

March 4th

Monday, March 4, 2019 2:49 PM

Important readings due today: Data Ownership & Belmont Report

Reading Response:

<https://docs.google.com/document/d/19Zw0hPvEuyPO939nDc58kJRyYHSP7sHeQa-qtS20m0/edit>

Informed Consent

- **Tuskegee Syphilis Experiment (1932-1972)**
 - Funded by CDC in order to understand syphilis
 - Recruited black sharecroppers (vulnerable group)
 - Doctors gained "consent" stating they were treating subject with spinal tap, but instead were diagnosing and did not even tell them
 - Gave them free food and free burial if they were to die from the disease
 - In 1947 medication was developed to treat syphilis, but patients were not told about it or given the medication
 - Only stopped because someone on the inside became whistle blower
- **Many other similar things (pre WWII)**
- **Many Many during WWII (Us, Germany, Japan)**
 - US, in return for not prosecuting for war crimes, was given access to Nazi and Imperialist Japanese data
 - Japan
 - Wounded people to train surgeons
 - Vivisection of live humans
 - Infecting humans with pathogens
 - Bio/chem weapons testing
 - Germany
 - Decompression studies
 - Mengele's experiments
 - Hypothermia studies
 - Wound-healing studies
- **Nuremberg code**
 - [Nuremberg Code](#)
 - Ten points
 - Consent must be fully voluntary
 - Experiment has to be likely to yield fruitful results for population and participants
 - Avoid all unnecessary suffering
 - Can't experiment if death or disabling injury will occur
 - Conducted by scientists (qualified)
 - Human subject can revoke consent at any time
- **Declaration of Helsinki**
 - [Declaration of Helsinki](#)
 - Similar to Nuremberg, developed by WMA
 - Subject welfare takes precedence, even over laws
 - Subject to independent ethical review
- **IRB (Institutional Review Board)**
 - [Institutional review board](#)
 - Weigh harm vs benefit in studies involving humans
 - Composed of people from different backgrounds
 - Ensure minimum violation necessary for study

- **Belmont Report**
 - [Belmont Report](#)
 - Respect for persons
 - Beneficence
 - Justice
- **The Common Rule**
 - [Common Rule](#)
 - Adopted by govt. research - required
 - Risks to subject minimized
 - Risks are reasonable in relation to benefits to subject or society
 - Etc.

Application of Theories to Belmont Report

(See: [Principlism](#) - the combination of different ethical theories to form principles to follow)

- **Moral Law Theory**
 - Respect for persons is central to theory and Report
 - Ethical duty to respect humanity of others
 - Beneficence can be considered to be an example of a universal moral law
- **Rule Utilitarian**
 - Ensure benefits of research are distributed fairly so that the vulnerable party is not taken advantage of
 - People who can't think critically are able to follow these rules and be protected by them
 - Preference maximization
- **Act Utilitarian**
 - (Personally I *really* don't think this applies)
 - Could be used for beneficence in a similar way as rule utilitarianism (see above)
- **Contractualism**
 - The point is to create symbiotic situation
 - No factors relating to self (Ego), and is at its root about equality
 - Respect for persons - beneficence comes from this
 - Actualized beneficence is Justice
- **Virtue Theory**
 - These principles are essentially definitions of virtue
 - To follow these principles is to act virtuously
 - Virtue theory is a great method by which to apply these principles
 - Virtue theory justifies both parts of the research
 - Researchers want to do good with their research
 - Participants want to do good by being part of research

Case Study (A/B testing)

What constitutes research vs. normal testing

- **OkCupid**
 - Mission Statement: Match on what matters... A one of a kind algorithm matches people.
 - Research Questions
 - Do traditional couples and nontraditional couples meet in same way?
 - Have recent marriages met in same way parents and grandparents did?
 - Does meeting online result in less couple stability
 - Meeting online is super duper common now!
 - 1/4 straight couples, 2/3 gay couples

- Couples who meet online are not more likely to break up
- Middle age people are most likely to use online dating
- **Love is Blind Study:**
 - Turned off pictures for a day
 - Users engaged in more meaningful conversation
- **Power of Suggestion**
 - Is the match percentage actually real, or does telling someone they are a match make them work well together?
 - When the match % was high, people were more likely to engage in conversation
 - Suggestibility was significant factor
 - Each work equally (suggestion and real match %) , but combined works double!
- Blog by company displayed these experiments and was met by media backlash
- They stated that all online companies do this sort of thing and it is not abnormal
- Backtracked and said experiment was small - changed wording from experiment to "diagnostic test"

Computer died here so no more notes unfortunately :(