Comments of Anna Slomovic, PhD
Regarding Amendments to Regulations under the Americans with Disabilities Act

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U.S. Equal Employment Opportunity Commission
131 M Street, NE
Washington, DC 20507

Re: RIN 3046-AB01, dated April 20, 2015

I appreciate the opportunity to submit comments on the Equal Employment Opportunity Commission's proposed amendments to regulations and interpretive guidance implementing Title I of the Americans with Disabilities Act (ADA) relating to employer wellness programs. The proposal appears in the Federal Register of April 20, 2015 at https://www.federalregister.gov/articles/2015/04/20/2015-08827/amendments-to-regulations-under-the-americans-with-disabilities-act.

I am a consultant and a scholar, affiliated with George Washington University's Cyber Security Policy and Research Institute (CSPRI). For 15 years prior to returning to consulting and research, I served in various corporate positions, including positions as Chief Privacy Officer (CPO) of companies ranging in size from start-up to Fortune 500. One of these organizations was a nation-wide specialty health plan with 25 million members; another was a consumer-facing online health education and services company. As CPO I was responsible for privacy of both consumer and employee data. I have also served on federal and state-level work groups and commissions dealing with electronic health information. You can find additional information about my background on my website, www.annaslomovic.com. These comments reflect my own views and not the views of George Washington University, CSPRI, or any member of the university's faculty or staff.

For the past year I have been doing research on privacy in U.S. workplace wellness programs. The output of this research is a scholarly publication[1] and a series of short articles on specific issues that I published on my blog and elsewhere. I based my comments on this research.

Employer-sponsored wellness programs are at the intersection between rising healthcare costs and growing availability of fine-grained individual health data. Research continues on whether wellness programs improve health or reduce

[1] Anna Slomovic, "eHealth and Privacy in U.S. Employer Wellness Programs," *Under Observation - The Interplay between eHealth and Surveillance*, Ronald Leenes, Nadezhda Purtova, Samantha Adams (eds.), Springer, Forthcoming. Available at SSRN: http://ssrn.com/abstract=2613452

healthcare costs.[2] Regardless of the findings of this research, however, increasing employee participation in wellness programs through financial incentives and non-financial "engagement" techniques increases the amount of personal health information collected, analyzed, used and disclosed in the employment-related context. As more people participate in wellness programs, wellness vendors collect health and lifestyle data about more people and more data about each person.

I support the Commission's goal to limit wellness incentives in order to prevent economic coercion that could render involuntary the disclosure of medical information by employees and other participants in wellness programs. I believe that the approach taken by the Commission in the Proposed Rule achieves this goal in some areas. For example, I support the Commission's proposal to limit the total of all types and categories of wellness incentives to 30 percent of employee-only cost of coverage. This limit should include both health-contingent incentives and participation incentives, and it should apply to the value of financial and in-kind incentives.

I also support the Commission's proposal to prohibit employers from providing reduced health benefits or modified health benefit packages in any of their health plans for those who do not wish to participate in wellness programs. Without such prohibition employers can circumvent the incentive limit by creating "gated" plans that channel employees who refuse to participate in wellness programs into health plans with higher deductibles, fewer covered services or other restrictions.[3]

I suggest improvements to the Proposed Rule in several other areas with the goals of further protecting employees from discrimination and improving privacy protections for wellness program participants.

1. ***The EEOC should regulate all wellness programs, offered both inside and outside health plans.*** Although the Commission notes that wellness programs may be offered as part of or outside health plans, the Proposed Rule applies only to wellness programs that are part of a health plan. This leaves unregulated a number of wellness programs offered outside a health plan, even though these programs collect personal health data and use incentives in the same manner as programs that are part of a health plan. For example, some employers already offer wellness programs that tie rewards to purchasing certain types of foods or to performing a certain number of workouts at a gym or while wearing a fitness

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[2] See, for example, Soeren Mattke et al., "Workplace Wellness Programs: Services Offered, Participation and Effectiveness," Research Report RR724, RAND Corporation, Santa Monica, CA, 2014.

[3] Aon Hewitt, "Aon Hewitt Survey Shows U.S. Employers Interested in Exploring Stricter Rules Around Health Benefits and Reference-Based Pricing as Part of their Health Strategy," Press release, June 11, 2014.

tracker.[4] Such programs do not need to be offered within a health plan, but they can collect sensitive personal information about individuals and their lives outside work, and they are tied to financial incentives. Such programs need to be subject to incentive limits and offer employees privacy protections, just like programs offered as part of a health plan.

2. ***The EEOC should regulate wellness programs that do not include direct disability-related inquiries or biometric screenings.*** The Proposed Rule covers programs only if they include disability-related inquiries or biometric screenings. This approach is a mistake. It does not consider a wellness vendor's ability to discover disability-related and biometric information through the use of current and developing technology without asking program participants to provide such information or to undergo a medical exam. A wellness vendor can obtain disability-related and biometric information from health and laboratory claims provided by the employer.[5] Additionally, any wellness program that involves a fitness tracker can generate a significant amount of health-related information through the data collected by the device and associated mobile application, and through the combination of this data with data in public and private databases. Depending on the device, the collected data may include time- and location-stamped records of sleep, exercise and biometrics, as well as food, water and alcohol consumption. Some forecasting models are starting to incorporate data about household characteristics, shopping habits, social media use and other consumer attributes usually used for marketing to infer current and future health characteristics.[6] Analytic algorithms can use the combined data to derive patterns of work, exercise, leisure and sleep, and even to infer the activities that gave rise to the data.[7] Programs using analytics to derive information about health, lifestyle, and disability need to be subject to the same

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[4] See, for example, "As Health Incentives Rise, Many Get Paid To Work Out And Eat Kale," available at http://commonhealth.wbur.org/2015/02/health-incentives.

[5] See, for example, description of HealthMine Technology, available at http://www.healthmine.com/the-technology/, accessed on 31 March 2015; and authorization for the Zensey program from Audax, (now Rally Health, part of the United Health Group), available at https://www.zensey.com/corporate/hipaa.

[6] See, for example, Satish Garla et al., "What Do Your Consumer Habits Say About Your Health? Using Third-Party Data to Predict Individual Health Risk and Costs," SAS Institute, Paper 170-2013, available at https://support.sas.com/resources/papers/proceedings13/170-2013.pdf; Shannon Pettypiece and Jordan Robertson,, "Hospitals Are Mining Patients' Credit Card Data to Predict Who Will Get Sick," Bloomberg BusinessWeek, July 3, 2014, available at http://www.bloomberg.com/bw/articles/2014-07-03/hospitals-are-mining-patients-credit-card-data-to-predict-who-will-get-sick.

[7] For example, until individual user results became available in Google searches in July 2011, the activity database of the Fitbit fitness tracker included sexual activity, rated by level of effort. (Courtney Rubin, "Your Trainer Saw That: Devices Like Fitbit and Up24 Being Used by Gyms to Track Clients' Activity," *The New York Times*, April 16, 2014.)

rules as programs that make direct inquiries and perform testing directly on participants.

3. ***The Commission should strengthen employment non-discrimination protections beyond requiring disclosure of only aggregate information to the employer***. Employers have ways of gaining information about individual wellness program participants without receiving individual-level data from the wellness program. Many wearable fitness trackers are visible when worn. Security policies in some companies require the IT department to link fitness trackers to the company wellness program because only the IT department is authorized to install software or enable devices to access the corporate network. Employers can also gain information about program participants through two of the more popular wellness engagement strategies, gamification and social influencing. Gamification introduces game-like elements into non-game activities. These may include the ability to earn points and badges, progression from level to level, competitions, challenges, and quests. In wellness programs, the "games" seek to help participants maintain exercise regimens, achieve health goals or manage chronic illnesses.[8] Social influencing includes asking supervisory employees to act as wellness role models for their staff, as well as challenges or competitions between co-workers or departments. If an employee declines to participate in a wellness program or in group challenges or competitions, an employer can label him or her as not "a team player." This creates an atmosphere in which individuals feel pressure to participate or face the possibility of social and professional sanctions. Enforcing non-coercion and non-discrimination against techniques that do not involve financial incentives is difficult. Nevertheless, the Commission must make it clear that using non-financial means to induce employees to participate in wellness programs and any form of retaliation against those who decline to participate are not acceptable.

4. ***Privacy provisions within the Proposed Rule need to be significantly strengthened***. The Commission proposes that wellness programs provide notices to individuals, describing the types of medical information collected, the uses made of this information, and the entities with whom the information is shared. While such notices are an essential part of protecting the privacy of wellness program participants, they are not sufficient. Wellness programs should be subject to the full set of protections similar to those offered by the Privacy Rule under the Health Insurance Portability and Accountability Act (HIPAA), including notice, ability to obtain copies of all personal information collected as part of the program (access), ability to challenge completeness and accuracy of such information (amendment), a listing of all parties to whom such information was disclosed (accounting for disclosures), and ability to request

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[8] Wharton Business School, "From Fitbit to Fitocracy: the Rise of Healthcare Gamification," Knowledge@Wharton, January 2013, http://knowledge.wharton.upenn.edu/article/from-fitbit-to-fitocracy-the-rise-of-health-care-gamification/

confidential communication. These protections should cover all wellness data, including data collected via fitness trackers and mobile apps, and data about the level of individual's participation in a wellness program. Specifically,

a. Notices must provide sufficient information to enable individuals to understand what data is collected as part of the program and all the sources of such data, including data that is not collected directly from the individual, public data and non-health consumer data. Notices should also describe how analytic algorithms are used in combining and analyzing the data.
b. Individual rights with respect to wellness data should apply not only to employers or health insurers that sponsor the wellness program but directly to vendors that administer wellness programs. This is essential, particularly if employers receive only aggregate data.
c. Individuals should have the right to request that all their wellness data be deleted by the employer and wellness program administrator if they decide to stop participating in the program or leave their employer. De-identification of retained data is a second-best alternative, particularly in the case of genetic data.[9]
d. Wellness vendors should be required to demonstrate that they are actually basing their recommendations on the data they collect. Wellness programs should not be permitted to collect any and all data about program participants in hope that they will discover some health-related correlation in the data at some future time.

5. ***The EEOC should conduct a study by independent experts to determine whether additional protection is needed for low-income employees.*** Like the Commission, scholars who examined financial wellness incentives have been concerned about the disparate effect of such incentives on individuals at different income levels. A recent empirical study of one large employer by the Employee Benefit Research Institute (EBRI) showed that such concerns are justified.[10] The study showed that increasing the size of financial incentives increased participation in wellness programs. It also showed that employees who did not participate in the wellness program had the highest average income. The authors suggested that employers consider income when they set the size of financial incentives. The Commission should ask a group of independent experts to perform a study of the economic impact of wellness incentives on employees at various income levels and ways in which the impact can be equalized.

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[9] Researchers can no longer guarantee anonymity of genomic data. See, for example, Erika Check Hayden, "The genome hacker: Yaniv Erlich shows how research participants can be identified from 'anonymous' DNA," Nature, May 8, 2013, available at http://www.nature.com/news/privacy-protections-the-genome-hacker-1.12940.

[10] Fronstin, Paul and Roebuck, M. Christopher, "Financial Incentives and Workplace Wellness-Program Participation," Employee Benefit Research Institute, Issue Brief No. 412, March 2015.

6. ***The EEOC should strengthen the definition of wellness programs as "reasonably designed to promote health or prevent disease," e.g., by requiring them to comply with United States Preventive Services Task Force (USPSTF) recommendations or with another set of standards established by a recognized body of medical experts.*** I do not have professional expertise to comment on the content of wellness programs, but my research indicates that there is significant controversy in this area.[11] This is important because wellness program design has a privacy-related component. A loose definition of what constitutes a program that is "reasonably designed to promote health or prevent disease" leads to unlimited collection and analysis of health and lifestyle data as vendors hope to identify some correlation between behavior and health. Wellness program regulations promulgated by the Departments of Health and Human Services, Labor and Treasury exempt wellness programs from using clinical standards or scientific evidence.[12] While this exemption seeks to encourage innovation, there is evidence that it leads to overtesting, overdiagnosis and overtreatment. It certainly leads to unfettered collection of personal information by wellness vendors. In order to ensure that employees derive benefit from health and lifestyle information disclosed in wellness programs, the Commission should require these programs to demonstrate that their offerings and recommendations are based on the best available science and are regularly re-evaluated to include new or changed recommendations from recognized bodies of medical experts.

7. Comments on specific questions raised by the Commission.

- The Commission asks if an acceptable alternative to wellness program testing is providing a physician statement that medical risks are under active treatment. This approach might result in additional healthcare costs and in conflicts between employees and their physicians.[13] Nevertheless, it might be an acceptable alternative for employees who can find a physician who shares their view of health management. If offered, this alternative to wellness program testing should be limited to a certification by a physician selected by the employee. It should not be permitted to require employees or their physicians to provide medical data that would otherwise have been collected through the wellness program.
- The Commission asks if wellness incentives should be subject to limits based on health insurance affordability requirements. The regulations promulgated

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[11] See, for example John P. Caloyeras, Hangsheng Liu, Ellen Exum, Megan Broderick and Soeren Mattke, "Managing Manifest Diseases, But Not Health Risks, Saved PepsiCo Money Over Seven Years" *Health Affairs*, 33, no.1 (2014):124-131.

[12] Department of Health and Human Services, Department of the Treasury and Department of Labor, "Incentives for Nondiscriminatory Wellness Programs in Group Health Plans; Final Rule," Federal Register, Vol. 78, No. 106, pp. 33158-33192, June 3, 2013.

[13] See, for example, Matt Lamkin, "Healthcare Reform, Wellness Programs and the Erosion of Informed Consent," 101 Ky. L.J. 435 (2012-2013).

by the Internal Revenue Service already require employers to calculate affordability without assuming that employees will qualify for wellness incentives except for incentives associated with nondiscriminatory programs related to tobacco use.[14] However, the IRS regulations apply only to health-contingent incentives. The Commission can improve affordability of health insurance by bringing all wellness incentives, including participation-based incentives, within the scope of the affordability calculation.

- The Commission asks if employees should provide prior, written, and knowing confirmation that their participation in a wellness program is voluntary. I do not believe that this requirement would be a meaningful reflection of whether individual participation is, in fact, voluntary. Those who cannot afford to forego the financial wellness incentives will sign the form, whatever their real reasons for participation may be.
- The Commission asks if notice requirements should apply only to programs that offer more than *de minimis* incentives for participation. As noted above, wellness programs now use techniques, such as gamification and social influencing, that increase the number of participating employees without the use of financial incentives. These techniques induce or manipulate employees into participation in wellness programs and into providing data to these programs. Notice and all other privacy requirements should apply to all wellness programs, regardless of whether they offer financial incentives and regardless of size or type of such incentives.

I thank the Commission for the opportunity to provide these comments. I would be happy to discuss the comments or my research with Commission staff.

Respectfully submitted,

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[14] Internal Revenue Service, "Minimum Value of Eligible Employer-Sponsored Plans and Other Rules Regarding the Health Insurance Premium Tax Credit," Notice of Proposed Rulemaking, Federal Register, Vol. 78, No. 86, May 3, 2013, p. 25911.