

Ethics of Personal Genomics Today: Discrimination, Privacy and the Psyche

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What is personal genomics?

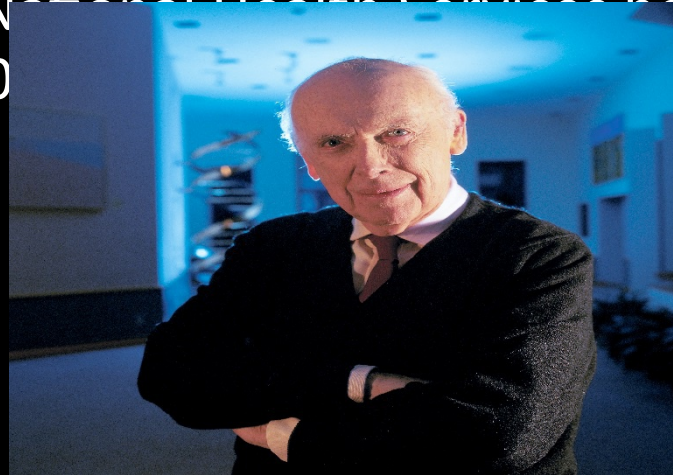
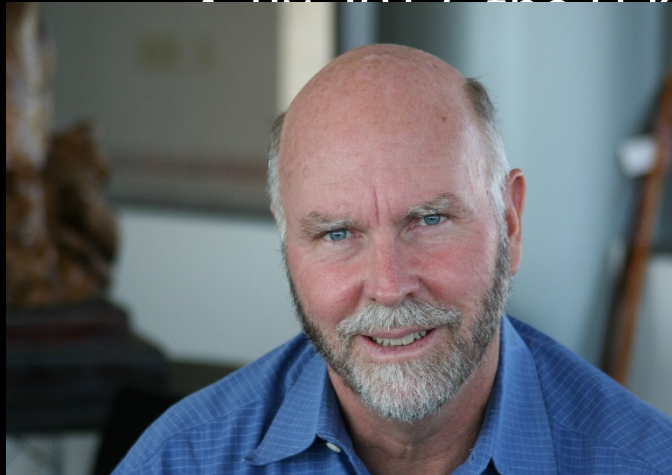
“Branch of genomics related to analyzing one’s specific genetic makeup”

Personal Genomics

- Services
 - Ancestry
 - Disease risk
 - Carrier status
 - Reaction to drugs
- Proactive disease prevention
 - Improving health behaviors and lifestyle factors
 - Allow for detection of disease and customized intervention

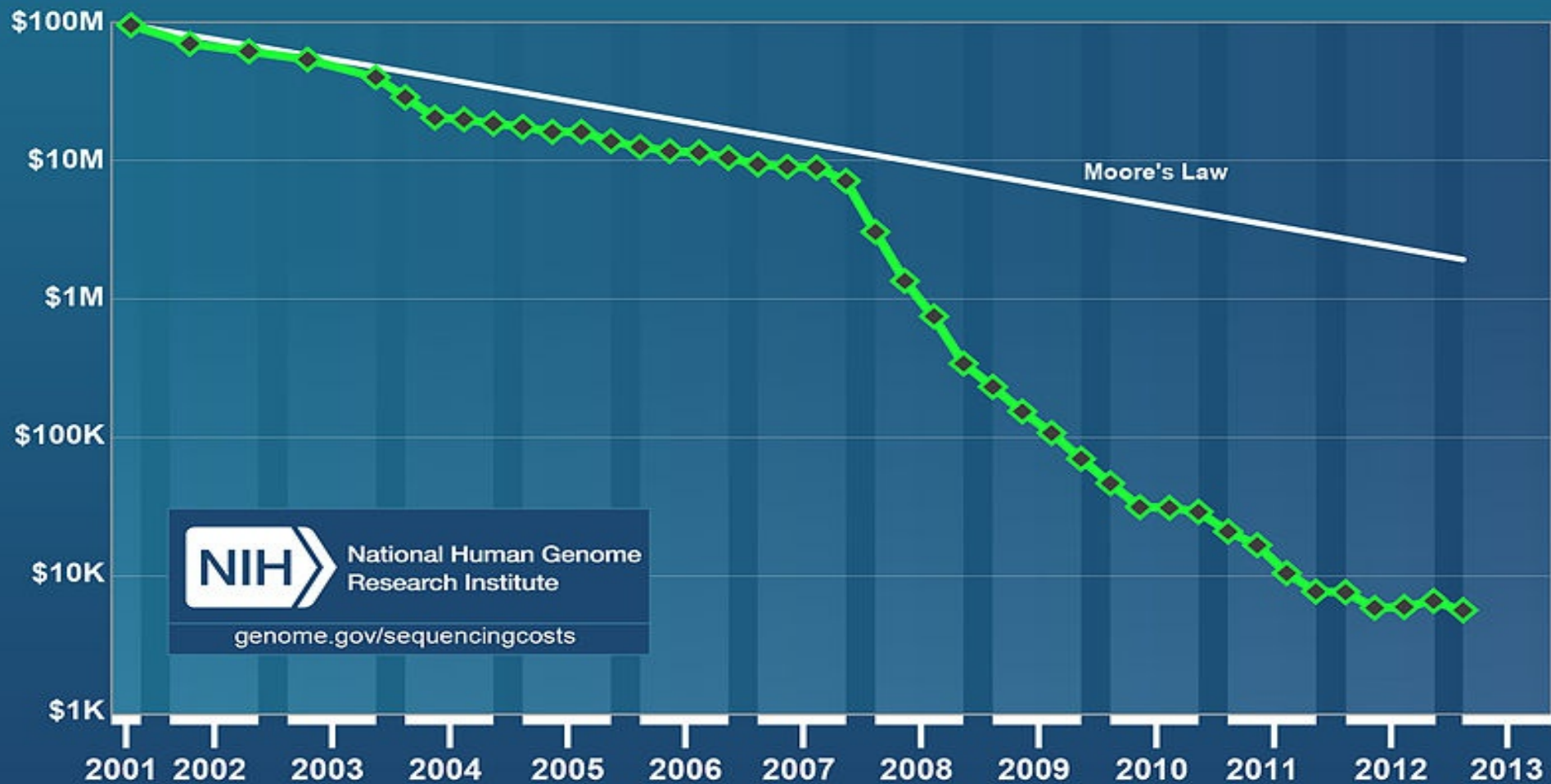
Genome Sequencing

- “Partial” genome sequencing
- Full Genome Sequencing
 - First nearly complete human genome sequenced in 2007
 - Craig Venter, James Watson, Steve Jobs
 - As of 2012, currently 69 nearly complete human genomes available



• By 2017, the U.K. National Health Service hopes to have sequenced the genomes of 100,000 people

Cost per Genome



Personal Genomics Companies

Partial Genome Sequencing



Gentle

Positive Bioscience



Full Genome Sequencing

Illumina

Sequenom

Complete Genomics

Ethics of Personal Genomics

<http://www.youtube.com/watch?v=ZppWok6SX88>

Genetic Discrimination

- Discrimination due to genetics
 - inherited disease, genetic mutation, defective gene, etc
- Insurance companies, Employers, Social Discrimination
- Cases include
 - Santa Fe Railroad Company
 - Many African Americans denied jobs due to sickle cell carrier status
 - Other cases include denying insurance or incurring a loss of health coverage

Genetic Discrimination Prevention

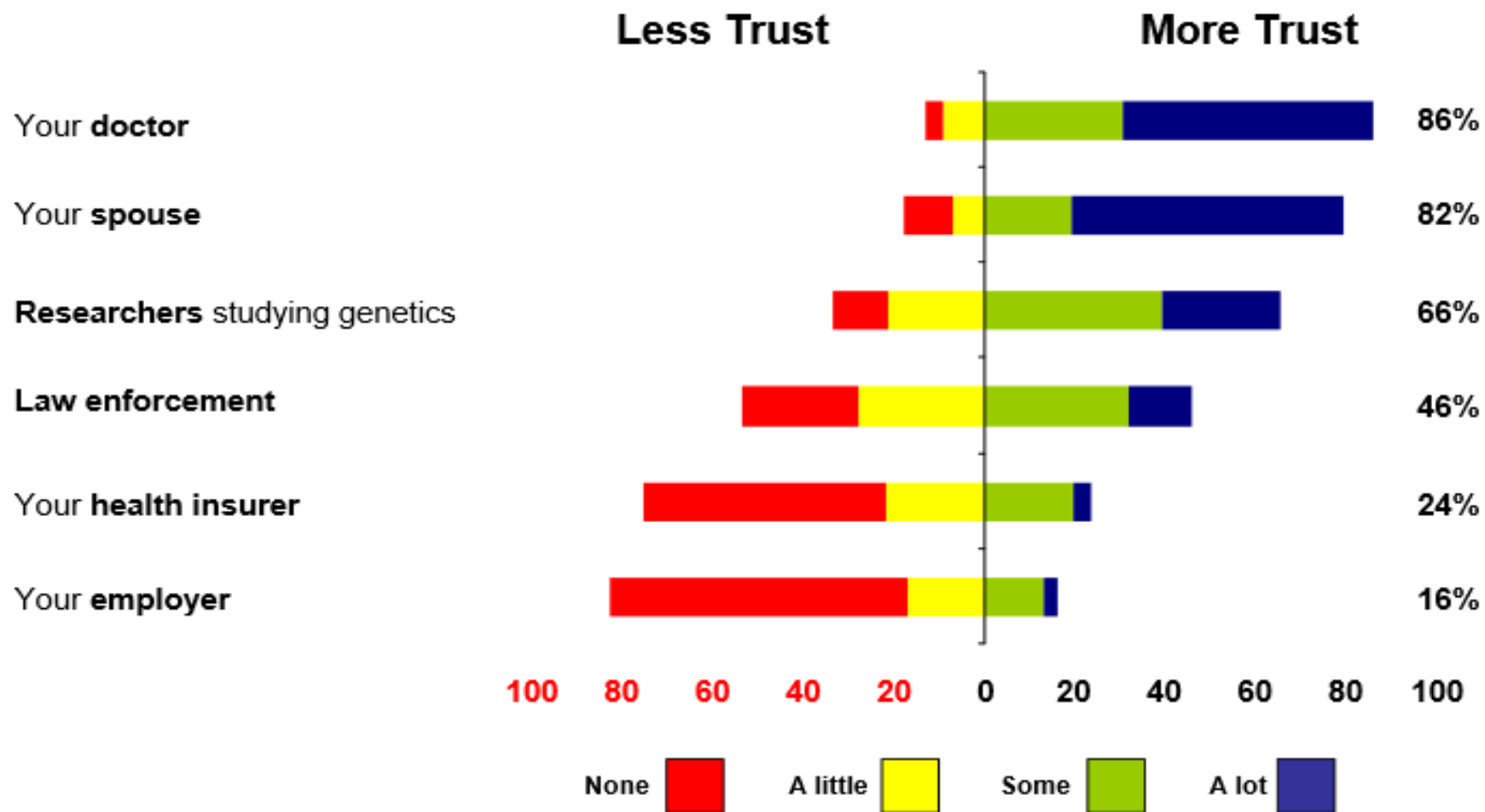
- Health Insurance Portability and Accountability Act (HIPAA)
 - prevented health insurers from excluding coverage due to medical problems
- Genetic Information Nondiscrimination Act (GINA)
 - Prevents employers and health insurers from using genetic information and genetic predispositions to discriminate
 - Excludes life insurance, disability insurance, long term care insurance and members of the US military

Privacy Concerns

“... total protection of privacy is increasingly unrealistic in an era in which direct-to-consumer (DTC) genetic testing is offered on the internet”

- PG results considered more revealing than medical records for both consumers and consumer families
- Information can be used for unauthorized scientific research, accessed by life and disability insurance providers

How much do you trust each of the following to have access to your genetic test results?



Genetics and Public Policy Center. <http://www.dnapolicy.org> 2/27/07-3/4/07, N=1199 adults 18 years of age or older

Psychological Impacts

- Psychological impacts may outweigh the benefits of knowledge
- Results may affect the behavior of patients
 - False Positive & False Negative cases
- Behavioral impacts include
 - Risky, unreasonable behavior
 - Anxiety, Depression
 - Reduced motivation to live a healthy lifestyle
 - Lead to unnecessary medical intervention

Past Personal Genomics Setbacks

- Havasupai Indians lawsuits
 - Unauthorized use of genetic information
 - Awarded 700,000 settlement
 - Considered one of the first settlement misuse of dna



Current Personal Genomics Setbacks

- Bankruptcy
- FDA cease and desist
- Lawsuits against PG companies
- Debates on accuracy of results



The Future of Personal Genomics

Is it useful?

Should we employ universal screening?

Should health insurance companies pay for screening?

Is genetic counseling feasible for all?

Bibliography

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Questions?