

Genetic Testing in the Workplace

One of the latest trends in employee benefits is offering a form of genetic testing (also known as genetic screening) in the workplace.

There's been a significant uptick in the number of organizations offering genetic testing and population genomic screening to help their employee benefits package stand out given the extreme competition for talent that many industries, like tech and legal, are navigating. Some employers are subsidizing the genetic tests or offering free genetic screenings and seeing great interest and participation by employees. However, employers should be aware this benefit doesn't come without its complications and risks.

Genetic Test versus Genomic Test

Per the [National Human Genome Research Institute](#), genetics is the study of genes inherited at birth that are passed down through generations. Genetic tests focus on an individual's inheritance of a single gene (e.g., does the person have this gene and what could it mean?), whereas genomic tests look at a wider inheritance of various genetic traits such as mutations (e.g., what is a particular inherited gene doing?). Genomic testing is sometimes recommended for cancer patients who stopped responding, or had a poor response, to conventional treatments like chemotherapy and radiation. In fact, [cancercenter.com](#) indicates that cancer researchers are hopeful for continued advancements in genomic testing to enable better targeting of tumor mutations and to increase the ability to tailor treatments for each individual.

Genetic Test Regulations

Currently, **genetic tests are not regulated** despite commercial availability and aggressive marketing by biotech firms. However, the [FDA has cleared the path](#)



for some genetic testing companies (e.g., 23andMe) to sell DNA tests for certain gene mutations such as those linked to breast cancer. The [ACLU has stated their concern](#) for the lack of regulation, declaring tests have no government oversight or quality control and the accuracy and reliability of the tests are not proven.

Genetic Testing Implications

While employees view genetic testing as an opportunity to be proactive about potential health concerns, the information gathered from a genetic test often has implications for their blood relatives as well. Typically, these blood relatives have not consented to have their own DNA tested. While that may seem obvious, with the advancements and resources available in technology today, it's quite easy for one's blood relatives to be identified through another relative's DNA. There are numerous articles on how genealogy and DNA was used to find clues that eventually connected a genetic testing participant to lost parents and siblings. Even the Golden State Killer was eventually found through DNA connected to his relatives.

Genetic implications can spread to a whole community within certain racial or ethnic groups. The [ACLU's Genetic Discrimination in the Workplace Factsheet](#) cites examples of how particular diseases, such as sickle cell anemia, can be directly correlated to those. Genetics can also be used to detect the presence of genetically determined traits that make a person susceptible to certain diseases if exposed to specific environmental factors or substances, according to [cancercenter.com](#). However, **the**

ACLU cites the American Medical Association's statement indicating there is “insufficient evidence for genetic susceptibility as a basis for employment decisions and no supporting data showing genetic abnormalities resulting from an unusually elevated susceptibility to occupational injury.”

Privacy Concerns

There are growing concerns around the genetics industry and its ability to maintain the privacy of the individuals who participate in a genetic test and the data derived from them. The reality is genetic testing companies cannot guarantee full privacy, as selling the data resulting from these tests can be quite lucrative. For example, in July of 2018, genetic testing company 23andMe announced that pharmaceutical giant, **GlaxoSmithKline, had purchased a \$300 million stake** in the company to gain access to the genetic data for the development of new drugs. In addition, the company has made multiple partnerships that focus on data for a particular disease (such as Parkinson's) to a **newly announced partnership with Lark Health** to provide genetics-based, personalized digital health coaching. But other biotech companies are selling data for similar purposes and creating partnership-based products that require genetic data to be shared. While these are exciting developments, they are further proof of the inability to control access to personal genetic information.

Employer Considerations

Offering the latest employee benefit trend is certainly a way to differentiate your organization from your competition, particularly if you are competing aggressively for talent. However, one of the very first steps employers need to take is careful evaluation of whether or not genetic testing is a culture fit for your organization.

If your organization is considering genetic testing in any form, it's important to be careful how you plan to offer it. Will it be offered to all employees or only those

who participate in your medical plan? Is it offered as a part of your health and wellness plan? Employers need to make sure employees understand the offer of genetic testing is voluntary and that testing (or results) will not affect employment.

If your organization is considering genetic testing included as an element in a more formal wellness plan, as opposed to just paying for mainstream market testing kits, it is vital to understand the strict rules under the Genetic Information and Nondiscrimination Act (GINA) on how the data will be used and who will have access to it. Employers should evaluate vendors thoroughly and avoid picking trendy products without first doing your homework. Employers should also consider setting up post-test coaching or counseling to help answer the “what's next” or “what does this mean for me?” questions resulting from the test.

Most important of all, work carefully with your consulting team to review for legal considerations. There are a number of nuances and parameters that need to be prudently addressed from multiple standpoints to ensure compliance and protect your organization from undue risk.

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