Ethical Challenges from Medical Big Data and Al

Risks, harms and potential solutions

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Al Winter





















"Tesla car that crashed and killed driver was running on Autopilot, firm says" *The Guardian* Mar 31, 2018







Al is Powerful Technology







Powerful Technologies Require Smart Regulation











Early Automobiles







Managing the Risks of Automotive Technology





What about medical technologies?

















Appendix Volume I

The Belmont Report Ethical Principles

Ethical Principles and Guidelines for the Protection of Human Subjects of Research

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research





Medical Ethics

- Respect for Persons
 - » Privacy
 - » Autonomy
- Beneficience
 - » Includes non-maleficence
- Justice





Scientific Ethics

- Creation and dissemination of knowledge
 - » Transparency
 - » Objectivity
 - » Open sharing
 - » Publication





Applying these principles to Al







• Does the AI system improve health?

• Does it have negative side effects?







Artificial Intelligence in Medicine 9 (1997) 107-138



An evaluation of machine-learning methods for predicting pneumonia mortality

 Gregory F. Cooper^{a,*}, Constantin F. Aliferis^a, Richard Ambrosino^a, John Aronis^b, Bruce G. Buchanan^b, Richard Caruana^c, Michael J. Fine^d, Clark Glymour^e, Geoffrey Gordon^c, Barbara H. Hanusa^d, Janine E. Janosky^f, Christopher Meek^e, Tom Mitchell^c, Thomas Richardson^e, Peter Spirtes^e





Pneumonia Mortality Model

- Goal: Stratify patient subgroups according to mortality risk
 - » Admit the high-risk patients
 - » Send the low-risk patients home





Pneumonia Mortality Model

- Unexpected effect: Asthmatic patients identified to be low risk
- Implication: hospital using this software would discharge asthmatic pneumonia patients to home
- Problem: Asthma increases mortality in pneumonia patients!

» Source: Caruana R et al. Proc. 21st ACM SIGKDD Int Conf on KDD (2015)





But what if...?

- The model had been developed for commercial purposes...
- Kept as a black box...
- Not been subject to extensive academic evaluation...

• What then?





#1 Source of error in AI models = Unidentified biases in training data











Opacity Problem in Machine Learning



Source: Bornstein A. *Nautilus* 2016





Al is full of biases

So...

And...

We can't directly study biases due to opacity





Privacy-related harms





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SECURITY & PRIVACY

How Target Knew a High School Girl Was Pregnant Before Her Parents Did

Save
 Save

By Keith Wagstaff @kwagstaff | Feb. 17, 2012

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V Tweet In Share

Read Later

In Charles Duhigg's new piece for the New York *Times*, a father finds himself in the uncomfortable position of having to apologize to a Target employee. Earlier he had stormed into a store near Minneapolis and complained to the manager that his daughter was receiving coupons for cribs and baby clothes in the mail.

Turns out Target knew his daughter better than he did. She really was pregnant.

(MORE: Google Wallet Hack Shows NFC Payments Still Aren't Secure)

It was a fact Target had obtained after carefully collecting information about her. The company, like many others, assigns each shopper a unique Guest ID. Every time you buy toilet paper with a credit card, visit its website, fill out a survey or, really, interact with the retailer in any way, Target assigns this



Joe Raedle / Getty Images

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How Companies Learn Your Secrets New York Times



Respect for Persons

- Can the patient make informed decisions about how their data is used?
- What if any data ownership rights does the patient have?





Do Americans Care about Control of their Health Information?

- Pew Study: 74% said "very important" to be in control of who can get info about you
 - » Source: Pew Research. Americans' attitudes about privacy, security and surveillance. 2015
- ONC Study: 8% of individuals had withheld information from a healthcare provider due to privacy or security concerns
 - » Source: ONC Data Brief No 27. 2015





Ownership of personal health data







The Legacy of Henrietta Lacks

Overview

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The Importance of HeLa Cells

Role of Johns Hopkins Hospital

Upholding the Highest Bioethical Standards

The Immortal Life of Henrietta Lacks

Honoring Henrietta Lacks

Frequently Asked Questions



Honoring Henrietta: The Legacy of Henrietta Lacks

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The Legacy of Henrietta Lacks

In 1951, a young mother of five named Henrietta Lacks visited The Johns Hopkins Hospital complaining of vaginal bleeding. Upon examination, renowned gynecologist Dr. Howard Jones discovered a large, malignant tumor on her cervix. At the time, The Johns Hopkins Hospital was one of only a few hospitals to treat poor African-Americans.

As medical records show, Mrs. Lacks began undergoing radium treatments for her cervical cancer. This was the best medical treatment available at the time for this terrible disease. A sample of her cancer cells retrieved during a biopsy were sent to















Shouldn't we treat personal <u>data</u> the same way we treat <u>cells</u> and <u>organs</u>?







English EN

Search

Home > Priorities > Justice and fundamental rights > Data protection > EU data protection rules

EU data protection rules

Stronger rules on data protection mean people have more control over their personal data and businesses benefit from a level playing field.

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About the regulation and data protection

Background

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Documents



Rules for business and organisations

Application of the GDPR obligations, individuals' requests, enforcement



Rights for citizens

Protection of your personal data, your rights and redress

About the regulation and data protection

- What does the General Data Protection Regulation (GDPR) govern?
- What is personal data?





But what about de-identification?







Article Open Access Published: 23 July 2019

Estimating the success of reidentifications in incomplete datasets using generative models

Luc Rocher, Julien M. Hendrickx & Yves-Alexandre de Montjoye 🏁

Nature Communications 10, Article number: 3069 (2019) | Download Citation ± 79k Accesses | 1 Citations | 1784 Altmetric | Metrics ≫







Article Open Access Published: 23 July 2019

Estimating the success of reidentifications in incomplete datasets using generative models

Luc Rocher, Julien M. Hendrickx & Yves-Alexandre de Montjoye 🏁

"Using our model, we find that 99.98% of Americans would be correctly re-identified in any dataset using 15 demographic attributes."







• Does the AI system enhance fairness?

- Does it reduce health disparities?
- Does it improve affordability?





So what can we do about all this?





Scientific Ethics

- Creation and dissemination of knowledge
 - »Transparency
 »Objectivity
 »Open sharing
 »Publication





No Black Boxes!







Achieving Ethical AI in Medicine

- Need to update patient rights regarding PHI
 - » De-identification
 - » Right to be forgotten
 - » Data ownership/control











Achieving Ethical AI in Medicine

- Business relationships: AI vendors, health care orgs, academics
 - » Ethical downstream uses
 - » Fair/reasonable pricing on products
 - » Study and publication
 - » Patient data rights



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ARUP is a nonprofit enterprise of the University of Utah and its Department of Pathology.

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