Cockamamie state laws threaten genetic rights

Jennifer Wagner

In the US, states anxious to establish genetic rights are acting in the absence of clear, informed leadership. The result is specious legislative language and conflicting proposals that create confusion and disrupt genetic research and healthcare activities. It's time to look beyond our state and national borders for guidance.

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The passage of the Genetic Information Nondiscrimination Act of 2008, GINA, which prohibits genetic discrimination in health insurance and employment, was heralded as a major achievement. Yet GINA's specific focus and the rare, overwhelming bipartisan support it garnered should be seen not as 'mission accomplished' but as a symbolic baby step in the genetic rights movement. Major issues, for example, with property and privacy rights, remain unsettled. It's no surprise that, with the federal government in perpetual gridlock, states are champing at the bit to define genetic rights¹. Nonetheless, recently proposed state legislation is fraught with nonsensical provisions that have questionable legal meaning or create frustrating conflicts of law.

California S.B. 559, effective 1 January 2012, was accurately dubbed 'CalGINA' because it extends GINA's antidiscrimination protections to additional contexts (such as housing, mortgage lending and emergency medical care). Oklahoma S.B. 837, effective 1 November 2011, could be nicknamed similarly. But nondiscrimination is not synonymous with privacy: after all, the federal law is GINA, not GIPA, and that is no minor detail. So it would be inappropriate to call Alabama's proposed H.B. 78 or Vermont's proposed VT H. 368 extensions of GINA, as both bills address matters distinct from nondiscrimination (such as surreptitious testing and informed consent).

State laws have continued relevance even if federal laws like GINA exist. GINA sets a floor (not a ceiling) of protections and does not preempt state statutes unless they purportedly lower requirements. For example, it's unresolved whether Oklahoma's law, which seemingly permits a 'bona fide occupational qualification' defense for employers (a defense omitted from GINA) would pass scrutiny. Furthermore, GINA is not the only federal law or regulation that these various state bills would antagonize. Alabama's bill could be a headache for researchers, as fulfilling its proposed mandatory return of genetic test results may conflict with federal limitations of human research participant protections under the Common Rule and Clinical Laboratory Improvement Amendments (CLIA) regulations. Similarly, Vermont's bill could frustrate clinicians because of conflicts between its specifications requiring prior informed consent for disclosure of any records of genetic information (potentially including disclosures made for treatment) and current specifications of the Health Insurance Portability and Accountability Act (HIPAA)¹. Such vertical conflicts, which create confusion for in-house counsel and institutional review boards, are expensive and disruptive to research and care.

The absence of legal statutes using the term 'genetic' does not mean genetic rights are unprotected. Genetic interests may be protected by existing laws without the need to reinvent the wheel. For example, federal regulation specific to the largely web-based personal genomics industry may be redundant, as federal and international law already governs e-commerce generally. Moreover, 'genetic exceptionalism'—the

idea that genetic information is distinct from other types of information such that it requires its own laws—is predominately a symptom of widespread genetic illiteracy.

Property rights are important to the genetic rights movement, but states propose different approaches, and this jurisdictional variation could create a legal nightmare. Alabama's bill would make genetic samples and information "the personal property of whom it was taken." Similarly South Dakota's bill, SD 1260, would make them "the sole property of the person from whom it was derived." Both the Vermont bill and Massachusetts's "Genetic Bill of Rights," MA S.B. 1080, would protect material as "real property subject to one's individual control and dominion in accord with generally held precepts of property law." That sounds great unless you've finished one week of law school and

know 'real property' is a legal term of art, not interchangeable with personal property. Real property is limited to land and anything affixed to it. The last time I checked, neither my genome nor yours was affixed to the ground. Recognition of real property rights (which facilitate transfers) in DNA would cause a seismic shift in property law precepts and could clash with governance of organ transfers and human trafficking (which aims to limit or prevent such transfers).

Currently, the genetic rights movement is overly paternalistic and fixated on one interest: privacy. To ignore other interests at stake—such as contributing to and enjoying the benefits of biomedical research innovations—would be regrettable. We must carefully consider the legal consequences of property attributes conferred to biospecimens and corresponding information². We should look internationally for guidance, as well, including the applicability of previously recognized human rights, such as those found in the Universal Declaration of Human Rights (which outlines the right to "to share in scientific advancement and its benefits") and the International Covenant on Civil and Political Rights (which provides the right to "seek, receive, and impart information...through any media"). Most importantly, a progressive genetics rights movement must not perpetuate or codify genetic illiteracy but must think forward, promoting contextual integrity³ (not privacy per se), increasing the humanization (not anonymization) of research and facilitating genomic medicine and justice.

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1. Vorhaus, D. *Genomics Law Report* <<http://www.genomicslawreport.com/index.php/2011/03/16/is-the-genetic-rights-movement-picking-up-steam>> (2011).
2. Mitchell, R. *et al. Science* **332**, 309–310 (2011).
3. Nissenbaum, H.F. *Privacy in Context: Technology, Policy, and the Integrity of Social Life* 148–150 (Stanford Law Books, Stanford, California, 2010).