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Risks of sharing personal genetic information online need more study, bioethicists say

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With just $399 and a bit of saliva in a cup, consumers can learn about their genetic risk for diseases from breast cancer to diabetes. Now, thanks to social networking sites set up by personal genomics companies, they can also share that information with family, friends and even strangers on the Internet.

Bonding over a similar genetic background sounds relatively harmless. But according to bioethicists from the Stanford University School of Medicine, sharing genetic information online raises a host of ethical questions.

"Genetic information is unique in that it's not only relevant for the individuals who receive the information, but also for their family members, their children and even their children's children," said Sandra Soo-Jin Lee, PhD, senior research scholar at the school's Center for Biomedical Ethics.

Because genetic information applies to more than one person, issues of privacy and consent become complicated. "For example," Lee said, "if you receive information on your breast cancer risk and share it with others, you might also be sharing information about your daughter's risk for breast cancer — even though she never consented to have that information shared."

In cooperation with assistant professor of pediatrics and bioethicist LaVera Crawley, MD, MPH, Lee has been studying the potential implications of exchanging genetic information online. To fully understand the effects of sharing, the researchers say we need more data on who's giving out information and how it's being used. Their recommendations will be published in a special double-issue of the *American Journal of Bioethics* on June 5.

"We want to understand how consumers interpret and act upon personal genetic information, and we want to know who they share it with," Lee said. To answer these questions, Lee and Crawley plan to use an approach called "social network analysis" with deep roots in the field of anthropology.

"Social network analysis is a system of mapping how individuals are related to each other and how they form connections around certain institutions or ideas," said Lee, whose work was funded by a grant from the National Human Genome Research Institute. "In this case, we want to see how people forge connections based on their genetic information."

As the cost of DNA sequencing drops, the genetic testing industry is expanding rapidly. Lee estimates that nearly 100 companies around the world now provide some form of direct-to-consumer genetic testing. Two of the largest companies, 23andMe and Navigenics, are based in Silicon Valley.

In most cases, customers mail in a DNA sample for sequencing, and then get both raw data and an interpretation of their genetic profile. A few companies, including 23andMe, also let customers create a public profile and share their genetic data through a company-sponsored social networking site.

For now, there aren't any laws that govern the exchange of genetic

information online. But as genetic analysis becomes cheaper and more widespread, more and more people will have access to their DNA code — and experts fear that consumers may share genetic data without realizing the potential implications for themselves and their families.

"There's stuff in there that we can't interpret today, but we will be able to interpret in five years," said Russ Altman, MD, PhD, professor of genetics at Stanford and a scientific advisor for 23andMe, who was not involved in Lee and Crawley's work. That means an unsuspecting consumer could share data that's meaningless today, Altman said, but later reveals an elevated risk for a serious disease.

"Personally, I'm not anxious to share my genome," Altman said. "The information affects my daughters, my son and my parents, who might not want to learn about their genetic profile. If I share my information with strangers, there's a higher risk that it will get back to my family."

In addition, both consumers and their health providers may have trouble interpreting data provided by personal genetics companies, Lee said. Estimates of disease risk are often based on small, unreplicated studies in the biomedical literature, but consumers may not understand how preliminary this data is.

"Results depend on the number and type of markers that are used, as well as how robust their databases are," Lee said. "It's important for there to be a greater oversight of this information to ensure that consumers understand what their results actually mean."

Source: Stanford University Medical Center