

The Other Side of Genomics

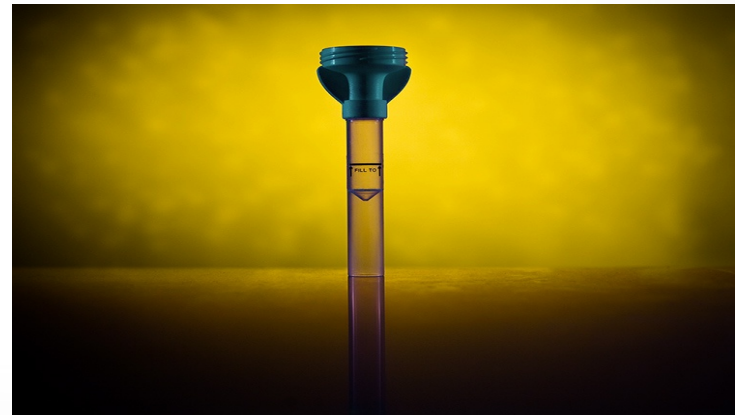
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Benefits

- Early detection of:
 - genetic diseases & disorders
 - risk factors
- understanding the causes, basis & processes of diseases
- Improvements in treatments & pharmacogenomics

Drawbacks

- Eugenics
- A lot of information, but not enough geneticists
- Social discrimination
- Violation of personal privacy rights
- How much do we really want to know?



Our discussion today...

- Social discrimination in health insurance, employment, etc.
 - Past lawsuits
 - Laws & amendments
- Potential non-medical uses of genomics
 - Military
- How much information do we really want to know?
 - Havasupai Tribe



Social discrimination

- Little to documentation due to fear and difficult in proving discrimination
- **Employment**
 - 1970s – forced screening for sickle cell anemia on African Americans → Sickle Cell Anemia Control Act of 1972
 - U.S. Equal Employment Opportunity Commission (EEOC) vs. Burlington Northern Santa Fe (BNSF) Railroad (2001)
 - Secret genetic testing for carpal tunnel syndrome, diabetes & alcoholism
 - Social worker with 50% chance of having Huntington's Disease was fired
- **Health Insurance**
 - Boy with Fragile X Syndrome was denied health coverage

Federal Anti-Discrimination Laws



- Americans with Disabilities Act of 1990 (ADA)
- Health Insurance Portability and Accountability Act of 1996 (HIPAA)
- HIPAA National Standards to Protect Patients' Personal Medical Records 2002
- Title VII of the Civil Rights Act of 1964
- Clinton's Executive Order prohibiting the use of genetic Information in hiring and promoting

Genetic Information Non-Discrimination Act (GINA)

- Took 13 years – passed in 2008
- Prohibiting the use of genetic information by
 - health insurers to determine health coverage & premiums
 - employers to make hiring, firing, or promotion decisions
- Cannot require a genetic test
- They can use your sequence to find a better treatments specific to you



Limitations

GINA excludes

- Life insurance
- Disability insurance
- Long-term care insurance
- Members of US military
- Health care from Department of Veterans Affairs (VA) & Indian Health Service





Besides for medical purposes,
where else can genetic testing be
used?



Use of Genetic Testing in Employment

According to Henry Greely, it is rare to find a situation in the world force where genetic information would be useful

- Very few people have genetic variations that make exposure to particular conditions or chemicals dangerous
- Employers could potentially avoid susceptible workers rather than improve safety in the workplace

However....



Genetic Screening in the Military

- DNA samples required to identify remains in battle
- Screen for sickle cell anemia & G6PD
- Detection of genetic diseases & risk factors can aid in assignment and relocation decisions
- National Defense Authorization Act of 2008: health coverage granted to all retiring members for at least 6 months of involvement in military and if disability was not detected initially





How much do we really want
to know?



The Havasupai Tribe

- Grand Canyon
- Devastating rates of diabetes (1960s – present)
- 1990 – help from Arizona State University
- No link to Pima Indians
- Other studies:
 - Mental illness
 - High degree of inbreeding – higher susceptibility to disease
 - Insight into tribe's geographical origins → crossing of Bering Sea



Results...



- The Havasupai reacted with anger
- Violation of trust and privacy
- Studies invalidated the tribe's traditional stories and spiritual right to the land

Resolution

- \$700,000 settlement
- Samples were returned and destroyed
- “banishment order” against Arizona State University

Implications:

- The rights of research subjects can be violated when they are not fully informed about how their DNA might be used

Questions to Consider:

- Is it necessary to ask someone who donated DNA for research on heart disease if that DNA can be used for Alzheimer's or addiction research?
- What is the researcher's responsibility in protect their subject's DNA?

How much control/regulation should the FDA have over genomics?

Federal regulation of genetic discrimination:

- Protect the people whose unlucky genetic inheritance makes them vulnerable to discrimination
- Protect those who are at risk for irrational and ill-informed genetic discrimination
- Relieve public fears that would disrupt important genetic research



We must:

- Protect human research participants and inform them of the risk and benefits of genomics studies.
- Ensure fair access to genomic medicine.
- Inform patients about the evolving nature of predictions based on genomic information.
- Inform society about the relationship between genes and environment.
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Things to consider?

- Should the physician only offer genetic tests that is believed to have a net benefit for the patient's health? Should they refuse despite the patient's request?
- If you had a high risk for a disease that you can't do anything about, do you still want to know?
- If you had a hereditary disease, should you be obligated by law to inform your parents, siblings, and children?
- Who's obligation should be it – the patient or the doctor?

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