The Other Side of Genomics

Hoa Mai
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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
  ○ 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?
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 addition 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.
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?
Sources

• National Human Genome Research Institute [http://www.genome.gov/12513979]


