



Wellness Program Privacy Act Fact Sheet: A7329 and S7262

Consumer Reports supports legislation that assures transparency and fairness in the marketplace. We therefore advocate for reasonable guardrails around wellness programs 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.

Information collected by wellness programs includes:

Medical history • Cholesterol levels • Blood pressure
Reported stress • Plans to become pregnant
Family circumstances, such as separation or divorce
Body mass index (BMI) • Smoking status
Eating habits • Exercise habits

Why this bill is needed:

Privacy protections are insufficient and inconsistent.

Laws that apply to wellness programs at all apply unevenly depending on the structure and operator of the wellness program, leaving critical gaps in consumer protections for wellness program enrollees.

Enrollee data can be misused. Wellness programs can conduct extensive and invasive research into enrollees' health background, which can then be shared with other companies.¹ Program data can also be mined for marketing purposes,² used in insurance underwriting,³ and harnessed by employers to determine which employees are at risk of costly/serious illness or pregnancy.⁴

Wellness programs overextend employer control over employees' data. Nearly 20% of large employers, and 10% of small employers, who offered health

insurance in 2019 collected data from their employees' wearable devices.⁵ Employers can access data from fitness devices provided to employees for wellness programs, without permission from the employee that wears the device. This type of worker surveillance goes beyond the original purpose for which the data was collected (to promote individual health).

Wellness programs may be a one-sided deal. Evidence shows that wellness programs are generally unsuccessful at improving participants' wellness,⁶ making the trade-off for compromising privacy more of a one-sided deal. Further, 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 personal information private.

A7329 and S7262's common sense privacy protection for consumers that enroll in wellness programs:

- Protects workers' privacy.
- Protects insurance enrollees' privacy.
- Ensures that consumers know their rights before they sign up to give up their data.
- Makes sure that consumers that want to participate in wellness programs can, without giving up their right to privacy.
- Makes sure that consumers that do not want to participate in wellness programs are not penalized.

Contact your New York lawmaker to support this bill to protect consumer privacy.

Notes on back

¹ AARP comments submitted to the EEOC, RIN 3046-AB02 Genetic Information Nondiscrimination Act of 2008, (January 28, 2016).

² 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).

³ 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). Medical underwriting is permitted for life, disability, and long-term care insurance.

⁴ R. E. Silverman, "Bosses Tap Outside Firms to Predict Which Workers Might Get Sick," Wall Street Journal, February 17, 2016.

⁵ Kaiser Family Foundation, 2019 Employer Health Benefits Survey, (September 25, 2019).

⁶ Adrianno McIntyre, Nicholas Bagley, Austin Frankt, Aaron Carroll, "The Dubious Empirical and Legal Foundations of Workplace Wellness Programs," Health Matrix Vol. 27 (2017).