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When I was offered the opportunity to take a class on personal genomics and have my genome analyzed, I jumped at the opportunity. For me, finding out my ancestry and health information was a bit like taking an online quiz. In fact, I am embarrassed to admit that, despite the informed consent lecture required of all members of the personal genomics course, I approached not only my genetic results but the consequences of knowing my genetic results with the same level of consideration that one would consider the consequences of the result of a Buzzfeed quiz.

It was not until after I began to analyze my raw genetic data that I was confronted with the question: what do I do with this information? For those who find themselves facing a significantly increased risk for a certain disease such as diabetes or cancer, the immediate response would be to consult a doctor. However, regardless of whether or not one's results are of significant concern, is simply telling your doctor your genetic predisposition enough? Or do we benefit from having raw genetic data and other genetic testing results included in our medical files?

For many people, myself included, gut instinct leans towards including all information in medical files. If you share your genetic information with your doctor, they can walk you through your results and help you understand what diseases you may be truly at risk for. Also, sharing your genetic predisposition with your doctor early on allows them to help you take measures that can potentially prevent or manage a disease in the future, something that often would not be possible once a patient is symptomatic.

While the predictive power gained is incredible, including genetic information in your medical file is also a powerful investment. Research on how genetic information can predict genetic predisposition for disease or response to a certain treatment is constantly improving. By having your genetic information included in your medical record, your doctor can continuously update your susceptibilities and help you make plans and decisions accordingly. In addition, having raw genetic data in your file may, in the future, allow others, such as a specialist or perhaps even a hospital, run your data through tailored programs to immediately get the most relevant information for a treatment plan.

However, there are also a number of downsides to having your genetic data in your medical file. While the 2008 Genetic Information and Nondiscrimination Act (GINA) prevents discrimination from health insurance companies or employers based solely on genetic predisposition, the act does not cover life, long-term care, or disability insurance. In addition, there is currently no standard protocol on how genetic information and test results should be incorporated in a patient's file, leaving individual doctors with the dilemma of how much information to include and how to include it in a way that is useful and understandable for other doctors, but not easily passed on to health insurance companies or other third parties. The American Medical Association has even proposed maintaining separate files for genetic information to ensure results are not sent to third-party individuals (1). Also, except for a select few disorders, your genetic results are nothing more than predictions that, if misinterpreted, could lead to unnecessary tests, diagnoses or surgeries - all of which cost time and money and, some of which, should not be taken lightly or performed simply on the basis of a genetic test result.

While the benefits of including one's genetic information in their medical file are substantial and likely to increase in the future, there are still a number of critical issues, such as the handling of sensitive genetic results, that need to be addressed before genetic information can be safely incorporated into a medical file with any regularity. In addition, doctors need to become better equipped with the tools and knowledge necessary to interpret, handle, and share genetic information with patients. As the availability of genetic testing increases, the burden of responsibility also falls on the consumer to understand the risks and benefits, and to consider how genetic testing will impact their own lives and the lives of their family members. As the world of personalized medicine expands, how patients are educated and how the medical infrastructure adapts to the growth and availability of genetic information is something that needs to be strongly considered sooner rather than later.

References

1. American Medical Association. [Accessed April 1, 2010.];Code of medical ethics, opinion 2.135: insurance companies and genetic information. http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2135.shtml.