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

Jasmine Johnson
Genomics and Medicine
Professor Doug Brutlag
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 Services hopes to have sequenced the genomes of 100,000 people
Personal Genomics Companies

Partial Genome Sequencing
- 23andMe
- deCODE
- Gentle
- Positive Bioscience

Full Genome Sequencing
- Illumina
- Sequenom
- Complete Genomics
- Navigenics
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?

<table>
<thead>
<tr>
<th></th>
<th>Less Trust</th>
<th>More Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your doctor</td>
<td>14%</td>
<td>86%</td>
</tr>
<tr>
<td>Your spouse</td>
<td>18%</td>
<td>82%</td>
</tr>
<tr>
<td>Researchers studying genetics</td>
<td>34%</td>
<td>66%</td>
</tr>
<tr>
<td>Law enforcement</td>
<td>54%</td>
<td>46%</td>
</tr>
<tr>
<td>Your health insurer</td>
<td>76%</td>
<td>24%</td>
</tr>
<tr>
<td>Your employer</td>
<td>84%</td>
<td>16%</td>
</tr>
</tbody>
</table>

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 settlements due to 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

http://www.nature.com/embor/journal/v11/n6/full/embor201069.html
http://www.nature.com/ejhg/journal/v17/n7/full/ejhg2008254a.html
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2892328/
http://www.genomicslawreport.com/
Ethics of Personal Genomics Today: Discrimination, Privacy and the Psyche

Questions?