CENTER for GENOMICS & SOCIETY at UNC-CHAPEL HILL

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genomicsandsociety

Center for Genomics and Society
Five-year Renewal, 2013-2018

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The overall aim of the Center for Genomics and Society (CGS) award is to carry out an integrated set of research, training, and policy activities focused on evaluating the prospect of using genomics to improve the health of the general public. Various forms of genomic testing are already being offered in an unstudied way by direct-to-consumer and direct-to-provider companies and through other venues. We propose to launch an interdisciplinary assessment of adult genomic screening, centered on recruitment of 1,000 individuals for testing within a controlled setting and informed by ongoing consideration of ethical, legal, social, and historical perspectives. We will focus initially on testing to identify those individuals with rare genetic mutations that place them at high risk for eminently preventable conditions and will also assess genomic risk for common disease. With consultation from our Community Advisory Board and other stakeholders, we will gather evidence relevant to recommending the further pursuit of such applications: What loci and analyses are most appropriate for population-based application? What segments of the general population would be the most appropriate users of such a service? How can population genomic sequencing be best implemented in practice, and with what consequences? We will formulate recommendations for future practice taking into account the costs and benefits, and the personal, clinical, and justice implications. This work has clear, immediate implications for health policy, for professional guidelines, and ultimately for policies on how best to realize the promise of genome medicine.

The Center for Genomics and Society was established in 2007 to examine the ethical, legal and social implications (ELSI) unique to large-scale genomic science. Major ELSI questions emerge in association with large-scale studies such as the creation of centralized DNA banks, use of genetic technologies in public health screening, and the rise of gene-based personalized medicine.

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