



Improving Collective Awareness in Education about the Privacy and Ethical Issues Connected with the Genome Technologies

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Abstract

From a single cell's genome we may know one person's disease risks; this knowledge could be extended to some of our relatives that share portions of our genome. Current genome technologies may enable insights on personal behavior and stress conditions which alter the DNA methylation in different tissues, for example the heart [1,2]. This paper focuses on how the education on genome technologies could impact the awareness on the ethical, privacy and legal issues regarding these technologies [see also 3,4,5]. Let's think at the opportunities of accessing good quality education for a little girl in a rural village in an African country and those of the son of two University Professors in Cambridge. The access to a good education is sometimes more unevenly distributed than other aspects of long life learning because opportunities build up on one after another in early years. For example, it is common that the acceptance in a good quality school creates the basis for the future entry to a similar quality school. The following pattern is observed for both education and health: despite the richness difference of the countries have remained the same or slightly reduced, the differences between the richest persons and the poorest person have increased everywhere, particularly in the richest and poorest countries. Scientists in developed countries are setting the basis to a proactive, genome –based, P4 medicine: personalized, predictive, preventive and participatory medicine [6] while in underdeveloped countries even vaccinations are limited. In a recent intervention, UKs Prime Minister Cameron opened up to the possibility that patients could become research patient with their medical details opened up to private and public research. This shift to health crowd-sourcing requires the agreement of boundaries for privacy, data ownership and liability. We believe that the scarce knowledge about the impact of genome technologies in health between poorly and highly educated people could drive both the exploitation of the genetic resources of poor people and the suboptimality of the medical treatment they will receive or their access to the job market. According to the Genetic Information Nondiscrimination Act, or GINA, an employer cannot fire someone because it doesn't like something in the employee's genes. Although health insurers cannot ask directly for genetic testing, long-term care insurers could legally require someone to get genetically tested before selling a policy. The reason is that if a large number of customers would sign on for policies because they've discovered that they are genetically predisposed to a expensive-to-manage disease, it could bankrupt the companies. Here we discuss scenarios and how education programs and online social health platforms facilitate the sharing of information, the discussion on new concepts of privacy to enable citizens to make better informed choices and even participating in the decision making process about the services they want to receive, in a democratic participatory fashion, beyond traditional dichotomies, such as cost vs. quality of treatment, economy vs health, demonstrating that it is possible to optimise conflicting choices.

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