

Genetic Information: Delineating the Technology and Privacy Intersection.

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This presentation will examine privacy issues arising in connection with the results of genetic testing. Evidence shows that countless patients have refused this type of testing due to fears of how the data would be handled and ultimately utilized if the results were positive. However, the information obtained from such tests is often exceptionally helpful in making treatment decisions and taking preventative measures to minimize the likelihood of the occurrence of many diseases.

In an attempt to alleviate the public's growing concerns, legislation aimed at preventing the misuse of genetic information was first introduced in Congress more than a decade ago. Nonetheless, the Genetic Information Nondiscrimination Act ("GINA") was not signed into law until just last year and will not become fully effective until November of 2009. Unfortunately, while this long-awaited Act does provide some much needed protection, it also has a number of major shortcomings. These deficiencies are made all the more problematic by the fact that health records are now increasingly in electronic form, allowing for this type of data to be exchanged much more readily. As such, the goal of dispelling patients' fears over how their genetic information might be used is unlikely to come to fruition.