Data and Society
Digital Rights 2 – Lecture 11

4/5/19
Announcements 4/5

• **Briefings due today.** Put hardcopy on Fran’s desk

• **Office hours today 3-4**

• Class Wednesday, April 10

• **Topic reports for Groups 2 and 3 due April 12**
<table>
<thead>
<tr>
<th>Wednesday Section</th>
<th>Friday Lecture (first half)</th>
<th>Second half of class</th>
<th>Assts.</th>
</tr>
</thead>
<tbody>
<tr>
<td>January 9: NO CLASS</td>
<td>January 11: INTRO – DATA AND SOCIETY</td>
<td>Fran presentation demo</td>
<td></td>
</tr>
<tr>
<td>January 16: NO CLASS</td>
<td>January 18: BIG DATA 1; Topic groups / Topic materials information</td>
<td>Student presentations</td>
<td></td>
</tr>
<tr>
<td>January 23: Student presentations</td>
<td>January 25: BIG DATA 2</td>
<td>Student presentations</td>
<td>Op-Ed instructions</td>
</tr>
<tr>
<td>January 30: NO CLASS</td>
<td>February 1: DATA AND SCIENCE</td>
<td>Student presentations</td>
<td></td>
</tr>
<tr>
<td>February 6: NO CLASS</td>
<td>February 8: DATA STEWARDSHIP AND PRESERVATION</td>
<td>Student presentations</td>
<td>Group Topics due</td>
</tr>
<tr>
<td>February 13: NO CLASS</td>
<td>February 15: INTERNET OF THINGS</td>
<td>Student presentations</td>
<td></td>
</tr>
<tr>
<td>February 20: Student presentations</td>
<td>February 22: DATA AND PRIVACY / FOUNDATIONS</td>
<td>Student presentations</td>
<td>Op-Ed Drafts due</td>
</tr>
<tr>
<td>February 27: NO CLASS</td>
<td>March 1: DATA AND PRIVACY / POLICY AND REGULATION</td>
<td>Student presentations</td>
<td>Briefing instructions Op-Ed Drafts Returned</td>
</tr>
<tr>
<td>March 6: Spring Break</td>
<td>March 8: Spring Break</td>
<td></td>
<td></td>
</tr>
<tr>
<td>March 13: Student presentations</td>
<td>March 15: DATA AND ENTERTAINMENT [ANDY MALTZ]</td>
<td>Student presentations</td>
<td>Topic Reports 1 due</td>
</tr>
<tr>
<td>March 20: TOPICS PRESENTATIONS 1</td>
<td>March 22: DATA AND DATING</td>
<td>Student presentations</td>
<td></td>
</tr>
<tr>
<td>March 27: NO CLASS</td>
<td>March 29: DIGITAL RIGHTS 1</td>
<td>Student presentations</td>
<td>Op-Ed Finals due</td>
</tr>
<tr>
<td>April 3: NO CLASS</td>
<td>April 5: DIGITAL RIGHTS 2</td>
<td>Student presentations</td>
<td>Briefings due</td>
</tr>
<tr>
<td>April 17: TOPICS PRESENTATIONS 2</td>
<td>April 19: CAREERS IN TECH [KATHY PHAM]</td>
<td>Student presentations (5)</td>
<td></td>
</tr>
<tr>
<td>April 24: Student presentations (6)</td>
<td>April 26: TOPICS PRESENTATIONS 3</td>
<td>Student presentations (2)</td>
<td></td>
</tr>
</tbody>
</table>
Digital Rights 2

• Data Rights, Research, and the Public Sector
  – Informed Consent
    • The Icelandic Health Database
    • Havasupai Tribe vs. ASU
  – China’s Social Credit System
What is informed consent

- **Informed consent** is a process for getting permission before conducting a healthcare intervention on a person, or for disclosing personal information. ... Informed consent is collected according to guidelines from the fields of medical ethics and research ethics. An informed consent can be said to have been *given based upon a clear appreciation and understanding of the facts, implications, and consequences of an action.* [Wikipedia]

- Informed consent part of GDPR, U.S. health data laws, etc.
- **Concept is useful in thinking about data rights for users and consumers.**
  - T&C provide a form of informed consent for consumers but it’s considered by most to be insufficient for data protection.
Informed Consent: the Icelandic Health Sector Database
Icelanders

- Iceland has a population of ~338,000 and is the most sparsely populated country in Europe.

- Iceland provides universal health care to its citizens and spends a fair amount on health care, ranking 11th in health care expenditures as a percentage of GDP and 14th in spending per capita.
  - Health care system is ranked 15th in performance by the World Health Organization.

- Ethnically homogeneous. Most Icelanders descendants of Germanic and Gaelic (Celtic) settlers.
  - 91% Icelandic
  - 4% Polish
  - 5% Other

- Iceland has extensive genealogical records dating back to the late 17th century and fragmentary records extending back to the 9th century.

Source: Wikipedia articles on Iceland, Icelanders
Whole Country Health Data

- **1996**: deCODE Genetics corporation (private) founded to identify human genes associated with common diseases using populations studies and apply the knowledge gained to guide the development of candidate drug treatments.

- Company lobbied government on the **1998 Health Sector Database Act** with the intention of creating a national biological database (the Icelandic Health Sector Database [HSD]) to store health information which could be used for research.

- deCODE won the bidding process to build the database.

- Act allowed company to use data for profit but required protection of privacy.
Scientific and health promise – the devil is in the details ...

• **DeCode press release:** “Based on the unique genetic properties of the Icelandic population DeCode will map and discover genes causing disease.”

• **HSD Act:** “The objective of this legislation is to authorize the creation and operation of a centralised database of non-personally identifiable health data with the aim of increasing knowledge in order to improve health and health services.”

HSD Act

• Act authorized licensing of all medical record data to the licensed company (deCODE chosen in 2000) for commercial development without the express consent of individuals, “presuming consent” (assume consent unless opt-out).
  – Information on deceased individuals would be automatically included.
• Act specified encryption architecture for health information and fees for non-commercial access to the database.
• Act provided virtual control, use, and ownership of (government-supported) health data to government.

• Trouble in the making:
  – Many Icelanders opted out of providing their data and many Icelandic doctors refused to provide data from their patients without specific consent
  – Issues about what terms meant, who was overseeing deCode and deCode’s private/public conflicts
deCODE Genetics

• Focus of deCODE was to use the HSD to identify human genes associated with common diseases using population studies, and apply the knowledge gained to guide the development of candidate drugs.

• deCODE made strong economic, political, cultural and health arguments to make their case.

• HSD never built. Company claims that it has gathered data and medical records from over 160,000 volunteers.

Decode Genetics, https://www.decode.com/, 2019

Fran Berman, Data and Society, CSCI 4370/6370
HSD effectively killed by Icelandic Supreme Court in 2003

- *Gudmundsdóttir vs. Iceland* case concerned woman who asked that her deceased father’s information NOT be transferred to the HSD. Request was denied based on “presumed consent” and case went to court.

- Woman wanted to prevent her father’s genetic data from being in the database as it would have made it more possible to infer hereditary characteristics that would have applied to herself.

- Icelandic Supreme Court ruling includes the statement:

  “Extensive information is entered into medical records on people’s health, their medical treatment, lifestyles, social circumstances, employment and family. They contain, moreover, a detailed identification of the person that the information concerns. It is unequivocal that the provisions of Paragraph 1 of Article 71 of the Constitution apply to information of this kind and that they guarantee protection of privacy in this respect”

- Supreme Court ruling effectively ruled HSD Act of 1998 unconstitutional.
Many problems with the HSD

- deCODE failed to reach deals with the key partners needed to build the HSD, including the Icelandic Data Protection Commission
- Issues around ethics of individual health privacy vs. open access to scientific data
- Issues around a for-profit commercial company stewarding the data and making money off it
- Issues around insufficient specification for infrastructure to support privacy
- Issues around lack of informed consent
  - By June 2001, around 20,000 (7%) Icelanders had opted out of the HSD.
- deCODE still retained volunteer data and went through a series of corporate iterations.
Scientific progress: Results from the data

• Although the HSD was never built, deCODE pursued traditional genome-wide association studies to try to identify genetic changes contributing to common diseases.

• deCODE data used for discoveries about genes that increase risk for kidney disease, cancer, lupus, vascular disease, schizophrenia, osteoporosis, etc.
  – One result identified a gene that protects against Alzheimer’s
  – DeCODE identified mutations in BRCA2 that convey sharply increased risk of breast and ovarian cancers.

• Subsequent studies showed that both data and representation not as unique as deCode claimed. Other populations represented heterogeneity more accurately and were at least as successful in developing large-population scientific results (e.g. Estonia)

Information from http://www.els.net/WileyCDA/ElArticle/refId-a0005180.html
Medical ethics conundrums

- DeCode collected full DNA sequences of 10K individuals and claims that it can impute the DNA of 320K citizens.
- Data can identify 2K people with BRCA2 gene mutation in Iceland but cannot inform citizens as volunteers were promised anonymity. People with imputed data never submitted samples or gave consent.

[Source: https://www.technologyreview.com/s/536096/ genome-study-predicts-dna-of-the-whole-of-iceland/]

Fran Berman, Data and Society, CSCI 4370/6370
Complicated trajectory

- DeCODE went bankrupt in 2009 but continued as private company (NextCODE) and was bought by Amgen in 2012. No compensation was given to Icelanders.
- Services and assets of DeCODE went through many transitions:

  - deCODE founded in 1996; filed for bankruptcy in 2009
  - Saga Investments LLC purchased deCODE services and assets in 2010
  - Amgen purchased deCODE in 2012, spun off NextCODE Health in 2013
  - NextCODE acquired by WuXi PharmaTech in 2015

https://www.genengnews.com/topics/omics/wuxi-snaps-up-nextcode-health-for-65m/
Ethics of informed consent in the U.S.: Havasupai Indians and Arizona State University

- Havasupai Indians gave informed consent for researchers from Arizona State University to take DNA samples to ascertain genetic clues to the tribes’ high rate of Type 2 diabetes.
- Collected blood samples used to study other things including mental illness and theories of the tribe’s geographical origins that contradict original stories.
- Havasupai sued Arizona State University for violation of Informed Consent.

Background 1

- Havasupai Indians live in a village on the floor of the western Grand Canyon. Only way out is hiking, helicopter or horse.
- Increasing incidence of Type 2 diabetes making it increasingly hard for members to leave or get medical care such as dialysis.
- In 1989, members of a tribe of ~650 Havasupai Indians approached Arizona State University professor John Martin (with whom the tribe had a preexisting and trusted relationship) to investigate why the incidence of diabetes within their community was increasing.
  - Based on the experience of a different tribe, they were concerned that the problem was genetically linked and wanted to use the information to assess risks.
- Martin approached colleague Therese Markow, a geneticist and researcher in medical disorders, to assist in the study.
- 100 members of the tribe signed a broad consent document “to study the causes of behavioral/medical disorders”. Not clear that they understood what they were signing.
  - Members believed they were donating blood specifically for the diabetes study.
  - Blood has deep spiritual meaning in community.
Background 2

• ASU researchers determined that the genetic link to diabetes they were seeking did not exist.

• Research into medical disorders continued without seeking additional consent.
  – Other ASU researchers also utilized the samples for their work and published papers about inbreeding, alcoholism, and the origin and migration of the tribe from Asia.
  – Publications and dissertation research for other scientific questions done with the samples

• Havasupai Tribe brought a lawsuit against ASU [Havasupai Tribe vs. the Arizona Board of Regents] that included lack of informed consents, violation of civil rights, and intentional or negligent infliction of emotional distress.
  – Tribe’s traditional beliefs and stories were that they had originated in the canyon and were assigned to be its guardian.
  – Studies violated informed consent and theories about the tribe’s origin conflicted with their core beliefs.
Penalties and Ethical Challenges

• ASU paid $1.7+M to investigate the case and attempt to keep it out of the courts.

• 41 members of the Havasupai Tribe settled in April 2010 and received $700,000, return of the blood samples, and additional assistance (including scholarships and help in obtaining federal funding for a health clinic).
  — Some tribes still refuse to work with ASU.

• Scientific benefit vs. individual consent: When should data / samples donated for one purpose be legitimately used for another?
China’s Social Credit System

• National reputation system being developed by the Chinese government.
  – Expected to be live by 2020.

• Focus is to develop a “sincerity culture”, where “sincerity and trustworthiness become conscious norms of action among all the people”.

• Unified system standardizes the assessment of citizens’ and businesses’ economic and social reputation.
  – System is a form of mass surveillance, powered by big data analysis technologies.

• Jurisdiction: Companies and foreign companies operating in the Chinese market on mainland China
Sincerity Culture Goal by 2020 (from https://chinacopyrightandmedia.wordpress.com/2014/06/14/planning-outline-for-the-construction-of-a-social-credit-system-2014-2020/)

• “Take the lead in using credit information and credit products in administrative permission, government procurement, tendering and budding, labour and employment, social security, scientific research management, cadre promotion and appointment, management and supervision, application for government financial support and other such areas, and foster the development of a credit services market.”

• System will manage rewards or punishments of citizens on the basis of their economic and personal behavior.

Punishments may include:
• Flight bans
• Exclusion from private schools (parents’ scores affect children)
• Slow internet connection
• Exclusion from high prestige work
• Exclusion from hotels
• Registration on a public blacklist
• Public inclusion of scores on dating sites

Rewards include:
• Easier access to loans and jobs
• Priority during bureaucratic paperwork
• Better access to better goods and services
Social experiment in transparency, accountability and compliance? “Authoritarian video game”?  

- System will be state-run, party-inspired, data-driven. Private companies working with the government help provide social media, online shopping, surveillance data, and other personal information.

- Personal records will be comprehensive and constantly updated and include citizen’s political persuasions, comments, associations, consumer habits, etc.

- Social credits: Each citizen starts off with a score of 1000.
  - 960-1000 is an “A”
  - 850-955 is a “B”
  - 600-840 is a “C”
  - Lower scores are “D”

- Rankings can be reduced for both major and minor infractions, including drunk driving, embezzlement, fraud, playing too many video games, spreading “fake news”, refusing military service, etc.

- **High credit scorers will gain social privileges while low credit scorers will encounter more roadblocks.**

---

Fran Berman, Data and Society, CSCI 4370/6370
Not so far from current U.S. practice?

• Close in some respects to U.S. practice: people with more resources get more financial breaks while people with fewer resources are routinely punished:
  – Not illegal for employers to deny an applicant a job offer based on information in their credit report.
  – People with poor credit may be turned down for housing.
  – Historical barriers for people of color pursuing homeownership
  – People with bad credit pay more for car insurance

• 2019 UltraFICO score (based on financial behavior) may remedy some of these inequities.
  – UltraFICO takes into account whether one saves regularly, maintains a $400 bank balance, avoids overdrafts and pays bills on time, rather than focusing on length of credit history.
When should your government be allowed to gather your data and what should be permissible to do with it?

• Data about you that to support the public good?
• Data about you to ensure compliance with the rule of law?
• Data about you for national security purposes?

Which data?
Under what circumstances?
Is it OK if you don’t know about it?
Should the rules be different than the private sector?

Fran Berman, Data and Society, CSCI 4370/6370
Lecture 11 Sources (not already on slides)

- Wikipedia entries on Social Credit System, Iceland
- “China’s Surveillance State should scare everyone,” The Atlantic, [https://www.theatlantic.com/international/archive/2018/02/china-surveillance/552203/](https://www.theatlantic.com/international/archive/2018/02/china-surveillance/552203/)
- “Is UltraFICO score good or bad for consumers?”, USN&WR, [https://creditcards.usnews.com/articles/is-the-ultrafico-score-good-or-bad-for-consumers](https://creditcards.usnews.com/articles/is-the-ultrafico-score-good-or-bad-for-consumers)
Break
Presentations
April 10


- “What will online dating be like in 2030?” Mashable, https://mashable.com/article/future-online-dating/#gBYFaVsRCZqf [Charlie Y.]

April 12


• “Can we teach machines moral behavior? Three perspectives on ethics for artificial intelligence”, Medium, https://medium.com/@drpolonski/can-we-teach-morality-to-machines-three-perspectives-on-ethics-for-artificial-intelligence-64fe479e25d3 [Jacob S]


April 19


April 24


April 26 [Last Day for a Presentation]

• “Are we ready for an implant that can change our moods?”, NPR, https://www.npr.org/sections/health-shots/2019/03/29/707883163/are-we-ready-for-an-implant-that-can-change-our-moods

Today’s Presentations


