Comments of the World Privacy Forum

To

The Equal Employment Opportunity Commission

Regarding Proposed Rule: Amendments to Regulations Under the Americans with Disabilities Act, *RIN number* 3046-AB01

Via www.regulations.gov

Bernadette Wilson, Acting Executive Officer,
Executive Secretariat,
Equal Employment Opportunity Commission,
U.S. Equal Employment Opportunity Commission,
131 M Street NE.,
Washington, DC 20507.

June 19, 2015

Re: Amendments to Regulations Under the Americans with Disabilities Act, *RIN number* 3046-AB01

The World Privacy Forum welcomes this 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.

The World Privacy Forum is a non-profit public interest research and consumer education group. We have published many research papers and policy comments focused on privacy and security issues. Much of our work explores technology and health-related privacy issues, biometrics, consent, data analytics, and many other rapidly evolving areas of privacy. You can see our publications and more information at www.worldprivacyforum.org.

I. General Comments

In general, the WPF supports the main purpose and approach of the Commission in its proposal. We see the proposal as guiding and limiting employers and protecting employees. Those are the proper objectives. Our concerns about employee wellness programs fall in several areas.

Personally identifiable information and wellness programs

First, we are concerned about the privacy of personally identifiable information collected and used in wellness programs. Much wellness information falls outside of the protections of the privacy and security rules of the Health Insurance Portability and Accountability Act (HIPAA). Much wellness program information also falls outside of the protections of other federal and state privacy laws. Individuals often erroneously think that the HIPAA rules protect the privacy of any health information, and they may let their privacy guard down as a result. This is particularly true of wellness programs, and it is a serious concern that remains unaddressed at all levels.

When wellness programs employ health and fitness (or other types of) monitoring devices manufactured and supported by independent companies, the companies may use the personal information generated in ways wholly unrelated to the wellness program. The information is typically subject to no health privacy law. Each device manufacturer or other independent vendor supporting wellness programs can have its own privacy policy, and some have no privacy policy, or have a privacy policy that offers no meaningful protections to individuals. Further, company privacy policies are typically subject to change at the whim of a company, so if a policy actually offers real privacy protections, the protections can disappear at any time and often without notice.[1]

There are many examples of health and fitness monitoring devices that allow for information sharing at a variety of levels, from APIs to aggregate sharing to "check box" consent for use of the data in human subject-related research to use for predictive analytics about individual consumers or groups of consumers.[2] Wellness plan executives who allow unfettered data sharing

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[1] The problem of material retroactive changes in privacy policies has been analyzed at length by the FTC. *In The Matter of Gateway, Corp.* was an important FTC case in this regard. See https://www.ftc.gov/enforcement/cases-proceedings/042-3047/gateway-learning-corp-matter. See also: https://www.ftc.gov/news-events/press-releases/2004/07/gateway-learning-settles-ftc-privacy-charges. The issue of material changes to privacy policies is also relevant in the area of mergers, which is relevant to the nascent fitness and health device market, which we expect to undergo much change in the next five to ten years. See FTC, Mergers and policy changes: https://www.ftc.gov/news-events/blogs/business-blog/2015/03/mergers-privacy-promises.

[2] "The New World of Health Sensors" is a video WPF prepared for a 2015 presentation at the Georgia Technology Institute. It provides a helpful overview of fitness devices, biosensors, and device trends. The video reviews the newest devices released at the 2015 Consumer Electronics Show, and is available online: https://www.worldprivacyforum.org/2015/03/video-the-new-world-of-health-sensors/. Additionally, WPF has a broader health technology video series exploring other fitness and health

and secondary use of consumer data may not fully understand the extent to which identifiable – or re-identifiable – data about individual consumers may be entering the secondary marketplace.

Device manufacturers are not the only merchants in the wellness arena that may exploit personal information. Wellness program operators may do the same. We are not aware of any privacy best practices for wellness activities. In fact, the business proposition of wellness vendors often depends on collecting, combining and analyzing data from many sources — ranging from health claims to detailed geo-location data to records of grocery purchases. Employers may not be sufficiently motivated to control secondary uses of wellness information about their employees, and the employees have no leverage, even if they understand how a wellness program many use or misuse employee data.

The result is that personally identifiable information that starts out as part of a wellness program may become input to American marketers, database companies, and other data profilers. Worse, the consequences of marketing uses of health information are likely to work at cross-purposes with the goals of wellness programs. When marketers identify individuals who are overweight, diseased, or have unhealthy habits, the marketers will be armed with the information to selectively target and sell vulnerable individuals a variety of goods and services.[3]

Regrettably, we now know that not all companies are good actors. Due to a profound lack of regulatory control in this area, we have learned through a variety of FTC enforcement actions, reports, and other research – including our own -- that marketers can and do sell dubious remedies[4] and in some cases, additional opportunities to engage in unhealthy habits.[5] Even if wellness programs first aggregate or de-identify personally identifiable information from wellness programs, the use of that information to target ads and services will have the same negative health effects as ads based on identifiable data.

For more on commercial uses of personal information, we direct you to the WPF report titled *The Scoring of America: How Secret Consumer Scores Threaten Your Privacy and Your Future*. The report, which has been cited by the White House Big Data report among others,[6] documents how marketers, profilers, and advertisers collect personal data from an increasing number of

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technology devices that may be helpful: https://www.worldprivacyforum.org/category/video-health-tech-series/.

[3] WPF has written and testified extensively about data broker activities in regards to health data. See, for example, our Congressional testimony on data brokers: (2013) http://www.commerce.senate.gov/public/?a=Files.Serve&File_id=e290bd4e-66e4-42ad-94c5-fcd4f9987781. See also: (2011) http://www.worldprivacyforum.org/wp-content/uploads/2011/10/PamDixonConsumerExpectationTestimonyfsshort.pdf. See also: (2009) http://www.worldprivacyforum.org/wp-content/uploads/2009/11/TestimonyofPamDixonfs.pdf.

[4] For a list of FTC enforcement actions against companies engaging in fraudulent and deceptive activities around weight loss products, services, or marketing, see: https://www.ftc.gov/search/site/marketing%20of%20weight%20remedies.

[5] See supra note 3.

[6] *Big Data: Seizing Opportunities, Preserving Value*. Executive Office of the President, May 2014. Available at: https://www.whitehouse.gov/sites/default/files/docs/big_data_privacy_report_5.1.14_final_print.pdf.

available sources and use that data to make decisions about and present offers, goods, and services to individuals. The information may affect individual lives and opportunities in many meaningful ways, most of them totally opaque to the individuals. Marketers especially prize health data. Increasing revenues is the priority of marketers, not increasing the health of those who receive offers and advertising. The WPF report is available at https://www.worldprivacyforum.org/2014/04/wpf-report-the-scoring-of-america-how-secret-consumer-scores-threaten-your-privacy-and-your-future/.

Potential for conflicts within families / Genetic information

Second, wellness programs have the potential to create conflicts within families. If programs demand that family members covered by a worker's health insurance comply with testing, monitoring, or lifestyle requirements, the result is likely to be new tensions within a family. Individuals required to comply with demands from a spouse's wellness program may be unhappy about the obligations or the sharing of information necessary to justify an exception. If requirements extend to children, teenagers may be unwilling to cooperate with their parents. College students, especially those living away from home, may not comply with the demands made by the wellness program of a parent's employer.

Other types of conflicts may arise when a marriage is under stress; spouses could be living under a separation agreement; or a family could be experiencing domestic violence. Given the complexities of families, wellness programs could very well exacerbate existing tensions within families and undermine rather than improve health. We believe that the problem of family conflicts resulting from wellness programs is a subject that needs more study and attention.

We note that many different conflicts can arise over the collection and use of genetic information, and these have long been the subject of debate in the genetics community and elsewhere. We note that the Commission has promised a rulemaking (footnote 3 in the notice) on the extent to which Title II of the Genetic Information Nondiscrimination Act of 2008 affects an employer's ability to condition incentives on a family member's participation in a wellness program.

We hope the Commission will consider the various work, family, and other conflicts resulting from increased use of genetic information in wellness programs as part of this rulemaking. We also urge the Commission to include in its rulemaking specific consideration of rare and orphan diseases that are genetically linked. Rare and orphan diseases in this category present special problems to policy holders and their family members.[7]

Fairness and due process

Third, we wonder whether wellness programs can be efficiently administered in a way that assures fairness and due process to individuals. A certain percentage of individuals will be

[7] For more about this topic, as well as additional statistics, see NORD, National Organization for Rare Disorders http://rarediseases.org. See also the Rare Action Network information at the same URL. See also HHS, Office of Rare Diseases Research https://rarediseases.info.nih.gov . See in particular GARD, Genetic and Rare Disease Information Center: https://rarediseases.info.nih.gov/gard.

unable to meet wellness program requirements for valid reasons such as pregnancy, disability, allergy, temporary illness, family emergencies, or travel. When an individual is unable to meet program requirements for medical reasons, wellness programs must provide an alternative. Proving the excuse for non-involvement may be cumbersome, expensive, and disputatious.

We note that individuals with orphan and rare diseases -- and 30 million of these individuals exist -- may well have conditions which are diagnosed, but incurable.[8] These individuals, particularly spouses of policy holders, may not wish to disclose these conditions to a plan or wellness program, particularly when viable treatments do not exist. Yet these same individuals may not be able to participate in the wellness program due to disabilities introduced by the illness. This puts individuals in a terrible position where having to prove medical reasons for non-involvement offers only downsides for them.

We note that the requirement for a wellness program to provide an alternative does not apply to those who cannot participate for non-medical reasons. Individuals facing penalties (and it does not matter whether the consequences are positive or negative) must have rights to present the reasons they did not comply with program standards. In some cases, obtaining a doctor's letter may require an office visit, adding to the cost of health care. In other cases, explaining a reason for non-participation may require an individual to reveal additional personal information about the individual or another person, such as an elderly parent or a child.

Convincing wellness program staff (who may not be health care professionals) to accept valid excuses will be a burden for employees, raise health care costs, and produce unfair results some of the time. We offer a suggestion later in these comments for addressing fairness issues.

Factual evidence of wellness program efficacy

Fourth, we have doubts that wellness programs are, in fact, cost-effective measures that actually improve the health of employees and their families or that meaningfully lower health care costs. We note the controversy, which is beyond our area of expertise to address. However, given the dispute as well as the negative privacy, fairness, and other consequences of wellness programs, we suggest that **each** wellness program must clearly demonstrate significant value. Obviously, wellness programs are in place and authorized by law today, but we suggest that the policy, facts, and science supporting wellness programs need regular reexamination to retest the premises of the programs with current facts.

We recommend that the EEOC reopen its inquiry into wellness programs in four years and collect new data to determine if the elements of wellness programs rely on valid clinical evidence demonstrating effectiveness. We do not intend this recommendation to be an impediment to adoption of the current proposal. The EEOC should plan to require that wellness programs place evidence on the public record so that others have an opportunity to review and question that evidence.

II. Specific Comments

[8] See supra note 7.

Following, we offer specific comments on elements of the Commission's proposal.

Notice, Secondary Use, and Fair Information Practices

We strongly support the proposed requirement that "an employer must provide a notice that clearly explains what medical information will be obtained, who will receive the medical information, how the medical information will be used, the restrictions on its disclosure, and the methods the covered entity will employ to prevent improper disclosure of the medical information."

We observe, however, that the notion of "medical information" may not be clear in all circumstances. For example, is the number of steps walked "medical information?" Some data collected through or used in wellness programs will not be "medical information" (e.g., home address). Trying to set a national definition of "medical information" will prove onerous. Under HIPAA, **all data held by a covered entity is protected health information, no matter the nature of the information**. **The same policy should apply to wellness programs.**

We urge the EEOC to avoid ambiguities by subjecting *all* wellness information to HIPAA standards and Fair Information Practices, and not just "medical information." If allowed to stand, the proposed "medical information" language opens enough definitional uncertainty so as to weaken privacy over the course of time, potentially significantly. We note that other industry bodies trying to define "medical information" outside of HIPAA have defined health information down to the narrowest of nubs over time, which has had impacts on consumer privacy in the advertising and marketing sector.[9]

We ask that the Commission **expressly require** that an employer's notice identify as specifically as possible:

> a) Each third party who obtains personally identifiable information in connection with a wellness program;
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> b) the uses and disclosures that the third party can make of the information for wellness program activities; and

[9] See for example, two self-regulatory codes. First, the Digital Advertising Alliance's definition of medical/health information in its self-regulatory guidelines: http://www.aboutads.info/resource/download/OBA%20Self-Reg%20Implementation%20Guide%20-%20Full%20Text.pdf. See also the IAB definition in its self-regulatory code, which is although stronger than the DAA definition is still very narrow: http://www.networkadvertising.org/sites/default/files/NAI_Code15encr.pdf. These two self-regulatory codes, which have been deeply discussed by industry participants for years now, are indicative of the challenges of defining medical information held outside of HIPAA, and of the challenges of putting forward a generalized phrase relating to medical information without specific definitional boundaries that align with HIPAA. The need for definitional alignment with HIPAA is especially important for wellness programs and associated vendors.

c) any uses and disclosures that the third party can make of the information for activities unrelated to wellness programs.

Beyond the requirements for notice, we also ask that the Commission require employers to give employees a say about any non-wellness uses and disclosures of the data gathered through or used for the wellness program.

The best outcome would be a rule that all non-program uses and disclosures require the informed and affirmative consent of each affected individual, including spouses and children who can lawfully have a say in their own health care.

A second choice would provide each individual with the opportunity to decline any or all uses and disclosures of data gathered through or for the wellness program (an opt-out). The EEOC should not allow any employer or wellness program to penalize any individual for declining to allow the use or disclosure of wellness data.

Providing notice of practices is just a beginning of what must be done to address privacy – and providing notice without providing agency for individuals is a de minimus action. Data uses and other Fair Information Practices also need to be addressed. Notice does not address any use, and notice is just one element of Fair Information Practices (FIPs).

FIPs are a set of internationally recognized practices for addressing the privacy of information about individuals. FIPs provide the underlying policy for many national laws addressing privacy and data protection matters, including the HIPAA health privacy rule and the Privacy Act of 1974. See Robert Gellman, *Fair Information Practices: A Basic History*, http://bobgellman.com/rg-docs/rg-FIPshistory.pdf for a discussion of FIPs. Protecting privacy means that all wellness programs address each of the eight FIPs elements as a baseline set of privacy protections.

Anyone who processes personal information about individuals for wellness programs should be required to provide agency regarding secondary data use and comply with FIPs. In addition to notice, there should be appropriate limits on the collection of personal information, data quality requirements, specification of the purpose for the collection of personal information, limits on the use of the information, reasonable security measures, individual rights of access and the ability to seek correction of records, and accountability for record keepers. The Commission should mandate compliance with FIPs as well a privacy policies for each organization that plays a role in a wellness program and processes personal information in any way.

We reiterate our support for robust notice. But we also urge the Commission that all non-program uses and disclosures also require the informed and affirmative consent of each affected individual, including spouses and children who can lawfully have a say in their own health care. A second choice would provide each individual with the opportunity to decline any or all uses and disclosures of data gathered through or for the wellness program (an opt-out).

Aggregation and De-identification

The WPF strongly supports the proposal that the disclosure of medical information obtained by wellness programs to employers only in aggregate form, except as needed to administer the health plan. We also support using the de-identification standards in the HIPAA health privacy rule, at least until a better set of standards is available. The HIPAA health privacy rule treats information as de-identified upon removal or generalization of specified data elements.

The HIPAA rule also allows reliance on an expert determination that the "risk is very small that the information could be used, alone or in combination with other reasonably available information." We ask that the Commission specify that when an employer relies on an expert determination, the expert must be entirely independent from the employer and from any of the companies that collect, maintain, or use wellness program data.

We worry about the possibility that a company will rely on a captive or hired-gun "expert" who will provide the opinion that the company seeks. The HIPAA "expert" option is insufficient because it fails to specify the credentials that an expert must have, and it fails to require independence from the expert. The Commission can cure those defects in its rule.

Voluntariness

We agree with the Commission's concerns that wellness programs may not be truly voluntary. Requiring the collection of participation authorizations is likely to do little to help if financial incentives leave individuals little choice. For low-income or even individuals with incomes qualifying as mid-level income levels, any penalty that increases out-of-pocket costs or reduces income in any way will render any wellness activity not truly voluntary. A well-paid corporate executive may be able to afford paying more for health insurance, but individuals who live from paycheck to paycheck or who have high housing costs or educational or other debt do not have that luxury.

We support the Commission's proposal to include participation-based incentives in the 30 percent overall limit on wellness incentives. Additionally, we believe that incentives for participation in wellness program should only be positive ones. Commission rules should ban negative incentives that impose additional costs on non-participating employees. If all incentives are positive, then the problem of offering incentives to employees who cannot participate in wellness programs for medical (or religious!) reasons is a smaller concern. If incentives are positive only, then the problem of determining the affordability of health insurance diminishes as a concern.

Burden of proof

The Commission asks for best practices that ensure that wellness programs do not shift costs to employees with health impairments or stigmatized conditions. One way to accomplish this is to require that programs must accept any reasonable statement of an employee about the employee's inability to participate. At that point, the burden of proof should shift to the employer

or wellness program to disprove the employee's assertion. This is a better policy structure than shifting burden of proof to employees.

If the burden of proof falls entirely on the employee, any wellness program can simply refuse to accept the employee's evidence and demand additional evidence, statements from more doctors, or anything at all. This could lead to very unfortunate privacy consequences, as well as social consequences. It is also generally an unfair practice to place all burden entirely on the employee. We observe that if a single employee feels mistreated and chooses to file a lawsuit about the fairness of an employer's program, the costs of the lawsuit could wipe out most or all of the potential cost savings that may result from a wellness program.

Other types of wellness programs

The Commission asks "whether employers offer (or are likely to offer in the future) wellness programs outside of a group health plan or group health insurance coverage that use incentives to promote participation in such programs or to encourage employees to achieve certain health outcomes and the extent to which the ADA regulations should limit incentives provided as part of such programs."

We want to emphasize that all employer wellness programs regardless of relationship to a health plan and regardless of technologies used to enable that wellness plan should be subject to the same set of rules and a single overall incentive limit. From the perspective of an employee, the concerns about coercion, privacy, and unfairness are exactly the same, regardless of type of program and regardless whether a program is part of or outside a health plan. Having a sound fairness structure in place is important, because the technology for wellness monitoring – and the market for that technology – is substantial and increasing.

The rise of the use of fitness and health monitoring and tracking devices is well-documented,[10] with wellness programs seen as the main driver for fitness tracker adoption.[11] The range of current wearable devices includes everything from EEG headbands to devices that monitor diabetes and heart disease to fitness trackers, mobile phones, wearable patches, and sensor-enriched clothing. An important study on wearable sensors and their relationship to wellness programs found that wellness programs will become the "key drivers" of wearables at work, and that wearables will become part of the everyday workflow by 2020.[12] Wearables are set to

[10] See: *Wearable Technology Market Forecast 2015-2020*, 2015, Visiongain. https://www.visiongain.com/Report/1421/Wearable-Technology-Market-Forecast-2015-2020.

[11] See: *Digitally Fit: Products and Services for Connected Consumers*, Parks Associates, 2015. http://www.parksassociates.com/marketfocus/dh-1q-2015. See also Tractica, *Wearable Devices for Enterprise and Industrial Markets, Corporate Wellness, Manufacturing, Warehouse, Field Maintenance, Mobile Workforce Management, First Person Communications, Holographic Modeling, Workplace Authentication, and Other Applications*. 2015. https://www.tractica.com/research/wearable-devices-for-enterprise-and-industrial-markets/.

[12] Tractica, *Wearable Devices for Enterprise and Industrial Markets, Corporate Wellness, Manufacturing, Warehouse, Field Maintenance, Mobile Workforce Management, First Person Communications, Holographic Modeling, Workplace Authentication, and Other Applications*. 2015. https://www.tractica.com/research/wearable-devices-for-enterprise-and-industrial-markets/. See also

increase in use in the next five years.[13] Much research exists in this area, and it would be helpful for the Commission to consider how these technologies may impact wellness programs that exist both as part of health plans and as independent programs.

While currently, many wellness programs use single monitoring devices, like a step counter, looking ahead, we anticipate that multiple wearable devices and sophisticated sensors will be integrated across domains of individuals' lives, and even embedded in the clothing worn. For this reason, we urge the Commission to think beyond the use of single health tracking devices in considering policy and to consider the role and impact of *multiple* connected devices as well as the impact of the Internet of Things (IoT) platforms on wellness programs.

The IoT promises to connect sensors to smartphones to smart homes to smart cars and other sensor-rich items such as health and fitness monitoring devices. The IoT is set to become a way that health monitoring can be seamlessly integrated into an individual's daily life, and fitness and health-related wearables as part of this equation are forecast to grow substantially, driven in part -- some research indicates driven largely -- by wellness programs.[14] As the IoT rolls out, wellness programs could be expanded in both the scope and precision of tracking. It is reasonable to forecast that some wellness programs tied to IoT platforms will develop both as part of health plans and independently of health plans.[15]

III. Conclusion

Thank you for the opportunity to comment on these issues of vital importance to individuals. The WPF is grateful for the opportunity to submit these comments on the Commission's proposal, and we welcome the opportunity to discuss these comments with the Commission and work with the Commission further on these issues.

Caroline Wall, *Wearables to be part of everyday workflow by 2020* . FierceMobileIT, May 22, 2015. See also Michele Chandler,

[13] A broader study of wearables (not in strict relation to wellness plans) estimated connected fitness trackers will account for $5.4 billion in revenue by 2019. Wearables accounted for about $2 billion in 2014. See: *Digitally Fit: Products and Services for Connected Consumers*, Parks Associates, 2015. http://www.parksassociates.com/marketfocus/dh-1q-2015. See also Tractica study, supra note 14. See also: Judy Mottl, *Study: Wearable patch market holds promise, but challenges must be addressed*. FierceMobileHealthCare, May 28, 2015 for additional discussion.

[14] Tractica, *Wearable Devices for Enterprise and Industrial Markets, Corporate Wellness, Manufacturing, Warehouse, Field Maintenance, Mobile Workforce Management*, *First Person Communications, Holographic Modeling, Workplace Authentication, and Other Applications*. 2015. https://www.tractica.com/research/wearable-devices-for-enterprise-and-industrial-markets/.

[15] Althought it is beyond the scope of these comments to discuss specific IoT platforms, many examples exist. See for example, Tome Inc. http://tomesoftware.com. See also Tom Henderson, *Tech projects take Tome Inc. from seed to flourishing*, Crain's Detroit Business, April 20, 2015. See also Michele Chandler, *Wearables in Workplace seen on rise Apple, Google in the mix,* Investor's Business Daily, April 9, 2015.

Respectfully submitted,

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