Published in final edited form as:

Am J Bioeth. 2014 November ; 14(11): 57–59. doi:10.1080/15265161.2014.957422.

Policy and the Inevitability of Sharing: GINA and Social Media

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In “Protecting Posted Genes: Social Networking and the Limits of GINA,” Sandra Lee and Emily Borgelt present a deep and thoughtful consideration of the challenges of protecting genetic privacy in a digital era dominated by social media. According to Lee and Borgelt, while there is “little doubt that GINA represents a significant advance in protection against discriminatory use of genetic information,” “[n]onetheless, practical issues in the context of social networking and PGI may stymie the enforceability of the statute” (Lee and Borgelt 2014, 19). Following their analysis, Lee and Borgelt make three policy recommendations to address the limits of GINA: (1) consumer and user education regarding the limits of GINA and the burden of proof in litigation, (2) recognition that all social media may house genetic information, and (3) legislation to limit or prevent employers from requesting access to employees’ social media accounts (Lee and Borgelt 2014).

These three policies, if adopted, may potentially have some beneficial effects and we do not mean to suggest these policies should not be adopted. Ultimately however, we think they are an attempt to put the genie back in the bottle. These recommendations all attempt to decrease the *availability* of and *access* to genetic information shared online via social media. For example, the first recommendation—user education—seeks to increase the likelihood that consumers understand that health insurers and employers (and other third party institutions) may gain access to their genetic information when shared on social media. Presumably, based on this understanding of risks, at least some consumers will choose to share less of their genetic information online than they would have otherwise. The second and third recommendations—recognition under GINA that social networking sites contain genetic information and additional legislation limiting third party institutions’ access to employees’ and applicants’ social media passwords—seek to limit third party institutions’ access to information consumers have shared online. (We recognize Lee and Borgelt’s second and third recommendations are more closely tied to GINA’s prohibitions on third-party access to genetic information rather than discrimination, but from the consumer’s perspective, the ultimate concern likely remains whether access by a third party results in discrimination.)

Despite the reasoned basis for these recommendations, we think the chances of these strategies successfully curtailing the availability of and third party access to genetic

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information is low. Consumers' urge to share thoughts and information with their online networks of friends and family through social media is in large part unstoppable. According to the Pew Internet Project, as of January 2014, 74% of all internet users use social network sites, ranging from 49% among users 65 years and older to 89% among 18 to 29 year olds (2014). While the responsibilities of middle age may reduce use of social media as the current generation of young people mature, experts think that these youthful "digital natives" will continue to share their personal information online as they mature because they perceive that the advantages of personal disclosure outweigh privacy concerns (Pew Research Center 2010). Relatedly, once information is available online in widely used social networking sites, any attempt to prevent third parties from accessing it (as is contemplated in Lee and Borgelt's second and third recommendations) is doomed to have marginal utility at best. As Lee and Borgelt note, there are many scenarios by which third party institutions may nonetheless obtain such information. An employer (manager, boss, or simply another employee at the same company) who is connected with an employee via a social networking site may completely unintentionally be presented with a range of personal and family health information just by swiping through the constant deluge of status updates or news feeds provided to her.

But even though consumers inevitably will continue to choose to share a large amount of information about themselves, including genetic information, in a public or semi-public setting online, the original goals of GINA continue to ring true. In passing GINA, Congress found that federal legislation was necessary to prevent discrimination because otherwise consumers would forego participating in genetic testing and genetic therapies that could benefit them. GINA states that "Federal legislation establishing a national and uniform basic standard is necessary to fully protect the public from discrimination and allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies" (Genetic Information Nondiscrimination Act (GINA) of 2008 § 2, Pub. L. No. 110–233, 122 Stat. 881). In an era marked by widely accessible direct-to-consumer genetic testing, rapidly expanding clinical implementation of whole exome and genome sequencing, and concomitant expectations that multiple genetic results derived from sequencing will be offered to individuals across a life time (Yu 2013), the goal of GINA remains of fundamental import (Prince and Roche 2014).

If we are unlikely to be able to meaningfully limit consumers' desire to share genetic information with their social media contacts and, in turn, third party institutions' ability to gain access to that information, what can be done to further the original goals of GINA in the age of social media? One answer lies in GINA's prohibition on discrimination, which applies regardless of how the health insurer or employer becomes aware of genetic information (GINA, Pub. L. No. 110–233, §§ 101, 201). Thus, the third party institution's ability to *use* genetic information, regardless of how obtained, does not turn on whether the consumer treats her genetic information as private, public enough to be shared with a limited set of social media contacts, or fully public. Another possible approach is legislative expansion of the framework of GINA to additional types of third-party institutions, such as educational institutions.

In addition, social media itself may change in both function and form such that current modes of virtual interaction and their associated concerns no longer hold sway, or differ in material respects. While the recipient of information on social media will likely always have some ability to preserve and record and thereby further share information she has received, new forms of social media are trending toward “ephemerality,” or lack of preservation as the default (Holmes 2014; Perez 2013). This type of social media, while not a failsafe, decreases the likelihood of third party institutions gaining knowledge of genetic information shared or discussed on such platforms. In conjunction with an ephemeral turn, the content and function of social media may change in other related ways. For instance, location-based temporary social media networks allow people to “see” and connect to whoever is literally in the room. Thus, social media may be transformed into a vehicle that captures or facilitates a social moment in real life, rather than a medium for launching individual updates or content that then remains static and easily accessible online. In this sense, the future direction of social media focuses on bringing ephemerality to digital tribes, valuing greater intimacy and a sense of personal connection over independent, individual decisions to push one’s own content online. If social media changes in this way, it may diminish some of the concerns advanced by Lee and Borgelt, but of course any change in technology can bring new concerns for policy makers to address as well.

Regardless of changes in social mediums and technologies, consumers remain opposed to genetic discrimination and expect to benefit from genetic information and treatment options when needed. Therefore, maintaining broad protections irrespective of how third parties may access such information will continue to be a priority in genomics.

Acknowledgments

This manuscript was supported by the National Human Genome Research Institute of the National Institutes of Health under the award number K99HG007076 (Yu). As a partner at Perkins Coie LLP, Ms. Engrav represents social media companies, among other clients. The content is solely the responsibility of the authors and does not necessarily represent the official view of the National Institutes of Health, Perkins Coie LLP or Ms. Engrav’s clients.

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