Medical Data Privacy and Ethics in the Age of Artificial Intelligence

Lecture 3: Ethical Issues in Biomedical Research and Informatics

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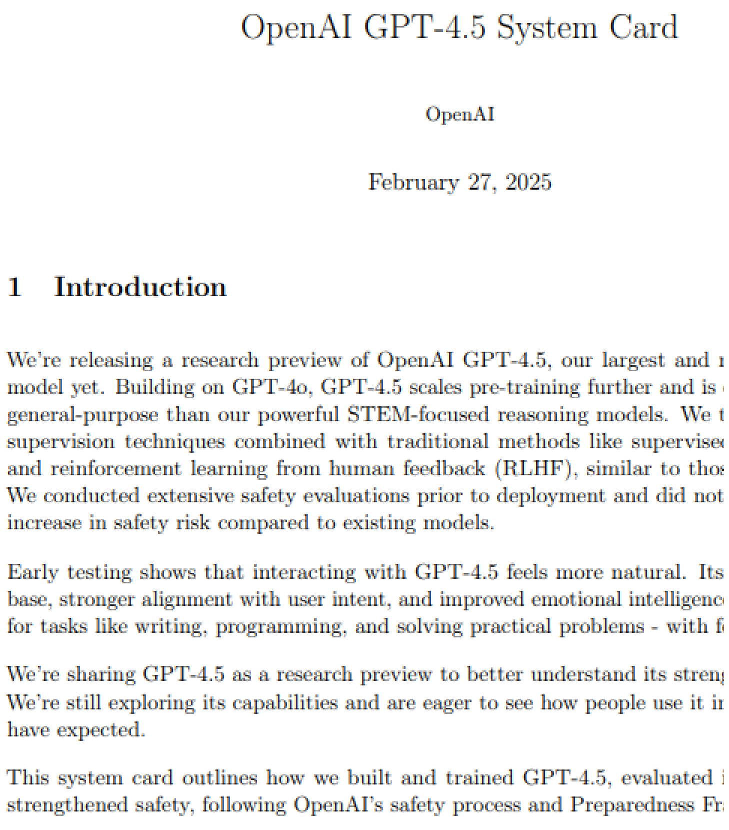
February 28, 2025

Latest News ab



OpenAI GPT-4.5 System Card

OpenAI

February 27, 2025

1 Introduction

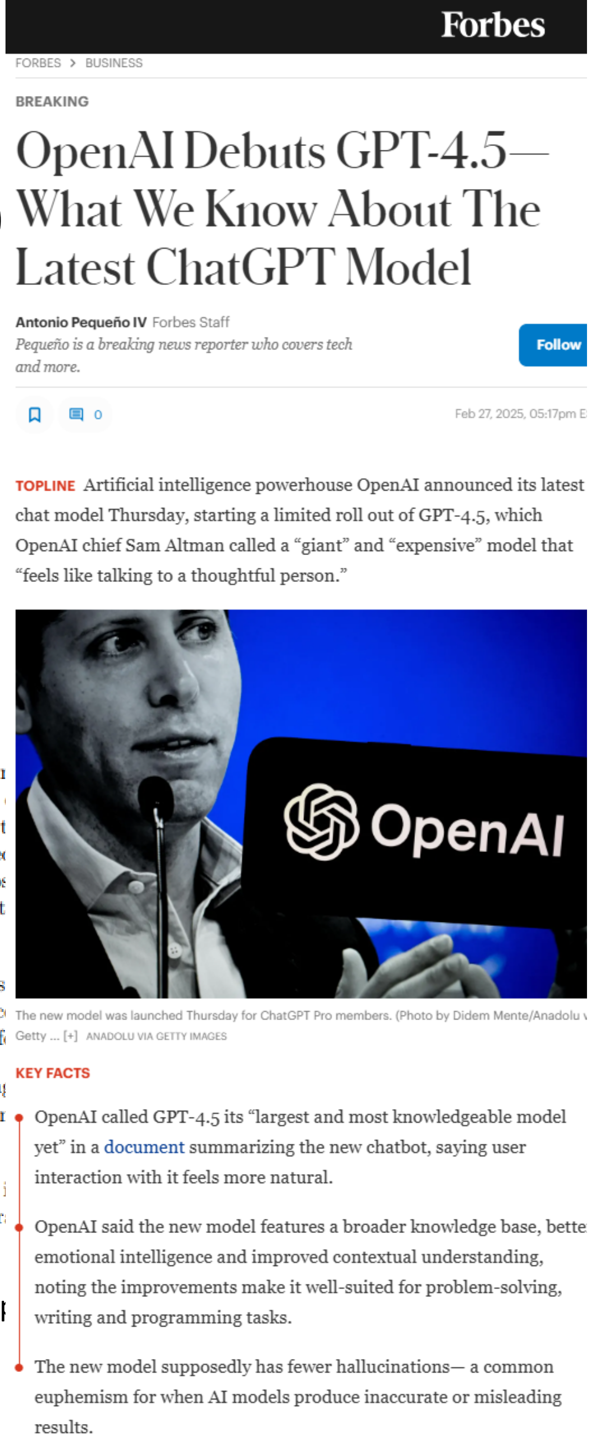
We're releasing a research preview of OpenAI GPT-4.5, our largest and
model yet. Building on GPT-4o, GPT-4.5 scales pre-training further and is
general-purpose than our powerful STEM-focused reasoning models. We
supervision techniques combined with traditional methods like supervise
and reinforcement learning from human feedback (RLHF), similar to thos
We conducted extensive safety evaluations prior to deployment and did not
increase in safety risk compared to existing models.

Early testing shows that interacting with GPT-4.5 feels more natural. Its
base, stronger alignment with user intent, and improved emotional intelligenc
for tasks like writing, programming, and solving practical problems - with f

We're sharing GPT-4.5 as a research preview to better understand its stren
We're still exploring its capabilities and are eager to see how people use it i
have expected.

This system card outlines how we built and trained GPT-4.5, evaluated
strengthened safety, following OpenAI's safety process and Preparedness Fr

https://cdn.openai.com/gpt-4-5-system-card-2272025.



Forbes

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BREAKING

OpenAI Debuts GPT-4.5—What We Know About The Latest ChatGPT Model

Antonio Pequeño IV Forbes Staff
Pequeño is a breaking news reporter who covers tech and more.

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0

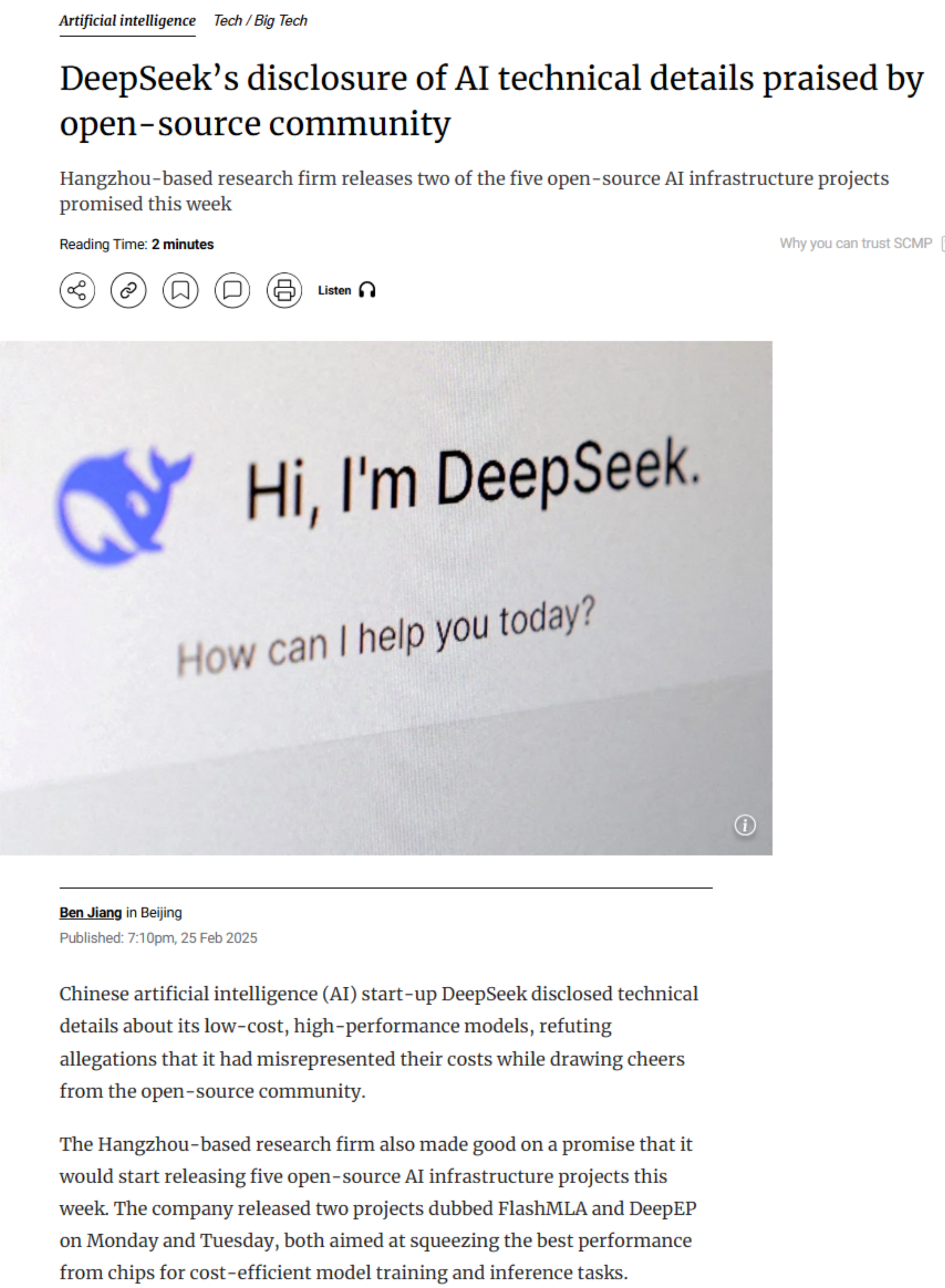
Feb 27, 2025, 05:17pm E

TOPLINE Artificial intelligence powerhouse OpenAI announced its latest chat model Thursday, starting a limited roll out of GPT-4.5, which OpenAI chief Sam Altman called a "giant" and "expensive" model that "feels like talking to a thoughtful person."

The new model was launched Thursday for ChatGPT Pro members. (Photo by Didem Mente/Anadolu v Getty ... [+] ANADOLU VIA GETTY IMAGES

KEY FACTS

- OpenAI called GPT-4.5 its "largest and most knowledgeable model yet" in a document summarizing the new chatbot, saying user interaction with it feels more natural.
- OpenAI said the new model features a broader knowledge base, bette emotional intelligence and improved contextual understanding, noting the improvements make it well-suited for problem-solving, writing and programming tasks.
- The new model supposedly has fewer hallucinations— a common euphemism for when AI models produce inaccurate or misleading results.



Artificial intelligence *Tech / Big Tech*

DeepSeek's disclosure of AI technical details praised by open-source community

Hangzhou-based research firm releases two of the five open-source AI infrastructure projects promised this week

Reading Time: **2 minutes**

Why you can trust SCMP

Listen

Ben Jiang in Beijing
Published: 7:10pm, 25 Feb 2025

Chinese artificial intelligence (AI) start-up DeepSeek disclosed technical details about its low-cost, high-performance models, refuting allegations that it had misrepresented their costs while drawing cheers from the open-source community.

The Hangzhou-based research firm also made good on a promise that it would start releasing five open-source AI infrastructure projects this week. The company released two projects dubbed FlashMLA and DeepEP on Monday and Tuesday, both aimed at squeezing the best performance from chips for cost-efficient model training and inference tasks.

Learning Objectives of This Lecture

- Understand the importance of informed consent and institutional review boards (IRBs) in biomedical research.
- Know the concept and sensitive personal information.
- Know better about the concept and definition of privacy.

Ethical Issues in Biomedical Engineering

- Unacceptable risk-benefit ratios
- Issues of informed consent
- Problems of fairness and accessibility
- Persistent academic misconduct.
  - Case study: Haruko Obokata falsified images and data in her research paper. (2014)
  - Fabrication, falsification, plagiarism, providing fake peer reviews, and paper submission on behalf of others.
  - 834 papers with authors from China retracted from SCIE from Web of Science during 1997-2016, in which **31% due to plagiarism**, **19% due to falsification**, 14% withdrawal, **12% providing fake peer reviews**.

Page 297

Li Z et al. Ethics in Engineering (Ed.2) (Ch.12) 2019.

Ethical Guidelines for Biomedical Engineering

- According to "*Nuremberg Code*", "*Belmont Report*", "*International Ethical Guidelines for Biomedical Research Involving Human Subjects*", "*Declaration of Helsinki*", ethical guidelines for biomedical engineering include:
  1. Informed choice
  2. Risk minimization
  3. Benefit maximization
  4. Collaboration and mutual assistance
  5. Fairness and transparency
  6. Honesty and integrity
  7. Accountability

Ethical review points for biomedical engineering projects or activities involving human subjects

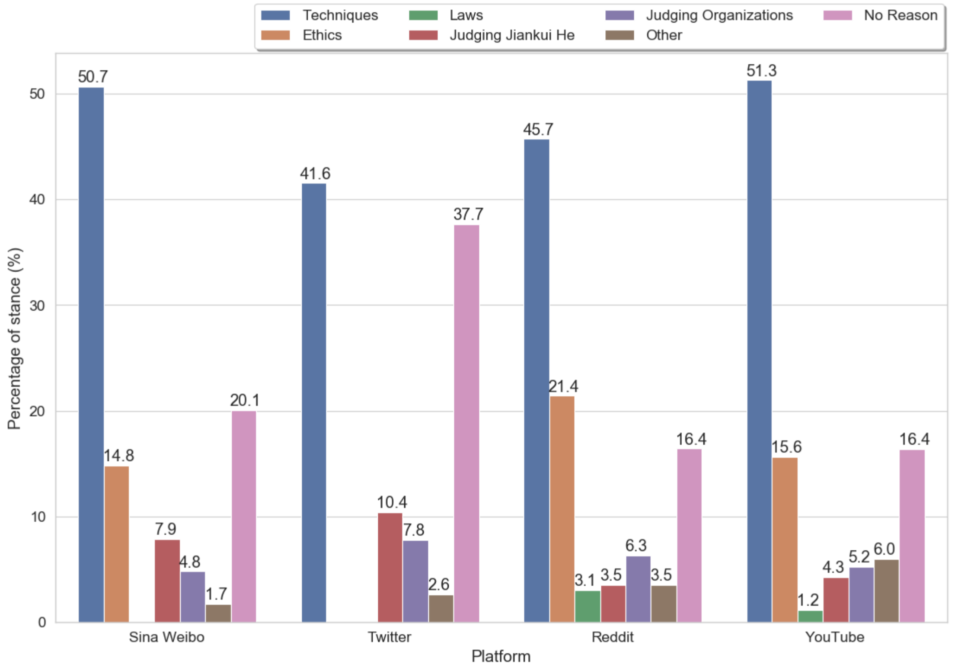
- Whether it truly helps to address specific biomedical issues;
- Whether it is scientifically and technologically reliable and feasible;
- Whether the interests and well-being of the subjects are truly prioritized;
- Whether informed consent is genuinely obtained from the subjects, and whether privacy protection is ensured;
- Whether benefits are maximized and risks minimized;
- Whether the principle of fairness is strictly followed;
- Whether there are any conflicts of interest.

Ethical Issues in Genetic Technology

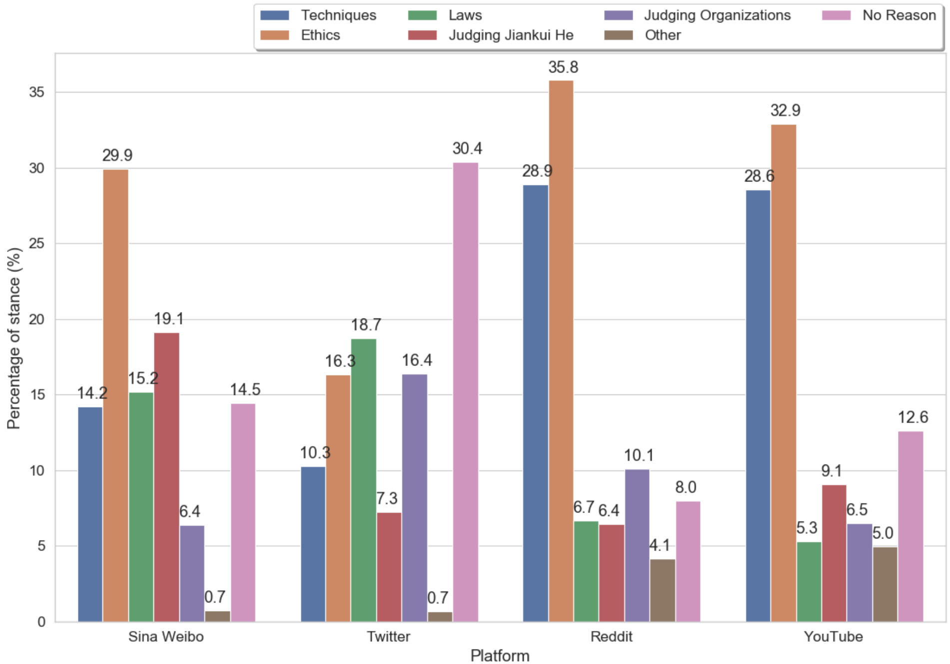
- Issues in genetic testing:
    - Misunderstanding and misuse of genetic information.
    - Commercialization has led to dilemmas in decision-making
    - Genetic privacy breaches.
    - **Case studies**: Genetic discriminations, BRCA gene patent. Page 301
- Issues in Gene Therapy and Enhancement
    - Editing Human Embryo Genes using CRISPR-Cas9 technology
    - **Case study**: 2018 Gene-edited Babies "Jiankui He" event
- Collection and Use of Human Genetic Samples
    - Re-consent
    - Ownership

Li Z et al. Ethics in Engineering (Ed.2) (Ch.12.2) 2019.

Salient words for supporting (green) and opposing (red) stances within each web-based platform.



The reasons for supporting stances within 4 platforms.



The reasons for opposing stances within 4 platforms.

Ni C, **Wan Z**, Yan C, Liu Y, Clayton EW, Malin B, Yin Z. The Public perception of the# GeneEditedBabies event across multiple social media platforms: observational study. Journal of Medical Internet Research. 2022 Mar 11;24(3):e31687.

Ethical Issues in Organ Transplantation

- Tissue Engineering and Organ Regeneration
  - Case: *The Immortal Life of Henrietta Lacks*, 2011 -- Rebecca Skloot
- Informed Consent in Organ Donation
- Fair Distribution of Transplantable Organs

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NOT FOR REAL ID PURPOSES
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DUPS: 00
3 DOB: 01/07/1973
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2 ANDREW JASON
8 123 MAIN STREET
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4b EXP: 01/08/2026
4a ISS: 01/07/2022
15 SEX: M 18 EYES: BRO
16 HGT: 5'-11"
9 CLASS: C
9a END: NONE
12 RESTR: NONE
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Andrew Sample
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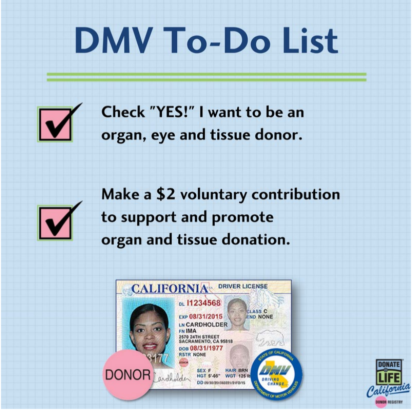
♥ ORGAN DONOR

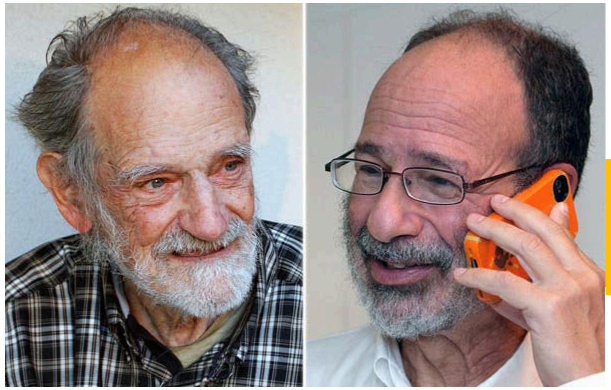


DMV To-Do List

☑ Check "YES!" I want to be an organ, eye and tissue donor.

☑ Make a $2 voluntary contribution to support and promote organ and tissue donation.

Harvard
Princeton
UCLA



Lloyd S. Shapley   Alvin E. Roth

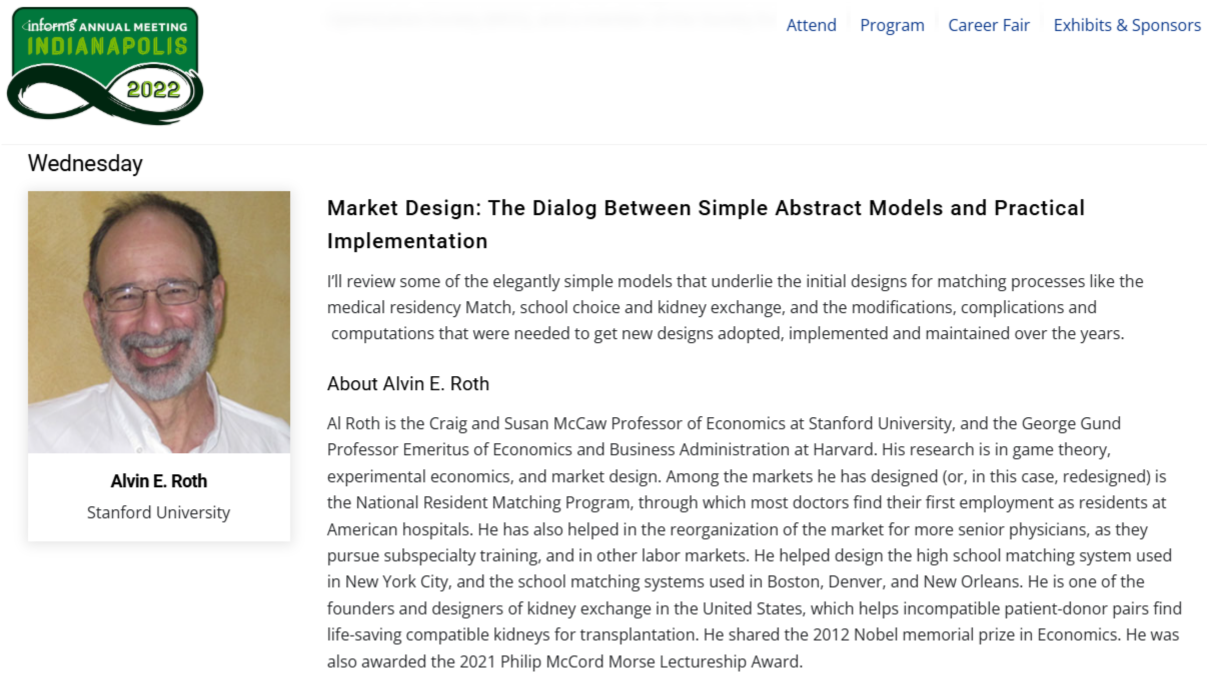
Columbia
Stanford
Harvard

- The theory of stable allocations
- The practice of market design

The 2012 Nobel Prize in Economic Sciences

Alvin E. Roth is an economist who helped improve kidney donation by using economic theory to create kidney exchanges. His work has led to thousands of more kidney transplants worldwide and earned him the 2012 Nobel Prize in Economics.

Li Z et al. Ethics in Engineering (Ed.2) (Ch.12.3) 2019.



Wednesday

Alvin E. Roth

Stanford University

Market Design: The Dialog Between Simple Abstract Models and Practical Implementation

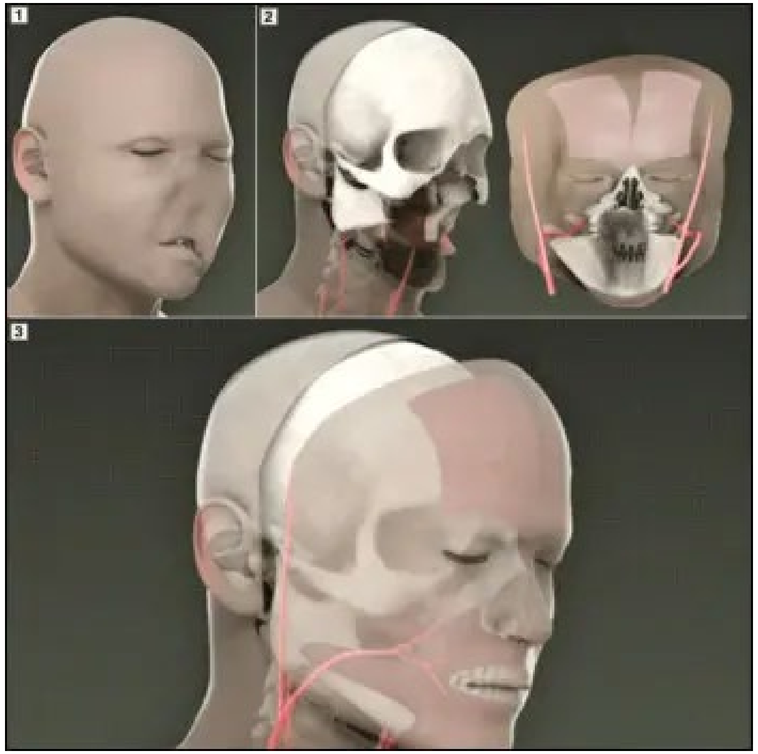
I'll review some of the elegantly simple models that underlie the initial designs for matching processes like the medical residency Match, school choice and kidney exchange, and the modifications, complications and computations that were needed to get new designs adopted, implemented and maintained over the years.

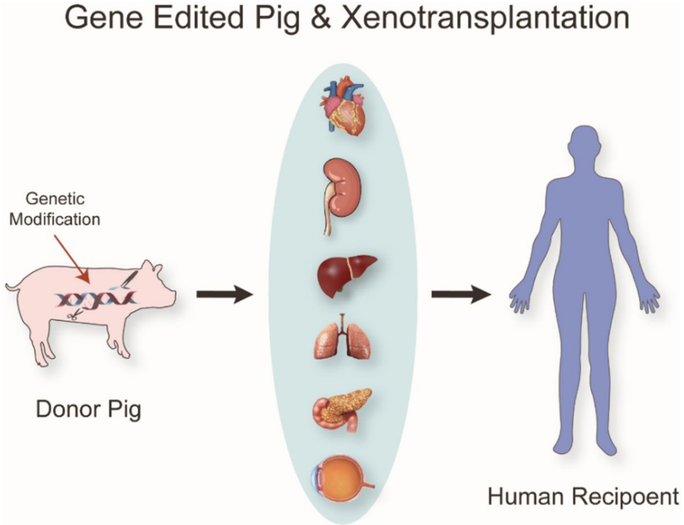
About Alvin E. Roth

Al Roth is the Craig and Susan McCaw Professor of Economics at Stanford University, and the George Gund Professor Emeritus of Economics and Business Administration at Harvard. His research is in game theory, experimental economics, and market design. Among the markets he has designed (or, in this case, redesigned) is the National Resident Matching Program, through which most doctors find their first employment as residents at American hospitals. He has also helped in the reorganization of the market for more senior physicians, as they pursue subspecialty training, and in other labor markets. He helped design the high school matching system used in New York City, and the school matching systems used in Boston, Denver, and New Orleans. He is one of the founders and designers of kidney exchange in the United States, which helps incompatible patient-donor pairs find life-saving compatible kidneys for transplantation. He shared the 2012 Nobel memorial prize in Economics. He was also awarded the 2021 Philip McCord Morse Lectureship Award.

Ethical Issues in Organ Transplantation (cont.)

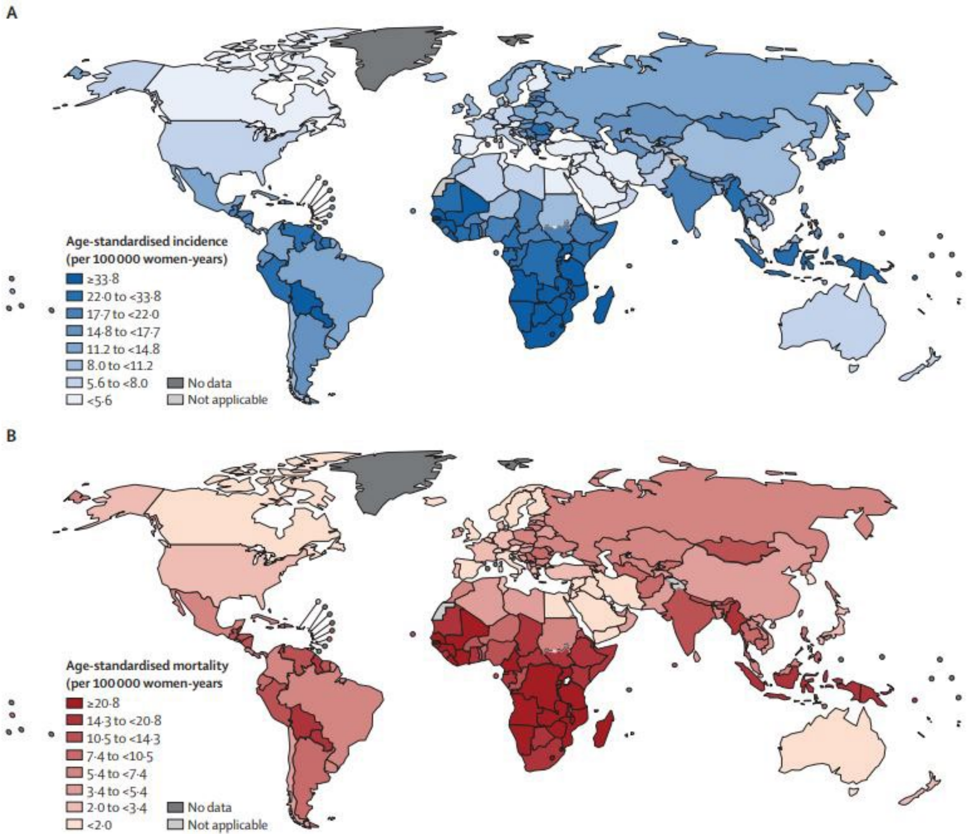
- Ethical Dilemmas in Special Organ Transplantation
  - Head Transplantation
  - Face Transplantation
  - Xenotransplantation

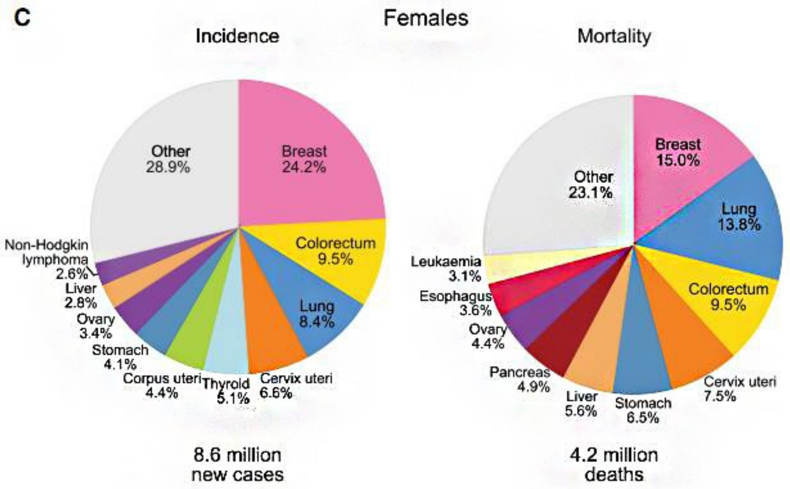




Ethical Issues in Organ Transplantation (cont.)

- Ethical Dilemmas in Special Organ Transplantation
    - Head Transplantation
    - Face Transplantation
    - Xenotransplantation
    - Uterus Transplantation





Singh D, Vignat J, Lorenzoni V, Eslahi M, Ginsburg O, Lauby-Secretan B, Arbyn M, Basu P, Bray F, Vaccarella S. Global estimates of incidence and mortality of cervical cancer in 2020: a baseline analysis of the WHO Global Cervical Cancer Elimination Initiative. The lancet global health. 2023 Feb 1;11(2):e197-206.

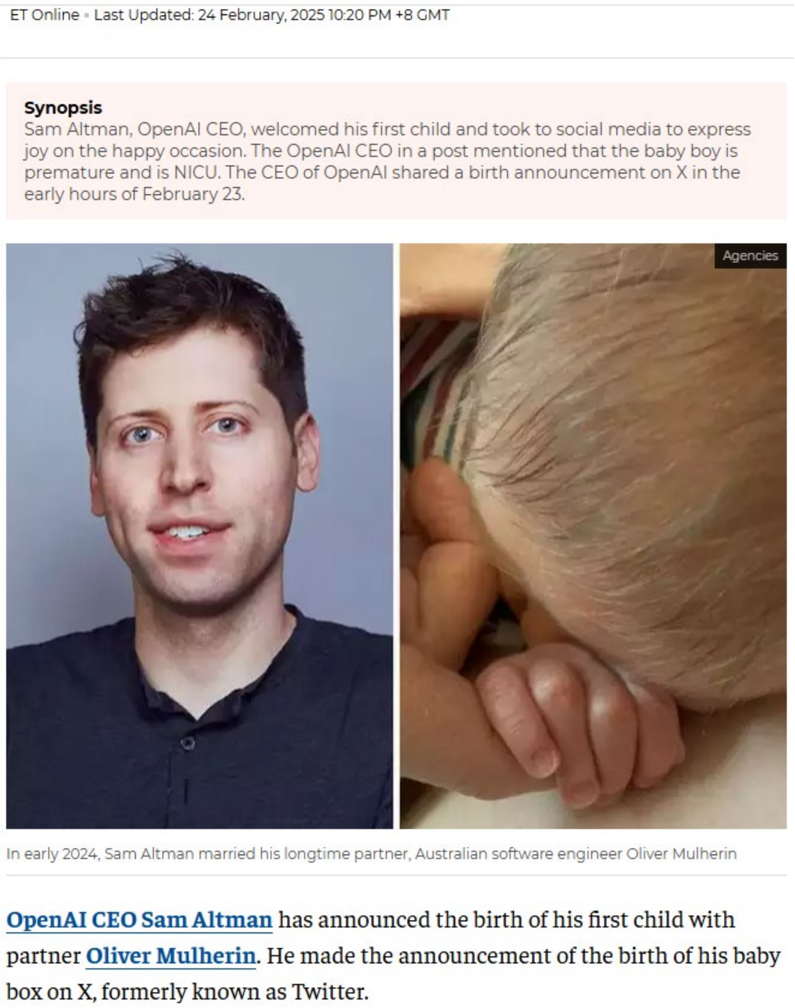
Ethical Issues in Pharmaceutical Engineering

- Ethical Issues in Clinical Trials for Drugs
  1. Lack of Scientific Rigor in the Research Proposal
  2. Violation of the Right to Informed Consent
  3. Unfair Distribution of Risks and Benefits
  4. Data Falsification in Clinical Trials
  5. Inadequate Oversight and Review
- Ethical Guidelines in Clinical Trials for Vaccines
  - Scientific Rigor, Informed Consent
  - Fair Selection of Participants
  - Safety and Efficacy, Fair Distribution

Li Z et al. Ethics in Engineering (Ed.2) (Ch.12.4) 2019.

Other Ethical Issues in Life Sciences

- Reproductive Technology
- Stem Cell Research



ET Online • Last Updated: 24 February, 2025 10:20 PM +8 GMT

Synopsis
Sam Altman, OpenAI CEO, welcomed his first child and took to social media to express joy on the happy occasion. The OpenAI CEO in a post mentioned that the baby boy is premature and is NICU. The CEO of OpenAI shared a birth announcement on X in the early hours of February 23.

In early 2024, Sam Altman married his longtime partner, Australian software engineer Oliver Mulherin

OpenAI CEO Sam Altman has announced the birth of his first child with partner **Oliver Mulherin**. He made the announcement of the birth of his baby box on X, formerly known as Twitter.

Ethical Issues in Human Subjects Research

- Tuskegee Study
  - 1932-1972 in Macon County Alabama
  - 600 impoverished black sharecroppers
  - 399 with syphilis, 201 without
  - Study effects of untreated syphilis
  - Given free healthcare and hot meals
  - Penicillin became standard treatment for Syphilis in 1947
  - Subjects were never informed
  - Public outcry in 1972 ended study
  - Led to Institutional Review Boards (IRBs)

Informed Consent (Tuskegee)

- Human Subject must be
  - Informed about the experiment NO
  - Must consent to the experiment YES
    - Voluntarily, without coercion
  - Must have the right to withdraw consent at any time NOT QUITE
- Benefit vs Harm was assessed by experimenter

Consent Models for Health Data

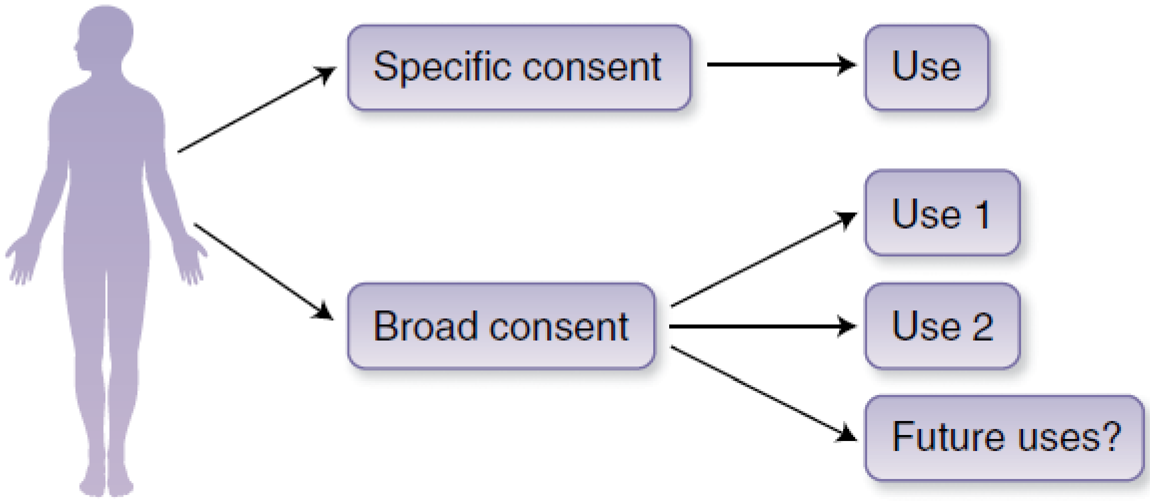


Fig. 1 | Consent models for health data. Specific consent allows individuals to control each specific use of their data. In broad consent, individual give blanket consent for all uses of their data.

- Examples: Biobanks

I. Glenn Cohen
Harvard Law School

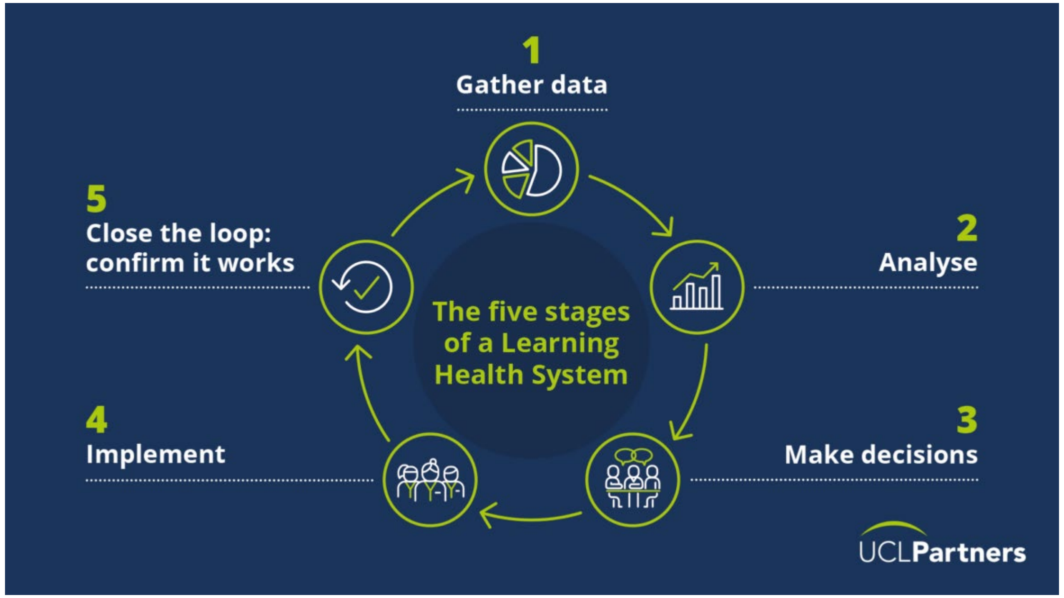
Prof. Cohen is one of the world’s leading experts on the intersection of bioethics (sometimes also called “medical ethics”) and the law, as well as health law.

Price WN, Cohen IG. Privacy in the age of medical big data. *Nature medicine*. 2019 Jan;25(1):37-43.

More about informed consent on April 30 in Week 11

Learning Health Systems

- In learning health systems, data are collected routinely in the process of care, with the explicit aim that those data be used for the purpose of analyzing and improving care.
- Just as data are continuously collected, they are continuously analyzed to reveal patterns in the process of care, procedures that can be improved, and other underlying patterns such as differential patient response to different treatments.



- Finally, these new insights are routinely incorporated back into the clinical care pathway, whether explicitly (in practice guidelines or publications) or implicitly (in the context of recommendations or procedures automatically embedded into electronic health record (EHR) systems).

Price WN, Cohen IG. Privacy in the age of medical big data. *Nature medicine*. 2019 Jan;25(1):37-43.

Institutional Review Boards (IRBs) in the US

- Primary role is the protection of human subjects.
- Reviews and monitors biomedical and behavioral research
- Composition (sketch)
    - Minimum of 5 members, with representation for both genders, such that there is sufficient expertise to make informed decisions on whether research is ethical and safeguards exist
    - If study includes members of “vulnerable” populations, then a member of such a population should participate on the IRB
    - Members can not all be of same profession
    - Must be at least one person not affiliated with the organization (i.e., the “community” member)
    - Must be at least one scientist AND one non-scientist

(Adapted from Brad’s Slides)

Institutional Review Boards (IRBs) in the US

- Minimal requirement for IRB Approval is when research is federally funded – but the organization can impose IRB oversight whenever it believes it is necessary.

- Exemptions to oversight will be provided if the data is believed to be sufficiently anonymous.

- Manages necessary violations of informed consent
  - E.g. in psychology experiments

(Adapted from Brad's Slides)

Ethical Issues of Information and Big Data

- Ethics in Information and Cyber Space
    - The Concept of Computer Ethics
        - *What is Computer Ethics?* – James H. Moor, 1985
    - Virtualization of Interpersonal Relationships
    - Accountability of Online Behavior (Due to Anonymity)
    - Extended Inequality for vulnerable populations
    - Intellectual property disputes
    - Global Information Exchange and Governance

Li Z et al. Ethics in Engineering (Ed.2) (Ch.10.2) 2019.

Big Data Ethics

- Digital Identity
  - Anonymization VS. Real-name Systems
  - USA: Communication Decency Act 1996 VS. Freedom of Speech (Constitution)
  - China: Online real-name verification system 2007 – Daily visit > 100,000
  - China: Decision on Strengthening the Protection of Network Information 2012 – Service providers are responsible for real-name verification. (Real-name registration in the background, anonymous display in the foreground.)

Li Z et al. Ethics in Engineering (Ed.2) (Ch.10.3) 2019.

Privacy in the Age of Big Data

- Personal Data Collection

Collection Methods	Cases	Major Technology	User Awareness	Opt-out Option
Collect public data	Web Crawler	Open API	No	No
Collect data publicly	Online Survey	Web application	Yes	Yes
Log file	Online shopping, search engine, maps	Cookies	Yes (Neglect), No	Yes (Neglect), No
Collect secretly	GPS location, Wi-Fi probe	Phone API	Yes (Neglect), No	Yes (Neglect), No
Attack/Hack	Ashley Madison Data Breach (2015)	Hacking	No	No
Purchase	Burma scam syndicates	Darknet, Black market	No	No
Linkage, inference	Membership inference, **re-identification attacks**	Statistical analysis, machine learning	No	No

Li Z et al. Ethics in Engineering (Ed.2) (Ch.10.4) 2019.

Re-identification of Governor’s Health Record

- In the 1990s, the state of Massachusetts purchased health insurance for state employees and subsequently released records summarizing every state employee’s hospital visits at no cost to any researcher who requested the data.
- Then-Governor **William Weld** assured the public that the data had been scrubbed to defeat reidentification by removing information such as names, addresses, and Social Security numbers. Unfortunately, many patient attributes were not scrubbed.
- In 1997, **Latanya Sweeney**, then a graduate student, knew Weld resided in the city of Cambridge, and so she purchased this city’s complete voter rolls, which contained the name, address, ZIP code, birth date, and sex of every voter in the city.
- She paired that data with the state health insurance data to demonstrate that one could reidentify Weld’s prescriptions, diagnosis, and medical history.

Price WN, Cohen IG. Privacy in the age of medical big data. *Nature medicine*. 2019 Jan;25(1):37-43.

From Public Data to Open Data

- Data Sharing VS. Data Publication VS. Open Data

Type	How to access	Data requirement	Agreement methods	Examples
Data Sharing	1 to 1, 1 to many, many to many, no public access	Case by case	One by one	BioVU
Data Publication	1 to many, 1 to all, everyone can download	Meta data available before download	Public data use agreement	UKBiobank, dbGaP, "All of US" Research Program
Open Data	Many to many, everyone can download and upload	Structured Data	Public data use agreement	OpenSNP, Personal Genome Project, Zenodo, GitHub

Kaggle, www.data.gov

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From Public Data to Open Data (cont.)

- Case study: A masterpiece in Nature completed through crowdsourcing -- The article with the most authors in the world

Harvard
UC Berkeley
U of Washington


Published as: *Nature*. 2010 August 5; 466(7307): 756–760.

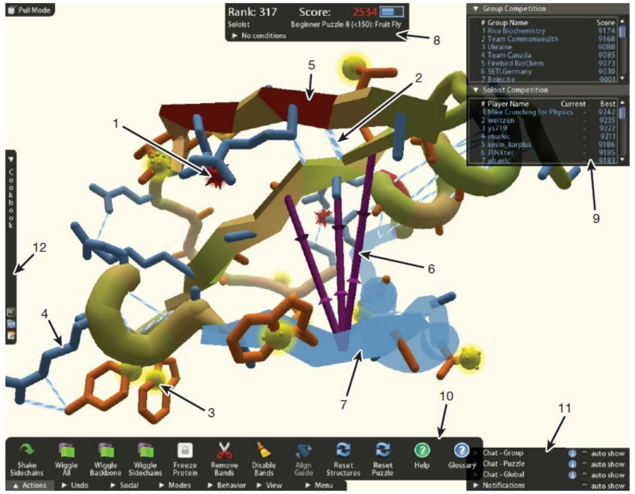
Predicting protein structures with a multiplayer online game

Seth Cooper[1], **Firas Khatib**[2], **Adrien Treuille**[1,3], **Janos Barbero**[1], **Jeehyung Lee**[3], **Michael Beenen**[1], **Andrew Leaver-Fay**[2,4], **David Baker**[2], **Zoran Popović**[1], and **>57,000 Foldit players**[5]

[1]Department of Computer Science & Engineering, University of Washington

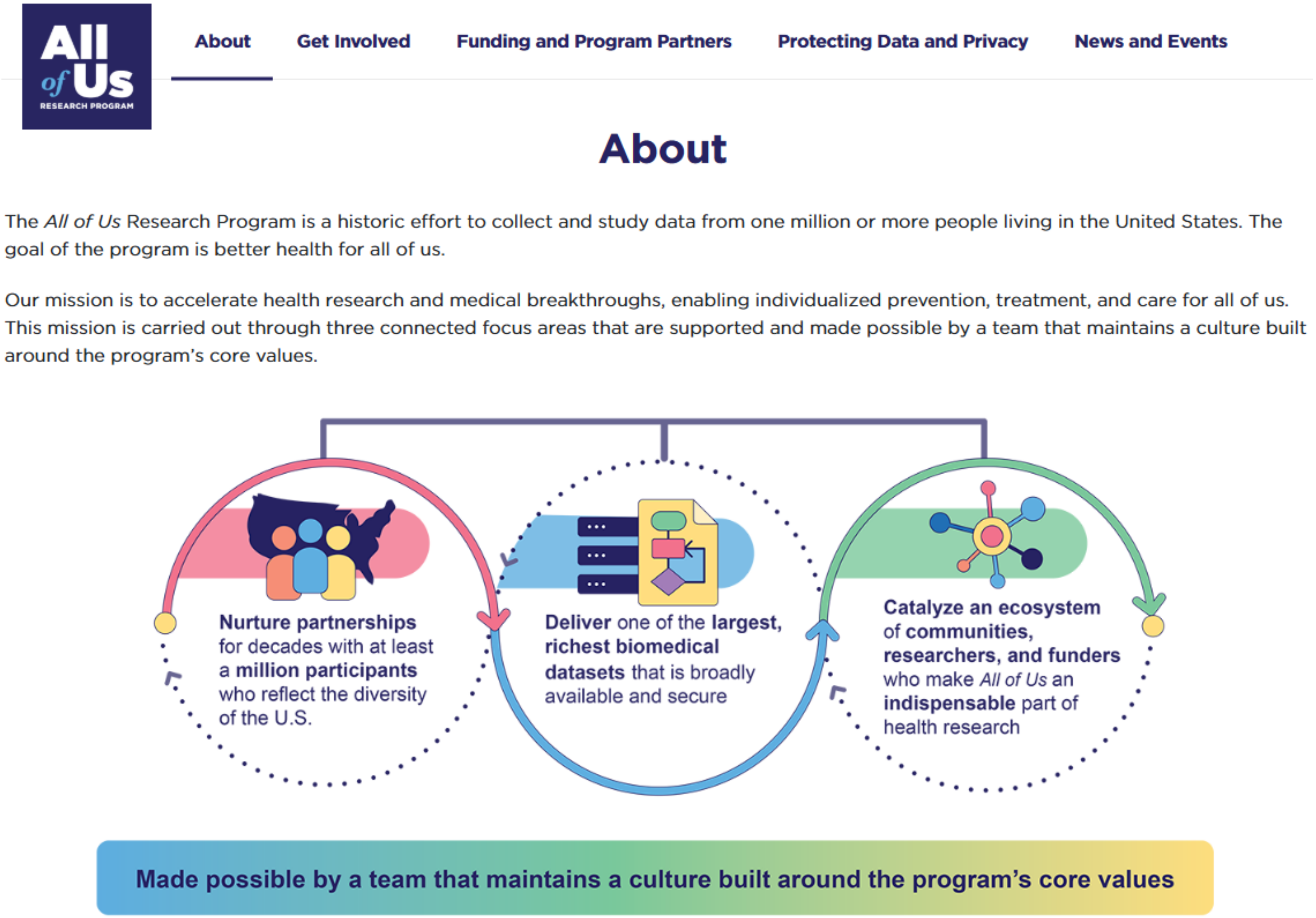
[2]Department of Biochemistry, University of Washington

[3]Department of Computer Science, Carnegie Mellon University



Equitable Data Collection

- Data collection is not occurring equitably.
- The **All of Us research program**, for instance, aims to develop a nationally representative sample for its genomic work.



About

The *All of Us* Research Program is a historic effort to collect and study data from one million or more people living in the United States. The goal of the program is better health for all of us.

Our mission is to accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us. This mission is carried out through three connected focus areas that are supported and made possible by a team that maintains a culture built around the program's core values.

Nurture partnerships for decades with at least a **million participants** who reflect the diversity of the U.S.

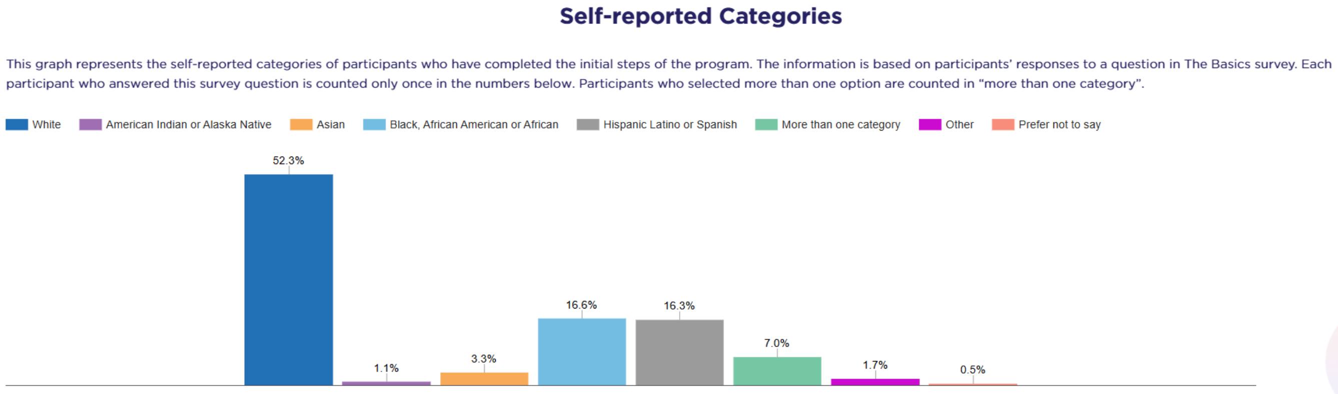
Deliver one of the **largest, richest biomedical datasets** that is broadly available and secure

Catalyze an ecosystem of **communities, researchers, and funders** who make *All of Us* an **indispensable** part of health research

Made possible by a team that maintains a culture built around the program's core values

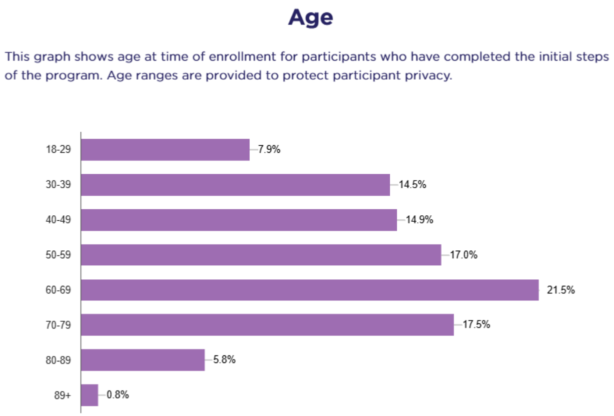
1. Price WN, Cohen IG. Privacy in the age of medical big data. *Nature medicine*. 2019 Jan;25(1):37-43.
2. https://allofus.nih.gov/about/

All of Us Research Program



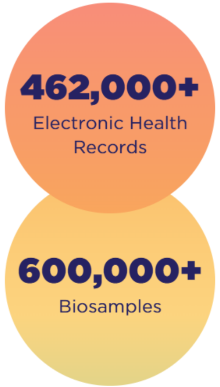
Self-reported Categories

This graph represents the self-reported categories of participants who have completed the initial steps of the program. The information is based on participants' responses to a question in The Basics survey. Each participant who answered this survey question is counted only once in the numbers below. Participants who selected more than one option are counted in "more than one category".



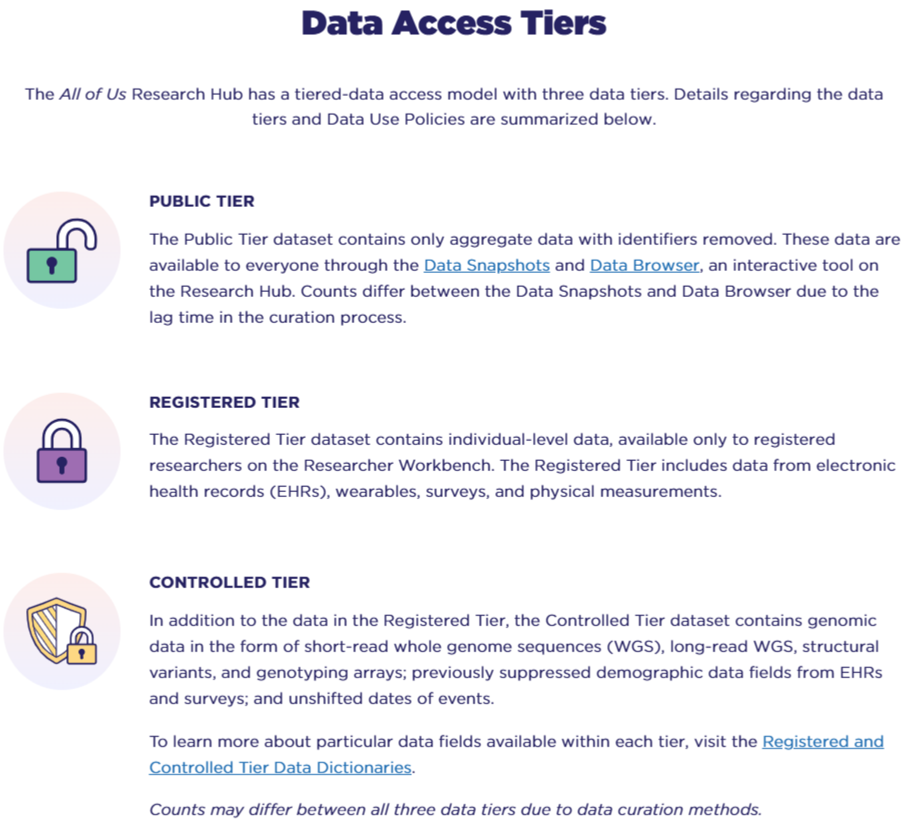
Age

This graph shows age at time of enrollment for participants who have completed the initial steps of the program. Age ranges are provided to protect participant privacy.



462,000+
Electronic Health Records

600,000+
Biosamples



Data Access Tiers

The *All of Us* Research Hub has a tiered-data access model with three data tiers. Details regarding the data tiers and Data Use Policies are summarized below.

PUBLIC TIER

The Public Tier dataset contains only aggregate data with identifiers removed. These data are available to everyone through the Data Snapshots and Data Browser, an interactive tool on the Research Hub. Counts differ between the Data Snapshots and Data Browser due to the lag time in the curation process.

REGISTERED TIER

The Registered Tier dataset contains individual-level data, available only to registered researchers on the Researcher Workbench. The Registered Tier includes data from electronic health records (EHRs), wearables, surveys, and physical measurements.

CONTROLLED TIER

In addition to the data in the Registered Tier, the Controlled Tier dataset contains genomic data in the form of short-read whole genome sequences (WGS), long-read WGS, structural variants, and genotyping arrays; previously suppressed demographic data fields from EHRs and surveys; and unshifted dates of events.

To learn more about particular data fields available within each tier, visit the Registered and Controlled Tier Data Dictionaries.

Counts may differ between all three data tiers due to data curation methods.

1. https://allofus.nih.gov/data-tools/data-snapshots/
2. https://www.researchallofus.org/data-tools/data-access/
3. Xia W, Basford M, Carroll R, Clayton EW, Harris P, Kantacioglu M, Liu Y, Nyemba S, Vorobeychik Y, **Wan Z**, Malin BA. Managing re-identification risks while providing access to the All of Us research program. Journal of the American Medical Informatics Association. 2023 May 1;30(5):907-14.

Differences in Public Governance Values between China and the West

- Chinese Values
  - Responsibility > Freedom
  - Obligation > Rights
  - Collective > Individual
  - Harmony > Conflict

Li Z et al. Ethics in Engineering (Ed.2) (Ch.10.6) 2019.

Regulatory Protection of Personal Information

- Personal Information VS. Sensitive Personal Information VS. Privacy
  - Personal Information: Linkage or Identification
    - Linkage: Individual to Information
    - Identification: Information to Individual
  - Sensitive Personal Information:
    - Personal information that, if leaked, illegally provided, or illegally used, **may cause harm** to an individual's personal dignity, physical and mental health, property safety, or result in discriminatory treatment.
    - Personal information of minors under the age of fourteen. -- *Personal Information Protection Law (PIPL) of China* 2021.
  - Privacy
    - The tranquility of a natural person's private life, as well as private spaces, private activities, and private information that they do not wish to be known by others. – *Civil Code of China* 2020.

Li Z et al. Ethics and morality in information science and technology (Ed.2) (Ch.5) 2019.

Sensitive Personal Information

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- *Information security technology - Personal information security specification* 2020 (National Standard)

Type	Contents
Personal Financial Information	Bank account numbers, authentication information, deposit information, real estate information, credit records, credit information, transaction and consumption records, flow records, virtual currency, virtual transactions, and game redemption codes, etc.
Personal physiological health information	**Medical records** generated from an individual's illness treatment, such as symptoms, hospitalization records, doctor's orders, test reports, surgical and anesthesia records, nursing records, medication records, drug and food allergy information, reproductive health information, medical history, diagnosis and treatment details, family medical history, present illness, and history of infectious diseases, etc.
Personal biometrics	**Personal genetic information, fingerprints, voiceprints, ear prints, irises, and facial recognition features, etc.**
Personal Identity	ID card, military officer's ID, passport, driver's license, work ID, social security card, and residence permit, etc.
Others	Sexual orientation, marital history, religious beliefs, undisclosed criminal records, communication records and content, contacts, friend lists, group lists, location tracks, web browsing history, accommodation information, and precise location information, etc.

More about privacy regulations in China on March 14 in Week 4.

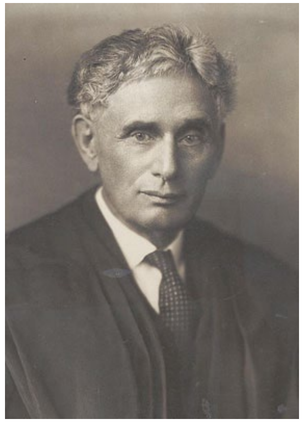
What is Privacy?

- Freedom from Intrusion
- Public-Private Divide / Body Privacy
- Communications Privacy
- Identity Management
  - Information privacy
  - Survival value of information
  - Individual facts vs. collected knowledge
  - Surveillance

(Adapted from Brad’s Slides)

The Warren & Brandeis Model

Samuel Warren



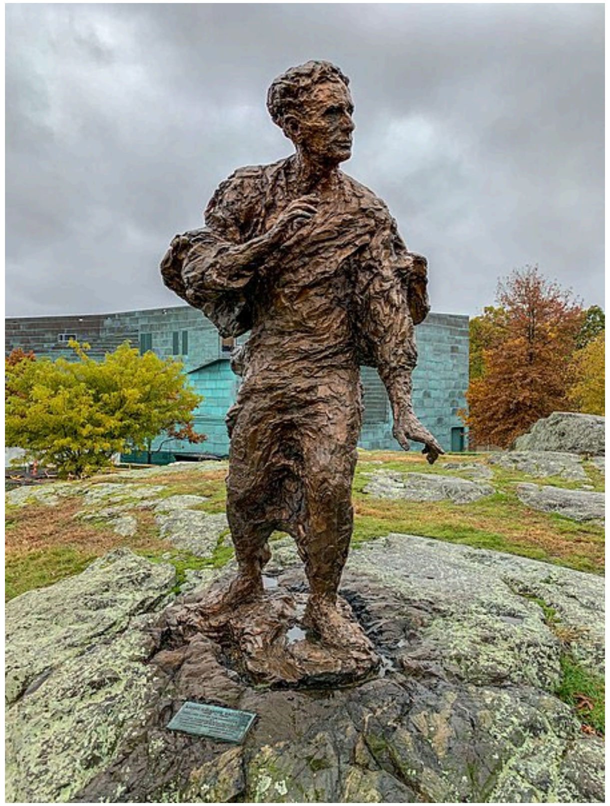
Louis Brandeis

- Couple of Harvard Law grads from late 1800s
- Founded Boston law firm Nutter, McClennen, and Fish (it's still around)
- Brandeis went on to the Supreme Court for 23 years (1916 – 1939)
- Warren went on to a very high-profile marriage to Mabel Bayard
  - Daughter of Thomas F. Bayard: 3 time senator of Delaware, U.S. Secretary of State, U.S. Ambassador to the U.K.

(Adapted from Brad's Slides)

Brandeis University

- A private research university in Waltham, Massachusetts, United States. Founded in 1948, the university is named after Louis Brandeis, a former Justice of the U.S. Supreme Court. U.S. News & World Report ranked Brandeis No. 63 in its 2024 annual list of Best National Universities.



https://en.wikipedia.org/wiki/Brandeis_University

Brandeis & the US Supreme Court

- Olmstead v. U.S. (1928)
  - ❑Case: People were convicted for an alleged conspiracy to violate the National Prohibition Act
  - ❑An additional 72 people were indicted based on telephone conversations
  - ❑Overwhelming evidence
    - Roy Olmstead, general manager (50% of profits)
    - 50 employed people
    - Proof of sea vessels for transporting bootleggers and alcohol
    - Underground storage facility in Seattle
    - Central office with executives, accountants, salesmen, and… an attorney

(Adapted from Brad’s Slides)

Brandeis & the US Supreme Court

- Olmstead v. U.S. (1928)
  - ❑ Four federal prohibition officers installed wiretaps
    - Not in the homes or offices
    - Rather, in the streets near their homes and the basement of the office building
  - ❑ Reviewed if “wiretapped” private telephone conversations, obtained by federal agents WITHOUT judicial approval and subsequently used as evidence in a court of law, constituted a violation of the defendant’s rights as defined in the 4th and 5th Amendments of the U.S. Constitution

(Adapted from Brad’s Slides)

4th Amendment to the US Constitution

- Protection from illegal search and seizure
- Protects against government intrusion into private life
  - Goal: Prevent suppression of peaceful political dissent

"The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated, and no Warrants shall issue, **but upon probable cause**, supported by Oath or affirmation, and particularly describing the place to be searched, and the persons or things to be seized."

(Adapted from Brad's Slides)

4th Amendment to the US Constitution

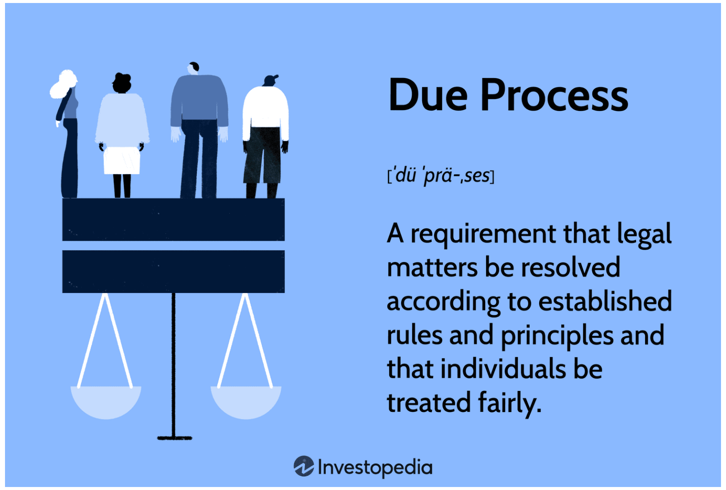
- Protects activities that a reasonable person would not expect to be visible to other than known observers
  - Most location-based data likely to fail this test

- Caveat: Only addresses federal actors
  - 14th Amendment extends to states
  - Does not address actions of private citizens nor organizations

(Adapted from Brad's Slides)

5th Amendment to the US Constitution

- Famous for “I plead the 5th”
- Principle interest is that you do not incriminate yourself
- Requirement for “due process”
  - Government must adhere to a person’s legal rights



Due Process

[*ˈdü ˈprä-ˌses*]

A requirement that legal matters be resolved according to established rules and principles and that individuals be treated fairly.

Investopedia

(Adapted from Brad’s Slides)

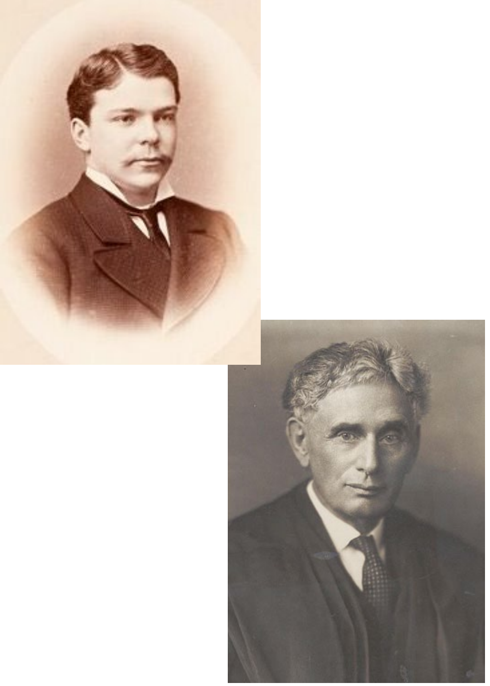
Brandeis & the US Supreme Court

- Olmstead v. U.S. (1928)
  - Official Ruling: No
    (majority opinion delivered by Chief Justice Taft)
  - Brandeis offered the minority opinion:
    - Argued that the “right to privacy” was protected under the U.S. Constitution
    - “most comprehensive of rights”
    - “right most valued by civilized men”
    - Based on a little something he wrote almost 40 years earlier

(Adapted from Brad’s Slides)

What is Privacy?

- Freedom from intrusion
  - Brandeis and Warren (1890): Right to be left alone



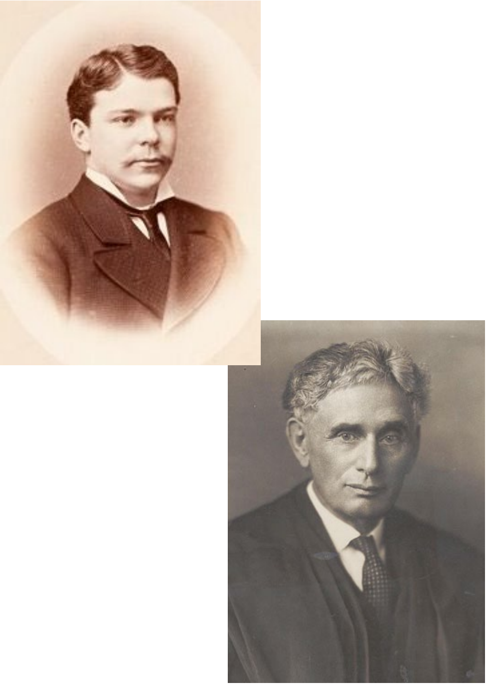
1. "does not prohibit any publication of matter which is of public or general interest"
2. "does not prohibit the communication of any matter … [that is] privileged communication"
3. "[does] not grant any redress for the invasion of privacy by oral publication in the absence of special damage"

S. Warren and L. Brandeis. The right to privacy. *Harvard Law Rev.* 1890; vol 4, no 5.

(Adapted from Brad's Slides)

What is Privacy?

- Freedom from intrusion
    - Brandeis and Warren (1890): Right to be left alone



4. “right to privacy ceases upon the publication of the facts by the individual, or with his consent”

5. “truth of the matter published does not afford a defense”

6. “absence of ‘malice’ in the publisher does not afford a defense”

S. Warren and L. Brandeis. The right to privacy. *Harvard Law Rev.* 1890; vol 4, no 5.

(Adapted from Brad’s Slides)

A Broader Perspective

- Prosser (1960) organized the concept of privacy into four distinct torts, or “civil wrongs”:

Violation of seclusion, solitude, or private matters

Public disclosure of facts that are, or could be embarrassing

Publicity that puts an individual in a false light to the public

Misappropriation of name or likeness

William L. Prosser. Privacy. *California Law Review*. 1960; 48(3): 383-424.

(Adapted from Brad’s Slides)

A Conceptual Perspective

Solitude
Just leave me alone

Confidentiality
We agree to share information, but only with trusted entities

Anonymity
I don't want you to know who I am!

Reserve
"the creation of a psychological barrier against unwanted intrusion"

Alan Westin. Privacy and Freedom. *New York: Atheneum*. 1967.

More about privacy regulations in the West on March 7 in Week 3

(Adapted from Brad's Slides)

Two types of health privacy concerns

- Consequentialist concerns
  - Result from negative consequences that affect the person whose privacy has been violated
- Deontological concerns
  - manifests even if no one uses a person’s information against this person or if the person never even becomes aware that a breach has occurred

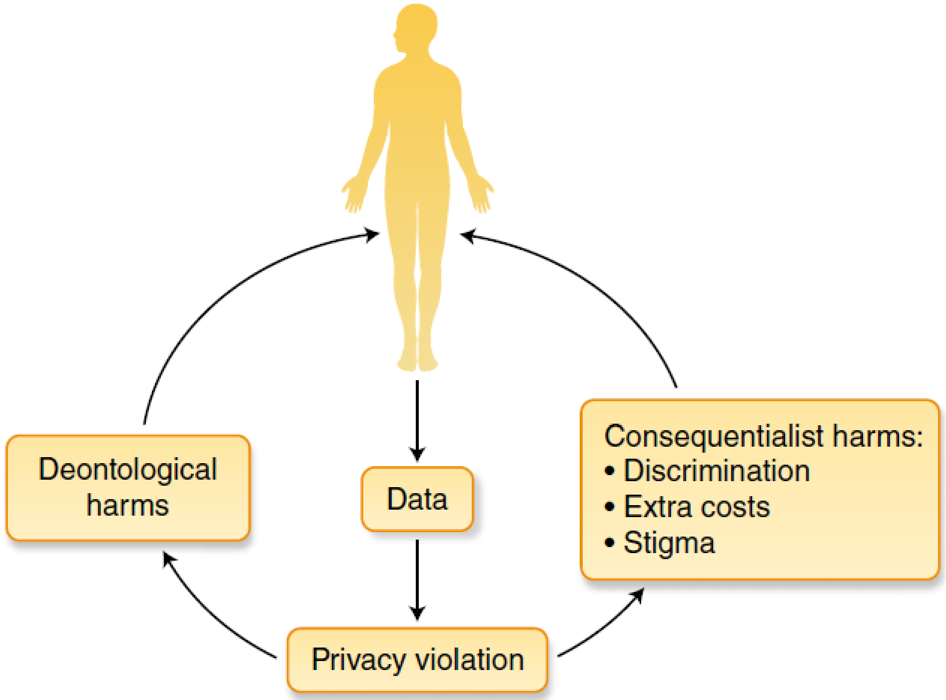


Fig. 3 | Potential harms to the individual if data is breached. The types of harm that can befall an individual once their data is leaked.

Price WN, Cohen IG. Privacy in the age of medical big data. *Nature medicine*. 2019 Jan;25(1):37-43.

A Path Forward for Health Privacy

- Privacy Protection Techniques
  - Pseudonymized data
  - Differential privacy
  - Privacy audits
- Privacy vs Secrecy
  - Case Study: Myriad Genetics' data about BRCA1 and BRCA2 genes associated with breast and ovarian cancers are not available
- Privacy under-protection and overprotection each create cognizable harms to patients

Price WN, Cohen IG. Privacy in the age of medical big data. *Nature medicine*. 2019 Jan;25(1):37-43.

Virtual and Reality

- Privacy in the Metaverse
- Deepfake: Pros and Cons

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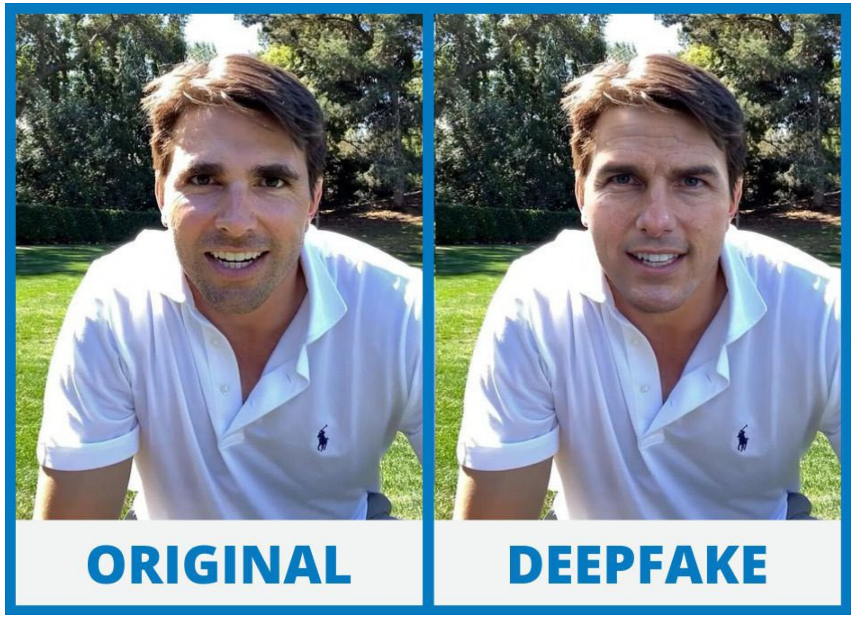

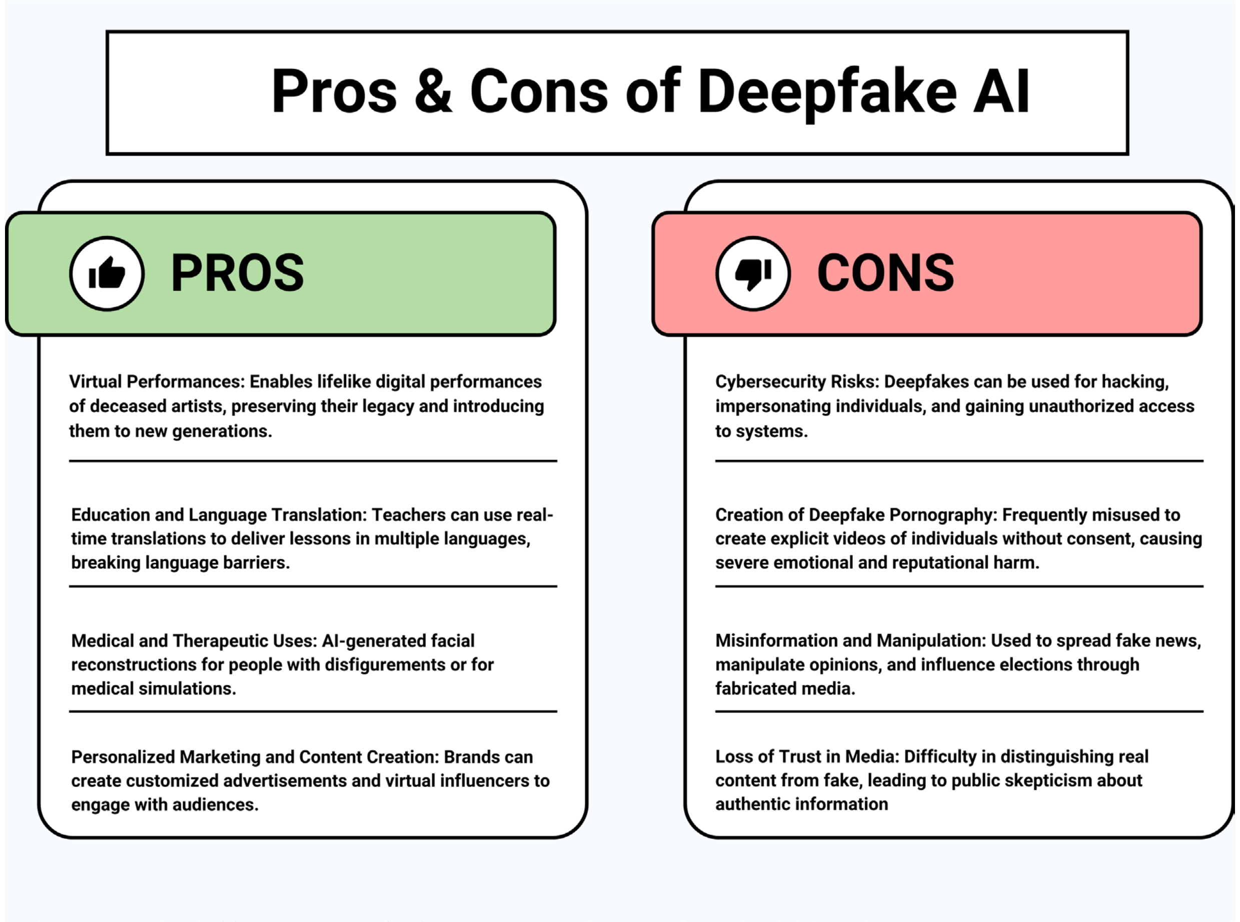

Pros & Cons of Deepfake AI

👍 PROS	👎 CONS
Virtual Performances: Enables lifelike digital performances of deceased artists, preserving their legacy and introducing them to new generations.	Cybersecurity Risks: Deepfakes can be used for hacking, impersonating individuals, and gaining unauthorized access to systems.
Education and Language Translation: Teachers can use real-time translations to deliver lessons in multiple languages, breaking language barriers.	Creation of Deepfake Pornography: Frequently misused to create explicit videos of individuals without consent, causing severe emotional and reputational harm.
Medical and Therapeutic Uses: AI-generated facial reconstructions for people with disfigurements or for medical simulations.	Misinformation and Manipulation: Used to spread fake news, manipulate opinions, and influence elections through fabricated media.
Personalized Marketing and Content Creation: Brands can create customized advertisements and virtual influencers to engage with audiences.	Loss of Trust in Media: Difficulty in distinguishing real content from fake, leading to public skepticism about authentic information

https://mitrai.com/ai/the-houdini-in-pandoras-box-of-pixels-the-wonders-and-woes-of-deepfake-ai/

Li Z et al. Ethics and morality in information science and technology (Ed.2) (Ch.7) 2019.

Readings for the Next Week

- Malin B, Benitez K, Masys D. Never too old for anonymity: a statistical standard for demographic data sharing via the HIPAA Privacy Rule. *Journal of the American Medical Informatics Association*. 2011 Jan 1;18(1):3-10.
  - https://doi.org/10.1136/jamia.2010.004622
- Optional
  - McGraw D, Dempsey JX, Harris L, Goldman J. Privacy as an enabler, not an impediment: building trust into health information exchange. *Health affairs*. 2009 Mar;28(2):416-27.
    - http://content.healthaffairs.org/content/28/2/416.full.pdf+html
  - Xu J, Xiao Y, Wang WH, Ning Y, Shenkman EA, Bian J, Wang F. Algorithmic fairness in computational medicine. *EBioMedicine*. 2022 Oct 1;84.
    - https://www.thelancet.com/pdfs/journals/ebiom/PIIS2352-3964(22)00432-7.pdf
  - Kearns M, Roth A. *The ethical algorithm: The science of socially aware algorithm design*. Oxford University Press; 2019 Oct 4. (Ch.2)
  - U.S. Department of Health and Human Services. *Summary of the Privacy Rule of the Health Information Portability and Accountability Act (HIPAA)*
    - http://www.hhs.gov/ocr/privacy/hipaa/understanding/summary/index.html