#### Carnegie Mellon University CyLab

#### Health and Genetics

Rebecca Balebako

Advisor: Dr. Lorrie Cranor

## Engineering & Public Policy



### Agenda

- Quiz
- Schedule change
- Homework
- Intro to genetic privacy
- GINA: Employment Discrimination
- DNA Testing for Consumers

#### Schedule

- Guest Lecturer November 25<sup>th</sup> on Drones
  - The readings will stay the same but the lectures switched.
- Today's lecture Genetic Privacy

Reminder: November 20 – Draft project paper due

#### **Homework Questions**

# How much do you already know about genomics?

- What is a genome?
- http://www.pbs.org/wgbh/nova/body/publicgenomes.html

#### Genetic diversity

Our genomes are over 99% identical.

Remaining <1% difference => GENETIC VARIATION

Terminology:

How do we talk about our genetic differences?

**MUTATIONS** 

**VARIANTS** 

## Complex relationship between your DNA and environment







Environment and Social Factors

#### **Examples:**

PKU (phenylketonuria): A genetic disease with an environmental cure (diet).

Inherited cancer susceptibility:
Women with same BRCA1 variant differ in whether they develop cancer, type of cancer and age of onset.

Type 2 Diabetes: Common disease with environmental and genetic contributions.

http://www.flickr.com/photos/barl0w/3036412907

#### **DNA Testing for Consumers**

- DTC testing does not produce full genome sequence (unlike Human Genome Project)
- Can report on
  - Ability to taste bitter flavors
  - Photic sneeze reflex
  - Risk for developing heart disease
  - Diabetes

#### 23andme

- Sells genetic profiles on-line: \$99
- Previously offered
  - health reports

returns-with-new-health-report-submission/

- chances of getting dozens of diseases
- likely response to various drugs
- FDA said need to be approved as 'medical device'
- Main business model 'create a massive database' so pharmaceutical and academic researchers can do trials more cheaply

Robert Hof "Seven Months After FDA Slapdown, 23andMe Returns With New Health Report Submission" Forbes.com 6/20/2014 http://www.forbes.com/sites/roberthof/2014/06/20/seven-months-after-fda-slapdown-23andme-



#### Drug response

| Alcohol Consumption, Smoking and Risk of Esophageal Cancer                            | *** |
|---|-----|
| Oral Contraceptives, Hormone Replacement Therapy and Risk of Venous Thromboembolism Q | *** |
| Fluorouracil Toxicity   | *** |
| Pseudocholinesterase Deficiency   | *** |
| Thiopurine Methyltransferase Deficiency new   | *** |
| Caffeine Metabolism   | *** |
| Hepatitis C Treatment Side Effects  | *** |
| Metformin Response  | *** |
| Antidepressant Response   | **  |
| Beta-Blocker Response   | **  |
| Floxacillin Toxicity  | **  |
| Heroin Addiction  | **  |

## Genetic Information Nondiscrimination Act (GINA)

- Signed into law 2008
- Protect people to encourage them to participate in DNA testing and research
- Employers can not use genetic info for hiring or promotion decisions
- Insurers can not use it to make decisions to add or drop people from policies

#### Class Discussion Choice

- GINA: Employment discrimination
- Personal Kits debate

#### GINA: Group Discussions

- You will be in an 'expert' and 'home' group.
- Each expert group will receive information on a case, which you will discuss.
- Then return to your home group and summarize what you learned.

#### GINA: Expert group questions

- How did the company use or try to use genetic information about its employees or job applicants?
- Was a person fired or not hired because of a genetic test or medical condition?
- Was there a lawsuit? If so, what was the result?
   Was an employee rehired, was there a settlement, etc.?
- Do you agree with how the case you studied was resolved? Why or why not?

### DTC: Congressional Hearing

#### Characters who support direct-to-consumer (DTC) genetic testing (Panel A):

- Doctor A Believes DTC testing is beneficial
- Patient A Wants access to DTC genetic testing
- Founder of a DTC company
- Senator A Leaning toward supporting DTC testing; questions witnesses

#### Characters who are against or doubtful of DTC genetic testing (Panel B):

- Doctor B Thinks genetic testing through a doctor is valuable, but is skeptical
  of DTC testing
- Patient B Against DTC genetic testing
- Senator B Is skeptical of DTC tests; questions witnesses

#### DTC: Schedule

- 10 minutes: Work with your group to research or develop the position of your character
- Select one person to represent your group and make a quick statement (3-5 sentences)
- Senators will take turns ask questions

#### Genetics

http://video.pbs.org/video/2215641935/

 www.pbs.org/nova/body/tanzi-genetic-tests.html www.pbs.org/nova/body/public-genomes.html