

In Need of a Wellness Program Privacy Act

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I. Executive Summary

Wellness programs, which have a long history, were expanded under the Patient Protection and Affordable Care Act (ACA). But those programs come with unspoken tradeoffs: they require people to give up their personal data, including sensitive personal health information, in exchange for unsupported promises of wellness and, in some cases, rewards.

Federal laws and, (to a lesser extent), state laws exist that protect enrollees of wellness programs. But those laws apply unevenly depending on the structure and operator of the wellness program. Further, wellness programs are marketed as an avenue to wellness, but the fact is that these programs are not necessarily evidence-based and their efficacy is questionable. Because of that, the deal being made – relinquish some privacy in exchange for improved wellness and incentives – is one-sided. It may be that the only party guaranteed to gain from wellness programs are those that can benefit from the collected data.

Wellness programs can also be discriminatory whether by design or in practice. There are many reasons why program candidates may be unable to participate in a wellness program, ranging from disabilities to health issues and across the broad span of social

determinants of health.¹ Several federal laws require that wellness programs offer alternatives for health-based programs, but these laws do not apply to wellness programs offered by life insurers. They also do not regulate programs that consumers cannot do because of reasons other than health. For example, if the consumer lives where it is unsafe to exercise outside of work hours. When employers or insurers offer programs that do not work for everyone, candidates bifurcate between those who can participate and those who cannot. Whether by accident or design, the outcome is the same. When incentives come into play, consumers who cannot participate are in effect penalized.

Consumer Reports supports legislation that assures transparency and fairness in the marketplace. To that end, we advocate for reasonable guardrails so consumers who choose to participate in wellness programs are not misled about how their data will be used and so their personal data is not abused by companies involved in wellness programs.

II. What are wellness programs?

“Wellness programs” are broadly defined as “an employment-based activity of employer-sponsored benefit aimed at promoting health-related behaviors (primary prevention or health promotion) and disease management (secondary prevention).”² The Public Health Services Act defines wellness programs as programs “that are reasonably designed to promote health or prevent disease.”³ Life insurers also now operate wellness programs.⁴

There are two kinds of wellness programs. *Health-contingent* wellness programs are programs that base the reward on the enrollee satisfying a health-related improvement, such as weight loss. *Participatory* wellness programs hinge on participating in a program such as a walking competition and may or may not offer a reward. The majority

¹ The *social determinants of health* recognizes that many factors, not just one, influence an individual's health. Those determinants include (but are not limited to): income and social status, employment and working conditions, social support networks, culture, food security, housing and transportation, personal health practices and coping skills. Any one of these – including lack of childcare or a long commute – could affect an individual's choice or ability to participate in a wellness program.

² Adrianna McIntyre, Nicholas Bagley, Austin Frankt, Aaron Carroll, “The Dubious Empirical and Legal Foundations of Workplace Wellness Programs,” *Health Matrix* Vol. 27 (2017) citing RAND Corp., “Do Workplace Wellness Programs Save Employers Money?” (2014); RAND Corp. “Workplace Wellness Programs Study: Final Report 2” (2013).

³ A program complies with this requirement if it (1) has a reasonable chance of improving the health of, or preventing disease in, participating individuals; (2) is not overly burdensome; (3) is not a subterfuge for discrimination based on a health factor; and (4) is not highly suspect in the method chosen to promote health or prevent disease. Tri-Agency *FAQs About Affordable Care Act Implementation (Part XXV)*, (April 16, 2015). Available at <https://www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/Downloads/Tri-agency-Wellness-FAQS-4-16-15pdf-AdobeAcrobat-Pro.pdf>.

⁴ For example, Hancock insurance added optional wellness programs to all of its life insurance products in 2018. See <https://www.johnhancockinsurance.com/vitality-program.html>. That same year, Hancock started testing a wellness program for LTC Insurance members. <https://www.investmentnews.com/article/20180928/FREE/180929910/john-hancock-testing-wellness-programs-for-long-term-care>

of wellness programs are participatory, not health-contingent, programs.⁵ The following table illustrates the types of wellness programs.

Category		Example
Participatory	No reward	• Pay for a gym membership • Smoking cessation program • Reward an employee who completes a health risk assessment
	Reward contingent on satisfying an activity related to a health status factor	
Contingent	Reward is contingent on a health-related activity or health outcome	• Walking competition • Cessation of smoking • Achieving biometric measure

Many wellness programs could be called “lifestyle management” wellness programs, which focus on primary prevention. Popular among these types of programs are preventive programs that focus on nutrition, weight management, fitness, and smoking cessation. In 2012, over 70 percent of programs were this type of lifestyle management program.⁶

Although the principles espoused by lifestyle management programs are objectively positive, there is growing evidence that:

- wellness programs have insufficient and inconsistent privacy protections⁷;
- enrollee data can be misused;
- wellness programs overextend employer control over employees’ data;
- wellness programs are a one-sided deal because wellness programs are not required to actually promote wellness.⁸

⁵ AARP v. EEOC at p.21 citing AR 7557.

⁶ Adrianna McIntyre, *supra* FN2 at p.60.

⁷ See Appendix II for how and which protections apply.

⁸ Internal Revenue Service, Department of the Treasury; Employee Benefits Security Administration, Department of Labor; Centers for Medicare & Medicaid Services, Department of Health and Human Services, *Nondiscrimination and Wellness Programs in Health Coverage in the Group Market*,

71 Federal Register at 75018-75019.

III. Who participates in, or sponsors, wellness programs?

Employers sponsor wellness programs for their employees. In most cases, those programs are operated by health plans, health insurers, or third party wellness program operators. Over half of U.S. employers offer some kind of wellness program.⁹ Some of these programs include:

- Health risk assessments: 37 percent of small firms and 62 percent of large firms offer health risk assessments to employees. A health risk assessment may collect information about employees' medical histories, health statuses, and lifestyles. The purpose of these assessments is to identify potential health issues for enrollees, such as high cholesterol or elevated blood pressure. Fifty-one percent of large firms that offer health risk assessments couple them with incentives to participate, such as gift cards, merchandise or similar rewards, lower premium contributions or cost sharing, and financial rewards such as contributions to HSAs or avoided payroll fees.¹⁰
- Biometric screenings: Twenty-one percent of small firms and 50 percent of large firms provide workers the opportunity to complete a biometric screening. Through in-person health examinations, biometric screenings reveal a number of health risk factors: BMI,¹¹ cholesterol, blood pressure, stress, and nutrition. Sixty percent of large firms offer incentives to participate in biometric screening.¹²
- Health and wellness promotion programs: this is a popular type of wellness offering, with 53 percent of small firms and 82 percent of large firms offering a program in: smoking cessation, weight management, or behavioral or lifestyle coaching. As shown in the following Kaiser Family Foundation bar graph,¹³ of the large firms that offer a health and wellness promotion, 35 percent offer incentives to participate, with the top quarter of those receiving incentives receiving \$1,000 or more.¹⁴

Life insurers can also offer wellness programs as a component of a life insurance product. There appear to be few if any restrictions on how these programs are designed, what incentives can be offered, and what can be done with the information

⁹ *Health and Big Data: An Ethical Framework for Health Information Collection by Corporate Wellness Programs*, by Ifeoma Ajunwa, Kate Crawford, and Joel S. Ford, *Journal of Law, Medicine & Ethics*, (2016) citing M. Pitt-Catsouphes, J. B. James, and C. Matz-Costa, "Workplace-Based Health and Wellness Programs: The Intersection of Aging, Work, and Health," *The Gerontologist* 55 no. 2 (2015): 262-270, 263.

¹⁰ Kaiser Family Foundation, *2018 Employer Health Benefits Survey*, (October 3, 2018).

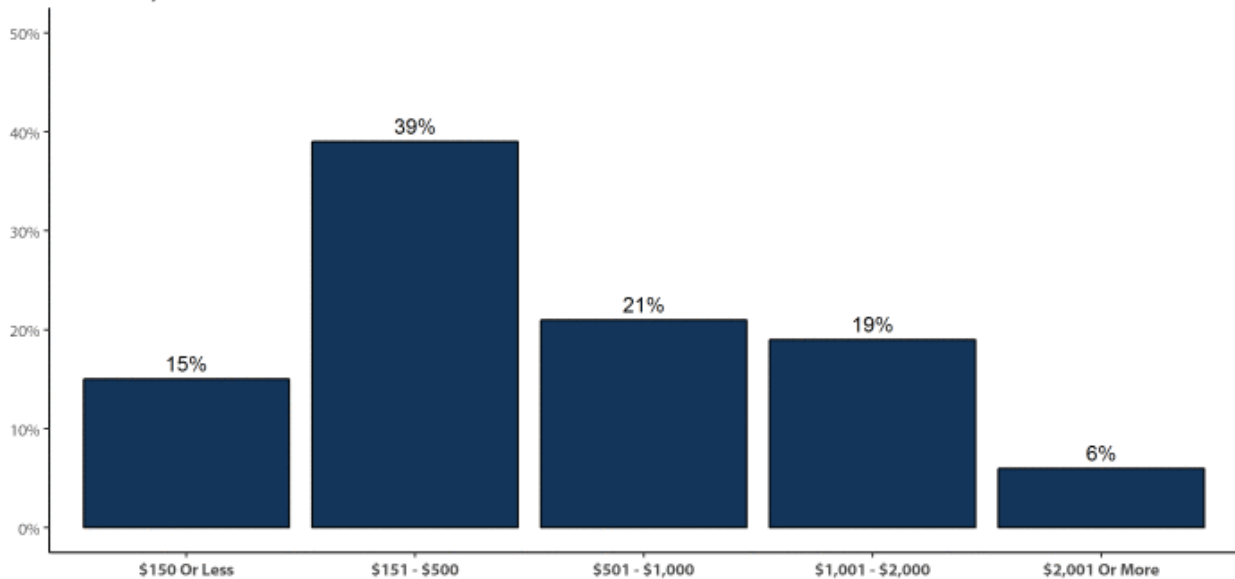
¹¹ The BMI measurement, or body mass index, is no longer considered the gold standard health measure, but yet continues to be used in wellness programs and other places.

¹² Kaiser Family Foundation, *Employer Health Benefits 2018 Annual Survey*, (2018) at p.15.

¹³ Kaiser Family Foundation, *Employer Health Benefits 2018 Annual Survey*, (2018).

¹⁴ Kaiser Family Foundation, *Employer Health Benefits 2018 Annual Survey*, (2018) at p.15.

Health Promotion Programs, Maximum Annual Value of the Incentive for All Programs Combined, 2018



NOTE: Large firms have 200 or more workers. Includes incentives for health risk assessments, biometric screenings, and wellness programs. Firms with at least one of the listed health promotion programs were asked to report the maximum incentive an employee and his/her dependents could receive for all of the firm's health promotion programs combined. Forty-five percent of large offering firms have an incentive to complete any of their health promotion programs.

SOURCE: KFF Employer Health Benefits Survey, 2018

that is collected. John Hancock for years offered a wellness program in a subset of its insurance products and in 2018 announced the life insurer would convert all of its term life insurance products to include wellness programs.¹⁵

IV. What data is captured in wellness programs

Depending on the type of wellness program, a wide range of personal data is collected in wellness programs. For example:

- Health risk assessments: may collect information about employees' medical histories, health statuses, and lifestyles.¹⁶ "Health assessments have been a recurring source of confusion"¹⁷ because of the sensitive nature of information collected in these assessments, especially when coupled with financial incentives/penalties. For example, Pennsylvania State University asked employees to answer questions such as "whether they have recently had

¹⁵ John Hancock press release, *John Hancock Leaves Traditional Life Insurance Model Behind to Incentivize Longer, Healthier Lives*, (September 19, 2018), accessed December 21, 2018.

¹⁶ Kaiser Family Foundation, *2018 Employer Health Benefits Survey*, (October 3, 2018).

¹⁷ Adrianna McIntyre, Nicholas Bagley, Austin Frankt, Aaron Carroll, "The Dubious Empirical and Legal Foundations of Workplace Wellness Programs," *Health Matrix* Vol. 27 (2017), p.73.

problems with a supervisor, a separation or a divorce, their finances or a fear of job loss; another question asks female employees whether they plan to become pregnant over the next year.”¹⁸

- Biometric screenings: through in-person health examinations, biometric screenings reveal a number of health risk factors, such as BMI, cholesterol, blood pressure, stress, and nutrition.
- Wellness promotion programs, such as walking competitions: fitness wearables can collect information in physical activity, sleep patterns, and GPS location data.
- Lifestyle management programs collect information on an enrollee’s smoking status, eating and exercise habits, and reported stress.

IV. Concerns surrounding wellness programs

Wellness programs are controversial. On their face, they are an avenue for companies to offer employees and consumers opportunities to improve their wellness. Beneath the surface lie multiple concerns about privacy and whether wellness programs offer a fair deal.

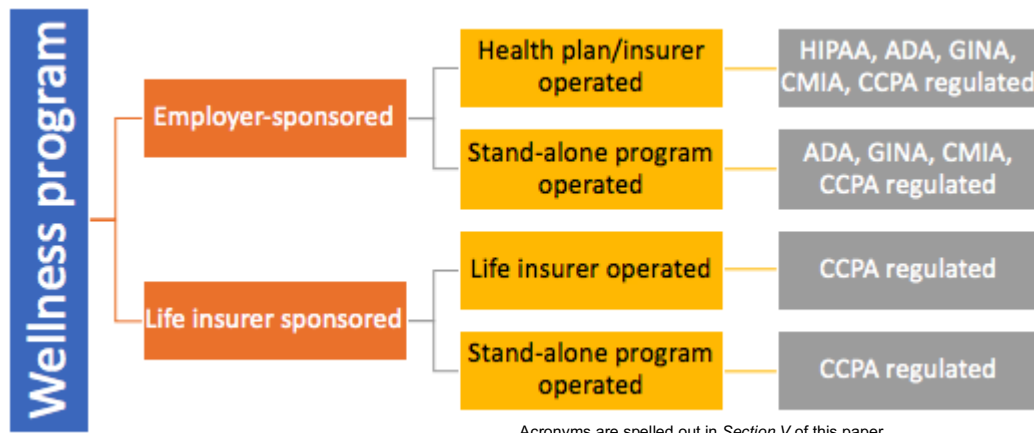
Privacy protections are insufficient and inconsistent

Consumers will always have a privacy interest in data collection, use, retention, or sharing because once private information is out of their exclusive control there is always a chance of misuse. For example, data could be publicly breached, accessed through mandatory legal process, or used for price discrimination to decrease a consumer's share of consumer surplus from any transaction.¹⁹ From the perspective of the consumer, there is necessarily privacy risk when someone else has their data.

The type of organization that operates a wellness program will determine which if any privacy protections apply. In general, there are three different types of operators of wellness programs: health insurers/health plans, life insurers, and stand-alone third party programs. Employers that sponsor wellness programs frequently outsource the operation of that wellness program to either a health insurer/plan or a stand-alone program.

¹⁸ Adrianna McIntyre, Nicholas Bagley, Austin Frankt, Aaron Carroll, “The Dubious Empirical and Legal Foundations of Workplace Wellness Programs,” *Health Matrix* Vol. 27 (2017), p.73 citing *Natasha Singer, On Campus, A Faculty Uprising Over Personal Data*, *N.Y. TIMES* (Sept. 14, 2013), <http://www.nytimes.com/2013/09/15/business/on-campus-a-faculty-uprising-over-personal-data.html>.

¹⁹ Justin Brookman & G.S. Hans, *Why Collection Matters: Surveillance as a De Facto Privacy Harm*, Future of Privacy Forum Big Data & Privacy Workshop Paper Collection (2013).



Health insurers/health plans: Privacy protections appear the most straightforward for wellness programs that are operated by health plans. In those cases, the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”) applies.²⁰ In addition, wellness programs sponsored by employers are regulated by the Americans with Disabilities Act (ADA) and the Genetic Information Nondiscrimination Act of 2008 (GINA) as well. State-based medical privacy and employment protections may also apply.

Stand-alone programs: to the extent that they are neither health plan nor healthcare provider, stand-alone wellness programs are not considered “covered entities,” and so HIPAA privacy protections do not apply. But ADA and GINA do still apply to wellness programs sponsored by employers. State-based medical privacy and employment protections may also apply.

Life insurers: It does not appear that life insurers are considered “covered entities” under HIPAA²¹. We have not found any clearly applicable federal privacy protections for wellness programs sponsored and operated by life insurers. Although it is possible that a state-based law applies, we are not aware of such a protection.

Health or fitness apps and fitness wearables: these tools are not wellness program operators in themselves, but they are critical in the operation of some wellness programs. They are not directly governed by HIPAA except where they interact with health plans or healthcare providers.²² So, for example, if a health insurer contracts with a fitness wearable manufacturer to outfit enrollees with the fitness device, then that

²⁰ U.S. Dep’t of Health & Human Services, *Summary of the HIPAA Privacy Rule 4* (2003). For more on HIPAA, see Section V of this paper.

²¹ The HIPAA Privacy Rule applies to health plans, healthcare providers who electronically transmit health information in connection with certain transactions, and healthcare clearinghouses.

²² In the case that these third party companies are engaged by a “covered entity” to provide services, they are considered a “business associate” of the covered entity and must adhere to certain Privacy protections under HIPAA.

manufacturer would likely be governed by HIPAA as a business associate. On the other hand, if enrollees in a wellness program are provided with fitness devices in a more informal way, or the employee supplies their own device, that fitness wearable manufacturer will not be held as a business associate or required to adhere to HIPAA or other consumer protections normally associated with wellness programs. Other state-based privacy laws may still apply.

Ultimately, health-related technology is rapidly evolving creating an ever-growing regulatory gap. Given this, privacy protections for data collected in wellness programs should be raised in order to fully protect consumers, and brought into uniformity so that all enrollees are protected no matter who sponsors or operates the program.

Enrollee data can be misused

Even though HIPAA sets a privacy rule for how health data is held by covered entities, that does not mean that enrollees' data will be kept private to the extent that enrollees may expect. Rather, the Privacy Rule allows for a degree of collection and sharing of data on individuals' health status and health risks by wellness program vendors, wearable fitness device companies, and health plans and insurers. Also, by leveraging passive consent and well-hidden authorizations, wellness programs can conduct extensive and invasive research into employee's health background, which can then be share with other companies.²³ As AARP explained, "the objective of many wellness programs is to acquire massive quantities of health data from multiple sources, to compile it into big data, and then to sell or 'share' it for profit."²⁴ Indeed, health plans that operate wellness programs can use the data to learn more about its enrollees, a hidden activity an enrollee may consent to but not fully understand.²⁵ Similarly, consumers consenting to data collection as part of a wellness program may not realize it can be mined for marketing purposes.²⁶ Consumers enroll in wellness programs to improve their health, not to hand over personal data – this type of data collection and inspection is not a legitimate use of the data.

Life insurance companies in particular may be interested in collecting as much consumer data as possible, because the health data is valuable for pricing life insurance products. Unlike health insurers, life insurers are permitted to set premiums based on the risk they calculate for each individual consumer, a practice known as "underwriting." Enrollees who opt into a wellness program operated by a life insurance company likely do not realize that the data collected during the wellness program creates "an 'incredibly

²³ AARP comments submitted to the EEOC, *RIN 3046-AB02 Genetic Information Nondiscrimination Act of 2008*, (January 28, 2016).

²⁴ AARP *supra* at 21, citing Karen Pollitz and Matthew Rae, *Workplace Wellness Program Characteristics and Requirements*, Kaiser Family Foundation (May 2016) and stating "However, the industry is fragmented with few barriers to entry, *id*, and estimates vary, as there is little consensus on how to define or measure this unregulated industry."

²⁵ Alexandra Troiano, *Wearables and Personal Health Data: Putting a Premium on Your Privacy*, January 1, 2017 at 1735.

²⁶ AARP comments *supra* at 21. Citing: S. Pettypiece, *Wellness Programs at work May Not be As Private As You Think*, Bloomberg Business (December 16, 2014).

detailed and rich picture' of a policyholder based on data collected from wearables and that [insurers] can price insurance premiums based on this data.”²⁷ Further, there are ongoing efforts to reverse recent protections against underwriting in health insurance, which could lead to a future in which health insurers can base health insurance premiums on a trove of health information inadvertently supplied by consumers over years of wellness program participation. In addition, some employers are harnessing wellness programs to use as big data tools to determine which employees are at risk of costly/serious illnesses or pregnancy.²⁸ Wellness programs are supposed to be about improving wellness, not a means for insurers to price and balance risk.

Data collected by third party apps and wearables fall into a regulatory void and the information that is collected can be sold to advertisers, for targeted advertising, or shared with insurance companies, financial institutions, and employers.^{29, 30} As a recent ProPublica report explained, the health insurance industry and data brokers are combining information collected about enrollees and feeding “this information into complicated computer algorithms that spit out predictions about how much your health care could cost them.”³¹ Insurers are in the business of predicting the risks of insuring consumers, but consumers do not enroll in wellness programs in order to furnish data to insurers, which can then be used against them. To use the data in that way constitutes misuse and exploitation.

Finally, large-scale collection of personal information leaves enrollees vulnerable to data breaches.³² One researcher found “that large databases containing health information are an attractive target for hackers... a hack could result in medical identity theft or personal health information being sold to data brokers.”³³ There are federal and state laws that set data security baselines, but they are no guarantee. As one researcher found, “while HIPAA does instill safeguards for the consumer, the regulation itself fails to adequately protect consumer privacy information – the information is nonetheless subject to breach.”³⁴ Of course, any time data is collected, breach is a possibility. But,

²⁷ Alexandra Troiano, *Wearables and Personal Health Data: Putting a Premium on Your Privacy*, January 1, 2017 citing Transcript of Federal Trade Commission, Insurance of Things Workshop at 169 (Nov. 19, 2013).

²⁸ R. E. Silverman, “Bosses Tap Outside Firms to Predict Which Workers Might Get Sick,” *Wall Street Journal*, February 17, 2016.

²⁹ Alexandra Troiano, *Wearables and Personal Health Data: Putting a Premium on Your Privacy*, January 1, 2017 citing Emily Field, *Biggest Privacy Problems in Fitness Trackers Still to Come*, *Law360* (Aug. 19, 2015).

³⁰ “For stand-alone wellness program vendors who are not considered health care providers, the information they collect is not covered by HIPAA, and they may sell health data to third parties without informing employees.” I. Ajunwa, *Workplace Wellness Programs Could be Putting Your Health Data at Risk*, (January 19, 2017); Derek Kravitz and Marshall Allen, *Your Medical Devices Are Not Keeping Your Health Data to Themselves*, *ProPublica* (November 21, 2018).

³¹ ProPublica, *Health Insurers are Vacuuming Up Details About You – And it Could Raise Your Rates*, (July 17, 2018).

³² AARP comments *supra* at 21. Citing: *Fifth Annual Study on Medical Identity Theft* (Ponemon Institute for Medical Identity Fraud Alliance, February 2015) (medical identity theft incidents increased by 22% between 2013 and 2014); S. Kellogg, *Every Breath You Take: Data Privacy and Your Wearable Fitness Device*, *Washington Lawyer* 22, 27 (Dec. 2015) (“data brokers buy information as quickly as it is created,” and then sell it to companies, including employers doing background checks on new hires); J. Craver, *Health Care Companies at Severe Risk of Cyberattacks*, *BenefitsPro* (Aug. 31 2015).

³³ I. Ajunwa, *Workplace Wellness Programs Could be Putting Your Health Data at Risk*, (January 19, 2017).

³⁴ *Wearables and Personal Health Data Putting a Premium on Your Privacy* at 33.

where data is collected and held by necessity – for example medical records or banking information – the risk of data loss is outweighed by the purposes for which it is collected and held. In the case of wellness programs, the calculation is not as balanced. This is especially true of programs that collect more data than they actually need, and that hold the data past the time that it is useful for the purpose of the program. The best way to ensure that enrollees' personal information is not released in a breach is by minimizing the amount of data that is collected in the first place.³⁵ Program operators should hold the data they collect for as short a period of time as possible, and destroy that information as soon as possible after the program concludes.

Wellness programs overextend employer control over employees' data

Employees may be giving away more of their private information than they realize when they enroll in an employer-sponsored wellness program. For example, a fitness device provided by an employer to an employee is the property of the employer, as is the data collected by the device. As a result, employers can access data from the devices at any time, without permission from the employee that wears the device.³⁶ For many enrollees, this type of worker surveillance may seem like more than they signed up for, even if it is quite literally what they signed up for.

Wellness programs: a one-sided deal?

Support for wellness programs in the ACA can be traced to a study released by Safeway in 2009, which claimed to prove the efficacy of wellness programs;³⁷ however, this study has since been discredited.³⁸ As early as 2013, the Department of Labor released a report concluding that “screening large numbers of individuals for health risks combined with education and one-on-one coaching for those with risks appears not to be effective or cost-effective enough to have a meaningful impact on the health of America’s workers and the cost of health coverage.”³⁹ In 2017, a paper that analyzed several mega-analyses of the experiences of participants in wellness programs, concluded that: “Wellness programs aimed at improving employee lifestyles yield little, if any, savings.”⁴⁰ (They also concluded that: “Programs that focus on managing

³⁵ Allen St. John, *Stopping the Data Breach Epidemic*, Consumer Reports, (December 21, 2018).

³⁶ I. Ajunwa, K. Crawford, and J. Schultz, “Limitless Worker Surveillance,” *California Law Review*.

³⁷ Steven A. Burd, *How Safeway is Cutting Health-Care Costs*, *Wall St. J.* (June 12, 2009).

³⁸ David S. Hilzenrath, *Misleading Claims about Safeway Wellness Incentives Shape Health-Care Bill*, *Wash. Post* (January 17, 2010).

³⁹ Soeren Matke et. al., *Workplace Wellness Programs Services Offered, Participation, and Incentives*, RAND Corporation, Research Report sponsored by the United States Department of Labor (2014).

⁴⁰ Adrianna McIntyre, Nicholas Bagley, Austin Frankt, Aaron Carroll, “The Dubious Empirical and Legal Foundations of Workplace Wellness Programs,” *Health Matrix* Vol. 27 (2017), p.65.

employees' chronic diseases,⁴¹ however, hold substantially more promise."⁴²). And, most recently, a comprehensive randomized control trial (RCT) out of Illinois, which studied wellness program participation and outcomes among nearly 5,000 employees in Illinois over a two year period plus an extended tail, reported:

"We fail to find significant treatment effects on average medical spending, on different quantiles of the spending distribution, or on any major subcategory of medical utilization (pharmaceutical drugs, office, or hospital). We find no effects on productivity, whether measured using administrative variables (sick leave, salary, promotion), survey variables (hours worked, job satisfaction, job search), or an index that combines all available measures. We also do not find effects on visits to campus gym facilities or on participation in a popular annual community running event, two health behaviors a motivated employee might change within one year."⁴³

Please see *References*, at the end of this document, for additional resources.

Wellness program operators are within their rights to offer wellness programs that are more experimental than evidence-based. The ACA and wellness program regulations set standards for the design of wellness programs, particularly health-contingent wellness programs, but they do not require that the program be evidence-based. Rather, the CMS explains "The wellness program regulations are intended to allow experimentation in diverse and innovative ways for promoting wellness."⁴⁴ As a result, a wellness program operator could argue that a wellness program is "reasonably designed to promote health or prevent disease,"⁴⁵ but for an individual enrolled in a wellness program, the activities required of them could run counter to medical advice or make inquiries for which there is no legitimate need for information. The AARP details one such scenario:

A wellness firm called Newtopia is offering free genetic testing for "genetic markers associated with metabolism, weight gain and overeating," and then claiming to offer personalized diet and exercise coaching based on the genetic results. There does not appear to be any scientific evidence to back up this approach. Not coincidentally, employees who answer Newtopia's HRA are offered the chance to purchase Newtopia's nutritional supplements and vitamins, an approach that appears "highly suspect."⁴⁶

⁴¹ The distinction between lifestyle programs versus chronic disease management programs is that lifestyle programs engage enrollees in an effort to change unhealthy lifestyle choices, like smoking. Chronic disease management programs, on the other hand, are designed to help employees with chronic disease to manage their conditions and improve their health.

⁴² *Id.*

⁴³ Damon Jones, David Molitor Julian Reif, "What do workplace wellness programs do? Evidence from the Illinois Workplace Wellness Study," *Harvard Quarterly Journal of Economics* (2019).

⁴⁴ *FAQs About Affordable Care Act Implementation (Part XXV)*, (April 16, 2015), answer to Question 1.

⁴⁵ 42 USC 300gg-4, Sec. 2705(a)(3)(B) available at <https://www.congress.gov/bill/111th-congress/house-bill/3590/text>.

⁴⁶ AARP comments submitted to the EEOC, *RIN 3046-AB02 Genetic Information Nondiscrimination Act of 2008*, (January 28, 2016), citing R. Silverman, *Genetic testing may be coming to your office*, *Wall St. J.* (December 15, 2015); D. Shaywitz, *The Science – or lack of it – behind genetic tests offered in the workplace*, *Forbes* (December 18, 2015); T. Murphy, *Genetic testing moves into world of employee health*, *Dallas Morning News* (April 28, 2015).

Enrollees may join a poorly designed program with hopes of improved wellness, not understanding the wellness program they enroll in is not proven to actually improve wellness.

Failures in equipment leveraged for wellness programs also leave the programs vulnerable. Lack of accuracy of fitness trackers – either because of mechanical imperfections⁴⁷ or simple inability to track all forms of exercise – can result in inaccurate assessment of an enrollee’s health and their health risks, and erroneous assessment of wellness achievement or program participation. Similarly, enrollees in activity-based wellness programs who do not want to share precise geolocation data 24/7 with their employer or insurer will be in a bind: they can remove their geolocation tracker but lose “credit” for activities with the sensor removed, or they can capture all their activities but have to give access to all their geolocation data.

Finally, even where consumers understand the privacy tradeoffs of participating in wellness programs and can assess whether participating is a good or fair deal, some may still participate simply because they feel they have no choice. In certain cases, where incentives to enroll effectively make joining compulsory, enrollees find themselves in a hard place between complying with an experimental wellness program and keeping their private information private. Some legal scholars question whether the incentives offered to participate in wellness programs “cloud the asymmetrical power relationship between the employer and the employee.”⁴⁸ These scholars have questioned whether “the employee is being called upon to relinquish valuable and sensitive health information for a mere pittance in the form of premium reductions.”⁴⁹ Along this line, in 2019, the AARP sued Yale University on behalf of 5400 union employees who were actually penalized \$25 a week, or \$1300 a year, for opting not to participate in a wellness program that required enrollees to undergo invasive medical testing and questionnaires. As the AARP lawsuit says, “The weekly fine is a high price to pay for privacy and protection from discrimination”.⁵⁰

Employees have also suspected employers of using wellness programs to engage in employment discrimination, a suspicion echoed by the Equal Employment Opportunity Commission (EEOC) in lawsuits filed against companies.⁵¹ The EEOC itself was also

⁴⁷ “Data from fitness trackers can be irregular and unreliable. Furthermore, the data from trackers requires interpretation...One problem with this, as scholars have noted, is that medical and health research rapidly changes, such that standards as to what is ‘healthy’ are not the same as they were in the past. Yet, the companies interpreting the data from wearables lawfully operate as black boxes, concealing their data sets and the algorithms they use for interpretation.” I. Ajunwa, “Limitless Worker Surveillance,” *California Law Review* citing footnotes 174-177.

⁴⁸ I. Ajunwa, K. Crawford, and J. Schultz, “Limitless Worker Surveillance,” *California Law Review*.

⁴⁹ See Ajunwa et al., *supra*, note 4.

⁵⁰ Kenneth Terrell, “Workers Sue Yale Over Wellness Program,” AARP Politics & Society Advocacy site (July 16, 2019).

⁵¹ In *EEOC v. Orion Energy Systems*, (August 20, 2014) and *EEOC v. Flambeau, Inc.* (September 30, 2014), the issue was mainly whether forcing an employee to pay the full health insurance premium belies the “voluntariness” of the wellness program. In *Orion Energy Systems*, court did find the program was voluntary, but the company acknowledged shortcomings with its program and agreed to a consent decree, a payment to the wronged employee, modified its wellness program, and trained its management and

sued over its wellness program-related regulations and, in 2018, retracted its 2016 rule permitting employers to penalize employees who refused to share personal information as part of a wellness program.⁵² While the update to Americans with Disabilities Act (ADA) and Genetic Information Nondiscrimination Act of 2008 (GINA) regulations balanced the scales in favor of enrollees, it is not clear how this modification will change wellness programs in the years to come, and even whether potential enrollees will be adequately informed of their rights to decline to share protected information. In addition, this recent change does not affect wellness programs operating outside the bounds of those laws, not the least of which including wellness programs offered by life insurance companies.

V. Legal privacy protections for wellness plan enrollees

Please see the appendix for a table that applies federal standards to wellness programs.

Federal laws and regulations

The **Patient Protection and Affordable Care Act (ACA)**, Sec. 2705, supports wellness programs and, in amending the Health Insurance Portability and Accountability Act (HIPAA) and the Public Health Services Act (PHSA), it granted greater leeway in terms of what rewards could be offered for joining wellness programs. A lesser-discussed aspect of the ACA is that, because health insurers are prohibited from individual underwriting, the health data collected as part of a wellness program cannot be mined against consumers who shop for their own health coverage. If the ACA is significantly modified or dismantled, this protection could be eliminated and years of data collected in wellness programs could be repurposed in ways enrollees did not anticipate and likely would not have approved.

The **Health Insurance Portability and Accountability Act (HIPAA)**, 45 CFR 160 et. seq. applies to health plans, rather than employers, and prevents health plans and insurers from discriminating on the basis of “any health status related factor.” A wellness program that is part of an existing group health plan will be considered a group health plan, as will a stand-alone program that provides or pays for health benefits.

Amendments made by the ACA allows covered entities, (health insurers, healthcare providers, and healthcare data clearinghouses), to offer premium discounts or rebates for health plan/insurance copayments or deductibles as a reward for participating in and complying with a wellness program.⁵³ Under enacting rules, health plans and insurers may offer incentives of up to 30 percent off the cost of health insurance or health plan

employees on the law against retaliation and interference under the ADA. The EEOC was unsuccessful in *Flambeau*, with the court finding the case moot as the involved employee was by then retired and had not suffered actual harm.

⁵² U.S. Equal Employment Opportunity Commission, *EEOC’s Final Rule on Employer Wellness Programs and the Genetic Information Nondiscrimination Act and Removal of Final ADA Wellness Rule Vacated by Court*, 83 FR 65296.

⁵³ 45 CFR 164.502.

coverage as a reward for participating in a *health-contingent* wellness program. (The original cap was 20 percent, but it has since been raised.) The Secretaries of the Treasury, the Department of Labor, and Health and Human Services are authorized under the ACA to increase the cap to 50 percent of the cost of coverage.⁵⁴ Neither the ACA nor HIPAA imposed a cap on incentives to be offered to enrollees in *participatory* wellness programs, or wellness programs that do not hinge rewards on satisfying a health condition.

Whether a wellness program is *health-contingent* or *participatory* dictates which laws apply. Programs that require employees to satisfy a certain result related to a health factor in order to obtain an award have more requirements under HIPAA and ACA rules than others.

The **Employee Retirement Income Security Act (ERISA)** regulates self-insured employer health coverage and preempts state laws. It prohibits discrimination by group health plans based on an employee's individual health status. This law was amended, in 2010, by the ACA, to allow group health plans to adopt health-contingent wellness programs.⁵⁵ The US Department of Labor (DOL) permits incentives in health-contingent wellness programs that meet five standards.⁵⁶ The first is a cap on rewards: 30% of the total cost of self-only group health plan coverage and 30% of family coverage if the family is also able to participate in the wellness program. The cap is raised to 50% for tobacco-related health-contingent programs. This cap could amount to thousands of dollars in savings for those who participate, or increased costs for those who do not participate.⁵⁷ The remaining four standards are that the wellness program must:

1. be "reasonably designed to promote health or prevent disease;
2. meet notice requirements;
3. provide waivers or alternative ways for participants to earn rewards;
4. make rewards available to participants at least on an annual basis.

These standards do not apply to participatory wellness programs, but other employment discrimination rules such as ADA and GINA do still apply.

The **Genetic Information Nondiscrimination Act of 2008 (GINA)**, Pub.L. 110–233, 122 Stat. 881, is a federal law that protects individuals from discrimination based on genetic information. This law only protects individuals in the context of health insurance and employment – it prohibits employers from using genetic information in decisions on hiring, firing, promotions, pay, or other employee privileges such as health insurance – it does not block insurers from using individuals' genetic information for eligibility and

⁵⁴ 42 U.S.C. § 300gg-4(j)(3)(A).

⁵⁵ The ACA added section 715(a)(1) to ERISA.

⁵⁶ Department of Labor, Employee Benefits Security Administration, 29 CFR 2590, *Incentives for Nondiscriminatory Wellness Programs in Group Health Plans* (June 3, 2013).

⁵⁷ Karen Pollitz and Matthew Rae, *Workplace Wellness Program Characteristics and Requirements*, Kaiser Family Foundation (May 2016).

underwriting of life, long-term care, and disability insurance. There is a narrow definition for which wellness programs are covered by GINA. The law applies if a wellness program asks for information about the employee's or employee's spouse's family medical history or about any of their genetic information. Although GINA restricts what employers can do with employees' genetic information, employers are permitted to collect genetic information as part of a wellness program, so long as the information is provided voluntarily.⁵⁸ What is "voluntary," though, is not defined in the statute and was the heart of *AARP v. EEOC*. In December, 2018, the EEOC updated its rule to remove the penalty section of the GINA regulations⁵⁹; as a result, employers can no longer require employees submit information protected by GINA. GINA also restricts what information may be collected in a wellness program subject to GINA – a wellness program will not be considered to be reasonably designed if it "consists of a measurement, test, screening, or collection of health-related information and that information is not used either to provide results, follow-up information, or advice to individual participants or to design a program that addresses at least some conditions identified."⁶⁰

The **Americans with Disabilities Act** (ADA), Pub. L. No. 101-336, 104 Stat. 328 (1990), applies to wellness programs that:

1. requires a medical exam, or
2. asks any disability-related questions.

The ADA limits medical inquiries in wellness programs, generally only permitting employers to collect medical data that is connected with a voluntary employee health program.⁶¹ Again, "voluntary" is not defined in the statute. Under an EEOC rule published May 17, 2016, employers that offer wellness programs that collect employee health information must notify employees of what information will be collected, how it will be used, who will receive it, and what will be done to keep it confidential.⁶² Under a rule finalized in 2016, incentives offered to employees who participate were not considered coercive if incentives or penalties did not exceed 30 percent of total employer and employee cost of sole-employee coverage. In December, 2018, the EEOC updated its rule to remove the penalties section of the ADA regulations⁶³; as a

⁵⁸ 42 U.S.C. § 12112(d)(4)(B).

⁵⁹ U.S. Equal Employment Opportunity Commission, *Removal of Final GINA Wellness Rule Vacated by Court*, (December 20, 2018), 83 FR 65296.

⁶⁰ U.S. Equal Employment Opportunity Commission, *EEOC's Final Rule on Employer Wellness Programs and the Genetic Information Nondiscrimination Act*, 83 FR 65296, available at <https://www.eeoc.gov/laws/regulations/qanda-gina-wellness-final-rule.cfm> (accessed December 28, 2018).

⁶¹ 42 U.S.C. § 12112(d)(4)(B).

⁶² EEOC website, *Sample Notice for Employer-Sponsored Wellness Programs* available <https://www.eeoc.gov/laws/regulations/ada-wellness-notice.cfm>.

⁶³ U.S. Equal Employment Opportunity Commission, *Removal of Final ADA Wellness Rule Vacated by Court*, (December 20, 2018), 83 FR 65296. Available at <https://www.federalregister.gov/documents/2018/12/20/2018-27539/removal-of-final-ada-wellness-rule-vacated-by-court>.

result, although wellness programs can still offer health-contingent wellness program incentives, they may not require employees submit any information that is protected under ADA.

The **Pregnancy Discrimination Act (PDA)** was enacted in 1978 under Title VII, 42 U.S.C. §§ 2000e et seq., to extend the prohibition of sex discrimination to include pregnancy-related discrimination. It is silent on wellness programs. The PDA does not prohibit asking about pregnancy or family planning, which may be a question in a health assessment. The law only prohibits the employer from firing or otherwise taking an adverse employment action against the employee because of her pregnancy status. Although it may not be advisable to ask pregnancy-related questions at all, in order to avoid the appearance of violating the PDA, “Many wellness programs buck that advice, perhaps because they generally do not share identifiable data with employers that might enable pregnancy discrimination.”⁶⁴

Pending federal legislation

HR 1313 the Preserving Employee Wellness Programs Act⁶⁵ was introduced 2017 but did not make significant headway. This bill would exempt workplace wellness programs from:

1. limitations under the Americans with Disabilities Act of 1990 on medical examinations and inquiries of employees,
2. the prohibition on collecting genetic information in connection with issuing health insurance, and
3. limitations under the Genetic Information Nondiscrimination Act of 2008 on collecting the genetic information of employees or family members of employees.

This exemption applies to workplace wellness programs that comply with limits on rewards for employees participating in the program.

S. 1842 the Protecting Personal Health Data Act⁶⁶, was introduced in June, 2019. Consumer Reports endorsed the bill when it was introduced. This federal law would regulate otherwise non-regulated health technology. If enacted, it would require the secretary of Health and Human Services to create privacy regulations for wearable fitness trackers, along with other health technology. Among other things, that regulation would enable consumers to review, change and delete any health data collected by companies, and would also create a National Task Force on Health Data Protection. The purpose of the task force would be to evaluate and provide input on any potential cybersecurity and privacy risks of consumer products that use customer health data.

⁶⁴ Adrianna McIntyre, Nicholas Bagley, Austin Frankt, Aaron Carroll, “The Dubious Empirical and Legal Foundations of Workplace Wellness Programs,” *Health Matrix* Vol. 27 (2017), p.74 citing Julie Appleby, *Pregnancy—A Touchy Subject in Employee Wellness Health Assessments*, Kaiser Health News (Aug. 4, 2015).

⁶⁵ Available at <https://www.congress.gov/bill/115th-congress/house-bill/1313/actions>

⁶⁶ Available at <https://www.congress.gov/bill/116th-congress/senate-bill/1842/text/is>

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Appendix II: Application of Federal Standards to Wellness Programs

This table identifies which laws (columns) regulate various aspect of wellness programs (rows).

A ✓ indicates regulation applies, X indicates the regulation does not apply.

		HIPAA	ERISA	GINA	ADA	PDA
		HIPAA applies to group health plans when the program is part of an existing group health plan*.	ERISA applies to self-insured employer health coverage and preempts state laws and regulations.	GINA applies to employers , with 15+ employees, that ask about employee/family medical history or genetic information.	ADA applies to employers , with 15+ employees, that require a medical exam or asks any disability-related questions.	PDA applies to employers taking employment action such as hiring or firing.
Type of Wellness Program	Participatory wellness program with no reward	✓	✓	✓	✓	✓
	Participatory wellness program with rewards	✓	✓	✓	✓	✓
	Health contingent reward program	✓ Caps incentives at 30%	✓ Caps incentives at 30% (50% for tobacco-related programs)	✓ Cannot financially coerce employee to share protected info	✓ Cannot financially coerce employee to share protected info	✓
	Life insurer wellness programs	X	X	X	X	X
Critical Criteria	Does the law require a reasonable alternative for a health-based program?	✓	✓	✓	✓	X
	Does the law have a notice requirement prior to enrollment?	✓	✓	✓ Detailed requirements	✓ Detailed requirements	X
	Does the law restrict disclosure of health information by the program?	✓ General HIPAA Privacy Rule	X	✓	✓	X
	Does the law require data minimization?	X	X	✓ Some limits	X	X