consumers to screen their genes for disease risk from the convenience of their own homes. For example, in 2018 the FDA approved the first direct-to-consumer DNA test for three BRCA1/BRCA2 genetic mutations, each of which sharply increases the risk of breast cancer.⁹ Meanwhile, the National Institutes of Health (NIH) aims to enroll a million people by 2019 in its Precision Medicine Initiative,¹⁰ a research effort intended to tailor the delivery of health care to a patient's specific genetic

8. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (codified as amended in scattered sections of 29 & 42 U.S.C.).

9. See *FDA Authorizes, with Special Controls, Direct-to-Consumer Test that Reports Three Mutations in the BRCA Breast Cancer Genes*, U.S. FOOD & DRUG ADMIN. (Mar. 6, 2018), <https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm599560.htm> [https://perma.cc/ZNB9-UYDS].

10. Precision Medicine Initiative Working Grp., *The Precision Medicine Initiative Cohort Program – Building a Research Foundation for 21st Century Medicine*, NAT'L INST. HEALTH 2 (Sept. 17, 2015),

makeup and disease profile.¹¹ And private DNA ancestry databases made headlines in 2018, when law enforcement used that technology to solve a string of decades-old murders.¹² Careful thinking about genetic privacy is now more critical than ever.

Third, we argue that GINA's role as a privacy statute highlights the need for greater employee-privacy measures in general. In particular, GINA's statutory design might well function as a blueprint for additional employment protections. GINA provides an important case study for safeguarding sensitive employee information that could be extended to a whole host of other areas, such as social media profiles, browser searches, and fitness-tracking data.

We tell the story of GINA in three acts. Part I introduces the statute and explains what legislators designed GINA to accomplish. Part II examines the first decade of GINA. We begin with our case-study findings. Next, we turn to the common misreading of GINA as a failure based on its performance in the courts. We argue that the cases decided and settlements reached reveal that GINA is hitting its stride as a privacy statute. Finally, Part III argues that genetic privacy – and privacy in ancillary fields – is more important than ever before and that GINA is precisely the kind of protection we need in an age of big data and increasingly invasive technologies. Moreover, GINA provides a conceptual blueprint for protecting employees from discrimination in a variety of other areas. GINA's first ten years reveal that it may be a prototype for future antidiscrimination laws.

I. GINA IN THEORY

Congress did not design GINA as a broad employee-privacy statute. Rather, it intended to prophylactically address fears about genetic testing by stopping a

<https://www.nih.gov/sites/default/files/research-training/initiatives/pmi/pmi-working-group-report-20150917-2.pdf> [https://perma.cc/9ZHQ-5BE8].

11. See Office of the Press Sec'y, *Fact Sheet: President Obama's Precision Medicine Initiative*, WHITE HOUSE (Jan. 30, 2015), <https://obamawhitehouse.archives.gov/the-press-office/2015/01/30/fact-sheet-president-obama-s-precision-medicine-initiative> [https://perma.cc/R3TC-LQJH].
12. See Abigail Abrams, *How Did They Catch the Golden State Killer? An Online DNA Service and His Genetic Relatives Revealed the Suspect*, TIME (Apr. 26, 2018), <http://time.com/5256835/how-did-golden-state-killer-genealogy-websites-online-dna-police> [https://perma.cc/9AE9-DMPK]; Jessica L. Roberts, *Opinion, A Houston DNA Company Helped Catch the Golden State Killer. What Does It Mean for Your Privacy?*, HOUS. CHRON. (May 17, 2018), <https://www.houstonchronicle.com/opinion/outlook/article/A-Houston-DNA-company-helped-catch-the-Golden-12920214.php> [https://perma.cc/H3AW-9NZK].

new form of discrimination before it started.¹³ Discrimination based on genetic information was not a widespread social problem when Congress passed GINA. But supporters hoped that GINA might encourage genetic testing by giving people peace of mind about their genetic information. Indeed, Congress crafted the law to deal with the specific risks related to health insurance and employment that could discourage people from seeking genetic testing altogether. This Part introduces GINA's statutory protections and places it in its historical context, explaining why Congress opted to pass an antidiscrimination statute absent a longstanding history of discrimination.

A. A Brief Introduction to GINA

Hailed as the first civil rights law of the twenty-first century, GINA protects against discrimination on the basis of genetic information. Congress designed the statute to alleviate people's anxieties about genetic testing by prohibiting health insurers and employers from using genetic-test results and family medical history to discriminate. In this Section, we outline the contours of GINA's protections, discussing the statute's structure and its definitions of genetic information and discrimination.

The statute has two substantive titles. Title I contains the health-insurance provisions, which prevent insurers from requesting genetic information and from using that information in their underwriting and rating decisions. Title I amends several federal health-insurance statutes to close any gaps in those laws.¹⁴ Because GINA draws from existing legislation, it has no independent enforcement mechanisms for its health-insurance sections. Instead, it relies on the enforcement mechanisms of those underlying laws, most of which have no private right of action.¹⁵ But Title II, which contains GINA's employment provi-

13. See Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 439, 470-71 (2010) (discussing legislative history that demonstrates Congress's intent to address genetic-information discrimination even while acknowledging it was not yet occurring widely).

14. See *id.* at 452 (explaining that Title I, like the Health Insurance Portability and Accountability Act of 1996 (HIPAA), amends preexisting insurance legislation); *id.* at 443-44 (identifying gaps in HIPAA's coverage that Title I would later address).

15. See Nat'l Human Genome Research Inst., "GINA": *The Genetic Information Nondiscrimination Act of 2008: Information for Researchers and Health Care Professionals*, U.S. DEP'T HEALTH & HUM. SERVICES (Apr. 6, 2009), <https://www.genome.gov/pages/policyethics/geneticdiscrimination/ginainfodoc.pdf> [<https://perma.cc/5ALZ-F6RY>] (discussing the enforcement of Title I of GINA by various agencies whose laws were amended by the statute, including the Department of Labor, Department of the Treasury, and Department of Health and Human Services).

sions, is its own standalone portion of the federal code with an independent private right of action.¹⁶

GINA defines statutorily protected genetic information as (1) a person's genetic tests, (2) the genetic tests of her family members, and (3) manifested conditions in her family members.¹⁷ Pursuant to GINA's Title II regulations, a person's family members are her dependents, regardless of whether through birth, marriage, or adoption, as well as her first, second, third, and fourth degree relatives.¹⁸ Congress included family medical history in the definition of genetic information because it understood that employers could use family medical history "as a surrogate for genetic traits."¹⁹ The statute specifically excludes any information about sex,²⁰ age,²¹ or an individual's own health conditions²² from its definition of genetic information. Finally, Title II of GINA prohibits employers and other employment-related entities like unions, agencies, and training programs from discriminating on the basis of genetic information. Instead of defining employer, GINA adopts the definitions of employer found in Title VII of the Civil Rights Act, the Government Employee Rights Act, and the Congressional Accountability Act.²³

Importantly, GINA's text includes no element of genetic risk. In other words, nothing in the definition of genetic information requires the covered data to speak to a person's propensity for developing a particular health condition. Indeed, as GINA was being debated, some legislators lamented that the definition of genetic information was too broad and argued it should cover only predictive information.²⁴ Still, the language of the bill was not amended, leaving GINA

16. Genetic Information Nondiscrimination Act of 2008 § 207, 42 U.S.C. 2000ff-6 (2018).

17. *Id.* § 201(4)(A)(i)-(iii).

18. 29 C.F.R. § 1635.3(a)(2) (2018). The statute defines each of these relational degrees:

(i) First-degree relatives include an individual's parents, siblings, and children.

(ii) Second-degree relatives include an individual's grandparents, grandchildren, uncles, aunts, nephews, nieces, and half-siblings. (iii) Third-degree relatives include an individual's great-grandparents, great-grandchildren, great uncles/aunts, and first cousins. (iv) Fourth-degree relatives include an individual's great-great-grandparents, great-great-grandchildren, and first cousins once-removed (i.e., the children of the individual's first cousins).

Id.

19. H.R. REP. NO. 110-28, pt. 1, at 36 (2007).

20. Genetic Information Nondiscrimination Act § 201(4)(C).

21. *Id.*

22. *Id.* § 210.

23. *Id.* § 201(2)(B).

24. See H.R. REP. NO. 110-28, pt. 3, at 69-71.

with “sweeping breadth.”²⁵ Thus, on its face, GINA would appear to cover all genetic-test results—including DNA forensics²⁶ and DNA ancestry tests²⁷—as well as all manifested conditions in family members, regardless of whether those conditions are genetic in nature. In addition to its more traditional antidiscrimination protections, GINA’s health-insurance and employment provisions both prohibit requesting, requiring, or purchasing genetic information. Hence, to violate GINA, a health insurer or employer need not even receive—let alone act on—genetic information. The covered entity merely needs to ask. In this way, GINA uses privacy as a bulwark, preventing access to the very information health insurers or employers could use to discriminate.²⁸

B. GINA’s Purpose

While outlawing conduct that is not yet occurring may seem like a waste of legislative energy, Congress was responding to a unique set of social and historical factors when it passed GINA. The statute was, in fact, a long time coming. In this Section, we provide the historical background for GINA, outline Congress’s intent, and take a deeper dive into the statute’s protections.

1. Background Information

Fully understanding GINA requires knowing about both the genetic-testing industry and the American health-insurance system. We begin with a brief introduction to genetic science before turning to the characteristics of the health-insurance industry that prompted Congress to act.

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25. *Id.* at 66 (complaining that Title II failed to take a cue from the HIPAA Privacy Rule and the “numerous exclusions for use and disclosure” in the Americans with Disabilities Act (ADA)).
 26. *See, e.g.,* *Lowe v. Atlas Logistics Grp. Retail Servs. (Atlanta), LLC*, 102 F. Supp. 3d 1360, 1364 (N.D. Ga. 2015) (finding that employer-conducted genetic testing for investigative purposes violates GINA).
 27. *See* Trina Jones et al., *DNA-Based Race?* 47-53 (unpublished manuscript) (on file with authors).
 28. *See* Bradley A. Areheart, *GINA, Privacy, and Antisubordination*, 46 GA. L. REV. 705, 710 (2012) (arguing that antidiscrimination principles are natural allies to privacy); Jessica L. Roberts, *Protecting Privacy to Prevent Discrimination*, 56 WM. & MARY L. REV. 2097, 2099-2103 (2015) (arguing that privacy law can do the work of antidiscrimination law, and vice versa).

a. *Rise of Genetic Information*

Members of Congress began introducing prophylactic genetic legislation in the early 1990s, around the time that scientists started sequencing the human genome.²⁹ The possibility that genetic information could jeopardize health-insurance coverage was on everyone's minds.³⁰ By the time GINA passed in 2008, almost every state had some kind of protection already on the books.³¹ The motivation for these laws, as well as for GINA, was not so much actual discrimination or invasions of privacy, but hypothetical ones.

Although genetic science has a variety of uses, first and foremost it predicts disease risk.³² Genetic tests can tell people whether they have a heightened proclivity for a host of hereditary conditions, from Alzheimer's to Zellweger Syndrome. At the beginning of the genetic revolution, the technologies available to sequence genetic data were expensive and time-consuming. The Human Genome Project, in fact, took thirteen years to fully sequence a single human genome, at a cost of somewhere between five hundred million and one billion dollars.³³ Today, a high-quality whole-genome sequence can be generated for around a thousand dollars and in as little as twenty hours.³⁴

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29. See Francis S. Collins, *Shattuck Lecture – Medical and Societal Consequences of the Human Genome Project*, 341 *NEW ENG. J. MED.* 28, 34 (1999); Karen Rothenberg et al., *Genetic Information and the Workplace: Legislative Approaches and Policy Challenges*, 275 *SCIENCE* 1755, 1756 (1997) (providing a discussion of federal legislation related to genetic information resulting from the efforts of the Working Group on Ethical, Legal, and Social Implications of the Human Genome Research).
30. See Mark A. Rothstein, *Is GINA Worth the Wait?*, 36 *J.L. MED. & ETHICS* 174, 174 (“When the Human Genome Project officially began in 1990, the potential for genetic discrimination in health insurance was the first issue to receive the attention of scholars, policy analysts, and state legislatures.”).
31. See Roberts, *supra* note 13, at 446 n.27 (citing *Genetics and Health Insurance State Anti-Discrimination Laws*, NAT'L CONF. ST. LEGISLATURES (Jan. 2008), <http://www.ncsl.org/research/health/genetic-nondiscrimination-in-health-insurance-laws.aspx> [<https://perma.cc/QM2K-ZQTY>]).
32. See, e.g., William S. Bush & Jason H. Moore, *Chapter 11: Genome-Wide Association Studies*, *PLOS COMPUTATIONAL BIO.*, Dec. 2012, at 1 (“The ultimate goal of GWAS is to use genetic risk factors to make predictions about who is at risk and to identify the biological underpinnings of disease susceptibility for developing new prevention and treatment strategies.”).
33. *The Cost of Sequencing a Human Genome*, NAT'L HUM. GENOME RES. INST. (July 6, 2016), <https://www.genome.gov/27565109/the-cost-of-sequencing-a-human-genome> [<https://perma.cc/LU3P-LGDK>].
34. *Id.*; see also Abigail Fagan, *From 13 Years to 20 Hours, Genome Sequencing Breaks Record*, *GENOME MAG.* (Mar. 1, 2018), <http://genomemag.com/2018/03/from-13-years-to-20-hours-genome-sequencing-breaks-record> [<https://perma.cc/7BNC-BS6Q>].

b. *The American Health-Insurance System*

American health care is some of the most expensive in the world,³⁵ and necessary medical treatment may be prohibitively expensive absent health-insurance coverage. Thus, access to meaningful health insurance is often a proxy for access to health care. For some patients, losing health-insurance coverage can be a death sentence.

Complicating things further, the United States does not have a uniform health-insurance system. Instead, it has a patchwork of public and private options that rely on various qualifying criteria. For example, the government covers its citizens at the beginning and the end of life: Medicaid covers almost half of all births each year,³⁶ and Medicare provides coverage for the elderly.³⁷ Other populations that enjoy government-sponsored health benefits include veterans, people with disabilities, Native Americans, and low-income individuals.³⁸ Everyone else must obtain their health-insurance policies from private companies.³⁹ Most working-age Americans with health insurance have employer-provided plans.⁴⁰ The rest can purchase health insurance on the individual market.⁴¹

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35. Ezekiel J. Emanuel, *The Real Cost of the US Health Care System*, 319 J. AM. MED. ASS'N 983, 983 (2018).
36. Vernon K. Smith et al., *Implementing Coverage and Payment Initiatives: Results from a 50-State Medicaid Budget Survey for Fiscal Years 2016 and 2017*, HENRY J. KAISER FAM. FOUND. 10 (Oct. 2016), <http://files.kff.org/attachment/Report-Implementing-Coverage-and-Payment-Initiatives> [<https://perma.cc/Q5GG-4SB3>].
37. *Who Is Eligible for Medicare?*, U.S. DEP'T HEALTH & HUM. SERVICES (Sept. 11, 2014), <https://www.hhs.gov/answers/medicare-and-medicaid/who-is-eligible-for-medicare/index.html> [<https://perma.cc/S4U7-28XP>].
38. See 25 U.S.C. § 1621 (2018) (Native Americans); 42 U.S.C. § 423 (2018) (disabled people); 42 U.S.C. § 1396(a)(10)(A)(i)(IV) (2018) (low-income families); 38 C.F.R. § 17.38 (2017) (veterans).
39. T.R. REID, *THE HEALING OF AMERICA: A GLOBAL QUEST FOR BETTER, CHEAPER, AND FAIRER HEALTH CARE* 20-21 (2009); cf. JESSICA C. BARNETT & MARINA S. VORNOVITSKY, U.S. CENSUS BUREAU, *HEALTH INSURANCE COVERAGE IN THE UNITED STATES: 2015*, at 1-3 (2016), <https://www.census.gov/content/dam/Census/library/publications/2016/demo/p60-257.pdf> [<https://perma.cc/CR7W-JWFA>]. Even under the Affordable Care Act, the government has assembled private insurance companies to create health-insurance marketplaces that, in their ideal formulation, allow Americans to “one-stop shop for a health care plan, compare benefits and prices, and choose the plan that’s best for them.” Barack Obama, *Letter to Senate Democratic Leaders on Health Care Reform* (June 2, 2009), <https://www.govinfo.gov/content/pkg/DCPD-200900432/pdf/DCPD-200900432.pdf> [<https://perma.cc/A3UD-3H9N>].
40. See BARNETT & VORNOVITSKY, *supra* note 39, at 1.
41. See *id.*

Private health insurance in the United States is primarily for-profit. To make money, an insurance company must accurately assess risk to ensure that it is earning more in premiums than it is paying out in claims. Before Congress passed the Affordable Care Act (ACA) in 2010, private insurance companies had significantly more leeway regarding which policies they offered to whom and at what price. American health insurance, in other words, depended on risk rating.

Particularly in the pre-ACA individual market, if a person seemed to be a “bad risk,” obtaining health insurance could be next to impossible. Consider the following hypothetical. A person with a cancer diagnosis wishes to purchase health insurance on the pre-ACA individual market. Given the high likelihood that she would require expensive treatment and drain the company coffers, a private, for-profit health insurer could have done a few different things. First, it could have offered her a policy but not covered her cancer expenses. This tactic is known as a “preexisting condition exclusion.”⁴² Second, the insurer could have capped the coverage it was willing to pay for the cancer treatment, either annually or over the lifetime of the policy. For example, it might have covered the first ten thousand dollars, but after that, the patient would have had to pay out of pocket. Third, the insurer could have offered the person a policy that provides comprehensive coverage for cancer but priced it at a very high rate. Such a policy would reflect the actual cost of cancer treatment, making it extremely expensive—so expensive that it might be unaffordable. Finally, if the chances of turning a profit were remote enough, the insurer might have deemed the person not worth insuring and refused to offer her a plan at all.

People on employer-provided plans also faced their own set of challenges before the ACA. Even now, linking health insurance to employment means that losing a job can also mean losing health insurance. Fears of giving up benefits and being left uninsured can lead people to stay in their current positions, a phenomenon known as “job lock.”⁴³ Also, the employer-provided system may encourage employers, particularly those offering small-group insurance, to employ only “good risks” to avoid hiking up their premiums or having to make big payouts. Congress attempted to regulate what employers could do as de facto providers of health insurance through statutes like the Employee Retirement Income Security Act (ERISA) and the Health Insurance Portability and

42. DICTIONARY OF HEALTH INSURANCE AND MANAGED CARE 226 (David E. Marcinko ed., 2006).

43. Dean Baker, *Job Lock and Employer-Provided Health Insurance: Evidence from the Literature*, AARP PUB. POL’Y INST. 1 (Mar. 2015), <https://www.aarp.org/content/dam/aarp/ppi/2015-03/JobLock-Report.pdf> [<https://perma.cc/6XSU-R8ZT>].

Accountability Act (HIPAA).⁴⁴ However, pre-GINA and pre-ACA, those laws still left employees vulnerable.⁴⁵

2. Congress's Intent in Passing GINA

Given the state of the American health-insurance system in the 1990s and early 2000s, fears of losing health insurance were justified. Discovering previously unknown health risks can make health care more difficult to access. Especially before the ACA, a quantifiable medical risk could mean higher premiums or losing coverage altogether. In the pre-GINA, pre-ACA era, health insurers could request genetic testing and engage in much more risk rating.⁴⁶ Against this backdrop, the combination of predictive genetics and private, for-profit health insurance created an ironic twist for medical genetic testing. If a person were tested and learned she was at a heightened risk, she might find herself uninsurable and therefore unable to access treatment, including treatment for the very condition that prompted her to take the genetic test in the first place. For example, a woman with a family medical history of breast cancer might seek BRCA1 testing. If her test revealed a genetic predisposition for breast cancer, her insurer might want to drop her. Losing coverage could jeopardize her ability to access care, either preventatively or if the cancer manifested. This fear was well understood; GINA's legislative history included stories of employees who tested positive for heightened genetic risk and were then asked to switch insurance policies to save their employers money.⁴⁷ It is no wonder then that people hesitated to take genetic tests. Learning of a medical risk could put them, as well as their family members, at risk of losing access to health care.

This rational decision on the part of consumers was bad news for the genetic-testing industry. Investors banked on the belief that once the tests became faster

44. See 29 U.S.C. § 1140 (2018) (making it unlawful for an employer to interfere with rights provided to an employee by an employee benefit plan); see also Baker, *supra* note 43, at 8 (describing the implementation of HIPAA as a way to minimize job lock).

45. For example, while HIPAA outlawed charging an individual group member more for a premium, it did not prevent hiking the premium rate for the group as a whole. See Roberts, *supra* note 13, at 443; Dale Halsey Lea, *The Genetic Information Nondiscrimination Act (GINA): What It Means for Your Patients and Families*, 14 ONLINE J. ISSUES NURSING (May 5, 2009), <http://ojin.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Vol142009/No2May09/Articles-Previous-Topics/The-Genetic-Information-Nondiscrimination-Act-GINA.html> [<https://perma.cc/N8R2-RH6T>].

46. Although HIPAA prohibits the use of genetic information in decisions about eligibility or premiums, it does not prohibit requesting or requiring genetic information, nor does it apply to the individual health-insurance market. See Roberts, *supra* note 13, at 443-44.

47. See *id.* at 466-67.

and more affordable, they would enjoy a significant market.⁴⁸ But when the science improved and the projected increase did not occur, stakeholders wanted to know why.⁴⁹ Not surprisingly, survey data reported that people were uncomfortable with genetic tests for a variety of reasons, especially because of concerns about employment discrimination and losing health insurance.⁵⁰

In passing GINA, Congress attempted to respond to this catch-22 by ensuring that a heightened genetic risk would not mean losing a job or health insurance. That reassurance might then encourage people to participate in medical genetic testing. If there is any doubt that Congress designed GINA to alleviate public concerns about taking medical genetic tests, lawmakers spoke their subtext. The last line of GINA's congressional findings reads: "Federal legislation establishing a national and uniform basic standard is necessary to fully protect the public from discrimination and allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic-testing, technologies, research, and new therapies."⁵¹ GINA thus represents a very specific response to a very specific problem.

Putting GINA in its social and historical context reveals that while the statute appears to be simple, straightforward antidiscrimination legislation, its purpose differs significantly from traditional civil rights legislation. Whereas those laws addressed existing social problems, GINA responded to anxieties about future social problems. Thus, the paradigmatic GINA claim seems to target a health

48. See Rothstein, *supra* note 30, at 175 ("In addition, genetics researchers, biotech companies, pharmaceutical companies, and genetic test developers realize that their efforts will be for naught unless individuals are willing to undergo genetic testing. Thus, researchers and commercial interests have been among the staunchest supporters of genetic nondiscrimination legislation.").

49. See, e.g., Roberts, *supra* note 13, at 471-73 (describing people's unwillingness to participate in research or to take genetic tests).

50. See Mark A. Hall & Stephen S. Rich, *Patients' Fear of Genetic Discrimination by Health Insurers: The Impact of Legal Protections*, 2 GENETICS MED. 214, 216 tbl.1 (2000) (showing that sixty-seven percent of genetic counselors reported that patients had a high level of concern about genetic discrimination regarding adult-onset conditions when deciding to be tested); Rothstein, *supra* note 30, at 175 ("There is considerable evidence that numerous individuals who are genetically at-risk for some serious disorders decline potentially efficacious genetic testing and medical intervention because they are concerned about the possibility of discrimination against themselves and family members."); see also Laura M. Amendola et al., *Why Patients Decline Genomic Sequencing Studies: Experiences from the CSER Consortium*, 2018 J. GENETIC COUNSELING 1220, 1225 (reporting that thirteen percent of patients declined genetic testing because of privacy and discrimination concerns).

51. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 2, 122 Stat. 881, 882-83.

insurer that either drops coverage or hikes up premiums based on a genetic test that reveals a previously unknown health risk.

GINA's other protections appear to grow out of this core concern. GINA covers employment because of its connection to health insurance. And because we share so much genetic information with our family members—a reality thrown into sharp relief when authorities recently apprehended a killer based on the genetic data of a family member⁵²—individuals reasonably fear that their genetic-test results could harm their loved ones. Pre-GINA, people reported avoiding genetic tests not because of anxieties surrounding their own health risks, but out of concerns for their families. In particular, they worried that their genetic-test results could cause their children to lose health-insurance coverage.⁵³ GINA, therefore, covers the genetic test results of family members. Congress also included family medical history—albeit not one's own manifested conditions—because it is hard to distinguish meaningfully between getting fired because your sister carries the BRCA1 gene and getting fired because your sister has breast cancer. Lastly, the privacy protection bolsters the antidiscrimination protection. After all, a person cannot lose her policy based on information that the insurer cannot access.

3. *GINA's Idiosyncratic Protections*

Considering Congress's intent, GINA's seemingly peculiar protections make sense. Four things make GINA different from other familiar federal antidiscrimination statutes: (a) its limited scope; (b) its narrow protected status; (c) its prohibited conduct; and (d) its broad exceptions.

a. *Limited Scope*

Compared to other civil rights laws, which tend to cover discrimination across a wide swath of contexts, GINA is relatively limited in scope.⁵⁴ For example, the Civil Rights Act has titles that pertain to voting, public accommodations,

52. See Roberts, *supra* note 12.

53. See Roberts, *supra* note 13, at 472 & n.168; see also Rothstein, *supra* note 30, at 175 (“There is considerable evidence that numerous individuals who are genetically at-risk for some serious disorders decline potentially efficacious genetic testing and medical intervention because they are concerned about the possibility of discrimination against themselves and family members.”).

54. *But see* Age Discrimination in Employment Act of 1967 (ADEA), Pub. L. No. 90-202, § 2(b), 81 Stat. 602, 602 (codified as amended at 29 U.S.C. § 621(b) (2018)) (describing the ADEA's purpose as the protection of older persons in employment).

government services, education, federal funding, and employment.⁵⁵ Likewise, the ADA has titles governing employment, government services, and public accommodations.⁵⁶ By contrast, GINA applies only to health insurance and employment. GINA's employment title provides that discrimination in health insurance, even discrimination that violates Title I, cannot be the foundation for a Title II claim.⁵⁷

From a practical perspective, GINA's limited coverage means that a significant portion of genetic-privacy invasions and discrimination goes unregulated. In most states, for example, it is perfectly legal for banks, landlords, schools, and even life insurers to make decisions based on genetic information.⁵⁸ However, given GINA's very specific goal of encouraging more people to take medical genetic tests, Congress's decision to limit the statute's scope to health insurance and employment was sensible. Health insurance and employment were the areas of greatest concern, and more expansive legislation would not have received adequate congressional support.

b. Narrow Protected Status

GINA protects against very limited forms of discrimination, whereas other federal antidiscrimination laws contain broader protections.⁵⁹ At present GINA only proscribes intentional discrimination. In fact, GINA explicitly excludes em-

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55. Civil Rights Act of 1964, Pub. L. No. 88-352, 78 Stat. 241 (codified as amended at 42 U.S.C. §§ 2000a-2000f (2018)).
56. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. §§ 12112, 12132, 12182 (2018)).
57. Roberts, *supra* note 13, at 450 (explaining that GINA includes a “firewall” provision, which prohibits claimants from suing under both the employment and health-insurance provisions to obtain separate remedies, to allay fears that employers providing insurance would get sued twice).
58. California, which passed its own comprehensive state legislation called CalGINA, is the notable exception. See CalGINA, ch. 261, 2011 Cal. Stat. 2774 (codified in scattered sections of the California Codes). CalGINA covers the use of genetic information in health insurance, employment, housing, restrictive covenants, emergency medical care and services, and financial institutions and amended the Education Code to provide schools more information needed to help combat genetic-information bias. *Id.*
59. For example, courts have construed Title VII to apply to all races and sexes. Similarly, after the Amendments Act, the ADA has an intentionally broad construction. See 42 U.S.C. § 12101(b)(1) (“The purposes of this Act are to carry out the ADA’s objectives of providing ‘a clear and comprehensive national mandate for the elimination of discrimination’ and ‘clear, strong, consistent, enforceable standards addressing discrimination’ by reinstating a broad scope of protection to be available under the ADA.”).

ployment discrimination actions for disparate impact.⁶⁰ Disparate impact actions cover claims for discrimination by effect, not by design. For example, genes associated with height may also carry with them an increased risk of heart disease. Thus, a height requirement could also have a disparate impact on the basis of genetic information.⁶¹ Because GINA covers only explicit discrimination, employers could even attempt to use the lack of disparate impact coverage as an end-run around the statute, adopting policies designed to screen out people with certain genetic attributes.⁶² Congress included a provision establishing a commission that would assemble six years from GINA's enactment to assess the potential need for a disparate impact protection.⁶³ However, as of this writing, that commission has not convened.

GINA also fails to require positive differential treatment, such as accommodations.⁶⁴ Genetic accommodations could allow employees to mitigate their genetic risk. For instance, an employer might accommodate an employee with a genetic proclivity for carpal tunnel syndrome by having that employee work a longer shift but with more breaks.⁶⁵ Commentators, including one of the authors of this Feature, have proposed that GINA could benefit tremendously from allowing employers to account for genetic difference.⁶⁶

Finally, while all people are potential beneficiaries of GINA because we all have genetic information, the law's actual coverage is quite narrow. As noted, the legal definition of genetic information excludes sex, age, and manifested condi-

60. Genetic Information Nondiscrimination Act of 2008 § 208(a), 42 U.S.C. §2000ff-7(a) (2018). The text expressly provides that there is no cause of action for unintentional practices that may have a disparate impact on the basis of genetic information. *Id.* (“Notwithstanding any other provision of this Act, ‘disparate impact’, as that term is used in section 703(k) of the Civil Rights Act of 1964 . . . , on the basis of genetic information does not establish a cause of action under this Act.”).

61. See Jessica L. Roberts, *The Genetic Information Nondiscrimination Act as an Antidiscrimination Law*, 86 NOTRE DAME L. REV. 597, 639-40 (2011).

62. *Id.* at 640.

63. Genetic Information Nondiscrimination Act § 208(b). The Act provides:

On the date that is 6 years after the date of enactment of this Act, there shall be established a commission, to be known as the Genetic Nondiscrimination Study Commission (referred to in this section as the ‘Commission’) to review the developing science of genetics and to make recommendations to Congress regarding whether to provide a disparate impact cause of action under this Act.

Id.

64. See Roberts, *supra* note 61, at 639.

65. See *id.*

66. See, e.g., *id.* at 638-39.

tions.⁶⁷ These omissions would confound any geneticist or genetic counselor who knows that chromosomes determine biological sex, that the telomeres protecting our genetic data shorten as we age, and that the line between a genetic predisposition and a diagnosed condition can be hazy. Yet age, sex, and manifested conditions are all relevant to the risk rating traditionally at the heart of the health-insurance industry.⁶⁸ Further, employees already enjoyed antidiscrimination protection for these attributes in the form of Title VII, the Age Discrimination in Employment Act, and the ADA. Again, GINA's modesty reflects its purpose. Congress designed the law to provide just enough protection to encourage people to undergo genetic testing for disease risk, not to create a robust, new antidiscrimination regime.

c. Prohibited Conduct

GINA also departs from traditional antidiscrimination legislation in the type of conduct it prohibits. It forbids not only discriminatory treatment, but also inquiries related to protected status. This novel form of protection has generated confusion about the remedies available under GINA's employment private right of action. What damages are appropriate when an employer seeks genetic information but fails to take a corresponding adverse employment action? As discussed at greater length in Part II, at least one jury thought 2.2 million dollars was a fair amount.⁶⁹ GINA seeks to make individuals more comfortable with genetic testing not only by protecting against discrimination, but also by safeguarding privacy.

GINA also adopts a relatively comprehensive definition of what it means to discriminate. The insurance title forbids using genetic information to determine coverage, eligibility, or premiums; obtaining genetic information for underwriting purposes; and treating genetic information as a preexisting condition.⁷⁰ The

67. See *supra* notes 20-22.

68. For example, Mark Rothstein observes that "GINA does not prohibit discrimination based on an individual's own health history because such a provision would prohibit health insurers from using health status in underwriting." Mark A. Rothstein, *GINA at Ten and the Future of Genetic Nondiscrimination Law*, 48 HASTINGS CTR. REP. 3, 5 (2018).

69. Daniel Wiessner, *Georgia Workers Win \$2.2 Million in 'Devious Defecator' Case*, REUTERS (June 23, 2015, 11:56 AM), <https://www.reuters.com/article/us-verdict-dna-defecator/Georgia-workers-win-2-2-million-in-deviuous-defecator-case-idUSKBN0P31TP20150623> [<https://perma.cc/9AW2-7MMW>].

70. Roberts, *supra* note 13, at 451-52.

employment title prohibits hiring, firing, classifying, or otherwise disadvantaging employees on the basis of genetic information.⁷¹

d. Broad Exceptions

GINA's employment provision offers six exceptions for legally obtaining genetic information. GINA permits an employer to obtain genetic information under a variety of conditions, including (1) inadvertently; (2) through voluntary wellness programs; (3) when processing medical leave; (4) via commercially available documents, like newspapers that contain obituaries; (5) for the occupational monitoring of toxic substances; and (6) to ensure quality control of DNA analysis in law enforcement.⁷²

Employees may inadvertently share genetic information with their coworkers, an issue GINA's supporters termed the "water cooler problem."⁷³ For example, if a person tells her boss that her sister was diagnosed with breast cancer, she has just shared statutorily protected genetic information with her employer. Foreseeing this issue, GINA's architects included an exception for inadvertently acquiring genetic information, as long as the employer safeguards it and does not use it to discriminate.⁷⁴

As noted, GINA includes an exception to its rule against requests for genetic information if employees participate in voluntary wellness programs.⁷⁵ While the distinction between mandatory and voluntary wellness programs may seem straightforward, what constitutes a "voluntary" program has been the subject of litigation. The salient question is whether employers may offer a financial in-

71. *Id.* at 452.

72. Genetic Information Nondiscrimination Act of 2008 § 202(b), 42 U.S.C. § 2000ff-1(b) (2018).

73. H.R. REP. NO. 110-28, pt. 1, at 37-38 (2007); Regulations Under the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. 68912, 68919 (Nov. 9, 2010) (codified at 29 C.F.R. pt. 1635) ("Congress did not want casual conversation among co-workers regarding health to trigger federal litigation whenever someone mentioned something that might constitute protected family medical history.").

74. Genetic Information Nondiscrimination Act § 202(b)(1) (excepting an employer who "inadvertently requests or requires family medical history"); *id.* § 202(c) (requiring that even if genetic information is obtained through an exception, it "may not be used in violation of [GINA's discrimination provisions] or treated or disclosed in a manner that violates [GINA's confidentiality provisions]").

75. *See id.* § 202(b) (insulating voluntary wellness programs that request genetic information or family medical history).

ducement to participate—and if so, how much of an incentive—and still ensure that participation is voluntary.⁷⁶

In 2016, the Equal Employment Opportunity Commission (EEOC) weighed in on this debate. It promulgated regulations clarifying that an employer may indeed offer an incentive for the employee or her spouse to participate in a wellness program that involves sharing medical data as long as the inducement does not exceed thirty percent of the cost of coverage under the plan.⁷⁷ An employer may not, however, offer the employee an incentive in exchange for her spouse's or children's genetic information.⁷⁸ Similarly, the employer may not provide any inducement to the employee or spouse to agree to the sale, exchange, or disclosure of genetic information.⁷⁹

However, in late 2017, a federal district court vacated these regulations as of January 1, 2019, finding that the EEOC “failed to adequately explain its decision to construe the term ‘voluntary’ in the ADA and GINA to permit the 30% incentive level [that was] adopted.”⁸⁰ The EEOC is now in the process of revising these regulations. Wellness programs are likely to continue to be scrutinized and face legal challenges since they disproportionately affect mobilized constituencies such as older workers, people with disabilities, and women.⁸¹

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76. Courts, however, have avoided deciding the issue. *See, e.g.,* EEOC v. Flambeau, Inc., 131 F. Supp. 3d 849 (W.D. Wis. 2015); EEOC v. Orion Energy Sys., 145 F. Supp. 3d 841 (E.D. Wis. 2015).
77. Genetic Information Nondiscrimination Act, 81 Fed. Reg. 31143, 31158 (May 17, 2016) (codified at 29 C.F.R. § 1635.8(b)(2)(iii)(A) (2018)). *But see* Ifeoma Ajunwa et al., *Limitless Worker Surveillance*, 105 CALIF. L. REV. 735, 768 (2017) (observing that while the EEOC's regulations define a voluntary wellness program as one which does not “penalize” employees for declining participation, they fail to take a position on what would constitute a penalty).
78. *See* 29 C.F.R. § 1635.8(b)(2)(iii) (“No inducement may be offered, however, in return for the spouse's providing his or her own genetic information, including results of his or her genetic tests, or for information about the manifestation of disease or disorder in an employee's children, including adult children.”).
79. *Id.* § 1635.8(b)(2)(iv) (mandating that a covered entity may not provide any inducement “in exchange for an agreement permitting the sale, exchange, sharing, transfer, or other disclosure of genetic information”).
80. AARP v. EEOC, 267 F. Supp. 3d 14, 37 (D.D.C. 2017), *amended by* 292 F. Supp. 3d 238 (D.D.C. 2017) (staying the effective date of the vacatur order until January 1, 2019).
81. *See, e.g.,* *Statement by AARP EVP Nancy LeaMond on EEOC Workplace Wellness Program Rules*, AARP (May 16, 2016), <https://press.aarp.org/2016-05-16-Statement-by-AARP-EVP-Nancy-LeaMond-on-EEOC-Workplace-Wellness-Program-Rules> [<https://perma.cc/2MAV-DHLA>] [hereinafter *LeaMond Statement*] (noting that older workers “are more likely to have the very types of less visible medical conditions and disabilities . . . that are at risk of disclosure by wellness questionnaires and exams”).

II. GINA IN PRACTICE

Despite GINA's lengthy legislative history and novel protections, the statute arrived with more of a fizzle than a bang. In Part II, we catalog all available GINA cases and consider how GINA has performed in the courts. Although Congress drafted the law primarily as a protection against discrimination based on genetic-test results, remarkably there have been no such claims in the entirety of GINA's first ten years.

This Part then turns to GINA's largely chilly reception as a piece of antidiscrimination legislation and outlines why many commentators labeled the statute a failure from the very start. Criticized for being ineffective, unnecessary, and irrelevant, the law might seem like a disappointment so far. While we do not challenge the predominant view that GINA has not delivered on its original aims, our case research suggests that—despite popular opinion—GINA has had significant, albeit unforeseen, benefits. Upon closer inspection, the cases reveal that GINA is enjoying a second life as an unexpected protection for employee privacy.

A. GINA's First Ten Years

Some data sets involve thousands of cases. At other times the bounded nature of the inquiry or the newness of a law will result in a smaller set of cases.⁸² For our case study, we reviewed all the published and unpublished federal decisions in which courts considered a GINA claim, spanning from November 2009, the month in which GINA's employment provisions became effective, until June 2018.⁸³ Of those 184 cases, we found seventy-seven orders that involved plausible

82. See, e.g., Vicki Schultz, *Telling Stories About Women and Work: Judicial Interpretations of Sex Segregation in the Workplace in Title VII Cases Raising the Lack of Interest Argument*, 103 HARV. L. REV. 1749, 1767 (1990) (analyzing fifty-four employment discrimination cases in which a lower federal court addressed the argument that sex segregation is a reflection of women's lack of interest in certain types of jobs); Joseph A. Seiner, *Pleading Disability*, 51 B.C. L. REV. 95, 116-17 (2010) (comparing fifty-nine cases decided prior to the Supreme Court's decision in *Twombly v. Bell Atlantic Corp.*, 550 U.S. 544 (2007), to sixty-five cases decided after, in order to determine the case's impact on motions to dismiss in the disability discrimination context).

83. The 184 decisions were compiled in the following way: We first identified our complete set of cases through searching "'Genetic Information Nondiscrimination Act' or 'Genetic Information Non-discrimination Act'" in the federal court databases on both Westlaw and Lexis. We restricted the date range to November 21, 2009—the date GINA's Title II employment provisions became effective—through June 17, 2018. For Westlaw, this yielded 253 cases and for Lexis, this yielded 278 cases. Notably, both Westlaw and Lexis had unique cases that the other database did not have, so that our total universe of unique cases across the two databases was 288 cases. After eliminating from the set of 288 those cases that only mentioned GINA,

GINA claims. We define a “plausible” claim to mean that the actual facts relate to GINA or that the plaintiff at least presents an argument for why GINA’s provisions should apply.⁸⁴ These seventy-seven federal orders pertain to forty-eight unique cases.⁸⁵ For our study, we selected the order for each case that was most relevant to the GINA claim.

Like any case study, our research has its limits. All of these disputes arise under GINA’s employment provision, as the health-insurance title does not include an explicit private right of action. Generally speaking, very few disputes are ever litigated, and even fewer go to trial or get appealed. Of those cases that come before a judge and result in an opinion, many are unreported.⁸⁶ Accordingly, some disputes that have arisen under GINA will naturally fall outside this study. Nevertheless, this study does give us a window into some of the claims being litigated,⁸⁷ the relative strength of those claims, and which fact patterns are likely to result in a finding of liability. Here we explore: (1) the judicial interpretation of GINA’s statutory terms; (2) common types of claims; and (3) the juridical challenges in proving GINA violations.

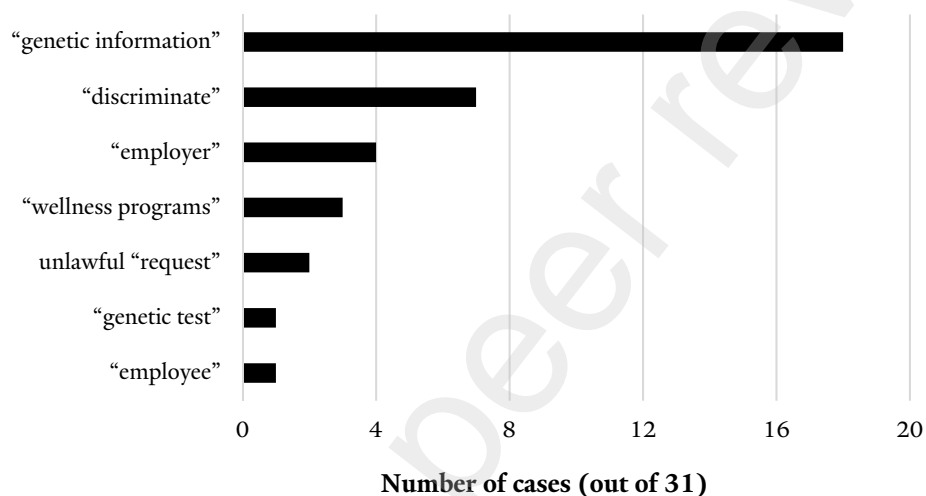
but did not involve an actual claim under the statute, we were left with a pool of 184 published and unpublished decisions.

84. Here, we largely sought to eliminate cases in which a plaintiff simply filed under the statute even though the facts did not begin to suggest a GINA claim. The typical case we cut at this point might involve a plaintiff who claimed race or sex discrimination at the EEOC, but then who showed up at the district court suing under every federal antidiscrimination statute. In approximately sixty percent of the 184 cases in which there was a GINA claim, the Plaintiffs did not plead any facts that could conceivably support such a claim.
85. These cases are noted in the Appendix. The forty-eight figure represents a subset of the 184 cases reviewed for this Feature. *See supra* note 83 and accompanying text regarding our methodology for arriving at this set of cases. For these forty-eight cases, we collected both factual and analytical data. *See infra* Appendix. The data compiled from each case included: the factual basis for a GINA claim; what other claims were brought; and the result of the order. We also coded cases for those that involved discussion of a statutory term; these included the meaning of “genetic information,” unlawful “requests,” “genetic tests,” “employees,” “employers,” and lawful wellness programs. Courts sometimes gave more than one reason for their decision and, in the interest of completeness, multiple reasons were listed if they were supplied by the court. Finally, we coded cases for those that involved common factual scenarios, such as requests for medical exams or records, family medical histories, fitness-for-duty exams, wellness programs, workers’ compensation claims, drug tests, DNA tests, and HIV tests.
86. As George Priest and Benjamin Klein observed in their landmark study, appellate cases are neither random nor representative of disputes, which makes it difficult to draw inferences from “legal rules to social behavior.” George L. Priest & Benjamin Klein, *The Selection of Disputes for Litigation*, 13 J. LEGAL STUD. 1, 1-4 (1984).
87. In particular, the claims that judges think are important enough to warrant an opinion.

1. GINA's Statutory Terms

First, the cases shed light on whom GINA has protected and how it has protected them. Like any statute, GINA requires interpretation. Our case study reveals that courts tend to resolve GINA claims on the basis of just a few statutory terms. Of the forty-eight cases, thirty-one involve orders that turned, in part or whole, on a specific provision of GINA, as depicted in Figure 1.⁸⁸

FIGURE 1.
CASES RESOLVED (IN PART OR WHOLE) UNDER GINA'S STATUTORY TERMS



Most cases turn on the meaning of "genetic information." Recall that Congress defined genetic information as genetic-test results, genetic-test results of family members, and family medical history.⁸⁹ Even with this relatively precise definition, plaintiffs appear to misuse the statute by treating "genetic discrimination" as a catch-all cause of action.⁹⁰ In particular, nine of the eighteen cases

88. The other seventeen orders either involve a procedural resolution (such as dismissal because the plaintiff failed to cooperate in discovery or prosecute the claim) or do not fully resolve the claims (such as failure to dismiss because the claim is plausible or the plaintiff is found to deserve more time to present supporting facts). Notably, the orders in these seventeen cases do not construe substantive provisions of GINA.

89. Genetic Information Nondiscrimination Act of 2008 § 201(4)(A), 42 U.S.C. § 2000ff(4)(A) (2018).

90. See *supra* note 84 (observing that in approximately sixty percent of cases in which there was a GINA claim, the plaintiffs either did not plead any facts to support such a claim or pled facts that could not conceivably warrant such a claim).

resolved by the meaning of “genetic information” involve plaintiffs arguing essentially that their discrimination claims somehow have their origins in biology and thus the employer violated GINA. This understandable but attenuated logic is reflected in cases where the plaintiff alleges an adverse action under GINA based on race,⁹¹ allergies,⁹² or manifested conditions, such as HIV,⁹³ Huntington’s disease,⁹⁴ or hyperthyroidism.⁹⁵

Courts have resisted such sweeping interpretations by upholding the distinction between genetic information and other types of medical information. Congress anticipated that plaintiffs might confuse biological conditions with genetic information and included a section in the statute expressly entitled “Medical Information that Is Not Genetic Information.”⁹⁶ This section explains that an employee’s “manifested disease, disorder, or pathological condition that has or may have a genetic basis” is *not* genetic information.⁹⁷ Plaintiffs with employment discrimination claims that relate to their own diagnoses or illnesses may well prevail on a claim under the ADA, but are unlikely to succeed under GINA. Another source of confusion may be that a diagnosis or illness in a person’s family constitutes genetic information. But once the person’s own genetic tendency becomes a diagnosable condition, that condition is not the person’s genetic information pursuant to GINA.

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91. *Robinson v. Dungarvin Nev., LLC*, No. 2:16-CV-00902-JAD-PAL, 2018 WL 547225, at *5 (D. Nev. Jan. 24, 2018) (“Race is protected under Title VII, not under GINA.”); *Booker v. Gregg*, No. 1:16-CV-187-JDF, 2016 WL 443798, at *1 (N.D. Ind. Aug. 23, 2016) (holding that stating that one’s “genetics are African American” does not bring a plaintiff within GINA’s ambit).
92. *Jacobs v. Donnelly Commc’ns*, No. 1:13-CV-980-WSD, 2013 WL 5436682 (N.D. Ga. Sept. 27, 2013) (finding that allergies are not “genetic information” under GINA).
93. *Hoffman v. Family Dollar Stores, Inc.*, 99 F. Supp. 3d 631, 637 (W.D.N.C. 2015) (“Neither Plaintiff’s HIV diagnosis, kidney failure, nor viral gastroenteritis, constitute genetic information about a manifested disease or disorder.”).
94. *Duignan v. City of Chicago*, 275 F. Supp. 3d 933, 939 (N.D. Ill. 2017) (“Because plaintiff specifically alleges that her psychosis ‘was organic in nature and a clinical manifestation of Huntington’s disease,’ I conclude that she has pled herself out of any claim that defendant took an adverse action against her based on her genetic information, as opposed to on her actual diagnosis of Huntington’s disease.”).
95. *Bell v. PSS World Med., Inc.*, No. 3:12-CV-381-J-99MMH-JRK, 2012 WL 6761660, at *3 (M.D. Fla. Dec. 7, 2012) (“Because Plaintiff has failed to provide any basis, factual or otherwise, for the Court to reasonably infer that her hyperthyroidism, the ‘confidential information,’ or the ‘confidential medical conditions’ equate to genetic testing and/or genetic information, Plaintiff has failed to properly allege a valid claim under GINA.”).
96. Genetic Information Nondiscrimination Act of 2008 § 210, 42 U.S.C. § 2000ff-9 (2018).
97. *Id.*

Perhaps the most surprising observation is that we did not identify any cases in which the plaintiff opted to have her DNA tested.⁹⁸ Even in the cases that involved actual DNA tests, which are discussed further below,⁹⁹ those employees did not choose to be tested and the employer did not take any negative action based upon the test results.¹⁰⁰

Notwithstanding a lack of actual genetic tests, plaintiffs have read GINA's provisions broadly to oppose a variety of tests that they argue solicit genetic information. In this type of case, employers ask employees to undergo assessments, and the workers resist. Employers make these requests for many reasons, from biometric screenings for employee-wellness programs to forensic genetic testing for suspected conduct violations. These are not stories of employees who, of their own volition, undergo testing and experience subsequent discrimination. These cases instead show that employers are seeking information about their employees, and employees are pushing back. But courts have found that drug tests,¹⁰¹ HIV tests,¹⁰² and biometric screenings¹⁰³ are not genetic tests.

Health information obtained through biometric screenings,¹⁰⁴ like those for cholesterol and blood pressure, is another source of potential confusion. Biometric screenings are particularly common in employer-provided wellness pro-

98. Of course, if employees are being fired after taking genetic tests, they might still be securing settlements from their employer.

99. See *infra* Section II.C.1.

100. *Lowe v. Atlas Logistics Grp. Retail Servs. Atlanta, LLC*, 102 F. Supp. 3d 1360, 1361 (N.D. Ga. 2015) (concerning an employer who required employees to submit to cheek swabs to try to solve the mystery of who was defecating in the warehouse); Complaint at 2, *Williamson v. Fermi Nat'l Accelerator Lab.*, No. 1:13-CV-04221, 2015 WL 360382 (E.D. Ill. Jan. 27, 2015) (involving an employer who required an employee to provide a DNA sample in the course of her employment).

101. *Lewis v. Gov't of the D.C.*, 161 F. Supp. 3d 15, 33 (D.D.C. 2015) (finding that "nothing in the Complaint suggests that, through its drug-test policy, the District requested genetic information as that phrase is defined by [GINA]" (emphasis omitted)).

102. *Hoffman v. Family Dollar Stores, Inc.*, 99 F. Supp. 3d 631, 637 (W.D.N.C. 2015) ("[G]iven that an HIV test is not a genetic test, any information Plaintiff alleges Defendant disclosed about his HIV diagnosis or test contained in Plaintiff's folder is not considered genetic information protected by GINA.").

103. See, e.g., *Ortiz v. City of San Antonio Fire Dep't*, 806 F.3d 822, 824, 826 (5th Cir. 2015) (holding that a required medical exam that included medical history, physical examination, blood tests, urinalysis, vision test, hearing test, lung capacity test, chest x-ray, and stress test did not fall under the meaning of "genetic test" in GINA); *Fuentes v. City of San Antonio Fire Dep't*, 240 F. Supp. 3d 634, 644 (W.D. Tex. 2017) (same).

104. According to the CDC, "biometric screening" is "the measurement of physical characteristics such as height, weight, body mass index, blood pressure, blood cholesterol, blood glucose, and aerobic fitness tests that can be taken at the worksite and used as part of a workplace

grams.¹⁰⁵ Some litigants have attempted to challenge these requests for medical information as violations of GINA.¹⁰⁶ Claims may arise when employees feel compelled to participate in a voluntary wellness program, perhaps because their employer offers to further subsidize their insurance premiums in exchange for participating. Employees may opt in but later resent participation and challenge the wellness program. Alternatively, the employer may lawfully *require* employees to participate in a wellness program if it does not seek genetic (or disability-related) information.¹⁰⁷ A biometric screening, like a test for drugs or HIV, is not “an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes.”¹⁰⁸ Under the plain language of the statute, these are neither genetic tests nor requests for genetic data. One court responding to a wellness-program claim quipped that the plaintiff “appears to misread the statute as forbidding *any* mandatory wellness program, regardless of whether it involves a request for or the acquisition of genetic information.”¹⁰⁹ Depending on the circumstances, a plaintiff may have a valid ADA claim related to nongenetic medical testing, but GINA does not cover such tests.

While the results of biometric screenings are not genetic information, family medical history is. Cases involving requests for family medical history, as discussed further below,¹¹⁰ have generally been the most successful. Litigants have also succeeded on claims alleging not just a request for family medical history, but *discrimination* on that basis. In *Bronsdon v. City of Naples*,¹¹¹ a firefighter was diagnosed with hypertension and coronary artery disease, both of which were

health assessment to benchmark and evaluate changes in employee health status over time.” Ctr. for Disease Control & Prevention, *Workplace Health Glossary*, U.S. DEP’T HEALTH & HUM. SERVICES <https://www.cdc.gov/workplacehealthpromotion/tools-resources/glossary/glossary.html> [<https://perma.cc/UF4Q-EC8Z>].

¹⁰⁵ Wellness programs are broadly defined as “program[s] of health promotion or disease prevention.” 26 C.F.R. § 54.9802-1(f) (2018). Healthcare.gov explains that wellness programs are “program[s] intended to improve and promote health and fitness [that are] usually offered through the work place, although insurance plans can offer them directly to their enrollees. The program allows [an] employer or plan to offer [the employee] premium discounts, cash rewards, gym memberships, and other incentives to participate.” *Wellness Programs*, HEALTHCARE.GOV, <https://www.healthcare.gov/glossary/wellness-programs> [<https://perma.cc/3R7H-29E9>]. It is therefore not the entity that provides the program but its content and services that defines a wellness program.

¹⁰⁶ *Ortiz*, 806 F.3d at 826-27; *Fuentes*, 240 F. Supp. 3d at 644-45.

¹⁰⁷ See, e.g., *Ortiz*, 806 F.3d at 826.

¹⁰⁸ Genetic Information Nondiscrimination Act of 2008 § 201(4)(A), 42 U.S.C. § 2000ff(4)(A) (2018) (defining “genetic tests”).

¹⁰⁹ *Ortiz*, 806 F.3d at 826.

¹¹⁰ See *infra* Section II.C.

¹¹¹ No. 2:13-CV-778-FtM-29CM, 2014 U.S. Dist. LEXIS 70502 (M.D. Fla. May 22, 2014).

related to his family medical history. When he filed for workers' compensation benefits, the City denied the claim based upon his "genetic information and family medical history."¹¹² The firefighter sued, claiming that the denial violated GINA. The City countered that his manifested conditions prevented him from advancing a claim under GINA.¹¹³ However, the court noted rather simply that employers cannot discriminate based on family medical history, even if the individual has already manifested a related condition.¹¹⁴ The court relied on the EEOC regulations, which make it clear that "genetic information of an individual with a manifested disease is protected genetic information under GINA and that discrimination against someone based on this information is prohibited."¹¹⁵ Much like a "mixed-motives" claim under Title VII,¹¹⁶ genetic information and an employee's manifested condition may sometimes fuse, making it hard to say which is responsible for an act of discrimination. In such instances, the employer may still be held liable because an impermissible consideration has tainted the decision.

Despite robust protection for family medical history, some courts have limited the scope of genetic information in contravention of the plain meaning of the statute. GINA's text covers "manifested conditions" in family members and does not limit those conditions to ones that are hereditary.¹¹⁷ Regardless, some courts have found that family medical history is only genetic information if it communicates genetic risk. In practical terms, these courts are taking the position that genetic information must be predictive.¹¹⁸

112. *Id.* at *3.

113. *Id.* at *8.

114. *Id.*

115. *Id.* (quoting Regulations Under the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. 68912, 68918 (Nov. 9, 2010) (codified at 29 C.F.R. § 1635.12(b) (2018))).

116. Most decisions in life are made for more than one reason, a reality that antidiscrimination law has sought to address. Under section 703(m) of Title VII, if race, sex, religion, color, or national origin is a motivating factor for the employment practice, that act is unlawful. The presence of other legitimate motives—even if the employer would have made the same decision absent the illegitimate motives—is not a defense for purposes of liability. However, in a mixed-motive discrimination case, the defendant can still avoid economic damages (such as back pay or front pay) or reinstatement by showing he would have made the same decision in the absence of the illegal motivating factor. If the defendant can make this showing, the plaintiff is entitled only to declaratory and injunctive relief, attorney's fees, and costs. *See* 42 U.S.C. § 2000e-5(g)(2)(B) (2018).

117. Regulations Under the Genetic Information Nondiscrimination Act, 75 Fed. Reg. at 68916.

118. The EEOC has also supported this view with its observation that "GINA is concerned primarily with protecting those individuals who may be discriminated against because an employer thinks they are at increased risk of acquiring a condition *in the future.*" *Background Information for EEOC Final Rule on Title II of the Genetic Information Nondiscrimination Act of*

Poore v. Peterbilt of Bristol, L.L.C.,¹¹⁹ the first in this line of cases, dealt with an employee whose wife had multiple sclerosis (MS). The court held that the wife's MS was not genetic information because it "has no predictive value with respect to Poore's genetic propensity to acquire the disease."¹²⁰ Further, while genetic information is defined to include the manifestation of a disease in a family member, family members are in turn defined in such a way as to exclude spouses.¹²¹ The court ultimately reasoned that because a spouse's MS does not communicate genetic risk, it cannot be genetic information.

Another court dismissed a GINA claim brought by an employee whose mother had HIV/AIDS.¹²² Diagnosed HIV/AIDS is quite clearly a manifested condition and, unlike spouses, mothers are unequivocally family members under the statute. Thus, on its face, GINA would seem to apply.¹²³ Yet the court found that the employee was not at risk of acquiring HIV/AIDS¹²⁴ because HIV/AIDS can only be transmitted from mother to child in three ways: during pregnancy, during childbirth, or through breastfeeding.¹²⁵ Thus, according to the court, the employee had no GINA claim because she had no actual genetic risk of acquiring HIV/AIDS.¹²⁶ However, *Poore* and its progeny may be misguided. As explained, nothing in the plain language of GINA's definition of covered genetic information requires that genetic tests or family medical history communicate genetic risk.¹²⁷

2008, U.S. EQUAL EMP. OPPORTUNITY COMMISSION, <https://www.eeoc.gov/laws/regulations/gina-background.cfm> [<https://perma.cc/APW8-3VJW>].

119. 852 F. Supp. 2d 727, 729 (W.D. Va. 2012).

120. *Id.* at 731.

121. Genetic Information Nondiscrimination Act of 2008 § 201(3), 42 U.S.C. § 2000ff(3) (2018) (defining family members as dependents and any other first-, second-, third-, or fourth-degree relatives).

122. *Conner-Goodgame v. Wells Fargo Bank, N.A.*, No. 2:12-CV-03426-IPJ, 2013 WL 5428448, at *11 (N.D. Ala. Sept. 26, 2013).

123. *See* Genetic Information Nondiscrimination Act § 201(3).

124. *Conner-Goodgame*, 2013 WL 5428448, at *32 (holding that an employee's mother's AIDS is not genetic information with respect to that employee because the employee has "no chance of acquiring HIV in the future as a result of her deceased mother's AIDS").

125. *See Preventing Mother-to-Child Transmission of HIV*, HIV.GOV (May 15, 2017), <https://www.hiv.gov/hiv-basics/hiv-prevention/reducing-mother-to-child-risk/preventing-mother-to-child-transmission-of-hiv> [<https://perma.cc/8TZQ-TKDJ>] ("An HIV-positive mother can transmit HIV to her baby [] during pregnancy, childbirth (also called labor and delivery), or breastfeeding.").

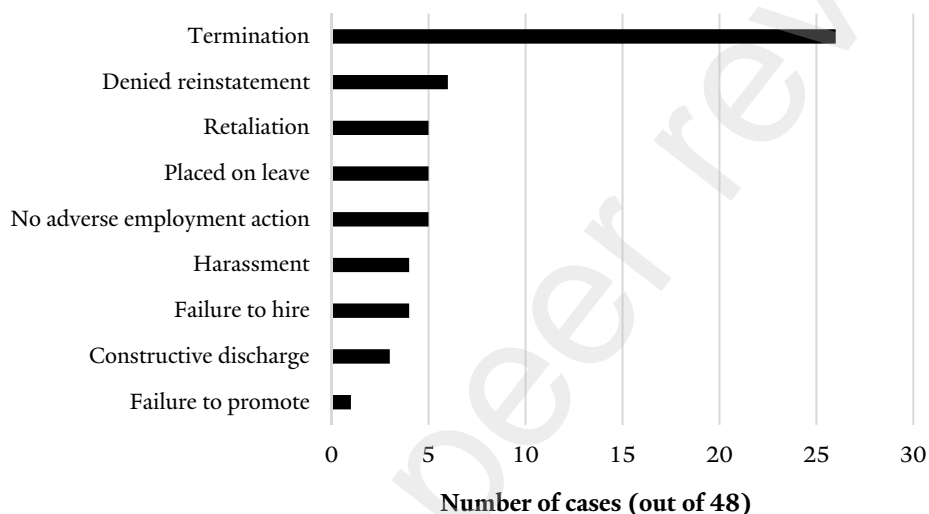
126. *Conner-Goodgame*, 2013 WL 5428448, at *32.

127. *See supra* notes 25-28 and accompanying text; *infra* notes 281-283 and accompanying text.

2. Common GINA Claims

A different way of analyzing GINA's cases is to cluster them by recurring factual scenarios. Of the forty-eight plausible GINA cases, certain types of facts and allegations tend to predominate. The starting point is the plaintiff's posture as it relates to employment.

FIGURE 2.¹²⁸
THE PLAINTIFF'S POSTURE



As Figure 2 indicates, the majority (twenty-six plaintiffs, or approximately fifty-four percent) sued after being terminated by their employer. Few cases involved claims that the employer failed to hire the plaintiff. This result is consistent with the frequently observed difficulty of bringing failure-to-hire employment discrimination cases.¹²⁹ Interestingly, five of the claims involved no

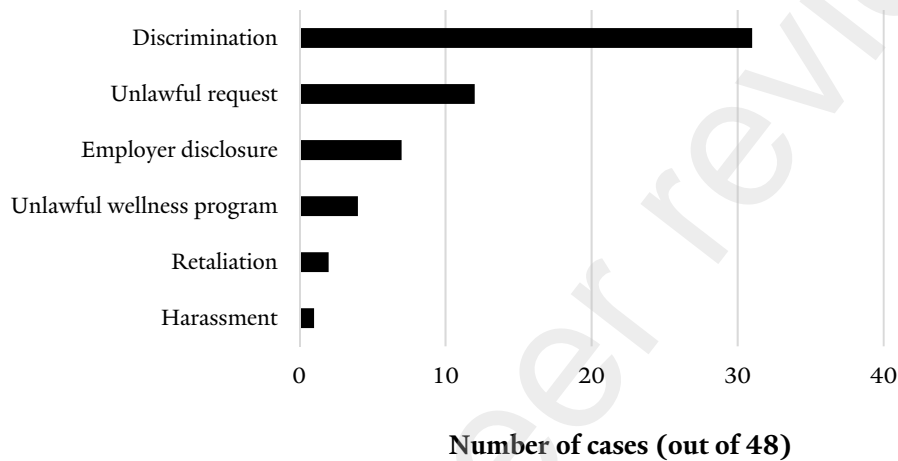
¹²⁸. These claims are a snapshot of what we coded and included in a table as the Appendix. The employment harms span forty-eight cases, but the number of employment harms here adds up to more than forty-eight because employees sometimes experienced more than one type of harm (for example, perhaps they were denied reinstatement, harassed, and subsequently terminated).

¹²⁹. There are stark informational barriers that prevent victims of discrimination from detecting and bringing failure-to-hire claims. Any contact between an applicant and an employer is "typically fleeting, the eventual outcome is unknown to the candidate, and the process itself

obvious adverse employment action or constructive discharge,¹³⁰ a result made possible by the fact that GINA forbids certain types of inquiries even where there is no actual discriminatory treatment.¹³¹

The actual claims provide a second frame that illuminates how plaintiffs use GINA, as shown in Figure 3.

FIGURE 3.¹³²
PREDOMINANCE OF CERTAIN CLAIMS



As explained in Part I, GINA has both privacy and antidiscrimination provisions. First, it is unlawful to “request, require, or purchase” genetic information, subject to several exceptions.¹³³ Second, employers cannot use genetic information – regardless of how it is obtained – to discriminate. Discrimination claims have naturally predominated. After all, this way of framing claims is

rarely signals exclusionary intent.” Michael Fix et al., *An Overview of Auditing for Discrimination*, in *CLEAR AND CONVINCING EVIDENCE: MEASUREMENT OF DISCRIMINATION IN AMERICA* 1, 14 (Michael Fix & Raymond J. Struyk eds., 1993).

130. These cases are coded as “n/a” under Employee’s Posture.

131. See *supra* Section I.B.3.c.

132. These claims are coded and included in a table as the Appendix. The number of cases here adds up to more than forty-eight because plaintiffs sometimes advance more than one claim under GINA.

133. Genetic Information Nondiscrimination Act of 2008 § 202(b), 42 U.S.C. § 2000ff-1(b) (2018). The three most notable anomalies are wellness programs, inadvertent requests of family medical history, and instances where an employer purchases publicly available documents that include family medical history. *Id.* § 202(b)(1)-(2), (4). The other three exceptions concern compliance with other laws, such as the Family and Medical Leave Act and genetic monitoring regulations, or ensuring the integrity of law enforcement. *Id.* § 202(b)(3), (5)-(6).

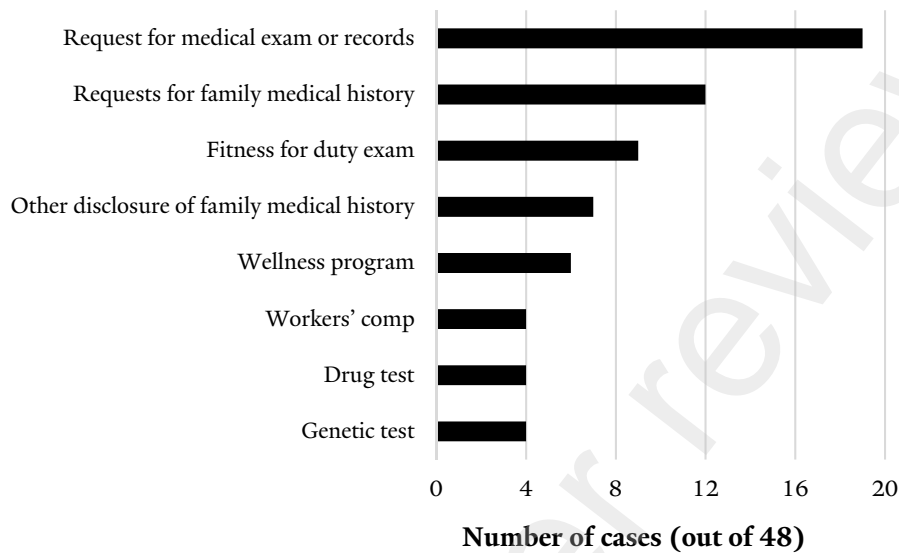
standard under existing federal discrimination laws. But many GINA claims in the past ten years have been simply for unlawful requests.

Another way that plaintiffs appear to be wielding GINA as a privacy shield is by claiming that an employer, who may have legally obtained genetic information, disclosed that information in violation of GINA. If an employer has acquired genetic information through one of GINA's statutory exceptions, it must safeguard that information. But in seven (approximately fifteen percent) of the cases, plaintiffs claimed that their employers disclosed or shared confidential genetic information with other employees or coworkers. This set of cases may demonstrate that employees do not want their confidential information shared with other people at work. We found that nearly forty percent of all cases involved claims based upon requests for family medical history, requests for medical exams or records, or the employer's alleged disclosure of genetic information.¹³⁴

Finally, wellness programs reemerge as another area of sensitivity for plaintiffs. Most recently, this issue has captured the attention of several important advocacy groups, such as AARP, an advocacy group for older Americans, and those that advocate for people with disabilities. They are concerned that health disclosures under wellness plans would create disadvantage for their members or clients in the workplace.¹³⁵

134. There are twelve cases that involve claims for unlawful requests and seven that involve the claim that the employer unlawfully disclosed genetic information. See *infra* Appendix.

135. See, e.g., *LeaMond Statement*, *supra* note 81 (“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 questionnaires and exams. By financially coercing employees into surrendering their personal health information, these rules will weaken medical privacy and civil rights protections.”).

FIGURE 4.¹³⁶**PREDOMINANCE OF CERTAIN FACTS**

As Figure 4 makes clear, a host of GINA cases involve plaintiffs bringing claims based on requests for medical exams or records. Many of these requests simultaneously solicit individual and family medical history, the latter often through questions about how one's parents died or whether family members have experienced certain medical conditions. Family medical history may also surface in a factual context where the employer asks an employee to undergo a fitness-for-duty assessment.¹³⁷ At other times, the allegedly improper request pertains to a legally sanctioned process, such as seeking accommodations under the ADA, unemployment benefits, or workers' compensation benefits.¹³⁸ Employers sometimes also request family medical history in conjunction with wellness programs as part of their health risk assessment.¹³⁹ Still other times, the family medical history is voluntarily disclosed or somehow otherwise discov-

¹³⁶. These facts are just a sampling of what we coded and included in a table as the Appendix.

¹³⁷. See *supra* fig.4; see also *infra* Appendix. (identifying nine federal cases with plausible GINA claims where the factual scenario included a fitness-for-duty examination).

¹³⁸. See *supra* fig.4; see also *infra* Appendix. (identifying federal cases with plausible GINA claims where the factual scenario included a workers' compensation claim and unemployment compensation claims, as well as other instances where genetic discrimination may be at issue).

¹³⁹. See *supra* fig.4; see also *infra* Appendix. (identifying federal cases with plausible GINA claims, including two where the factual scenario included a mandatory wellness-program assessment).

ered. Finally, falling outside of the family-medical-history context are direct tests that employees must sometimes undergo. The most common are drug tests – which are usually not a problem under the statute¹⁴⁰ – but there are other types of exams that may solicit genetic information and thus violate GINA.

3. Challenges in Proving Violations

Employees have encountered difficulty establishing valid GINA claims under both the privacy and antidiscrimination provisions. Specifically, GINA's many exceptions for acquiring genetic information may undermine a seemingly valid claim. Consider the exception for inadvertent acquisition, for example. In *Williams v. Graphic Packaging International*, the plaintiff was diagnosed with prostate cancer and, after inappropriate behavior at work, was eventually terminated.¹⁴¹ He alleged genetic discrimination, including that he was questioned repeatedly about cancer test results and treatment options.¹⁴² But the court noted that Williams *voluntarily* disclosed to three coworkers "that cancer ran in his family."¹⁴³ While a family medical history of cancer is unequivocally genetic information, the employer did not unlawfully request or obtain it.¹⁴⁴ (However, if the employer had asked Williams about his family medical history, that would have been enough to sustain a cause of action under GINA – even without an adverse employment action.)

Another difficulty for plaintiffs has sometimes come in the context of wellness programs. Recall that employers can request, through a health-care professional or genetic counselor, genetic information in the context of a wellness program as long as employees participate voluntarily and provide written

140. *But cf.* *Sullivan v. Lowe's HIW, Inc.*, No. C15-1184JLR, 2015 WL 6439097 (W.D. Wash. Oct. 22, 2015) (involving a drug test in the form of a cheek swab that enabled handlers to collect plaintiff's genetic data, but not answering the question of whether GINA permits the drug test and instead holding that the plaintiff failed to satisfy GINA's administrative-exhaustion requirement).

141. No. 1:16-CV-00102, 2018 WL 2118311, at *1-2 (M.D. Tenn. May 8, 2018).

142. Complaint at 1, 4-7, *Williams*, 2018 WL 2118311 (No. 1:16-CV-00102); *see also Williams*, 2018 WL 2118311, at *9 ("Plaintiff argues [that] Lee repeatedly questioned Plaintiff about his cancer.").

143. *Williams*, 2018 WL 2118311, at *9.

144. The court in *Williams* did not squarely address whether Graphic Packaging actually discriminated or acted based on information related to Williams's cancer.

consent.¹⁴⁵ Thus, as one court found, a mandatory wellness program that requests genetic information would violate the statute.¹⁴⁶ However, where the program was deemed voluntary, a misguided plaintiff could not claim his employer had impermissibly acquired genetic information.¹⁴⁷

Claimants have had even less luck establishing claims for genetic discrimination that turn on whether an employer took an adverse employment action based on genetic information. The first failure is the most rudimentary: an employee is sometimes unable to show that the employer possessed the employee's genetic information.¹⁴⁸ In these cases, employees allege genetic discrimination but fail to establish that decision-makers were actually aware of the employee's genetic information.¹⁴⁹ These claims are dead on arrival since an employer cannot base a decision on facts she does not know.

In a second category of unsuccessful claims of genetic discrimination, the employer may have had access to genetic information, but there is no evidence that the employer took any adverse employment action.¹⁵⁰ For example, in one federal appellate case – a rarity among GINA claims¹⁵¹ – a staffing agency termi-

145. See *supra* note 75 and accompanying text.

146. *Lee v. City of Moraine Fire Dep't*, No. 3:13-CV-222, 2015 WL 914440, at *15 (S.D. Ohio Mar. 3, 2015) (finding that a mandatory request for genetic information cannot qualify under the wellness-program exception since the touchstone of this exception is that the program is voluntary).

147. *Id.* at *12.

148. See, e.g., *Higgins v. Union Pac. R.R.*, 303 F. Supp. 3d 945, 962 (D. Neb. 2018) (noting that the plaintiff failed to present sufficient evidence for a jury to conclude that his employer received his “entire medical chart,” which allegedly included plaintiff’s genetic information); *Jones v. Foxx*, No. 16-2207-CM, 2018 WL 705665, at *4 (D. Kan. Feb. 5, 2018) (noting that “[t]he uncontroverted facts show that Smith was unaware that plaintiff had sickle cell”); *Rusthoven v. Victor Sch. Dist. No. 7*, No. CV 14-170-M-DLC, 2014 WL 6460190, at *4 (D. Mont. Nov. 17, 2014) (observing that the plaintiff did not allege that his genetic information was ever seen by a decision-maker or by plaintiff’s coworkers); *Tovar v. United Airlines Inc.*, 985 F. Supp. 2d 862, 874-75 (N.D. Ill. 2013) (finding no evidence that decision-makers were aware of the employee’s family medical history when they terminated the employee).

149. Alternatively, an employer is sometimes able to show that the genetic information in question was actually unavailable at the time of the adverse employment decision. See *Carroll v. Comprehensive Women’s Health Servs.*, No. 3:16CV1509, 2017 WL 4284386, at *7 (M.D. Pa. Sept. 27, 2017) (observing that the employee was fired one day after her genetic testing, and thus before her employer could have known the results).

150. See, e.g., *Leone v. N.J. Orthopaedic Specialists, P.A.*, No. 11-3957 (ES), 2012 WL 1535198, at *6 (D.N.J. Apr. 27, 2012) (observing that “the allegation fails to plausibly support the theory that [the defendant] based his decision on the results of genetic tests”).

151. Out of the 184 federal court decisions in which courts considered a claim under GINA, only four of those came from federal appellate courts, and only two involved plausible GINA claims. See *infra* Appendix.

nated a temporary employee after she missed a significant amount of work for breast-cancer testing.¹⁵² The employee alleged that she told various people at work about her family medical history of breast cancer.¹⁵³ She then claimed that her employer may have acted on assumptions about her need for treatment based on that information.¹⁵⁴ The court concluded that even though the employer possessed statutorily protected genetic information and took an adverse employment action, a finding of discrimination “would require rank speculation” about what the employer assumed “about the role of a family medical history of breast cancer on a breast-cancer patient’s treatment and recovery.”¹⁵⁵ In short, there was no compelling story to support the argument that genetic information motivated the decision to terminate the employee.

Strikingly, in GINA’s first decade, we uncovered no cases alleging discrimination based on genetic-test results, which could affirm commentators’ suspicions that GINA is not doing much work as an antidiscrimination statute. Insofar as people are successfully suing under GINA, requests for family medical history are carrying the day.¹⁵⁶ GINA cases also signal that plaintiffs have not had much success in reported decisions during the statute’s first ten years. In particular, out of the set of forty-eight cases, twelve came to positive results for the plaintiffs,¹⁵⁷ and seven of those twelve were either left unresolved¹⁵⁸ or were procedural victories for the plaintiff.¹⁵⁹ Finally, the small universe of cases seems to confirm the belief that GINA is useless or perhaps unnecessary. Our case study might thus appear to preliminarily validate some of the criticisms of the statute.

152. *Punt v. Kelly Servs.*, 862 F.3d 1040, 1044-45 (10th Cir. 2017).

153. *Id.* at 1044.

154. *Id.* at 1052.

155. *Id.*

156. See, e.g., *EEOC v. Cummins Power Generation Inc.*, 313 F.R.D. 93 (D. Minn. 2015); *Lee v. City of Moraine Fire Dep’t*, No. 3:13-CV-222, 2015 WL 914440 (S.D. Ohio Mar. 3, 2015); *EEOC v. Founders Pavilion, Inc.*, No. 13-CV-6250 (CJS), 2014 U.S. Dist. LEXIS 81439 (W.D.N.Y. Jan. 9, 2014); see also Mark A. Rothstein et al., *Limiting Occupational Medical Evaluations Under the Americans with Disabilities Act and the Genetic Information Nondiscrimination Act*, 41 AM. J.L. & MED. 523, 554 (2015) (reviewing valid GINA claims that showed violations predominantly involved requests for family medical history); sources cited *infra* note 211 (announcing settlements that have prevailed on this type of factual claim).

157. See *infra* Appendix.

158. For example, not dismissing a GINA claim for an alleged failure to arbitrate prior to filing a lawsuit. *Jefferson v. Fannie Mae*, No. 4:13-CV-00604-ALM-CAN, 2016 WL 5339702 (E.D. Tex. July 29, 2016).

159. For example, granting a plaintiff’s motion to compel discovery under GINA. *Harris v. Union Pac. R.R. Co.*, No. 8:16-CV-381, 2018 WL 2729131 (D. Neb. June 6, 2018).

B. GINA as a Failure

One interpretation of GINA's first ten years is that the statute is a failure. In fact, from the moment GINA passed, it garnered significant criticism.¹⁶⁰ Ten years later, the commentary is not much rosier.¹⁶¹ In fact, the scholarly reaction to GINA has been almost entirely negative.¹⁶² There is a significant disconnect between what the statute has done and what it was intended to do. Recall that the paradigmatic GINA violation is discrimination on the basis of a genetic test. It is now clear that courts are not deciding and reporting cases that fit the paradigm. Here, we explore the reasons why so many commentators have dubbed GINA a failure.

1. GINA Is Ineffective

Typical criticism includes that GINA is ineffective, useless, or both. Arguably, GINA did not yet deliver on its original promise in the ten years following the law's passage as the rates of medical genetic testing remained largely stagnant.¹⁶³

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- 160.** Scholars were quick to criticize the new law. See, e.g., Jessica D. Gabel, *Probable Cause from Probable Bonds: A Genetic Tattle Tale Based on Familial DNA*, 21 HASTINGS WOMEN'S L.J. 3, 50 n.384 (2010) (arguing that GINA "lacks bravado" and suffers from a variety of limitations); Pauline T. Kim, *Regulating the Use of Genetic Information: Perspectives from the U.S. Experience*, 31 COMP. LAB. L. & POL'Y J. 693, 700-02 (2010) (asserting that GINA's exceptions for lawfully obtaining genetic information could open the door to discrimination); Roberts, *supra* note 61, at 634-47 (arguing for amending the statute to prohibit unintentional discrimination and allow for accommodations); Rothstein, *supra* note 30, at 174 (calling GINA "fatally flawed").
- 161.** See, e.g., Kathy L. Hudson & Karen Pollitz, *Undermining Genetic Privacy? Employee Wellness Programs and the Law*, 377 NEW ENG. J. MED. 1 (2017) (arguing that GINA's wellness-program exceptions could be expanded to compromise genetic privacy); Rothstein, *supra* note 68 (criticizing GINA's applicability and coverage); Jessica D. Tenenbaum & Kenneth W. Goodman, *Beyond the Genetic Information Nondiscrimination Act: Ethical and Economic Implications of the Exclusion of Disability, Long-Term Care and Life Insurance*, 14 FUTURE MED. 153, 153-54 (2017) (arguing that disability and long-term-care insurance are more like health insurance than life insurance and should therefore be within GINA's coverage); Sarah Zhang, *DNA Got a Kid Kicked Out of School—And It'll Happen Again*, WIRED (Feb. 1, 2016, 7:00 AM), <https://www.wired.com/2016/02/schools-kicked-boy-based-dna> [<https://perma.cc/A5JV-WKX7>] (criticizing GINA for not covering education or housing).
- 162.** But see Barbara J. Evans, *The Genetic Information Nondiscrimination Act at Age 10: GINA's Controversial Assertion that Data Transparency Protects Privacy and Civil Rights*, 60 WM. & MARY L. REV. (forthcoming) (arguing that GINA has been unfairly criticized and that, through the federal regulations governing the HIPAA Privacy Rule, GINA implicitly includes a right to access one's genetic data).
- 163.** See Sharon Begley, *Consumers Aren't Wild About Genetic Testing—Nor Are Doctors*, STAT (Feb. 12, 2016), <https://www.statnews.com/2016/02/12/consumers-arent-wild-genetic-testing>

While stagnant rates of medical genetic testing may strike some readers as odd, there has only recently been a meaningful uptick in genetic testing, since the FDA approved direct-to-consumer testing for genetic disease risks in April of 2017.¹⁶⁴ But insofar as the goal of the legislation was to increase medical genetic testing, the law itself does not appear to have had a meaningful impact during its first decade. There are several possible reasons for that failure.

a. Lack of Awareness

Despite a grueling thirteen-year legislative history, GINA passed without much fanfare. In fact, the law barely registered as a cultural phenomenon. Several years after GINA was legislated, over eighty percent of Americans were unaware that the law even existed.¹⁶⁵ There are at least four reasons for this unawareness.

First, GINA was a relatively unexciting statute upon arrival, the product of an enfeebling compromise with the insurance community and other business

-doctors [<https://perma.cc/2XAF-ABLQ>]; *The Public and Genetic Editing, Testing, and Therapy*, HARV. T.H. CHAN SCH. PUB. HEALTH 5 (Jan. 2016), <https://cdn1.sph.harvard.edu/wp-content/uploads/sites/94/2016/01/STAT-Harvard-Poll-Jan-2016-Genetic-Technology.pdf> [<https://perma.cc/BW7P-QY7V>].

164. Alzheimer's Found, of Am., *Genetic Testing: Thinking About an At-Home Test for Alzheimer's Risk Gene?*, PR NEWswire (Oct. 5, 2018), <https://www.prnewswire.com/news-releases/genetic-testing-thinking-about-an-at-home-test-for-alzheimers-risk-gene-300725402.html> [<https://perma.cc/Y86U-ZMTZ>]. The direct-to-consumer genetic-testing industry has grown from \$15 million in sales in 2010 to more than \$99 million in 2017. Additionally, the genetic-testing industry is projected to reach \$310 million in sales by 2022, with approximately 100 million consumers by that time. Razib Khan & David Mittelman, *Consumer Genomics Will Change Your Life, Whether You Get Tested or Not*, GENOME BIOLOGY (Aug. 20, 2018), <https://genomebiology.biomedcentral.com/articles/10.1186/s13059-018-1506-1> [<https://perma.cc/6AZS-874Q>]; Ellen Matloff, *Building a Bridge from Direct-to-Consumer Genetic Tests to Reality*, FORBES (Sept. 23, 2018), <https://www.forbes.com/sites/ellenmatloff/2018/09/23/building-a-bridge-from-direct-to-consumer-genetic-tests-to-reality> [<https://perma.cc/QD6H-9XQF>]. Moreover, new findings from the National Poll on Healthy Aging show that one in ten older adults has taken genetic tests offered to consumers, and one in twenty has taken genetic tests ordered by a doctor. Kara Gavin, *Older Adults Have High Interest in Genetic Testing—And Some Reservations*, U. MICH. HEALTH LAB (Oct. 1, 2018), <https://labblog.uofmhealth.org/lab-report/older-adults-have-high-interest-genetic-testing-and-some-reservations> [<https://perma.cc/TQR6-8G4C>]. Most older adults surveyed “expressed interest in getting DNA tests to guide medical care, understand health risks or know their ancestry.” *Id.* In sum, genetic testing has not yet occupied a seat in mainstream society, but the second decade of GINA will likely see a significant uptick in genetic testing.
165. Louise Slaughter, *Genetic Information Nondiscrimination Act*, 50 HARV. J. ON LEGIS. 42, 62 (2013) (observing that “a nationally representative survey from 2011 indicated that fewer than one in five Americans (16%) are aware [GINA] exists”).

interests.¹⁶⁶ Second, unlike the social movements that propelled the Civil Rights Act of 1964 or the Americans with Disabilities Act of 1990, GINA was not backed by a dynamic and organized coalition that could champion the legislation. Third, one of GINA's two substantive titles became largely moot only two years after the law passed. In 2010, the ACA eliminated much of the need for GINA's health-insurance protections by outlawing preexisting-condition exclusions, shifting away from health-status-based ratings, and cobbling together near-universal health-insurance coverage for Americans. Finally, whereas earlier antidiscrimination laws targeted a history of discrimination, GINA did not respond to past or even current subordination. Rather, GINA was uniquely prophylactic, attempting to head off a form of bias before it could really harm anyone. Taken together, GINA was a federal antidiscrimination statute that the average person knew nothing about.

While genetic information continues to be a hot-button issue, very few Americans are aware of GINA's protections. Another study conducted three years after GINA's passage found that out of 295 respondents only twenty-six (a disappointing 8.8%) had heard of the law, and only ten (3.4%) understood the scope of its protections.¹⁶⁷ In fact, a study *after* GINA went into effect found that out of 1,699 individuals, 60.5% were concerned about health-insurance discrimination and 28.6% were concerned about employment discrimination based on genetic information.¹⁶⁸ Unsurprisingly, 54.3% of people surveyed in that study had not even heard of GINA.¹⁶⁹ The law has not performed much better with medical professionals. A survey of 401 physicians reported that 54.5% had no knowledge of GINA.¹⁷⁰ A law cannot alleviate fears over genetic testing or ward

166. Jeremy Gruber, *The New Genetic Nondiscrimination Act – How It Came to Pass and What It Does*, COUNCIL FOR RESPONSIBLE GENETICS 2 (2009), <http://www.councilforresponsiblegenetics.org/pagedocuments/pgwogj2f30.pdf> [<https://perma.cc/9CYU-Y4YB>] (“GINA suffered in obscurity for a number of years as the result of a Republican led Congress that was hostile to adding additional restrictions on the insurance industry and employer communities.”); Rothstein, *supra* note 68, at 5 (“The Congressional deliberations for GINA were long and difficult. The original bill was introduced in 1995, and for many years, it did not look as if the bill would ever emerge from committee. Several of its provisions raised concerns for insurers, employers, and other stakeholders. After thirteen years, the controversial provisions were either deleted, revised, or clarified.”).

167. Ming-Yi Huang et al., *Awareness of the US Genetic Information Nondiscrimination Act of 2008: An Online Survey*, 4 J. PHARMACEUTICAL HEALTH SERVS. RES. 235, 236 (2013).

168. Dawn C. Allain et al., *Consumer Awareness and Attitudes About Insurance Discrimination Post Enactment of the Genetic Information Nondiscrimination Act*, 11 FAMILIAL CANCER 637, 640 (2012).

169. *Id.* at 640-42.

170. Amanda L. Laedtke et al., *Family Physicians' Awareness and Knowledge of the Genetic Information Non-Discrimination Act (GINA)*, 21 J. GENETIC COUNSELING 345, 348 (2012).

off discrimination if no one knows about it. As such, GINA may be long overdue for a public-awareness campaign.

b. Limited Scope

Another line of critique posits that, regardless of how many people know about the statute, GINA does not cover enough potentially discriminatory conduct. Some have pointed out that GINA limits its protections to health insurance and employment, leaving people susceptible to discrimination in life insurance, long-term-care insurance, disability insurance, education, housing, criminal investigations, and commercial transactions.¹⁷¹ At least two states, Illinois and California, have taken action to address this limited scope.¹⁷² For example, California passed a law to add genetic information as a protected class to its antidiscrimination law. Drafters of the state legislation, dubbed CalGINA, explained that they found GINA's current scope "incomplete for Californians."¹⁷³ This law expanded genetic-information protection to include housing, emergency services, mortgage lending, and commercial transactions.¹⁷⁴

c. Narrow Protected Status

Other criticisms of GINA's reach center on its definitions of genetic information and discrimination. Some scholars believe that potential discriminators,

171. See, e.g., Rothstein, *supra* note 68, at 5 ("GINA does not prohibit genetic discrimination in life insurance, disability insurance, long-term care insurance, mortgage insurance, educational opportunities, or commercial and real property transactions. A broader bill would have been extremely unlikely to get the necessary support in Congress."); Mark A. Rothstein, *Putting the Genetic Information Nondiscrimination Act in Context*, 10 GENETICS MED. 655, 655 (2008) [hereinafter Rothstein, *Nondiscrimination Act in Context*] (observing that GINA is seriously deficient, in part because it does not apply to life insurance, disability insurance, long-term-care insurance, or other uses of genetic information); Tenenbaum & Goodman, *supra* note 161, at 154 (arguing that disability and long-term-care insurance are more like health insurance than life insurance and should therefore be within GINA's coverage); Zhang, *supra* note 161 (criticizing GINA for not covering education or housing).

172. See, e.g., Michael Bologna, *Illinois Lawmakers Decide to Support Enhancements to Genetic Privacy Law*, EMP. DISCRIMINATION REP. BNA No. 30 (June 25, 2008) (noting GINA prompted Illinois to pass state legislation that expands the universe of covered employers and creates a "stiffer enforcement regimen"); Jennifer K. Wagner, *A New Law to Raise GINA's Floor in California*, PRIVACY REP. (Dec. 7, 2011), <https://theprivacyreport.com/2011/12/07/a-new-law-to-raise-ginas-floor-in-california> [<https://perma.cc/5ZHY-LSBP>].

173. See CalGINA, ch. 261, § 1(j), 2011 Cal. Stat. 2774, 2776.

174. See *supra* note 58 and accompanying text (discussing protections provided by the California Genetic Information Nondiscrimination Act).

particularly insurers, will be interested in epigenetic information.¹⁷⁵ Yet at present it is unclear whether GINA covers epigenetic markers, the microbiome, or myriad other kinds of biological information related to new technologies.¹⁷⁶ GINA's failure to cover manifested conditions – even ones that are genetic in nature – has been identified as another area of vulnerability, because the line between asymptomatic and manifested conditions is often not clear-cut.¹⁷⁷ Finally, despite the inclusion of a privacy provision, GINA actually takes a relatively conservative approach to what constitutes discrimination. Other federal antidiscrimination statutes cover unintentional discrimination and offer positive differential treatment, like accommodations and diversity initiatives. As noted, GINA fails to cover unintentional discrimination or to require positive action.

GINA's exceptions have also ensured a narrowly protected status. GINA expressly allows health insurers and employers to lawfully obtain genetic information under certain circumstances, such as to conduct research,¹⁷⁸ to provide wellness programs,¹⁷⁹ to comply with medical-leave laws,¹⁸⁰ and to monitor exposure to toxic substances.¹⁸¹ These exceptions could create opportunities to discriminate. Indeed, when members of Congress proposed a bill to expand well-

175. Epigenetic discrimination refers to the adverse treatment or abusive profiling of individuals based on external changes to genes that do not alter the underlying DNA sequence. For example, epigenetic modifications occur in the body because of smoking. An employer with access to this information may then decide not to hire that person. See Charles Dupras et al., *Epigenetic Discrimination: Emerging Application of Epigenetics Pointing to the Limitations of Policies Against Genetic Discrimination*, 9 FRONTIERS GENETICS 1 (2018) (describing the possibility of epigenetic discrimination); Riya R. Kanherkar et al., *Epigenetics Across the Human Lifespan*, 2 FRONTIERS CELL & DEVELOPMENTAL BIO. 1, 11-12 (2014), <https://www.frontiersin.org/articles/10.3389/fcell.2014.00049/full> [<https://perma.cc/CS3M-S2KP>] (discussing the environmental impact of smoking on epigenetics).

176. See Rothstein, *supra* note 68, at 6 (“The definition does not appear to cover epigenetic marks, microbiome data, or various other emerging biological measures. As a matter of science, GINA has been frozen in time for at least ten years, and it may be increasingly difficult to prove discrimination resulting from information developed by emerging technologies.”).

177. See Roberts, *supra* note 61, at 637; Rothstein, *supra* note 68, at 6. (“The problem is that there is a large gap between these statutes, and some individuals may not be covered under either law. This would include individuals who have a biomarker of genome-environment interaction, a subclinical marker of aberrant gene expression, or an initial symptom of a gene-associated disease.”); Rothstein, *Nondiscrimination Act in Context*, *supra* note 171, at 655.

178. Genetic Information Nondiscrimination Act of 2008 § 101(c)(4), 29 U.S.C. § 1182(c)(4) (2018).

179. *Id.* § 202(b)(2)(A).

180. *Id.* § 202(b)(3).

181. *Id.* § 202(b)(5).

ness programs, some feared that these changes would undermine genetic privacy and lead to future discrimination.¹⁸²

2. *GINA Is Unnecessary*

Beyond merely being ineffective, GINA has also faced criticism for being unnecessary in the first place. By all accounts, genetic discrimination was not happening on a widespread basis when Congress passed the law.¹⁸³ Most of the examples in the legislative history were anecdotal,¹⁸⁴ and there were no reported cases under the thirty-four state statutes that predated GINA.¹⁸⁵ Thus, one opponent of GINA testified before Congress that GINA was “a remedy in search of a problem.”¹⁸⁶

Additionally, even if we needed GINA’s health-insurance protections in 2008, we arguably do not need them now. The ACA, passed two years after GINA, rendered moot some of GINA’s most central provisions.¹⁸⁷ The ACA solved many of the problems GINA sought to address – and it did so for all medically relevant information, not just genetic data.¹⁸⁸ It banned preexisting condition exclusions, eliminated health-status-based rating in the individual and small group markets, and outlawed medical underwriting.¹⁸⁹ After the ACA, health insurers could no longer deny coverage for preexisting conditions, set discriminatory premiums, or make eligibility decisions based on *any* medically relevant risk-related information, including genetic information. The ACA also regulates employer-provided wellness programs and prohibits insurance companies from using wellness programs to rate the risks of its members.¹⁹⁰

Consequently, the ACA rendered several key provisions of Title I of GINA useless; but that is not to say Title I of GINA has no value in a post-ACA world.

182. Hudson & Pollitz, *supra* note 161, at 1-2 (arguing that GINA’s wellness-program exceptions could be expanded to compromise genetic privacy).

183. Roberts, *supra* note 13, at 470.

184. *See id.* at 466-68.

185. Kim, *supra* note 160, at 696.

186. *Protecting Workers from Genetic Discrimination: Hearing Before the H. Subcomm. on Health, Employment, Labor & Pensions of the H. Comm. on Energy & Labor*, 110th Cong. 45 (2007) (statement of Burton J. Fishman, Counsel to the GINE Coalition).

187. Rothstein, *supra* note 68, at 5 (asserting that “[t]he Affordable Care Act, enacted in 2010, prohibits discrimination based on health status, making Title I of GINA largely irrelevant”).

188. *Id.*

189. Jessica L. Roberts, “Healthism”: A Critique of the Antidiscrimination Approach to Health Insurance and Health-Care Reform, 2012 U. ILL. L. REV. 1159, 1187-88.

190. 42 U.S.C. § 300gg-4(j) (2018).

For example, the law still prevents health insurers from asking for genetic-test results or family medical history. Of course, if Congress were to repeal the ACA or the Supreme Court were to revisit the statute's constitutionality following the recent conservative shift of the Court's composition, Title I of GINA would again have an important role to play.

One could also advance the argument that GINA's provisions are unnecessary based on data about the charges filed. Beginning in 2010, the first year that charges could realistically be filed based upon the effective date of the statute, the number of charges rose each year for several years.¹⁹¹ The EEOC reported 201 complaints of genetic discrimination in 2010, 245 complaints in 2011, 280 complaints in 2012, and 333 complaints in both 2013 and 2014.¹⁹² This steady progression led at least one commentator to observe "a trend towards increased occurrences of genetic discrimination."¹⁹³ But the upward trend has now reshaped into a bell curve. There were only 257 complaints in 2015, 238 complaints in 2016, and 206 complaints in 2017—representing a return to the volume of charges filed during the first full year the statute was in effect.¹⁹⁴ It is not clear exactly what is driving these statistics, but the EEOC's own numbers do not support a narrative of increasing genetic discrimination.

As explained above, Congress likely only included employment in GINA's protections because so many Americans hold employer-provided health-insurance policies. But in an interesting twist of fate, the employment title, which was perhaps somewhat of an afterthought, is now GINA's most important protection.

C. GINA as a Success

While one might be tempted to judge GINA as a failure based on our case study, that would be a mistake. Even though claimants have not brought many successful claims for genetic discrimination, they have won—at least in the reported cases—for violations of their privacy. A close study of these cases reveals that GINA has been interpreted broadly in the area of privacy. Thus, where GINA has not obviously been a robust bulwark against discrimination, it has succeeded in safeguarding sensitive information.

¹⁹¹ *Charge Statistics (Charges Filed with EEOC) FY 1997 Through FY 2017*, U.S. EQUAL EMP. OPPORTUNITY COMMISSION (2018) [hereinafter *EEOC Change Statistics*], <https://www.eeoc.gov/eeoc/statistics/enforcement/charges.cfm> [https://perma.cc/Z9K3-C246].

¹⁹² *Id.*

¹⁹³ Ifeoma Ajunwa, *Genetic Data and Civil Rights*, 51 HARV. C.R.-C.L. L. REV. 75, 78 (2016).

¹⁹⁴ *EEOC Change Statistics*, *supra* note 191.

1. Court Interpretations of GINA as a Privacy Protection

Courts have protected employee privacy broadly with respect to both genetic-test results and family medical history. Perhaps the most notorious lawsuit in GINA's first ten years was *Lowe v. Atlas Logistics*, also known as the case of the "devious defecator."¹⁹⁵ When a company discovered that a disgruntled employee was defecating in its warehouse, the employer required two suspects to take genetic tests to compare their results to the feces. Although the test results exonerated the employees, they sued, obtaining a \$2.2 million jury verdict. In a line of reasoning similar to *Poore*, the defendants invoked GINA's legislative history to argue that the statute, which was designed with medical genetic testing in mind, should not cover forensic genetic testing. Following the plain language of the statute and Congress's legislative intent,¹⁹⁶ the court rejected this narrow construction of genetic information, finding that GINA covers nonmedical genetic testing. The breadth of *Lowe's* finding could provide a foundation for applying GINA to a wide variety of nonpredictive genetic testing, including forensics, paternity, and ancestry.¹⁹⁷ In short, *Lowe's* construction supports understanding GINA as a robust protection for employee privacy.

Courts have been similarly generous in cases dealing with requests for family medical history. In *Lee v. City of Moraine Fire Department*, the city required firefighters to undergo an annual health and wellness physical, which included a questionnaire that asked about family medical history of heart disease.¹⁹⁸ When one firefighter refused the physical, the department fired him for insubordination.¹⁹⁹ He sued, alleging that the employer violated GINA by asking for his family medical history. The court observed that "the text of GINA is clear" and that the department had plainly requested genetic information.²⁰⁰ The fire depart-

195. *Lowe v. Atlas Logistics Grp. Retail Servs.*, 102 F. Supp. 3d 1360, 1361 (N.D. Ga. 2015).

196. *Id.* at 1367 ("It is not unreasonable for Congress to achieve this 'national and uniform basic standard' of full protection by broadly prohibiting employers from requesting, requiring, or purchasing genetic information of their employees, except under limited circumstances.").

197. For an example of a potential GINA ancestry claim, see Tim Marcin, *White Michigan Cop Files Racism Lawsuit After Ancestry.com Revealed He's Part Black*, NEWSWEEK (May 10, 2017), <http://www.newsweek.com/white-cop-sues-michigan-city-racism-after-ancestrycom-revealed-hes-part-black-607004> [https://perma.cc/8FNJ-REKL], which illustrates the discrimination one police officer experienced after revealing to his colleagues that he was partially black.

198. No. 3:13-CV-222, 2015 WL 914440, at *1 (S.D. Ohio Mar. 3, 2015).

199. *Id.* at *4-5.

200. *Id.* at *11.

ment countered that it was the doctor administering the physicals – not the department itself – that added the prohibited inquiry.²⁰¹ The court quickly cited GINA’s definition of “employer,” which includes agents of the employer.²⁰² It also quoted GINA’s regulations, which require employers to affirmatively instruct their health-care providers “not to collect genetic information, including family medical history, as part of a medical examination intended to determine the ability to perform a job.”²⁰³ After all, even though some genetic information may be necessary to positively diagnose a manifested disease or disorder, “there does not appear to be a case in which the diagnosis, as opposed to the signs and symptoms, is necessary to evaluate an individual’s ability to perform a particular job.”²⁰⁴

2. EEOC Interpretations of GINA as a Privacy Protection

The EEOC has also embraced a vision of GINA as an employee-privacy statute by pursuing cases for requests for family medical history. In *EEOC v. Grisham Farm Products, Inc.*, the employer required applicants to reveal whether they had consulted with any medical professionals in the last two years and to identify whether any future diagnostic testing had been discussed.²⁰⁵ The court observed that these questions “would require an applicant without the manifestation of, for example, high blood pressure, heart disease, or breast cancer, who has preventatively ‘consulted’ with a physician or been told by a physician to get diagnostic testing in light of their family medical history or risk factors, to reveal such information” to the employer.²⁰⁶ According to the court, this solicitation plainly violated GINA.

The EEOC has also settled cases related to requests for family medical history. In *EEOC v. Cummins Power Generation Inc.*, the employer sought family medical history in the course of a fitness-for-duty assessment.²⁰⁷ While the defendants attempted to argue that the third parties who drafted the medical releases were indispensable parties to the litigation, the court maintained that the

201. *Id.*

202. *Id.* at *11-12.

203. *Id.* (quoting 29 C.F.R. § 1635.8(d) (2018)).

204. Regulations Under the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. 68912, 68927 (Nov. 9, 2010).

205. 191 F. Supp. 3d 994, 998 (W.D. Mo. 2016).

206. *Id.*

207. 313 F.R.D. 93, 96 (D. Minn. 2015).

employer violated GINA, leading to a settlement agreement.²⁰⁸ *EEOC v. Founders Pavilion, Inc.* also resulted in a settlement related to an employer request for family medical history in conjunction with postoffer medical exams.²⁰⁹

GINA claims are adjudicated not only in courts, but also by the EEOC. While structural litigation by the EEOC has been characterized as typically achieving only “modest” or “managerialist” interventions,²¹⁰ the EEOC’s settlements reached under GINA appear to be more ambitious. First, the EEOC has aggressively pursued claims related to family medical histories.²¹¹ Second, the EEOC has also sought and recovered damages for requests for genetic information even where there is no corresponding claim of discrimination.²¹² Finally, the EEOC

208. *Id.* at 101-03; *EEOC v. Cummins Power Generation Inc.*, No. 14-CV-3408, 2016 U.S. Dist. LEXIS 184407 (D. Minn. May 6, 2016) (consent decree).

209. No. 13-CV-6250, 2014 U.S. Dist. LEXIS 81439 (W.D.N.Y. Jan. 9, 2014).

210. Margo Schlanger & Pauline Kim, *The Equal Employment Opportunity Commission and Structural Reform of the American Workplace*, 91 WASH. U. L. REV. 1519, 1525-27 (2014).

211. See *BNV Home Care Agency to Pay \$125,000 to Settle EEOC Genetic Discrimination Lawsuit*, U.S. EQUAL EMP. OPPORTUNITY COMMISSION (Nov. 1, 2016), <https://www.eeoc.gov/eeoc/newsroom/release/11-1-16a.cfm> [<https://perma.cc/73AV-RTAH>] [hereinafter *BNV Home Care Agency*] (settling a matter in which a company impermissibly asked for family medical histories); *Fabricut to Pay \$50,000 to Settle EEOC Disability and Genetic Information Discrimination Lawsuit*, U.S. EQUAL EMP. OPPORTUNITY COMMISSION (May 7, 2013), <https://www.eeoc.gov/eeoc/newsroom/release/5-7-13b.cfm> [<https://perma.cc/56MA-VTDD>] (settling a matter in which a company impermissibly asked for its employee’s family medical history regarding “heart disease, hypertension, cancer, tuberculosis, diabetes, arthritis and ‘mental disorders’”); *Guardsmark Settles EEOC Disability & Genetic Information Discrimination Cases for \$329,640*, U.S. EQUAL EMP. OPPORTUNITY COMMISSION (June 23, 2016), <https://www.eeoc.gov/eeoc/newsroom/release/6-23-16.cfm> [<https://perma.cc/LY3R-LRC7>] (settling a matter in which a company required applicants to complete questionnaires with questions pertaining to their family medical history); *Joy Mining Machinery Settles EEOC Genetic Information Non-Discrimination Act Lawsuit*, U.S. EQUAL EMP. OPPORTUNITY COMMISSION (Jan. 7, 2016), <https://www.eeoc.gov/eeoc/newsroom/release/1-7-16.cfm> [<https://perma.cc/K4MT-QRMV>] (settling a matter in which a company impermissibly asked applicants if they had a family medical history of “TB, Cancer, Diabetes, Epilepsy, [and] Heart Disease”).

212. See *Founders Pavilion Will Pay \$370,000 to Settle EEOC Genetic Information Discrimination Lawsuit*, U.S. EQUAL EMP. OPPORTUNITY COMMISSION (Jan. 13, 2014), <https://www.eeoc.gov/eeoc/newsroom/release/1-13-14.cfm> [<https://perma.cc/LAL2-96TY>] [hereinafter *Founders Pavilion*] (requiring a payment fund for people whose genetic information was improperly solicited); *Seed and Fertilizer Providers to Pay \$187,500 for Genetic Information and Disability Discrimination*, U.S. EQUAL EMP. OPPORTUNITY COMMISSION (Nov. 10, 2014), <https://www.eeoc.gov/eeoc/newsroom/release/11-10-14.cfm> [<https://perma.cc/K8YH-8TSX>] (settling for nearly \$200,000, the majority of which went to four applicants whose genetic information was improperly solicited) [hereinafter *All Star Seed*]; see also *BNV Home Care Agency*, *supra* note 211 (“Employers should take heed of this settlement, because there are tangible consequences to unlawfully asking employees and applicants about their family medical history.”).

has more procedural latitude to aggregate claims than do private litigants,²¹³ and it has recently had success in settling class actions under GINA.²¹⁴

Reading the favorable GINA cases together reveals that although GINA has not been used to defend against discrimination based on genetic-test results, it has provided employees relief when employers seek genetic data, particularly in the form of family medical history. Thus, GINA's most valuable provisions have been secondary to its legislative purpose to increase genetic testing. The statute has thus succeeded in unexpected ways.

III. GINA'S LEGACY

Having reflected on GINA's first decade, we now turn to GINA's future. As described above, GINA's greatest observable contribution has been as a safeguard against employer prying. Robust protections for employee privacy are more important now than ever before, as employees are particularly vulnerable to employer snooping in a world of big data. At present, employees have little meaningful protection for their privacy at work. GINA therefore offers a unique and valuable protection. Although not conceived as a big-data privacy statute, GINA safeguards a rich source of information that employers could otherwise mine.

GINA's unexpected second life as a privacy statute both demonstrates the need for greater protections for employee privacy and provides a blueprint for structuring those protections. This Part begins by arguing that GINA provides novel protection against data mining in the workplace. It then turns to the benefits of enacting GINA-like protections for other forms of sensitive employee data. Finally, we reflect on the normative implications of our findings.

A. Modern Privacy Landscape in a World of Big Data

Many of the cases from Part II show that employers want access to their employees' data. Read together, these lawsuits demonstrate that employers are interested in employee data throughout the duration of the employment relationship. They want access to information about their employees to make hiring

213. Michael Waterstone, *A New Vision of Public Enforcement*, 92 MINN. L. REV. 434, 463-64 (2007) (observing that under various employment discrimination statutes "the EEOC and DOJ have far more procedural breathing room to pursue class-type relief than private litigants.").

214. See *All Star Seed*, *supra* note 212 (settling a matter on behalf of a class of job applicants who were subjected to illegal medical and genetic-information inquiries); *BNV Home Care Agency*, *supra* note 211 (same); *Founders Pavilion*, *supra* note 212 (settling first-ever class action lawsuit alleging genetic discrimination).

decisions, assess fitness for duty, improve wellness, decrease costs, and regulate employee conduct.

1. *Big Data and the Threat to Employee Privacy*

Here we outline why employers feel employee data is valuable, how big data compounds existing threats to privacy, and the ways in which employers could use big data to monitor their employees.

a. *The Value of Employee Data*

Consider the example of Humanize from the Introduction. Employers have many reasons for wanting information about their employees. Most private employers care primarily about their bottom lines.²¹⁵ They want to maximize productivity while minimizing costs, and workers can cost their employers money in a variety of ways. They may waste valuable work hours using social media sites, chatting with coworkers, taking smoke breaks, or browsing the internet. They may not come in at all for health reasons or to fulfill family obligations. They may raise insurance or operating costs because of illness or injury. As a result, employers may be very interested in learning which employees are distracted or feeling stressed, which employees plan to get pregnant, or which employees are susceptible to disease or injury – to name just a few possibilities. Additionally, tracking communication and movement can let an employer know if departments are not working together or if space is being underutilized.²¹⁶ Having access to this kind of information allows employers to make more informed decisions about whom to hire, whom to fire, and whom to promote to ensure a workforce that is as productive and low cost as possible.

Importantly, the desired information need not have anything to do with the employee's ability to perform the job. Take, for example, off-duty smoking. A potential employee may have excellent credentials, relevant experience, and highly developed skills. She may only smoke in the privacy of her home and her habit could have no meaningful impact on her ability to perform her job. Nevertheless, some employers will not hire that candidate for reasons related to insurance costs or even animus.²¹⁷ In these cases, whether an employee smokes has

215. See Sharona Hoffman, *Citizen Science: The Law and Ethics of Public Access to Medical Big Data*, 30 BERKELEY TECH. L.J. 1741, 1774 (2015) (explaining that “[e]mployers go to great lengths to select employees carefully in order to maximize business productivity and profitability.”).

216. See *There Will Be Little Privacy*, *supra* note 1.

217. See JESSICA L. ROBERTS & ELIZABETH WEEKS, HEALTHISM: HEALTH-STATUS DISCRIMINATION AND THE LAW 7, 33-34, 42, 115-16, 184 (2018).

nothing to do with qualifications, ability, or job performance. Thus, a wide range of private information – not just conduct or attributes that affect whether a person can work – may be of interest to employers.

b. Big Data as a Growing Threat to Privacy

In the digital age, employees are particularly vulnerable to employer surveillance. Certainly, the degree of employee surveillance by Humanyze is extreme, but even more conventional employers may wish to track their workers. Employers have a vested interest in monitoring the private lives of their employees, and new technologies and big data give employers more access than ever before to information.²¹⁸

Employers have a variety of surveillance tools already at their disposal. First, employers can use productivity apps and software to monitor their workers. Employers can track when employees view a document, access the internet, read emails, and log on to social media.²¹⁹ Second, employers can collect information on physical health and activity. Wellness programs may include biometric screenings, health-risk-assessment questionnaires, and fitness-tracking devices like FitBits.²²⁰ Amazon recently patented wristbands for its employees that could track their locations and hand movements to allow the company to monitor its workers' accuracy and productivity in real time.²²¹ Finally, employers can obtain sensitive employee information like social media profiles and credit reports.²²² Employers today have potential access to an unprecedented amount of information about their employees.

If all these individual sources were not enough, big data compounds the threats to employee privacy. While there is no uniformly accepted definition of “big data,” it typically refers to a high-volume dataset that, although too large for traditional databases and analytical tools, can be analyzed using algorithms or other computational methods.²²³ One quality that makes big data unique is

218. See Ajunwa et al., *supra* note 77, at 738 (arguing that advances in the ability to monitor employees have “moved in lockstep with the advancement of technological capacities”).

219. See *id.* at 742-43, 769; *There Will Be Little Privacy*, *supra* note 1.

220. See Ajunwa et al., *supra* note 77, at 763-66.

221. *There Will Be Little Privacy*, *supra* note 1.

222. Hoffman, *supra* note 215, at 1775 (“Many employers reportedly access public profiles that applicants post on social media sites as part of their investigation of candidates’ credentials. They also ask applicants for permission to obtain their credit reports.”).

223. See *The Big Data Conundrum: How to Define It?*, MIT TECH. REV. (Oct. 3, 2013), <https://www.technologyreview.com/s/519851/the-big-data-conundrum-how-to-define-it> [https://perma.cc/F76S-VUUM] (discussing a survey of different definitions of “big data” provided

its ability to reveal trends, patterns, and relationships that would go unnoticed using more conventional models.²²⁴ It provides the opportunity to cross-reference datasets and to access even more intimate information. In a particularly provocative and unsettling example of what big data can achieve, the Target Corporation famously revealed that a teenager was pregnant before she told her parents.²²⁵ An angry man stormed into the retailer demanding to know why Target had started sending mailers featuring baby clothes and cribs to his high-school-age daughter. It turned out that the corporation had accurately predicted the young woman might be expecting a child, using data analytics to identify purchasing patterns of the women on its baby registries. Target learned that pregnant women buy certain products, like supplements and unscented lotion, at varying points in their pregnancies. The corporation had taken the algorithms it developed based on those patterns and applied them to its database of customers.²²⁶ In fact, Target could have even told the outraged father his daughter's approximate due date.²²⁷ Big-data analysis means that what seems like a simple visit to Target can reveal intimate information about a person's reproductive choices—information she may not yet have shared with her family and friends.

In another example of big data revealing intimate information, a recent study reported that social media giant Facebook—which recently came under attack for its lax privacy protections²²⁸—can infer a user's sexual orientation, even if she has not openly disclosed that orientation on her profile.²²⁹ The algorithm uses

by high-tech organizations); *see also, e.g., Big Data*, OXFORD ENGLISH DICTIONARY (3d ed. 2008) (“[D]ata of a very large size, typically to the extent that its manipulation and management present significant logistical challenges . . .”); James Manyika et al., *Big Data: The Next Frontier for Innovation, Competition, and Productivity*, MCKINSEY GLOBAL INST. 1 (2011), https://www.mckinsey.com/~media/McKinsey/Business%20Functions/McKinsey%20Digital/Our%20Insights/Big%20data%20The%20next%20frontier%20for%20innovation/MGI_big_data_full_report.ashx [https://perma.cc/DBN7-C8U8] (“[D]atasets whose size is beyond the ability of typical database software tools to capture, store, manage, and analyze.”).

224. See Dalim Basu & Jon G. Hall, *Big Data, Big Opportunities*, in *BIG DATA: OPPORTUNITIES AND CHALLENGES* 46, 48-51 (2014).

225. Charles Duhigg, *How Companies Learn Your Secrets*, N.Y. TIMES MAG. (Feb. 16, 2012), <https://www.nytimes.com/2012/02/19/magazine/shopping-habits.html> [https://perma.cc/2XZM-LTKP].

226. *Id.*

227. *Id.*

228. See Class Action Complaint at 3-4, *Price v. Facebook, Inc.*, No. 5:18-CV-01732, 2018 WL 1404892 (N.D. Cal. Mar. 20, 2018) (alleging that Facebook permitted Cambridge Analytica to gather personal information about its members without their permission).

229. See Daizhuo Chen et al., *Enhancing Transparency and Control When Drawing Data-Driven Inferences About Individuals*, 5 *BIG DATA* 197, 198, 203 (2017).

“Likes” for certain activities, musical artists, books and TV shows—dancing, Katy Perry, *Harry Potter*, and *True Blood*, for example—to predict whether the user might identify as LGBTQ. Facebook could then sell that information to advertisers who want to reach LGBTQ users.

In the same way that Facebook “Likes” can predict sexual orientation, big data can also be used to predict divorce and insurance risk. Using credit card purchase data, companies like Visa can forecast divorce rates. These predictions in turn allow them to determine future potential credit problems, as people going through a divorce are more likely to miss payments.²³⁰ Insurers likewise use big data to gain additional information about their insureds, such as using credit scores to infer risk.²³¹

c. *Big Data in Employment*

Employers are capable of harnessing the power of big data. They can hire data miners to aggregate and analyze information beyond what they learn from productivity apps, wellness data, and requests for information to gain a peek into the private lives of their employees.²³² Employers are already gathering information about their employees that they could then use to profile and flag potentially costly or otherwise undesirable workers.²³³ For example, Microsoft has a program that analyzes data from emails, calendars, and other sources to allow employees to assess whether they are using their time efficiently.²³⁴ Managers also have access to that information but only in aggregated form.²³⁵

The potential information available to employers about their workers is not confined to the workplace. Employers could take the information that they already have and gain additional insights about employees’ health, reproductive

230. See IAN AYRES, *SUPER CRUNCHERS: WHY THINKING-BY-NUMBERS IS THE NEW WAY TO BE SMART* 34, 179 (2007) (describing the allegation that Visa uses credit card purchases to predict divorce).

231. Darcy Steeg Morris et al., *Do Credit-Based Insurance Scores Proxy for Income in Predicting Auto Claim Risk?*, 14 J. EMPIRICAL L. STUD. 397 (2017).

232. See, e.g., Hoffman, *supra* note 215, at 1775 (“It is also possible that employers will hire data miners to re-identify medical information when doing so is not excessively difficult.”).

233. See Sharona Hoffman, *Big Data and the Americans with Disabilities Act*, 68 HASTINGS L.J. 777, 777 (2017) (arguing that employers can gather “[i]nformation about workers’ habits, behaviors, or attributes that is derived from big data” and that such information “can be used to create profiles of undesirable employees”).

234. *There Will Be Little Privacy*, *supra* note 1.

235. *Id.*

choices, relationships, and other aspects of their private lives by using big data. For example, health-care-analytics company Castlight made headlines in 2016 when it advertised services including being able to predict whether employees were pregnant or trying to conceive.²³⁶ The algorithm uses factors like a female employee's age, whether she has stopped filling a birth control prescription, and any fertility-related queries on her health application to determine the likelihood she may have a baby.²³⁷ Thankfully, Castlight stated that it would return aggregated (not individualized) data to its clients, share only the number of employees without their names, and not provide information about a group of fewer than forty people.²³⁸ But these restrictions are company-imposed policy designed to protect privacy and its public image. No law prevents Castlight from giving the names of potentially pregnant employees to its clients.²³⁹

Pregnancy is not the only intimate kind of information that might be revealed if employers use big data to pry. Say an employee has a family medical history of Huntington's disease, a debilitating neurological condition that may come on at middle age, and her employer contracts with a health insurer that offers big-data analytics as part of its services. To search for providers covered by the health insurer, employees must log on with their names and policy information. The website then keeps a record of their searches. If, when the employee starts experiencing the early warning signs of Huntington's, the employee logs on to look for neurologists, the data-analytics firm could easily take her family medical history and cross-reference it with her age and web searches to determine that she has active Huntington's disease. In fact, the employer might know that the employee is sick even before she herself knows. While health plans do not currently offer such services to employers, the Castlight example demonstrates that this kind of data mining is certainly possible.

Beyond physical health, employers can also peer into their employees' sense of well-being and interpersonal relationships. In Japan, keeping employees happy and productive is a serious area of concern for employers.²⁴⁰ One Japanese

236. Valentina Zarya, *Employers Are Quietly Using Big Data to Track Employee Pregnancies*, FORTUNE (Feb. 17, 2016), <http://fortune.com/2016/02/17/castlight-pregnancy-data> [<https://perma.cc/E7Y2-JBK3>].

237. Lindsey J. Smith, *Big Data Knows if You're Pregnant*, VERGE (Feb. 17, 2016), <https://www.theverge.com/2016/2/17/11032606/big-data-employers-health-info> [<https://perma.cc/9EDX-Z57D>].

238. Zarya, *supra* note 236.

239. *Id.*

240. See *There Will Be Little Privacy*, *supra* note 1.

company, Hitachi, markets a “happiness meter” to employers that uses an algorithm to assess its employees’ moods based on their physical movement.²⁴¹ An American firm, Veriato, offers a service that, among other things, scans emails to determine how employees’ feelings are changing over time.²⁴² Additionally, an employer with access to its employees’ social media profiles, emails, internet searches, and financial histories could – in the spirit of Facebook and creditors – learn about their intimate interpersonal relationships. For example, divorce is one of life’s most notoriously disruptive events.²⁴³ An employer might thus be interested in learning if its employees’ marriages are on the rocks because that added stress could very well affect job performance.

2. *Non-GINA Protections for Employee Privacy*

While much of this conduct goes unregulated,²⁴⁴ employers do not have unfettered access to employee information. In particular, privacy statutes and laws governing disability restrict access to certain kinds of employee information.²⁴⁵

a. *Workplace Privacy Law*

Certain statutes directly protect employees from invasions of privacy. While there is no federal law that broadly shields workers from snooping by their employers, the Privacy Act of 1974 regulates how federal agencies and their contractors collect, maintain, use, and disseminate information about individuals, including when the covered entities are acting as employers.²⁴⁶ The Electronic

241. *Id.*

242. *Id.*

243. Thomas H. Holmes & Richard H. Rahe, *The Social Readjustment Rating Scale*, 11 J. PSYCHOSOMATIC RES. 213, 216 (1967).

244. See Paul Ohm, *Sensitive Information*, 88 S. CAL. L. REV. 1125, 1138 (2015) (arguing that “[s]ensitive information laws can and should do more work”); see also *There Will Be Little Privacy*, *supra* note 1 (explaining that “[m]ost employment contracts in America give employers blanket rights to monitor employees and collect data about them”).

245. See Hoffman, *supra* note 215, at 1774 (“Employers may have good economic reasons to strive for the healthiest possible workforce, but they are constrained by federal and state laws prohibiting discrimination based on a variety of protected classifications, including disability and genetic information.”).

246. 5 U.S.C. § 552a (2018); see also *Workplace Monitoring Laws*, SOC’Y FOR HUM. RESOURCE MGMT., <https://www.shrm.org/ResourcesAndTools/hr-topics/employee-relations/Documents/State%20surveillance%20and%20monitoring%20laws.pdf> [<https://perma.cc/BRE6-HUG6>] (listing state statutes that regulate employers’ monitoring of their employees).

Communications Privacy Act (ECPA) prevents eavesdropping by employers when there is a reasonable expectation of privacy.²⁴⁷ However, two key exceptions limit the reach of that statute. The law permits employer monitoring in the ordinary course of business²⁴⁸ and with the employee's consent.²⁴⁹ Hence, scouring emails in the name of productivity—especially if employees have agreed to monitoring as a term of their employment—would not violate the statute. In fact, the consent exception does not require that the communication being monitored relate to employment.²⁵⁰ Further, most employer monitoring of emails will not meet the ECPA's definition of "intercept," which requires that the surveillance occur at the actual time that the email is sent.²⁵¹ Federal law, therefore, enables employers to read their employees' personal emails, as long as the employers obtain the requisite consent, or they access the email on a server after transmission. Most states also have laws that prohibit eavesdropping and secret recordings, which may apply to employers.²⁵² Of course, much like with the ECPA, an employer will not violate most of these laws as long as it conducts surveillance by means of a server or the employee knows that she is under surveillance.

Certain states have enacted laws protecting employee privacy with respect to social media and biometric screening. Social media privacy statutes prevent employers from requiring their employees or applicants to provide passwords to their private online accounts.²⁵³ Additionally, at least three states—Illinois, Texas, and Washington—have passed laws governing the collection, use, and

247. See 18 U.S.C. §§ 2510-2511 (2018) (prohibiting the interception of a person's communications but providing a defense for consent, under which no reasonable expectation of privacy would exist).

248. *Id.* § 2510(5)(a).

249. *Id.* § 2511(2)(d).

250. See *Managing Workplace Monitoring and Surveillance*, SOC'Y FOR HUM. RESOURCE MGMT. (Feb. 18, 2016), <https://www.shrm.org/resourcesandtools/tools-and-samples/toolkits/pages/workplaceprivacy.aspx>.

251. See, e.g., *Fraser v. Nationwide Mut. Ins. Co.*, 352 F.3d 107, 113 (3d Cir. 2003) (noting that "every circuit court to have considered the matter has held that an 'intercept' under the ECPA must occur contemporaneously with transmission" and thus, there can be no "intercept" of an email in storage).

252. See *Workplace Monitoring Laws*, *supra* note 246.

253. See *State Social Media Privacy Laws*, NAT'L CONF. ST. LEGISLATURES (Jan. 2, 2018), <http://www.ncsl.org/research/telecommunications-and-information-technology/state-laws-prohibiting-access-to-social-media-username-and-passwords.aspx> [<https://perma.cc/ST6A-A9YN>].

storage of biometric data of consumers, as well as employees.²⁵⁴ The Illinois statute, which includes a private right of action, has resulted in a stream of litigation with more than fifty companies having faced lawsuits as of 2018.²⁵⁵ The other two laws do not allow individuals to sue.²⁵⁶ Still, employers may monitor their employees' internet use at work, including their use of social media during work hours.

Finally, state statutes, many of which predate GINA, safeguard workers' genetic privacy.²⁵⁷ Almost three-quarters of states have genetic-specific employment protections and over half of states prohibit employers from requiring that their employees submit to genetic testing.²⁵⁸ These statutes have had an extremely limited impact. In fact, at the time GINA passed, no state lawsuit had ever been reported.²⁵⁹

b. Americans with Disabilities Act

The ADA offers some limited protection against employer snooping related to disability. What an employer can lawfully ask an employee depends on when that inquiry takes place: preoffer, postoffer, or during employment. Preoffer, a covered employer may ask applicants about their ability to perform job-related functions but it cannot make disability-related inquiries or request medical exams.²⁶⁰ Postoffer, not only can the employer require that prospective employees undergo medical exams, it can also request their health records, so long as it does not target individual employees, keeps the information confidential, and does not use the data to discriminate on the basis of disability.²⁶¹ Finally, after em-

254. Erin Marine, *Biometric Privacy Laws: Illinois and the Fight Against Intrusive Tech*, *FORDHAM J. CORP. & FIN. L. BLOG* (Mar. 20, 2018), <https://news.law.fordham.edu/jcfl/2018/03/20/biometric-privacy-laws-illinois-and-the-fight-against-intrusive-tech> [https://perma.cc/7H6K-WB5E].

255. *Id.*

256. Paul Shukovsky, *Washington Biometric Privacy Law Lacks Teeth of Illinois Cousin*, *BLOOMBERG NEWS* (July 18, 2017), <https://www.bna.com/washington-biometric-privacy-n73014461920> [https://perma.cc/ECA8-39HJ].

257. Rothstein, *supra* note 30, at 175.

258. See Bloomberg Law, *State Chart on Genetic Information Bias in Employment* (unpublished data) (on file with authors).

259. Kim, *supra* note 160, at 696.

260. 42 U.S.C. § 12112(d)(2) (2018).

261. *Id.* § 12112(d)(3) ("A covered entity may require a medical examination after an offer of employment has been made to a job applicant and prior to the commencement of the employment duties of such applicant, and may condition an offer of employment on the results of

ployment has begun, employers can only order medical exams or make disability-related inquiries when the information sought is “job-related and consistent with business necessity.”²⁶² Of course, in the age of big data, when employers can access information through a variety of sources other than medical examinations and inquiries, the ADA’s privacy protections look obsolete.²⁶³

B. GINA as a Blueprint for Employee-Privacy Protection

We now turn to GINA’s unique contributions and to its shortcomings. The statute’s greatest success has been in barring employers from accessing certain kinds of sensitive information. This is privacy by design.²⁶⁴ However, the desire for employee data is not restricted to genetic information. As noted, employers may also have an interest in information about health risks, relationships, or even reproductive choices. As such, GINA’s success as a protection for employee privacy can serve as a blueprint for additional protections both for recognized antidiscrimination classes and for other sensitive employee data.

1. Genetic-Information Nondiscrimination

Given that current workplace privacy laws and the ADA leave workers largely unprotected from employer surveillance, GINA is far more promising as a protection for employee privacy. Its prohibition on obtaining genetic information helpfully prevents employers from requesting, requiring, or purchasing genetic-test results of both employees and their family members. The hypothetical example of the employee with Huntington’s disease demonstrates that genetic data is exactly the kind of rich information source that could be mined using big-data analytics.²⁶⁵

such examination, if – (A) all entering employees are subjected to such an examination regardless of disability; (B) information obtained regarding the medical condition or history of the applicant is . . . treated as a confidential medical record . . .”).

²⁶² *Id.* § 12112(d)(4)(A).

²⁶³ For an excellent discussion of the ADA’s shortfalls when it comes to big data, see Hoffman, *supra* note 233, at 786–88.

²⁶⁴ Cf. WOODROW HARTZOG, *PRIVACY’S BLUEPRINT* (2018) (arguing that privacy is best effectuated through improving the design of popular technologies).

²⁶⁵ See Rothstein, *supra* note 68, at 6 (“Precision medicine promises to utilize genomic data in combination with diverse ‘big data’ sources, such as data from exposures, mobile devices and health apps, wearable devices, consumer transactions, geolocation logs, and numerous other publicly and privately available data sources. Computer algorithms will then calculate health risks or other end points.”).

Of course, as noted in Part II, GINA does not forbid all acquisitions of genetic information.²⁶⁶ The wellness-program and toxic-monitoring provisions, in particular, may give employers further access to employee data that they can then mine. However, the statute limits the conditions under which employers can acquire genetic information. Both exceptions require that the employee give “prior, knowing, voluntary, and written authorization”²⁶⁷ and that the employer only receives the genetic information “in aggregate terms that do not disclose the identity of specific employees.”²⁶⁸ Thus, GINA restricts substantially the conditions under which employers can lawfully obtain their employees’ genetic data.

Importantly, none of the reasons an employer might desire to mine data about its employees appears to fall within GINA’s exceptions. Actively acquiring genetic data to mine is not inadvertent. It does not relate to providing health services, applying for leave, monitoring toxic substances, or quality control in law enforcement. The most likely candidate for an applicable exception is purchasing commercially and publicly available documents, yet even that provision seems unlikely to shield snoopers from liability. The exception states that an employer does not unlawfully obtain genetic information “where an employer purchases documents that are commercially and publicly available (including newspapers, magazines, periodicals, and books, but not including medical databases or court records) that include family medical history.”²⁶⁹ Thus, the exception appears to apply only to documents that inadvertently contain genetic information. None of GINA’s exceptions appears to provide employers with a pathway for obtaining genetic data.

Consider the Huntington’s example. A third party has access to an employee’s family medical history as part of the datasets that it cross-references to gain predictive information, which it then passes to the employer. In such a scenario, the employer could incur legal liability under GINA if it pays a data-analytics company to mine its employees’ data, because the employer is effectively purchasing genetic information as part of the company’s services.²⁷⁰ Of course, the data-analytics firm could redact all genetic information from its reports to

²⁶⁶. See *supra* note 72 and accompanying text (detailing exceptions).

²⁶⁷. Genetic Information Nondiscrimination Act of 2008 § 202(b)(5)(B)(i), 42 U.S.C. § 2000ff-1 (b)(5)(B)(i) (2018). However, if federal or state law requires the genetic monitoring, the employer does not need authorization. *Id.* § 202(b)(5)(B)(ii).

²⁶⁸. *Id.* § 202(b)(2)(D), (b)(5)(E).

²⁶⁹. *Id.* § 202(b)(4).

²⁷⁰. Cf. *Lee v. City of Moraine Fire Dep’t*, No. 3:13-CV-222, 2015 WL 914440, at *11-12 (S.D. Ohio Mar. 3, 2015) (finding an employer liable under GINA for the behavior of a physician who was said to be an “agent” of the employer).

ensure that its clients do not run afoul of the statute. But depending on the nature of the predictive information that the company discloses, employers purchasing even redacted reports might violate GINA. The results of the data analytics – while not technically genetic information under the statute – may pertain to genetic risk and are thus only a small step removed from the letter of the law. GINA could possibly offer protection in the future against the acquisition and subsequent mining of genetic data.²⁷¹

2. *Lessons from GINA's First Ten Years*

One starting point for thinking about GINA as a blueprint for other privacy protections is to consider GINA's shortcomings to date – and what, if anything, might be done about them. Reflecting on GINA's first decade provides the opportunity to reassess some of the criticisms of the statute's usefulness. Drawing from our case review in Part II, we offer some prescriptive insights regarding how courts and other policy stakeholders should proceed on GINA.

a. *Lack of Awareness*

Given the lack of awareness about GINA, there must be a greater focus on educating the public. The EEOC and Department of Health and Human Services should implement a dedicated public-relations campaign to educate the public about GINA's varied protections. More sweeping judicial interpretations or amendments will matter little if the general public does not know about the statute.

271. Other discrimination laws have been interpreted over time to broaden the scope of the protected trait. This is especially the case when the broadening promotes the spirit or values of an underlying law. Perhaps the best example is Title VII's protection of "sex," which has been broadened over the decades to encompass gender nonconformance, sexual stereotyping, and transgender status. See KIMBERLY A. YURACKO, *GENDER NONCONFORMITY AND THE LAW* (2016) (discussing the evolution of U.S. sex discrimination jurisprudence during the twenty-first century); Bradley A. Areheart, *The Symmetry Principle*, 58 B.C. L. REV. 1085, 1087-88 (2017). More recently, some courts have even found that gay and lesbian individuals may be per se covered under "sex" – and not just when they tie discrimination to their performative defiance of gender norms. See *Zarda v. Altitude Express, Inc.*, 883 F.3d 100 (2d Cir. 2018) (en banc); *Hively v. Ivy Tech Cmty. Coll.*, 853 F.3d 339 (7th Cir. 2017) (en banc). In much the same way, interpreting GINA broadly to address data analytics that pertain to genetic risk might be seen as furthering two of the law's values: (1) the prevention of an underclass and (2) privacy.

There is also a need for public education about the nature of genomic risk,²⁷² which is a pronounced concern as more commercial DNA tests are coming to market. For example, take the recent FDA-approved DNA test for BRCA1/BRCA2 genetic mutations. Merely testing positive for one of several BRCA1/BRCA2 breast-cancer gene mutations does not provide definitive information about the risk of developing breast cancer, and “most BRCA mutations that increase an individual’s risk are not detected by this [new direct-to-consumer] test.”²⁷³ Further, “most cases of cancer are not caused by hereditary gene mutations but are thought to be caused by a wide variety of factors, including smoking, obesity, hormone use and other lifestyle issues.”²⁷⁴ All of this means that even something as seemingly straightforward as testing for breast-cancer gene mutations can contain many complications and uncertainties in forecasting risk.

Ensuring that potential litigants, health-care providers, employers, the employment bar, and the judiciary have at least some familiarity with GINA and its protections, as well as with genetic risk in general, is essential for GINA’s future. Health-care providers and employers must understand the law to comply with it. Lawyers and the public should be able to identify potential GINA violations when they arise to bring cases. Judges must properly apply the statute, and not read in their own meaning. All of these things require greater awareness.

b. Limited Scope

As discussed above, GINA has also faced criticism for its limited scope. Employers and health insurers are not the only ones who may have an interest in obtaining and acting on genetic data. One can imagine the common fact patterns from the GINA cases playing out in other settings. For example, the case of the devious defecator could well have occurred at a public middle school. In many states, nothing would stop the school district from requiring minors to provide genetic data. Perhaps, then, we should think more broadly about other threats and expand GINA’s scope. While augmenting GINA’s reach might be a commendable goal, expanding the statute to other spheres is unlikely to garner the requisite congressional support. GINA took thirteen years to pass and was the

272. Mark A. Rothstein, *Legal Conceptions of Equality in the Genomic Age*, 25 LAW & INEQ. 429 (2007).

273. *FDA Authorizes, with Special Controls, Direct-to-Consumer Test that Reports Three Mutations in the BRCA Breast Cancer Genes*, U.S. FOOD & DRUG ADMIN. (Mar. 6, 2018), <https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm599560.htm> [<https://perma.cc/4GBJ-CS7N>].

274. *Id.*

result of compromise on the part of lawmakers to appease various stakeholders, including researchers, employers, the insurance industry, and individuals at genetic risk.²⁷⁵ In the current climate of political divisiveness, common ground is even harder to come by.²⁷⁶ Thus, any expansion beyond GINA's current purview is most likely to happen via individual state laws, like CalGINA, and not a broad congressional mandate.²⁷⁷

c. Narrow Protected Status

Another source of criticism, which our case study bears out, has been GINA's narrow protected status. Although family medical history has been interpreted robustly and represents a broadly remedial edge to GINA's protections,²⁷⁸ some courts have already begun interpreting genetic information stringently—a move that has parallels in protected class gatekeeping, which scholars have observed at times under all of the employment discrimination statutes.²⁷⁹ While the definition of genetic information is incredibly specific, courts should interpret its meaning broadly.

As explained in Part II, *Poore* and *Conner-Goodgame* require that genetic information be predictive or communicate actual medical risk.²⁸⁰ This narrow application—for example, to exclude allegations of discrimination that stem from an employee's wife's MS or a mother's HIV—is needlessly restrictive. If the employer discriminated because it thought a wife's MS or a mother's HIV might relate to an employee's health—even if the employer is mistaken—GINA ought to provide recourse. This argument is akin to the ADA's protections, which de-

275. Rothstein, *supra* note 68, at 5 (explaining that GINA itself was a compromise because “[a] broader bill would have been extremely unlikely to get the necessary support in Congress”).

276. Carl Hulse, *Sharper State Divide in Congress Seen as ‘New Civil War,’* N.Y. TIMES (Jan. 15, 2018), <https://www.nytimes.com/2018/01/15/us/politics/hulse-congress-tax-cut-campaigns.html> [<https://perma.cc/L2A5-4226>].

277. Rothstein, *supra* note 68, at 5 (“Although there has been some movement at the state level, notably California’s adding genetic information to the prohibitions of the state civil rights laws, the prospect of future Congressional action seems remote.”).

278. See *supra* Section II.C (discussing the success of GINA as a privacy protection).

279. See Jessica A. Clarke, *Protected Class Gatekeeping*, 92 N.Y.U. L. REV. 101, 101 (2017) (arguing that “protected class gatekeeping is grounded in dubious constructions of antidiscrimination statutes, and that its routine use prevents equality law from achieving its central aim: dismantling sexism, racism, homophobia, religious intolerance, and other such biases”); see also, e.g., Bradley A. Areheart, *When Disability Isn’t “Just Right”: The Entrenchment of the Medical Model of Disability and the Goldilocks Dilemma*, 83 IND. L.J. 181, 209–25 (2008) (detailing a variety of ways in which federal courts keep ADA plaintiffs out of court).

280. *Supra* notes 119–126 and accompanying text.

fine the protected class to include those who are “regarded as” disabled.²⁸¹ The argument to protect information that does not communicate actual risk is also supported by the EEOC’s regulations, which define family members to include dependents by marriage and adoption.²⁸² Such an expansive interpretation would also answer the call of scholars who have observed the ADA’s deficiencies in failing to protect people who are perceived as likely to develop mental or physical impairments in the future.²⁸³ Of course, if an employee can no longer adequately perform her job, it would not be discrimination under either statute for the employer to take an adverse action.

Further, protecting the plaintiffs in *Poore* and *Conner-Goodgame* is sensible from the perspective of giving plaintiffs associational protections that relate to genetic information. Courts have allowed both Title VII and ADA plaintiffs to bring claims based on their association with members of the protected class.²⁸⁴ The same logic could be applied to the genetic context as well. In sum, genetic information should be interpreted by courts in a way that captures the spirit of GINA. Much like the court declared in *Lowe v. Atlas Logistics*, genetic information ought to be given a plain, nontechnical meaning that confers a broadly remedial impact.²⁸⁵ Such an interpretation would lay the groundwork to flexibly apply GINA to areas of innovation, such as big data, as well as other areas that have not yet arisen.

3. Taking a Cue from GINA

A broad employee-privacy statute presents several challenges for lawmakers. First and foremost, what should be the scope of such a protection? GINA’s potential as a blueprint for a big-data privacy statute can be understood in at least two different ways. On one hand, the ban on requesting, requiring, and purchas-

^{281.} 42 U.S.C. § 12102(1)(c) (2018).

^{282.} 29 C.F.R. § 1635.3(a)(1) (2018).

^{283.} Professor Sharona Hoffman has argued that, in the era of big data, Congress should amend the ADA “to protect individuals who might be categorized as likely to develop physical or mental impairments in the future.” Hoffman, *supra* note 233, at 777.

^{284.} See, e.g., 42 U.S.C. § 12112(b)(4) (defining discrimination to include “excluding or otherwise denying equal jobs or benefits to a qualified individual because of the known disability of an individual with whom the qualified individual is known to have a relationship or association”); *Parr v. Woodmen of the World Life Ins. Co.*, 791 F.2d 888, 892-93 (11th Cir. 1986) (holding that discrimination because of an interracial marriage or interracial association was discrimination based on race); *Barker v. Int’l Paper Co.*, 993 F. Supp. 10, 15-16 (D. Me. 1998) (holding that a nondisabled employee set forth an ADA retaliation claim by claiming he was fired for seeking accommodation for his disabled wife).

^{285.} 102 F. Supp. 3d 1360 (N.D. Ga. 2015).

ing genetic data is a prohibition on collecting information that relates to a recognized antidiscrimination category—genetic information. On the other, GINA's privacy provision restricts access to a particular type of private health information. Both readings could provide a model for future lawmaking.

a. Protecting Recognized Antidiscrimination Classes

While federal employment discrimination law prohibits discrimination based on race, ethnicity, national origin, sex, religion, age, disability, and genetic information, GINA is the only statute to broadly ban requesting, requiring, or purchasing information related to the protected status. Thus, these other protected statuses are more vulnerable to employer prying, particularly in the era of big data. We can return to the pregnancy example. The Pregnancy Discrimination Act (PDA) amends Title VII of the Civil Rights Act to outlaw discrimination against pregnant workers. However, nothing in that law stops employers from requesting, requiring, or purchasing information about their employees' potential pregnancies. Likewise, the ADA does not stop employers from obtaining information related to disability, so long as the employers are not conducting medical exams or making disability-related inquiries. Employers could therefore use big data to legally obtain all kinds of sensitive information about their employees, even information that relates to statuses protected by employment discrimination laws.

Taking a cue from GINA, Congress or states could pass laws that similarly prohibit employers from requesting, requiring, or purchasing employee information that pertains to a protected antidiscrimination category. For example, lawmakers could amend Title VII and the ADA to include GINA-like privacy provisions. Those amendments would prevent employers from requesting, requiring, or purchasing information related to a protected status. These protections would, by consequence, prohibit employers from mining that data.

Adding GINA-like privacy protections could also serve the antidiscrimination goals of those preexisting laws. Employers who mine data in an attempt to reduce costs may further disadvantage historically subordinated groups. Consider again the pregnancy example. Once an employer knows that at least forty of its employees are pregnant or trying, all women of reproductive age may become suspect.²⁸⁶ The employer may then—either consciously or because of implicit bias—opt not to hire or promote women of reproductive age out of the

286. Stephanie R. Morain et al., *What to Expect When [Your Employer Suspects] You're Expecting*, 176 JAMA INTERNAL MED. 1597, 1597-98 (2016).

concern that they may impose costs by filing insurance claims and taking parental leave,²⁸⁷ thus further disadvantaging a historically subjugated group. This conduct would, of course, violate the PDA. However, discrimination, particularly when it results from unconscious thinking, is notoriously hard to establish.²⁸⁸ Preventing employers from acquiring information that relates to a protected status could deny employers access to the very information they would, and do, use to discriminate.²⁸⁹ Thus, amending existing employment discrimination statutes to safeguard privacy also serves those laws' antidiscrimination ends.

b. Protecting Sensitive Information

While amending existing antidiscrimination laws is one path forward, employers want intimate information that falls outside the scope of those laws. Examples could include an employee's sexual orientation,²⁹⁰ political affiliation,²⁹¹ nongenetic health risks,²⁹² or socioeconomic class.²⁹³ Alternatively, instead of

287. *Id.* at 1598.

288. As the Seventh Circuit stated decades ago, "Proof of . . . discrimination is always difficult. Defendants of even minimal sophistication will neither admit discriminatory animus nor leave a paper trail demonstrating it; and because most employment decisions involve some discretion, alternative hypotheses (including that of simple mistake) will always be possible and often plausible." *Riordan v. Kempiners*, 831 F.2d 690, 697 (7th Cir. 1987). Studies have shown that employment discrimination plaintiffs have lower success rates than plaintiffs in other domains when it comes to settlement, pretrial adjudication, and trial. Kevin M. Clermont & Stewart J. Schwab, *Employment Discrimination Plaintiffs in Federal Court: From Bad to Worse*, 3 HARV. L. & POL'Y REV. 103, 131 (2009).

289. Roberts, *supra* note 28, at 2121-22.

290. While formally there is no federal statutory protection for sexual orientation, many states and municipalities prohibit discrimination based on sexual orientation. See *State Laws on Employment-Related Discrimination*, NAT'L CONF. ST. LEGISLATURES, <http://www.ncsl.org/research/labor-and-employment/discrimination-employment.aspx> [<https://perma.cc/EV44-A8QS>]. Additionally, two federal circuit courts have recently held that gay and lesbian individuals are always covered under "sex" – and not just when they tie discrimination to their performative defiance of gender norms. *Zarda v. Altitude Express, Inc.*, 883 F.3d 100 (2d Cir. 2018) (en banc); *Hively v. Ivy Tech Cmty. Coll.*, 853 F.3d 339 (7th Cir. 2017) (en banc). Nevertheless, most circuit courts have held that sexual orientation is not covered under Title VII's prohibition of "sex" discrimination.

291. While public employers may not discriminate based on political affiliation, private employers are generally not subject to the same kinds of constraints. See 10 LEX. K. LARSON, *EMPLOYMENT DISCRIMINATION* ch. 171 (2d ed. 2011).

292. See generally ROBERTS & WEEKS, *supra* note 217.

293. While there is no general protection against socioeconomic-status discrimination, a few laws have been passed at the state level to ban discrimination against those with poor credit.

looking to antidiscrimination statutes and historically subordinated groups, legislators could regulate employers' access to different sorts of information. GINA is unlike other antidiscrimination statutes because the status it protects is not a widely accepted, lived social category.²⁹⁴ GINA can therefore be understood not as protecting an attribute or a class of people but rather as protecting certain kinds of information, mainly genetic-test results and family medical history. Thus, another way to structure a GINA-like protection for employee privacy would be to forbid access to certain kinds of employee data.

The benefit of this model would extend beyond traditional antidiscrimination categories to provide more comprehensive protection for all employees. It would not matter if the data mining pertains to a protected status, just that it involves potentially sensitive information. For instance, whether Title VII forbids discrimination because of sexual orientation is an unresolved question.²⁹⁵ Amending Title VII to protect sexual orientation as a recognized class might still allow employers to use data analytics to acquire that information. However, if the law forbids access to social media profiles and browser histories, the employer could not derive inferences about an employee's sexuality from social media regardless of how courts resolve the question of whether Title VII protects sexual orientation. This strategy has the added benefit of avoiding identity politics and protected class gatekeeping,²⁹⁶ while also subverting the potential for discrimination.

Legislators could define the parameters of an employee-privacy statute in at least a couple different ways. First, they could limit employer access to certain *types* of data. Protected categories might include information that pertains to recognized zones of privacy (including medical treatment and intimate relationships). Such a legal protection would require creating an enumerated list, thus leaving information not captured in those categories unprotected. Another strat-

Heather Morton, *Use of Credit Information in Employment: 2015 Legislation*, NAT'L CONF. ST. LEGISLATURES (June 2, 2015), <http://www.ncsl.org/research/financial-services-and-commerce/use-of-credit-information-in-employment-2015-legislation.aspx> [https://perma.cc/T2PX-FPYU] (documenting the states that have introduced or passed legislation barring the use of credit information in hiring). Nevertheless, a compelling case can be made for extending the discrimination laws to socioeconomic-status discrimination. See Danieli Evans Peterman, *Socioeconomic Status Discrimination*, 104 VA. L. REV. 1283 (2018).

294. Roberts, *supra* note 61, at 623.

295. See *supra* note 290.

296. See Clarke, *supra* note 279, at 103, 119 nn.115-16 and accompanying text (describing the phenomenon of courts refusing to consider discrimination claims from individuals who are not members of protected classes where the alleged discrimination derived from their wrongly perceived membership in such classes).

egy might simply be to limit employer access to information that does not pertain to employment. Recall that once employment has begun, the ADA does not permit medical examinations or disability-related inquiries unless they are job-related and consistent with business necessity. Likewise, some states prohibit monitoring or retaliating against employees' lawful conduct away from work.²⁹⁷ A privacy law could forbid employers from seeking out information about their employees that is neither relevant nor necessary for the business.

Another possible strategy for protecting employee privacy would be to limit employer access to *sources* of potentially sensitive data, such as social media activity, internet queries, and fitness-tracking devices. A statute could then target any employer surveillance unrelated to work as a general matter.²⁹⁸ Some states already have laws that stop employers from accessing employees' social media profiles.²⁹⁹ Of course, the line between regulating the *type* of information and regulating *access* to its source can at times collapse. GINA, for example, prevents employers from obtaining a type of data – genetic information – but defines that type of data in part by referring to a source – genetic tests. These distinctions are not perfect. Instead, they are examples of possible strategies for approaching the issue of employee privacy.

4. Counterarguments and Qualifications

GINA offers a promising template for employment laws of the future. Yet it is not without its shortcomings. Here we respond to potential criticisms of adopting GINA-like protections to protect against employer prying.

a. Benefits of Disclosure

The first critique is that both employers and employees could possibly benefit from the information that these protections would shield. Information about protected classes like race, religion, and disability is what allow employers to en-

297. See, e.g., CAL. LAB. CODE §§ 96(k), 98.6 (West 2011); COLO. REV. STAT. ANN. § 24-34-402.5 (West 2015); 820 ILL. COMP. STAT. ANN. 55/5 (West 2012); MINN. STAT. ANN. § 181.938 (West 2018); MONT. CODE ANN. § 39-2-313 (West 2017); NEV. REV. STAT. ANN. § 613.333 (LexisNexis 2012); N.Y. LAB. LAW § 201-d (McKinney 2009); N.C. GEN. STAT. ANN. § 95-28.2 (West 2017); N.D. CENT. CODE § 14-02.4-03 (2017); WIS. STAT. ANN. § 111.321 (West 2018).

298. For such a proposal, see Ajunwa et al., *supra* note 77, at 774-75.

299. See, e.g., ARK. CODE ANN. § 11-2-124 (Supp. 2017); CAL. LAB. CODE § 980 (West Supp. 2018); COLO. REV. STAT. ANN. 8-2-127 (West Supp. 2017); N.J. STAT. ANN. § 34:6B-6 (West. Supp. 2018).

gage in positive differential treatment like affirmative action and accommodation. In the context of genetic information, Mark Rothstein has argued for the importance of recognizing genetic difference.³⁰⁰ GINA itself acknowledges, through its many exceptions, that employees can benefit from sharing their genetic data with employers for the purposes of wellness programs, occupational monitoring, and family medical leave. Both authors of this Feature have separately touted the potential benefits of recognizing genetic variation in the workplace. We have each argued in favor of the voluntary disclosure of genetic information for the purposes of accommodation and genetic diversity.³⁰¹ Too robust of a privacy protection could, therefore, undermine the central goals of antidiscrimination legislation.

Worker surveillance more generally could also have meaningful benefits. Employers could use sensitive information like social media and browser histories to ensure a safer, more productive workplace. Monitoring employees or screening applicants could allow employers to identify toxic behavior, such as racial animus or sexual harassment, early on. One potential justification for worker surveillance in high-risk jobs is that it may save lives. Computers can enlist visual scanning technology to ensure that workers are wearing the appropriate safety equipment before allowing them access to dangerous areas.³⁰² Cameras on the factory floor can observe employees in order to quickly identify risks.³⁰³ Invasions of employee privacy could, perhaps counterintuitively, improve the lives of workers.

While we acknowledge the validity of these critiques, we maintain that GINA offers a useful foundation for future lawmaking. GINA outlaws even rational discrimination. Nowhere is this clearer than in Title I, where GINA prohibits health-insurer access to and use of even actuarially sound genetic information.³⁰⁴ The statute's antidiscrimination mandate thus includes rational discrimination.³⁰⁵

300. See Mark A. Rothstein, *supra* note 272 (arguing for an equitable legal regime in which genetic differences are recognized rather than ignored).

301. See Areheart, *supra* note 28; Roberts, *supra* note 61.

302. See *There Will Be Little Privacy*, *supra* note 1.

303. *Id.*

304. GINA prohibits requesting, requiring, or purchasing genetic information. GINA § 202(b). It does not provide an exception for actuarial fairness.

305. For a pre-GINA discussion of rational versus irrational genetic discrimination, see Mark A. Rothstein & Mary R. Anderlik, *What Is Genetic Discrimination and How Can It Be Prevented?*, 3 GENETICS MED. 354 (2001), which differentiates between social and actuarial definitions of genetic discrimination.

Of course, some might argue that when a decision maker bases her choice on rational deliberation and accurate information, it is not in fact “discrimination” at all. But antidiscrimination law rejects such a narrow definition of what it means to discriminate. Statistical discrimination, where people make “*rational* statistical inferences about average differences among . . . groups,” is illegal under most federal employment discrimination laws as intentional discrimination.³⁰⁶ Perhaps the best example of an antidiscrimination law that rejects rational discrimination is the ADA, which requires an employer to provide reasonable accommodations at its own expense for qualified individuals with disabilities.³⁰⁷ Further, hiring employees with disabilities may have accompanying costs, making it sometimes economically rational—but illegal—to screen out applicants based on disability. Discrimination laws were never intended to maximize employer wealth or merely constrain employers to rational decision-making. Law has important social functions beyond securing rights or deterring certain behaviors.³⁰⁸ In this light, at least some of GINA’s value is expressive.³⁰⁹ It communicates that basing decisions on even accurate genetic risk is socially unacceptable.

Permitting even rational genetic discrimination is socially problematic. To begin, accurate genetic data merely conveys predictions, not certainties. Thus, a person with high genetic risk may never develop the accompanying condition. Allowing discrimination based on genetic data could penalize people for something that may never actually happen. But beyond efficiency concerns, widespread genetic discrimination could produce stigma and, by consequence, a genetic underclass.³¹⁰ Forming a genetic underclass would violate several important social norms and values, including humanity (by denying a person’s inherent value), democracy (by creating largely arbitrary class distinctions), im-

306. Ian Ayres, *Fair Driving: Gender and Race Discrimination in Retail Car Negotiations*, 104 HARV. L. REV. 817, 842-43 (1991).

307. 42 U.S.C. § 12112(b)(5) (2018) (noting the term “discriminate against a qualified individual with a disability” includes an unwillingness to make reasonable accommodations); *see also id.* § 12112(a) (prohibiting such discrimination).

308. *See Areheart, supra* note 271, at 1104-08 (“[L]aws do more than secure material rights and deter certain behaviors. Rather, they reflect social values and send messages to the public about both *what* society should value and *how* the relevant subject should be valued.”).

309. *Cf. Alex C. Geisinger & Michael Ashley Stein, Expressive Law and the Americans with Disabilities Act*, 114 MICH. L. REV. 1061 (2016) (exploring the expressive effects of the ADA).

310. Roberts, *supra* note 61, at 631-32.

mutability (by punishing people for something outside their control), and privacy (by leading to the disclosure of intimate information).³¹¹ Safeguarding individuals from genetic discrimination and, in so doing, preventing a genetic underclass are important aims of the law.

As written, GINA strikes a reasonable balance between antidiscrimination and efficiency. Through its exceptions, the statute acknowledges that some amount of employer access to genetic information is appropriate when an employee consents to the disclosure and the subsequent use of the information offers the employee some kind of benefit. We might then add additional provisions to the statute that would allow employees to voluntarily disclose their genetic information for purposes of accommodation and diversity.³¹²

Future laws based on GINA could also include these kinds of prudent exceptions. A law that prohibits requesting information about race, national origin, religion, gender, or disability must permit employees to share that information voluntarily for the purposes of diversity initiatives, accommodation requests, and leave applications. With respect to workplace monitoring, any GINA-like protection would require that employees consent, something already required by the state and federal anti-eavesdropping laws described above.³¹³ Voluntariness is essential to obtaining consent. Courts interpreting the law should scrutinize policies that make data gathering a condition of employment and other possibly coercive tactics. In short, lawmakers must carefully craft future employee-privacy laws to strike the proper balance between secrecy and disclosure, and GINA offers some – albeit imperfect – guidance. As well, courts should interpret GINA and future privacy laws with these competing objectives in mind.

b. Traditional Antidiscrimination Classes

Another possible criticism of adding GINA-like protections for previously recognized antidiscrimination classes is that those categories are often not private to begin with. Privacy can only preempt discrimination for invisible attributes. Not only are protected classes like race, gender, and disability often visible, but people interact with them in a way that gives them the weight to help define one's social reality.³¹⁴ People may be uninterested in, or unable to keep secret, statuses like race, gender, and disability.³¹⁵ Yet GINA-like privacy protections

^{311.} *Id.* at 611-17.

^{312.} See Areheart, *supra* note 28; Roberts, *supra* note 61.

^{313.} See *supra* Section III.A.2.a.

^{314.} Roberts, *supra* note 28, at 2143.

^{315.} *Id.*

may still have uses in antidiscrimination law, including for traditional antidiscrimination classes. People can be racially ambiguous, have hidden disabilities, not look their age, or identify with a gender that does not correspond to the sex denoted on their birth certificates.³¹⁶ In each of these situations, allowing employees to maintain some measure of control over their personal information could thwart subsequent discrimination. Furthermore, expanding protections for traditional antidiscrimination classes could have expressive value by demonstrating respect with regard to how people construct their identities.

c. Nature of Big Data

Critics might also ask whether GINA-like protections would succeed where ADA-like protections might fail, particularly with respect to big data. GINA is superior to the ADA in preempting the disclosure of medical information in three material respects. First, it bans all acquisitions of statutorily covered genetic information, including purchases from third parties, while the ADA contains no such prohibition. The ADA only stops employers from obtaining information that pertains to disability through medical examinations or disability-related inquiries. Purchasing medical information from a third-party source may violate the ADA's spirit but not its face. Second, the ADA expressly allows employers to obtain information about disability after an offer is on the table. This provision means that an employer could, postoffer, condition employment on medical disclosures. GINA's blanket prohibition on obtaining the protected information from any source at any point in the employment relationship makes that law a better prototype for workplace privacy legislation.

Third, the ADA fails to offer adequate protection in a world of big data in part because employers may no longer require medical examinations or disability-related inquiries to learn what they want to know. If employers do not need to rely on genetic data to get access to the information they desire, GINA's protections could well suffer from the same deficiencies. Big-data analysis can take seemingly innocuous information and use it to deduce highly intimate details about a person's life. In the Huntington's example discussed above, GINA took family medical history off the table, making it harder for the employer to deduce why the employee was seeing a neurologist. In that context, GINA could effectively combat employer snooping. But imagine that an employer had no access to health-related information at all. If Hitachi can use physical movement to measure happiness and apps can use "word choice in text messages, the speed of

316. *Id.* at 2143-47.

your speech, and [phone] usage patterns” to assess mental health,³¹⁷ it seems plausible that an employer could use those same technologies to detect neurological decline in its early stages, perhaps even before the individual secures a diagnosis or learns of the condition. In such an example, genetic data is not at stake, but the scenario raises the same kinds of concerns. Will big data simply render GINA-like laws obsolete as well?

The solution here lies in creating broad protections for potentially sensitive information. GINA’s narrow protected status—not its prohibition on requesting, requiring, or purchasing—is where the statute may fall short with respect to big data. We therefore maintain that GINA’s privacy provisions, complete with exceptions to strike the proper balance, offer meaningful guidance to lawmakers. As suggested above, courts should interpret genetic information broadly and legislators should consider amending the statute to expand its coverage. A move away from antidiscrimination classes to protect sensitive information of all stripes would be most beneficial to employees.

d. A Practical Limitation

GINA in its current form might suffer from at least one practical limitation. Rothstein points out that GINA’s privacy provisions are nearly impossible to respect. At present, technology lacks the capability to redact genetic information quickly and efficiently from medical records. As a result, employers may inadvertently receive genetic information as part of postoffer, ADA-compliant disclosures.³¹⁸ Inadvertent acquisition is, as explained above, not actionable. Thus, Rothstein asserts that as long as the ADA allows the postoffer release of comprehensive medical records, GINA’s prohibition on obtaining genetic information will have little practical value.³¹⁹ This flaw is more of a shortcoming of technology than of the underlying law. One possible way to solve this issue is to subject postoffer medical requests under the ADA to greater scrutiny. We will need to

317. Patrick Staples & John Torous, *Can Your Smartphone Read Your Mind?*, SLATE (Sept. 20, 2017, 2:06 PM), http://www.slate.com/articles/technology/future_tense/2017/09/why_we_should_be_cautious_about_mental_health_apps_that_collect_smartphone.html [<https://perma.cc/K89G-NRWS>].

318. See Rothstein, *supra* note 30, at 177 (“Effective protection of genetic information in the employment setting requires a ban on employer requests for comprehensive records at the postoffer stage; the research, development, and adoption of health information technology to facilitate the disclosure of only job-related health information; and the legal requirement to limit the scope of disclosures to job-related information.”).

319. *Id.* at 174-76.

develop better software and other tools to allow custodians of health data to redact covered information simply and quickly.³²⁰ Prohibitions on requesting, requiring, or purchasing private information are still valuable, and having those laws in place could encourage innovations that will eventually lead to better compliance.

C. Implications

Having outlined GINA's potential as a blueprint for future lawmaking, we now take a deeper dive into the theoretical and practical implications of offering GINA-like protections for employee privacy. One thing that made GINA a path-breaking statute is its combination of a novel privacy protection with traditional antidiscrimination protections in the spirit of Title VII and the ADA.³²¹ We begin with the relationship between antidiscrimination and privacy. We then demonstrate how GINA's bimodal framework offers superior protections to previous antidiscrimination statutes.

1. Intrinsic and Extrinsic Privacy Harms

Privacy and antidiscrimination are two separate but related areas of law. GINA's privacy protections serve two important goals. First, they protect employees from intrusions into their private lives. Second, they safeguard employees from discrimination. We can understand both objectives in privacy terms.

There are at least two kinds of privacy harms: intrinsic and extrinsic.³²² Intrinsic privacy harms violate privacy as an independent moral value. Disclosure creates intimacy. Privacy has independent moral value because it allows us to define our relationships through what we keep secret and what we disclose. Some scholars have even argued that having control over what is known about the self is the very basis of civilized society.³²³ With respect to intrinsic privacy harms, the detriment is the invasion itself, regardless of whether the intruder actually acts on that information.

320. Companies already market products designed to help redact protected health information from medical records. See, e.g., *Automated Data Redaction Software*, EXTRACT SYSTEMS (2018), <https://www.extractsystems.com/automated-data-redaction-software> [https://perma.cc/Y3GF-5XMC].

321. See Roberts, *supra* note 28, at 2101.

322. *Id.* at 2113.

323. ELLEN ALDERMAN & CAROLINE KENNEDY, *THE RIGHT TO PRIVACY*, at xiii (1995) ("Although we live in a world of noisy self-confession, privacy allows us to keep certain facts to ourselves if we so choose. The right to privacy, it seems, is what makes us civilized.")

Consider the devious defecator case. Rather than resulting in an adverse employment action, the privacy invasion actually exonerated the employees. Employment discrimination law is clear that being teased alone is not a harm that provides a sufficient basis for recovery.³²⁴ What then was the harm in requiring the plaintiffs to undergo genetic testing—a harm that jurors valued at \$2.2 million dollars? The answer appears to be a transgression of the employees' genetic privacy. Big data threatens to exacerbate the potential for these kinds of intrusions, as employees may feel violated when their employers learn information that the employees would have preferred to keep secret.³²⁵ Thus, one benefit of GINA-like protections is to uphold privacy in the workplace as an important independent moral value.

Discrimination based on previously unknown information can be considered an extrinsic privacy harm. Extrinsic privacy harms are the wrongs that flow from invasions. Privacy has instrumental value: it allows us to make certain choices free from the scrutiny of others. When a person uncovers a secret and acts on that new information, an extrinsic privacy harm occurs. An example would be if an employer uses big data to deduce that one of its employees is trying to get pregnant and then chooses not to promote her based on that acquired knowledge. Not only does she experience the independent harm associated with the invasion (the intrinsic privacy harm), she also experiences a subsequent adverse employment action (the extrinsic privacy harm). However, if the employer never learns she is pregnant, it cannot use that information to her detriment. In certain cases, then, protecting privacy can prevent discrimination.

Traditionally, antidiscrimination laws prohibit employers from taking adverse employment actions on the basis of protected classes. Insofar as they protect privacy, they almost exclusively cover extrinsic privacy harms.³²⁶ In many states, then, it is legal for employers to question their employees, even if those inquiries could open the door for subsequent discrimination.³²⁷ An employer

324. See, e.g., *Oncle v. Sundowner Offshore Servs.*, 523 U.S. 75, 80 (1998) (acknowledging that antidiscrimination laws are not civility codes for the American workplace and observing that such laws do not prohibit all verbal or physical harassment—just harassment that happens pursuant to a protected class); *Hunt v. City of Markham*, 219 F.3d 649, 653 (7th Cir. 2000) (“The idea behind requiring proof of an adverse employment action is simply that a statute which forbids *employment* discrimination is not intended to reach every bigoted act or gesture that a worker might encounter in the workplace.”).

325. *There Will Be Little Privacy*, *supra* note 1 (“As more companies rely on outside firms to collect and crunch employee information, privacy concerns will increase, and employees may feel violated if they do not think they have given their consent to sharing their data.”).

326. Of course, the ADA’s medical inquiry provisions are one exception to this generalization.

327. See Jessica L. Roberts, *Rethinking Employment Discrimination Harms*, 91 IND. L.J. 393, 441 (2016) (explaining that only half of the states prohibit employers from asking about protected status).

might obtain information about an employee's race, ethnicity, national origin, religion, age, or gender and then act on that information, either consciously or subconsciously. Absent meaningful privacy protections, employees could find themselves victimized twice, once from the unwanted invasion and again from the discriminatory act. GINA, however, safeguards against both kinds of privacy violations. Any future employment protection based on GINA would likewise have the benefit of simultaneously protecting privacy and preventing subsequent discrimination, giving employees the ability to recover for both kinds of privacy harms.

2. Antisubordination

Protecting people's privacy in data would likewise prevent them from suffering adverse employment actions based on that data. Employment discrimination claims are notoriously hard to prove,³²⁸ making it arguably easier to prevent an employer from obtaining sensitive information than to prevent an employer from acting upon it. Robust employee-privacy legislation could therefore have the added benefit of reducing opportunities to discriminate.

Preventing employers from prying into their employees' private lives could have especially important implications for antisubordination. As discussed at length, one area of interest to employers is health. Using big data to pry into medical history could disparately impact several groups, including women trying to conceive, people with disabilities who have existing or past health conditions (including invisible disabilities), racial and ethnic groups that may be at greater risk of certain diseases, and trans individuals who may be seeking or have sought gender reassignment unbeknownst to their employers. As a society, we may be more likely to label a group as "risky" if that group faces stigma.³²⁹ Robust employee-privacy laws could protect those people from potential discrimination. Moreover, a privacy-based approach bypasses some of the pitfalls of its antidiscrimination cousin. By not relying on protected class, it avoids identity politics in a time of especially inflammatory debate. It also avoids the problem of protected class gatekeeping, which incorrectly focuses courts' attention on membership in the enumerated statutory class as opposed to dismantling socially pernicious biases.³³⁰

328. See generally Clermont & Schwab, *supra* note 288; Michael Selmi, *Why Are Employment Discrimination Cases So Hard to Win?*, 61 LA. L. REV. 555 (2001) (demonstrating that employment discrimination cases are unusually difficult to win).

329. See Valarie K. Blake, *Ensuring an Underclass: Stigma Theory Applied to Insurance* 46 (unpublished manuscript) (on file with authors).

330. See Clarke, *supra* note 279, at 104-06.

CONCLUSION

Congress passed GINA as a solution to a very specific problem: public anxiety surrounding medical genetic testing. While the statute's limited scope, narrow protected status, and privacy provisions have led commentators to dismiss the law as truncated, ineffective, and even unnecessary, GINA's peculiarities make sense when understood in light of its original purpose. However, at GINA's ten-year anniversary, it is unclear whether GINA has had any impact on the public's willingness to take genetic tests. Given this reality, it may be tempting to dismiss GINA as a failure.

At first blush, our original research in Part II may appear to confirm the view that GINA has been a disappointment. However, a closer reading of the cases from GINA's first decade reveals that the statute has been an understated success. Despite being tangential to its central goal of preventing discrimination in health insurance, its protections of employee privacy have been of serious, albeit unexpected, value. Reflection on the first ten years of GINA leads to a surprising but critical insight: what employees need most is not protection against discrimination based on genetic-test results, but rather safeguards against employer prying more generally.

Privacy protections at work are more important now than ever. Through data mining, employers have vast access to information about their employees' private lives. In a world of big data, GINA offers a robust and unexpected safeguard against snooping by employers. The law prevents employers from obtaining information about a protected status and regulates access to data that employers could mine. GINA's protections could then be a model to better protect privacy on the job.

Technology could soon render other antidiscrimination statutes obsolete. Existing laws like the PDA and the ADA do nothing to stop employers from using big data to learn about their employees' reproductive lives and risks of disability. GINA's value, by contrast, is appreciating. It has the potential to achieve far more than what Congress intended. The law demonstrates an effective way of structuring much-needed protections for employee privacy in light of the big-data revolution. Far from being ineffective or useless, GINA may actually serve as a model for the employment laws of the future.

**APPENDIX: FACTS, CLAIMS, AND BASES FOR RESOLUTION IN
FEDERAL CASES WITH PLAUSIBLE GINA CLAIMS**

By plausible, we mean only that the facts pled could conceivably support a claim under GINA or the plaintiff at least attempted to make an argument about how genetic discrimination was at issue. These orders pertain to forty-eight unique cases; we selected the order for each case that was most pertinent to the GINA claim.

Abbreviations for Employee's Posture: Constructive Discharge (CD), Denied Reinstatement (DR), Failure to Hire (FH), Failure to Promote (FP), Harassment (H), Placed on Leave (PL), Demotion (D), Retaliation (Ret), and Termination (T). The employee's posture for some cases was not available in the opinions; for such cases, we obtained the information from the complaints on the actual dockets.

Abbreviations for Factual Scenarios: Disability Accommodation (DA), Disclosure of Genetic Information (DGI), DNA Test (DNA), Drug Test (DT), Fitness-for-Duty Examination (FDE), Genetic Test (GT), HIV Test or Diagnosis (HIV), Mandatory Wellness Program (MWP), Other Disclosure of Medical Information (ODMI), Other Disclosure of Family Medical History (ODFMH), Request for Medical Exam or Records (RMER), Request for Family Medical History (RFMH), Unemployment (UN), Voluntary Wellness Program (VWP), and Workers Compensation (WC). The facts alleged for some cases were not fully available in the opinions; for such cases, we obtained the alleged facts from the complaints on the actual dockets.

Abbreviations for Claims: Disclosure of Genetic Information (DGI), Discrimination (Disc), Harassment (H), Retaliation (Ret), Unlawful Request (UR), and UWP (Unlawful Wellness Program).

Abbreviations for Substantive Resolutions: Definition of Discriminate (Disc), Definition of Employee (EE), Definition of Employer (ER), Definition of Genetic Information (GI), Definition of Genetic Test (GT), Unlawful Request (UR), and Definition of Wellness Programs (WP). Only thirty-one cases are resolved, in whole or in part, under GINA's statutory terms, and they are noted in this column with an asterisk (*). The other seventeen cases involve a plausible GINA claim that (a) was left fully unresolved (U) or (b) involved a procedural resolution (PR).

Abbreviations for Party Prevailing: Defendant (Def), Plaintiff (Pl).

Under the heading for Substantive Resolution, we have indicated resolutions that are only procedural as "PR." For example, if the defendant sought to dismiss the matter for purposes of arbitration, we have marked it as PR. If the matter is still pending, and not at all resolved, we have notated these cases as UR. If the defendant filed a motion to dismiss and that motion was denied as to the GINA

claim, we have noted the decision as UR. In all types of resolutions, we have sought to indicate the party prevailing on the GINA claim – even if the decision is not resolved under GINA (i.e., substantive) or a complete resolution. Accordingly, under the heading Party Prevailing on GINA Claim, we have sought to indicate which party has prevailed thus far. As such, some of these decisions are interlocutory in nature. Finally, if neither party prevailed under a substantive provision of GINA, we have marked those cases with a dagger symbol (†).

Case Name	Cite	Employee's Posture	Factual Scenarios	Claims	Substantive Resolution	Party Prevailing on GINA Claim
1. Punt v. Kelly Servs.	862 F.3d 1040 (10th Cir. 2017)	T	ODFMH	Disc	Disc*	Def
2. Ortiz v. City of San Antonio Fire Dep't	806 F.3d 822 (5th Cir. 2015)	Ret	MWP	Disc, Ret	GI*	Def
3. Higgins v. Union Pac. R.R. Co.	303 F. Supp. 3d 945 (D. Neb. 2018)	T	RMER, FDE, DA	UR	UR*	Def
4. Duignan v. City of Chicago	275 F. Supp. 3d 933 (N.D. Ill. 2017)	PL, DR	FDE, RMER	UR, Disc	GI*	Def
5. Fuentes v. City of San Antonio Fire Dep't	240 F. Supp. 3d 634 (W.D. Tex. 2017)	D, DR, Ret	MWP	UWP, Ret	GI*, WP*	Def
6. Dittmann v. ACS Human Servs.	210 F. Supp. 3d 1047 (N.D. Ind. 2016)	Ret	VWP	UWP	PR	Def
7. AARP v. EEOC	226 F. Supp. 3d 7 (D.D.C. 2016)	n/a	VWP, RFMH	UWP	WP*	Pl
8. EEOC v. Grisham Farm Prods. Inc.	191 F. Supp. 3d 994 (W.D. Mo. 2016)	FH	RFMH, RMER	UR	GI*	Pl
9. EEOC v. Amsted Rail Co.	169 F. Supp. 3d 877 (S.D. Ill. 2016)	FH	RMER, RFMH, DT	Disc	U	Pl†
10. Lowe v. Atlas Logistics Grp. Retail Servs.	102 F. Supp. 3d 1360 (N.D. Ga. 2015)	n/a	GT, DNA	UR	GI*	Pl
11. Lewis v. Gov't of the D.C.	161 F. Supp. 3d 15 (D.D.C. 2015)	T	GT, DT	UR, Ret	GI*, GI*	Def

Case Name	Cite	Employee's Posture	Factual Scenarios	Claims	Substantive Resolution	Party Prevailing on GINA Claim
12. Hoffman v. Family Dollar Stores, Inc.	99 F. Supp. 3d 631 (W.D.N.C. 2015)	Ret	HIV	Disc, DGI	GI*	Def
13. Garnett-Bishop v. N.Y. Cmty. Bancorp, Inc.	49 F. Supp. 3d 321 (E.D.N.Y. 2014)	T	n/a	Disc	U	Pl [†]
14. Tovar v. United Airlines Inc.	985 F. Supp. 2d 862 (N.D. Ill. 2013)	T	ODFMH	Disc	Disc*	Def
15. Poore v. Peterbilt of Bristol, L.L.C.	852 F. Supp. 2d 727 (W.D. Va. 2012)	T	RFMH, RMER	UR, Disc	GI*	Def
16. Harris v. Union Pac. R.R. Co.	No. 8:16-CV-381, 2018 WL 2729131 (D. Neb. June 6, 2018)	DR	FDE, RMER	Disc	PR	Pl [†]
17. Williams v. Graphic Packaging Int'l, Inc.	No. 1:16-cv-00102, 2018 WL 2118311 (M.D. Tenn. May 8, 2018)	T	RFMH, ODFMH	UR, Disc	UR*	Def
18. Kennard v. Kaiser Permanente	No. 17-cv-03262-WHO, 2018 WL 1784084 (N.D. Cal. Apr. 13, 2018)	PL, T	WC	DGI, Disc	PR	Def [†]
19. Hawkins v. Jam. Hosp. Med. Ctr. Diagnostic & Treatment Ctr. Corp.	No. 16-CV-4265, 2018 WL 1521774 (E.D.N.Y. Mar. 28, 2018)	n/a	RFMH, RMER	UR	PR	Pl [†]
20. Jones v. Foxx	No. 16-2207-CM, 2018 WL 705665 (D. Kan. Feb. 5, 2018)	FP	ODFMH	Disc	Disc*	Def

Case Name	Cite	Employee's Posture	Factual Scenarios	Claims	Substantive Resolution	Party Prevailing on GINA Claim
21. Robinson v. Dunganarvin Nev., LLC	No. 2:16-cv-00902-JAD-PAL, 2018 WL 547225 (D. Nev. Jan. 24, 2018)	T	Race	Disc	GI*	Def
22. Carroll v. Comprehensive Women's Health Servs.	No. 3:16cv1509, 2017 WL 4284386 (M.D. Pa. Sept. 27, 2017)	T	GT	Disc	Disc*	Def
23. Booker v. HH Gregg	No. 1:16-CV-187JD, 2016 WL 4437989 (N.D. Ind. Aug. 23, 2016)	T	Race	Disc	GI*	Def
24. Dantes v. Kaiser Found. Hosps.	No. 16-cv-00934-HRL, 2016 U.S. Dist. LEXIS 110289 (N.D. Cal. Aug. 18, 2016)	H	DGI	DGI, H, Disc	U	Def [†]
25. Jefferson v. Fannie Mae	No. 4:13-CV-00604-ALM-CAN, 2016 WL 5339702 (E.D. Tex. July 29, 2016)	DR, T, Ret	DA, RMER, RFMH	Disc	U	Pl [†]
26. Townsend v. Staples, Inc.	No. 1:15-cv-2835-WSD, 2016 WL 3344579 (N.D. Ga. June 15, 2016)	T	RMER	UR, Disc, Ret	GI*	Def
27. Easterling v. VT Halter Marine, Inc.	No. 1:15CV238-LG-RHW, 2016 WL 2757759 (S.D. Miss. May 12, 2016)	T	DT	Disc	PR	Def

Case Name	Cite	Employee's Posture	Factual Scenarios	Claims	Substantive Resolution	Party Prevailing on GINA Claim
28. Hovery v. Boeing Co.	No. C14-01555RSM, 2016 WL 149009 (W.D. Wash. Jan. 13, 2016)	H, Ret, PL, T	FDE, RMER	Disc, H, Ret	PR	Def ^f
29. Sullivan v. Lowe's HIW, Inc.	No. C15-1184JLR, 2015 WL 6439097 (W.D. Wash. Oct. 22, 2015)	T	DT, WC	UR	PR	Def ^f
30. Lee v. City of Moraine Fire Dep't	No. 3:13-cv-222, 2015 WL 914440 (S.D. Ohio Mar. 3, 2015)	T	RMER, RFMH, FDE	Ret, UR	GI*, ER*, WP*	Pl
31. Williamson v. Fermi Nat'l Accelerator Lab.	No. 13 C 4221, 2015 WL 360382 (N.D. Ill. Jan. 27, 2015)	T	RMER, RFMH	Disc	PR	Def ^f
32. Ruethoven v. Victor Sch. Dist. #7	No. CV 14-170-M-DLC, 2014 WL 6460190 (D. Mont. Nov. 17, 2014)	n/a	ODMI, DGI	Disc	Disc*	Def
33. EEOC v. Honeywell Int'l, Inc.	No. 14-4517 ADM/TNL, 2014 WL 5795481 (D. Minn. Nov. 6, 2014)	n/a	VWP	UWP	PR	Def ^f
34. Maxwell v. Verde Valley Ambulance Co.	No. CV-13-08044-PCT-BSB, 2014 WL 4470512 (D. Ariz. Sept. 11, 2014)	T	FDE, RMER, RFMH	UR	GI*, ER*	Neither

Case Name	Cite	Employee's Posture	Factual Scenarios	Claims	Substantive Resolution	Party Prevailing on GINA Claim
35. Bronsdon v. City of Naples	No. 2:13-cv-778-FtM-29CM, 2014 U.S. Dist. LEXIS 70592 (M.D. Fla. May 22, 2014)	CD, H	WC, ODFMH	Disc, H	GI*	PI
36. Gray v. Brent	No. 7:13-CV-198-BR, 2014 WL 1327011 (E.D.N.C. Apr. 2, 2014)	FH	n/a	Disc, DGI	ER*	Def
37. Alston v. Foster	No. CIV-13-850-PHX-MHB, 2014 WL 12691066 (D. Ariz. Jan. 17, 2014)	T	UN, RMER	Disc, DGI	PR	Def
38. Bailey v. City of Chesapeake	No. 2:13CV333, 2013 WL 6145718 (E.D. Va. Nov. 20, 2013)	T	FDE, RMER	Disc	EE*	Def
39. Jacobs v. Donnelly Come's	No. 1:13-cv-980-WSD, 2013 WL 5436682 (N.D. Ga. Sept. 27, 2013)	H, CD	Allergies	Disc	GI*	Def
40. Conner-Goodgame v. Wells Fargo Bank	No. 2:12-cv-03426-IP], 2013 WL 5428448 (N.D. Ala. Sept. 26, 2013)	T	HIV, ODFMH	DGI, Ret	GI*	Def
41. Allen v. Verizon Wireless	No. 3:12-cv-482 (JCH), 2013 WL 2467923 (D. Conn. June 6, 2013)	T	RFMH, RMER	Disc	GI*	Def

Case Name	Cite	Employee's Posture	Factual Scenarios	Claims	Substantive Resolution	Party Prevailing on GINA Claim
42. Pearson v. Charlotte Mecklenburg Schs.	No. 3:12-cv-334-RJC, 2013 WL 427080 (W.D.N.C. Feb. 4, 2013)	FH	n/a	Disc	PR	Def
43. Bell v. PSS World Med., Inc.	No. 3:12-cv-381-J-99MMH-JRK, 2012 WL 6761660 (M.D. Fla. Dec. 7, 2012)	H, CD	n/a	DGI	GI*	Def
44. O'Carroll v. Hancock Bank	No. 11-640-BAJ-DLD, 2012 WL 5997542 (M.D. La. Nov. 30, 2012)	T	n/a	Disc	U	Pl [†]
45. EEOC v. Nestle Prepared Foods	No. 5:11-mc-358-JMH-REW, 2012 WL 1888130 (E.D. Ky. May 23, 2012)	T	FDE, ODFMH, RMER	Disc	U	Def [†]
46. Leone v. N.J. Orthopaedic Specialists, P.A.	No. 11-3957 (ES), 2012 WL 1535198 (D.N.J. Apr. 27, 2012)	T	DA	Disc	Disc*	Def
47. Tate v. Quad/Graphics, Inc.	No. 3:10CV00296 BSM, 2011 WL 4352301 (E.D. Ark. Sept. 19, 2011)	PL, DR	WC, RMER, REMH	Disc	U	Pl [†]
48. Sumter v. Hampton Rds. Shipping Ass'n	No. 2:10cv396, 2011 U.S. Dist. LEXIS 163656 (E.D. Va. Feb. 14, 2011)	DR	RMER, FDE	Disc	ER*, PR*	Def