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Direct-to-Consumer Genomics, Social Networking, and Confidentiality

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The social networking business ventures described by Lee and Crawley (2009) in their target article "Research 2.0: Social Networking and DTC Genomics" combine two twenty-first century inventions, direct-to-consumer (DTC) genetic testing and internet-based social networking (e.g. Facebook, MySpace). Private companies, such as *23andme*, are marketing genomic testing services to consumers, including ancestry tests, normal trait tests, disease tests, and tests for over 600,000 single nucleotide polymorphisms (SNPs). The companies also allow consumers to post their genomic and health information on a personal website and share it with other interested parties, such as other members of the social network (i.e. friends), family members, and researchers. According to Lee and Crawley, this combination of social networking and genetic testing represents a trend toward democratization and openness in genomic information that can promote consumer empowerment and innovation in biomedical research.

While this hybrid of social networking and genetic testing promises to yield much fruit, it also raises many difficult ethical and legal issues, including 1) validation and interpretation of genetic tests; 2) oversight of biomedical research using genomic and health information; 3) access to genetic and counseling testing services; 4) ownership and control of data and technology; and 5) confidentiality of genomic and health information. This commentary will address only the last set of issues.

Protecting the confidentiality of genetic information is one of the key pillars of genetic testing. Unauthorized disclosures of genetic information may lead to discrimination against individuals in insurance or employment (Brandt-Rauf and Brandt-Rauf 2004). Many people who undergo genetic testing are apprehensive about the possibility of genetic discrimination in employment or insurance (Hudson 2007). Confidentiality is important to protect the rights and welfare of individuals and to promote trust in biomedical research and clinical practice (Hudson 2007). In the U.S., state and federal laws prohibit various types of genetic discrimination, including the recently passed Genetic Information Nondiscrimination Act (Hudson et al 2008). Despite the protection afforded by these laws, individuals still have justified concerns about genetic discrimination (Hudson 2007, Hudson et al 2008).

Many of the confidentiality issues raised by DTC genetic testing and social networking are similar to those that arise in other types of genetic testing, such as taking appropriate security measures to safeguard genetic information, controlling access to genetic information, and informing individuals about confidentiality protections. But some of the issues are different from those that ordinarily occur in genetic testing. Normally, people who undergo genetic testing guard their information closely and share it only with a few selected individuals or organizations, such as their health care providers or close family members, following tightly

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controlled procedures. Under the social networking approach, individuals can choose to share their genetic and health information with a large group of individuals and organizations, including friends, health care providers, researchers, and others. They can even choose to make their information available to the public. This approach to genetic information promotes openness and collaboration but threatens to destroy traditional notions of genetic confidentiality.

The consequences of sharing genetic information with large social networks are difficult to predict. Though individuals do not include their name, address, other personal identifiers on their websites, this method of sharing information does not guarantee that confidentiality will be protected, since recent advances in biostatistics have demonstrated how to identify a de-identified individual in a complex genomic database if one has access to the individual's genome or the genome of a close relative (Homer et al 2008). Statistical methods can identify de-identified individuals in databases if enough information is known about their phenotypic characteristics, such as age, gender, and disease status (Linz et al 2004). If an individual can be identified in a database, it may also be possible to identify some of the individual's close relatives as well, due to shared genomic characteristics (Linz et al 2004). One implication of these and other studies is that removal of personal identifiers is no longer a surefire method for protecting confidentiality when sharing genomic information (Zerhouni and Nabel 2008).

In response to the limitations of using de-identification as a method for protecting the confidentiality of genomic data, several biomedical research organizations, including the National Institutes of Health (NIH), have moved away from open access data-sharing policies (Zerhouni and Nabel 2008). The NIH has decided that data from genome-wide association studies will be released only to researchers and institutions who sign an agreement stating terms and conditions pertaining to how the data will be used, protected, stored, and shared (Zerhouni and Nabel 2008).

Individuals who share the genomic and health information on social networks may not fully comprehend the potential consequences of data sharing. They may not understand that by sharing information on social networks they risk their own confidentiality as well as the confidentiality of their family members. Private companies that offer these services should take appropriate steps to inform individuals about confidentiality risks and take steps to protect individuals and their families from harm.

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