Health and Big Data: An Ethical Framework for Health Information Collection by Corporate Wellness Programs

Ifeoma Ajunwa, Kate Crawford, and Joel S. Ford

Within the last decade, workplace wellness programs have experienced a resurgence. Unlike in the recent scientific management era, when business contemplated achieving efficiency through mastery of the job task by breaking it down into small parts that might be studied, workplace wellness programs represent the idea that efficiency in business lies in the health of the individual worker. Healthier workers mean fewer sick days and lower healthcare costs for the firm. The pendulum of organization science has now swung from mastering the job to managing the worker's mental attitude via for example, team-building exercises, and now, to mastering the worker's physical body via wellness programs. This swing correlates with a renewed American focus on public health[1] and on prevention rather than treatment.[2] While the wellness programs of today do not represent a novel phenomenon, wellness programs in the age of big data present new challenges in terms of the capture, use, and storage of the health data from workers. The increasing corporate embrace of Big Data technologies as a matter of business procedure places wellness programs squarely in the middle of new ethical quagmires when it comes to the handling of worker's health information.

Consider a recent *Wall Street Journal* news article regarding how employers, with the aid of wellness program vendors, are harnessing the power of Big Data to determine which employees might develop serious illnesses or which female workers might get pregnant. For example, the retail giant Walmart employs wellness program vendors like Castlight Healthcare, Inc. to collect employee data and use them to identify, "for example, which workers are at risk for diabetes, and target them with personalized messages nudging them toward a doctor or services such as weight-loss programs." Companies like Castlight are also now able to discover, for the benefit of a corporate client, which, and how many, female employees might be pregnant.

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Castlight's method is to mine the Big Data on insurance claims to find women who have stopped using birth control. Castlight is also able to discover which women have made fertility-related searches on Castlight's health app, a resource the worker has downloaded as part of the wellness program. That data is matched with the woman's age, and if applicable, the ages of her children to compute the likelihood of an impending pregnancy, says Jonathan Rende, Castlight's chief research and development officer. The targeted employee would then start receiving emails or in-app messages with tips for choosing an obstetrician or other prenatal care. If the algorithm guessed wrong, she could opt out of receiving similar messages.[3] It is not surprising that some employees might find these activities imbued with a "Big Brotherish" tinge. Indeed workplace wellness programs in America enjoy the protection of the state.

Generally, the term, "Wellness Program" describes "any program designed to promote health or prevent disease."[4] While the origin story of these programs reflect cost-saving tactics employed by life insurance companies, early workplace wellness programs, known as Employee Assistance Programs, were promoted as benevolent programs for employees to receive assistance dealing with issues regarding mental health, substance abuse, and stress.[5] Wellness Programs have since evolved to offer health risk assessment, weight reduction and smoking cessation programs, and to promote healthful behavior in the workplace.[6] Wellness programs may vary widely in terms of their application. For example, one program may require that employees undergo a "health risk assessment," including screening for risk factors such as high cholesterol and high blood pressure. Another program may require that employees collaborate with advisors who create and monitor fitness plans on the employee's behalf.[7] While most of those programs are voluntary, some scholars have expressed some concern about the incentives (and penalties tied to these programs) and about the fact that some employers are now making these programs mandatory.[8]

Workplace wellness programs comprise a $6 billion annual industry. There are an estimated 500 vendors selling programs either individually or as an optional component of healthcare insurance. These workplace programs have an impact on a great number of U.S. residents, because more than 60 percent of residents in the United States receive health insurance coverage through an employer-provided plan.[9] Although the concept of "wellness" as an achievable status was introduced by Dr. Halbert L. Dunn in the 1950s, the modern concept of wellness as an organizational goal gained a foothold in corporate America starting in the 1970s.[10]

The 1970s saw the government start to take an active interest in promoting wellness via the workplace. The President's Committee on Health Education was established in 1973 and, in addition to other acts, this committee legitimized an emphasis on health and health education and a more hands-on role for government in developing model programs and providing seed money for their implementation. It recommended, for example, creation of a National Center for Health Education, which was instituted in 1975. The Center successfully pushed for expanded worksite programming as well as nation-wide programming, professional credentialing, and comprehensive school health education programs.

In 1979, *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention*, and the 1980 report entitled *Promoting Health, Preventing Disease: Objectives for the Nation* were instrumental in promoting the idea of wellness as a national goal. In 1980, the U.S. Government also created a separate Department of Education in the Department of Health and Human Services and gave the former responsibility for supporting health education, health promotion, and wellness programming. In 1981, *Objectives for the Nation in Disease Prevention and Health Promotion* was adopted as policy in the United States and again in 2001, with new goals established. The subsequent publication of *Healthy People 2010* has also aided in tilting public policy toward prevention through health education and health promotion programming in communities.

The idea of the government as a "residual guarantor" is one that has taken root in American society albeit in a limited manner. This concept is found in literature written by the government to explain its stance on health promotion in communities.[11] Whereas in socialist countries the government directly seeks to play a role in health outcomes, in the United States, the government feels compelled to recruit the private sector to facilitate the achievement of the government's overall health goals.[12] As a consequence of this belief in governmental paternalism when it comes to health,[13] the Obama Administration supports wellness programs officially through the *Patient Protection and Affordable Care Act*, also known as, the "Affordable Care Act."[14] The Act includes several provisions designed to promote wellness programs. Notably, it provides start-up grants to small firms; establishes a "10-state demonstration program on rewards for wellness program participation in the individual market; and assigns a technical assistance role for the Centers for Disease Control and Prevention."[15] An important

consequence of the ACA is that employers are granted greater discretion in regards to what rewards may be offered for joining wellness programs.[16] For example, as of 2014, the ACA, "raises the maximum incentive to employees for achieving health related standards, such as reaching a target weight, to 30 percent of the cost of their insurance coverage."[17] The ACA already allows up to 50 percent of the cost of the insurance coverage to be offered to individuals as an incentive for smoking cessation.[18]

(penalties), and which could take the form of modified premiums, smaller copays or deductibles, cash, gift cards, or merchandise.[26] Participation in wellness programs garnered a record award of $693 per employee, on average, in 2015 from $594 in 2014 and $430 five years ago.[27] Larger firms are, not surprisingly, more likely to give even bigger incentives, for example, companies with more than 20,000 employees are offering an average of $878 this year to entice workers to participate in wellness programs. In contrast, organizations

In this paper, we argue for a focus on the data collection, storage, and usage that is an important part of wellness programs, and we provide an ethical framework for employers, through the wellness program vendors they employ, to collect, store, and manage health data collected from employees. This ethical framework addresses three key areas of concern when it comes to health data collection from employees and its Big Data implications: (1) informed consent to collect the data; (2) data handling; and (3) employment discrimination concerns.

Wellness programs are not a passing fad. Rather, they appear to be rapidly entrenching themselves in the corporate space. Approximately half to two-thirds of U.S. employers offer some kind of wellness program.[19] Ninety-nine percent of large firms (with 200 or more workers) in 2013 offered at least one wellness program. Specifically, 69 percent offer gym membership discounts or on-site gyms, 71 percent offer smoking cessation programs, and 58 percent offer weight-loss programs. Among these firms, 36 percent offer some financial incentive to participate in wellness programs.[20] The most common objectives of wellness programs are smoking cessation and weight loss or the related behaviors of nutrition and fitness.[21] The amount of the incentives ranges from 3 to 11 percent of the total cost of individual coverage.[22] The use of these programs is likely to expand; 25 percent of employers report that one of the top areas of focus for their health care strategy was "[a]dopting or expanding the use of financial incentives to encourage healthy behaviors."[23]

As wellness programs are becoming increasingly marketed to the consumer as a work benefit, many researchers have turned a critical eye on the limitations of workplace wellness programs[24] and also their potential for privacy violations.[25] For example, past research has focused on the use of incentives which may be characterized as carrots (rewards) or sticks with 5,000 to 20,000 workers are offering $661, but still an increase from $493 in 2014.[28]

While some legal scholars question "whether these incentives cloud the asymmetrical power relationship between the employer and the employee"[29] and have raised the question of whether "the employee is being called upon to relinquish valuable and sensitive health information for a mere pittance in the form of premium reductions,"[30] we must also critically evaluate how the technological advances in Big Data acquisition and uses impact the health data collection that is an integral part of workplace wellness programs.

In this paper, we argue for a focus on the data collection, storage, and usage that is an important part of wellness programs, and we provide an ethical framework for employers, through the wellness program vendors they employ, to collect, store, and manage health data collected from employees. This ethical framework addresses three key areas of concern when it comes to health data collection from employees and its Big Data implications: (1) informed consent to collect the data; (2) data handling; and (3) employment discrimination concerns.

Informed Consent

Legal scholars have noted that "[t]he roots of informed consent doctrine lie in privacy theory, in three pertinent areas: the right to informational privacy, the right

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to bodily integrity, and the right to informed decision making."[31] Whereas, traditionally, doctors were solely concerned about acquiring informed consent "in the context of significantly invasive procedures,"[32] the collection of data from wellness programs, while not always physically invasive, nonetheless, holds such potential for privacy invasions that, ethically, workers should be informed of those potential hazards in order to obtain their informed consent for the collection of that data. Several legal cases have shown that the health data of employees has the potential to cause harm when wrongfully disclosed.[33] And the fact remains that health data breaches have become so ubiquitous as to become an unremarkable occurrence in the health care industry.[34] Furthermore, previous scholars have called into question, "the voluntariness of participation in wellness programs, the value of the testing being offered, and the appropriateness of wellness vendors exploiting the information they collect."[35]

The question that remains: What is the proper framework for acquiring informed consent to enroll employees in wellness programs? First and foremost, employees must be made fully aware of all potential benefits and disadvantages of joining a wellness program, including not just health effects but also privacy risks. As a consequence of their experience with doctors' offices and hospitals, some employees may wrongly assume that the Health Information Portability and Accountability Act (HIPAA) protects all health information, including those collected by wellness program vendors. While it is fact that HIPAA applies to healthcare providers, which include hospitals, doctors' offices, and insurance companies, it is not settled law that wellness program vendors meet the definition of healthcare provider. This means that whether wellness programs fall under HIPAA's jurisdiction is still an open debate. Given the issue of the liminality of health information collected by wellness programs, employees should be made aware that their personal health information, as collected by wellness program vendors, may not enjoy the protections afforded by HIPAA, such as confidentiality attached to the information and the worker's right to demand a copy of the information and to direct how said information may be used.

Second, the employee should be informed as to the scientific evidence underpinning the health imperatives being suggested by the wellness program. Currently, wellness programs are not subject to regulation by any government or licensing body such as the Department of Health or the American Medical Association (AMA), and there is no requirement that board-certified doctors who are well versed in scientific research on weight-loss, nutrition, or smoking cessation oversee these programs. Yet, many wellness programs provide directives to enrollees as to nutrition, weight-loss techniques, and also smoking cessation, etc. It is important to convey to the participant employee that the information being provided by the wellness program is not medical information and should not be treated as such. Consider the fact that some wellness programs employ Body Mass Index (BMI) as a measure of obesity and health risk. BMI as a measure of obesity has fallen out of favor in the medical field as BMI employs only two indices (height and weight) and does not differentiate between different types of mass, that is, muscle versus fat.[36] Thus, a more muscular individual may read as obese in comparison to another individual that has less mass but more fat composition. Furthermore, BMI does not account for the distribution of body fat, and this is problematic because different kinds of fat, for example, visceral fat found around the waistline, contribute more to obesity-related diseases than other types of fat.[37] Thus, new medical research suggests that BMI might not be an accurate measure of obesity and thus cannot be used to predict risk of obesity related diseases.[38] Given that wellness-program vendors may not have the most current information on medical research, obesity or weight-loss, it is important to stress to employees that any information they receive from wellness programs should not supersede the medical advice of their physicians.

Besides the accuracy and efficacy of the information being provided by wellness programs, another issue is the accuracy of the data being collected by the wellness programs, particularly via the use of wearable electronic devices and gadgets. Research on the functioning of wearable electronics indicate irregularities in the data being collected and that wearable devices are unreliable in, for example, accurately capturing the amount and intensity of physical activity.[39] A lack of education as to the limitations of wearable technologies would belie informed consent, particularly as the participant employee comes to rely on the wearable technology as a representation of activity levels.

Data Collection and Control

In the age of Big Data, joining a wellness program is less akin to a confidential visit to your family doctor than it is joining public social media, precisely because of the potential for porous flow of information through those programs. Wellness programs collect significant amounts of personal health information from the employees; in fact, because wellness programs enjoy the support of the government, the programs are enabled to collect such information as family medical histories and even to conduct genetic test-

ing information without running afoul of federal laws such as the Americans with Disabilities Act (ADA) and the Genetic Information Non-Discrimination Act (GINA). As highlighted by the case of Castlight, the type of data that a wellness program is enabled to collect can seem boundless; the current state of the law is such that there is no check against wellness programs trawling for health information that the employee has not volunteered.

The personal health information (PHI) that has been collected by wellness programs represents lucrative data. This information may be sold to pharmaceutical companies interested in developing drugs, or to data brokers to be used in creating various types of lists, including ones reflecting credit risk.[40] Thus, an important part of an ethical workplace wellness program is transparency concerning data collection, storage, and also data ownership. Would-be participant employees should be apprised of issues of data management and should also be informed about steps taken to safeguard the data. As health data security has been dubbed "the Wild West" and as the healthcare sector organizations increasingly experience data breaches, workers should be informed of the limits of data security and the potential harms that could arise from the wrongful or inadvertent disclosure of their data.

An ethical wellness program is one that clarifies that the employee retains ownership of the data entrusted to the program.

Another issue that arises from the collection of data in wellness programs is the matter of who controls the data. Many wellness programs employ electronic wearable fitness devices, and if these devices are owned by the employer, then any data collected from them may legally also be the property of employer. But even beyond that, the law is not well settled that employees own and can control the usage of the data that are collected as part of wellness programs.[41] Thus, an employee might find that a Personal Health Information (PHI) file shared with an employer's wellness program continues to live on, long after the employee has left the firm. Or, such information could be sold (in ostensibly anonymized form) to entities far outside the realm of the employee's contemplation when the file was created. For the employee, joining a wellness program is an act of trust, an act of investment in betterment of health. Most employees would not foresee that there PHI would serve ends other than helping them better their health and that the data they share with wellness programs might be traded or used in ways that benefit the wellness program vendors more than it benefits the employee. Yet, investigations have confirmed that wellness vendors do frequently sell the data entrusted to them by employee participants.[42]

An ethical wellness program is one that clarifies that the employee retains control of the data entrusted to the program. Such a program would also obtain the informed consent of the employee for any usage of the data that falls outside of the stated purposes of the wellness program. An ethical wellness program would recognize the employee's right to request the evaluation of data that the wellness program has collected regarding the individual and the program would provide opportunities to correct any misinformation. Furthermore, we believe that ethical business conduct requires that wellness programs affirm the employee's right to effectuate the deletion of their personal health information data from the wellness program records once the employee is no longer employed at the workplace.

Potential for Employment Discrimination

We must not overlook the fact that the types of personal information collected by wellness programs have the potential to be wielded for the purposes of employment discrimination. Consider that the data collected by wellness programs may reveal employees that are likely to represent higher healthcare costs for the employer. Thus, there is the temptation for the thrifty employer to deputize wellness programs as surveillance systems that would root out "costly" employees, who could then be targeted for termination.[43] Note that many wellness programs focus on weight loss and smoking cessation. Note also that, generally, obesity and smoker status are not protected categories under employment anti-discrimination laws.[44] In fact, some legal scholars have detailed how obesity as an unprotected status leaves an individual vulnerable to harassment, shaming, and even termination from work.[45] Similarly, workers who are smokers often face shaming and job insecurity.[46]

Thus, an ethical wellness program is one that maintains an impenetrable barrier between the information it collects and the employer. Furthermore, any information shared with the employer should be in the form of aggregated statistics and should be anonymized in order to prevent the individual employee from being targeted for discrimination. It is unethical for a wellness program to share health information

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that employees have entrusted to it, knowing full well that such information could place the employees' jobs in jeopardy.

Given these concerns, we have developed a model for an ethical workplace wellness program that includes ten core promises that an ethical wellness program should adopt and that also advises innovative approaches to wellness that corporations should consider.

A Model for an Ethical Workplace Wellness Program

Core Promises

1. Commit to accountability in data collection and use.
2. Guarantee no penalty for non-participation.
3. Adopt gold standard practices for data security.
4. Provide awareness of discriminatory potential of data.
5. Allow for portability of data by employee.
6. Minimize data lifespan to the period of employee participation.
7. Disclose to employees that collected health information may not fall under the protection of HIPAA.
8. Guarantee that all health recommendations are backed by peer-reviewed research that is provided to the employee.
9. Provide clear information about the irregularities and unreliability of data from wearable electronic devices.
10. Inform employees about the potential of the data to be used as evidence in court.

We also think it behooves corporations to consider whether and how wellness programs can truly achieve the healthcare cost reductions they are seeking. For one, research suggests that employees are more willing to join and persist in programs that allow them some ownership in its design and direction. For example, research has shown that stress from work (and not necessarily solely lifestyle factors such as diet and exercise) can contribute to the ill-health of the employee. Such work stress can flow from workplace harassment, bullying, or the microagressions experienced by minorities. As such corporations should consider innovative approaches, directly impacting the workplace, that could improve the health of workers. We provide some examples of such innovative approaches.

Innovative Approaches

1. Involve employees in the design and improvement of the wellness program (surveys, suggestion boxes, etc.)
2. Employ data collected from the wellness program to make the workplace better – sole responsibility for change should not be on the employee.
3. Take a more holistic approach to health, for example, address issues of stress arising from harassment, bullying, and microaggressions.
4. Practice mental-health parity by valuing mental health as equally as physical health and providing recommendations regarding rest, relaxation, and downtime that seeks to achieve the goal of overall wellbeing.

Conclusion

Both the employer and employee share an interest in the health of the employee. While the interest of the employer is pecuniary, that is, it wishes to diminish healthcare costs, that financial interest does not trump the employee's interest in informational privacy and the right to be free from unfair employment discrimination. We believe that a wellness program that adopts ethical data collection and handling practices could reconcile employer and employee interests while maintaining efficacy. By committing to the well-settled ethical principles of informed consent, accountability, and fair use of personal health information data, wellness programs can safely navigate the ethical quagmires associated with the collection of sensitive personal health information from employees. Furthermore, by adopting innovative approaches to wellness that encourage employee input and oversight, rather than merely placing the responsibility for healthful behavior solely on the employee, employers may have a better chance at realizing the healthcare cost reductions that is their primary objective without undue disadvantages to the employee.

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