International Society of Nurses in Genetics (ISONG)

Health Contingent Workplace Wellness Programs in the United States and Disclosure of Genetic Information – an Issue Paper with the Intent of Stimulating International Dialogue

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Background

Nurses routinely take family medical histories and follow clinical guidelines that may include recommending their patients undergo genetic testing for risk assessment, diagnosis, and treatment of genetic disorders. This genetic information (family medical history that includes the employee's and spouse's genetic test results) may lead to genetic discrimination (Sarata, 2015; National Human Genome Research Institute [NHGRI], 2015). Nurses, charged with safeguarding their patients' genetic information, need to be aware that their patients', as well as their own, personal genetic information may be used to discriminate against them when they elect to voluntarily participate in workplace wellness programs.

Issues for those in the United States with Workplace Wellness Programs

Workplace Wellness Programs Before January 2017

Establishment of voluntary wellness programs (also known as employer-sponsored, employee, or workplace wellness programs) was recommended by the *Patient Protection and Affordable Care Act of 2010* (PPACA) and their provisions were implemented in January 2014. There are currently two different types of voluntary wellness programs: ***participation-based*** and ***health-contingent*** wellness programs. Neither wellness programs are required to be evidence-based and are unregulated, that is these programs are not required to report their efficacy (i.e. improvement of the participants' health) to any federal regulator (Hudson & Pollitz, 2017). These wellness plan can be developed and implemented internally by the employer or may be sourced outside the employee's workplace to a third-party (outside the workplace) vendor (Thompson, 2019).

1. ***Participation-based wellness programs*** are required to be offered to **all** employees if the employer is a large enough organization to be required to offer a plan. Incentives for employees to participate in this type of program may include free or reduced gym memberships, free diagnostic testing, and/or tobacco cessation programs. Employees are **not** penalized if they do not participate or fail to adopt any of the program's goals (Roberts, 2017).

2. ***Health-contingent wellness programs*** are to be "reasonably designed", (undefined term in PPACA) and must be offered to the employee at least once a year to encourage a positive change in their health behavior(s). This type of program must be made available to "similarly situated" (undefined term in PPACA) employees and must give reasonable alternatives for the employee to achieve the program's goals. Health-contingent wellness programs require that the employee ***must*** **meet certain targets** (such weight loss, exercise parameters, tobacco cessation) for the employee to reap its incentives (Hudson & Pollitz, 2017). Employers cannot require the employee to participate, cannot deny an employee health insurance for not participating, restrict an employee from choosing another alternative health plan (one without a wellness program), or take any negative action against an employee who chooses not to participate in a wellness program, or does not meet the program's health goals.

Before January, 2017, employee incentives to participate in health-contingent wellness programs **were** largely financial, such as a reduction (up to 30%) of the employee's contribution or up to 60% reduction for both the employee's and the spouse's contribution to a group health insurance plan or up to 50% reduction of health premium if the employee enrolled in a tobacco cessation program (Roberts, 2017). Conversely, these incentives could have taken the form of a penalty for employees who did not participate, as they could have seen the cost of their employer-provided health insurance increase if the employer decided to use it as a penalty instead of an incentive (National Human Genome Research Institute [NGHRI], 2017).

Genetic Discrimination Laws and Wellness Programs Before 2019

Three federal laws prevent discrimination based on genetic information in the workplace: the *American with Disabilities Act of 1990* (ADA), the *Health Information Portability and Accountability Act of 1996* (HIPAA) and the *Genetic Information Nondiscrimination Act of 2008* (GINA) (U.S. Equal Employment Opportunity Commission [EEOC], 2017; Kaiser Family Foundation [KFF], 2017). The ADA allows for **voluntary** medical histories to be obtained, as part of an employee health program available to **all** employees. HIPAA includes privacy protections for personal health information, when employees are applying for an employer-sponsored health insurance plan (Hudson & Pollitz, 2017). GINA allows employers, **with over 15 employees**, **to request, but not require**, that employees provide genetic information **only** if the request is made through a voluntary workplace wellness program. Additionally, GINA states that an employee who chooses **not** to provide their genetic information to a voluntary workplace wellness program **should not be penalized** (Genetic Alliance, 2016). Both the ADA and GINA possess regulations that employers **can** only acquire de-identified, aggregated health information from their wellness programs (Roberts, 2017).

Wellness programs in 2019

In 2017, the American Association of Retired Persons (AARP) filed suit in the U.S. District Court of the District of Columbia, which ruled that the EEOC regulations that allowed employer-sponsored wellness programs to offer financial incentive were coercing employees to provide their private health information in order to qualify for their employer-sponsored benefits. As of January 1, 2019, **health-contingent workplace wellness programs** can no longer offer financial incentives to employees and their spouses (O’Connell, 2018).

However, employees’ (and their spouse’s) genetic information continue to be at risk for disclosure since many employers create contracts with third-party companies’ web-based wellness programs. These third-parties (also known as digital wellness program vendors) collect employees’ biometric data, using this data to design workplace health interventions, and may share the employees’ (and spouses’) personal information to the vendors’ marketing partners (Banarjee, Hemphill & Longstreet, 2017; KFF, 2015; NHGRI, 2017; Wadyka, 2019), since third party wellness program vendors are not considered health care providers and are **not** held to HIPAA provisions (Wadyka, 2019). Additionally, these web-based wellness programs obtain passive authorization, including limited power of attorney, from employees to access the employees’ and their spouses’ health information, including their past insurance claims and current medical records (Genetic Alliance, 2016; Hudson & Pollitz, 2017). Examples of these vendors’ terms of service and privacy policies are available at

https://www.werally.com/corporate/terms/us/ and
https://www.werally.com/corporate/privacy/en-US.

It is now legal for workplace wellness programs to gather an employee's family medical history, the least expensive and most accessible pathway to genetic information. By legalizing financial incentives for 'voluntary' employee participation in a health-contingent wellness program, this amendment 'urges' employees to give employers and wellness program vendors their genetic information, increasing the chances it could be used in discriminatory ways (Genetic Alliance, 2016). It is still legal under Title II of GINA to discriminate against individuals who have disclosed their information when applying for disability, long-term care and life insurance, which may also be offered by employers (NGHRI, 2015, 2019). The disclosure of individuals' and their spouses' genetic information may involve additional costs for the employees if their employers refuse to offer them employer-sponsored disability and life insurance by considering history of genetic illness in the family, that may or may not affect all family members, as pre-existing conditions. Insurance companies may be careful about assuming such risks in order to avoid big payouts.

Executive Summary

It is noted by recognized by the International Society of Nurses in Genetics (ISONG) that nurses in the United States protect their patients' genetic information and help patients recognize that health information must be protected, so that they can make informed decisions without fearing employer discrimination. While this is an issue, ISONG is an international organization and cannot therefore take a position for any one country, but rather, a world view. The premises of this paper are recommended by the authors and gratefully supported by the ISONG Ethics and Public Policy Committee and the ISONG Board of Directors. Further discussion with input from those in other countries is welcomed.

In addition to nurses' own careful behavior about recording genetic information in health records, patients and their families must be educated about the risks of disclosing their genetic information and the areas in which our current laws do not provide protection. Employee genetic information should only be shared with those healthcare professionals providing care to the patient. In the age of electronic medical records (EMRs), where the entire document may get transferred to others with a keystroke, this is a daunting task. Employers must waive penalties for employees and their spouses who refuse to disclose their genetic information (Hudson & Pollitz, 2017). By removing these penalties, employees will have the freedom to make decisions that are best for them and their families without coercion from the employer.

Consumers need to be aware if an employee wellness program is covered under the Health Insurance Portability and Accountability Act (HIPAA) and not just be HIPAA- compliant which does not cover privacy protection (Wadyka, 2019). It is incumbent upon nurses who are connected in meaningful ways with genetics and genomics to raise their own and others' general levels of awareness that personal health information is being passed to proprietary companies that use these data to achieve marketing targets. Others who gain access in these ways have used and may continue to use third party data for nefarious purposes, including insurance denials and employment vulnerability. This is especially important in an era when whole genome or whole exome sequencing is an emerging norm for newborn screening. Those future employees may be requested to present their whole genome sequences upon hire if this disturbing practice becomes the norm. Nurses must educate their colleagues in nursing and all other health professions to guard against such personal intrusion.

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