

AI & Community-Engaged Research

- February 11, 2025 -

COMMUNITY ENGAGEMENT
THE HARVARD CLINICAL
AND TRANSLATIONAL
SCIENCE CENTER |  HARVARD
CATALYST

  CENTER FOR CLINICAL AND
TRANSLATIONAL SCIENCE

 Clinical & Translational Science Institute:
Community Engagement Program

Tufts
CTSI
Tufts Clinical and
Translational
Science Institute

We will start shortly. While you wait, please enter your name and organization in the chat to “everyone.”

AI and Community-Engaged Research

LOGISTICS

- Participants are muted on entry. Only panelists may unmute during the session.
- Enter your questions (and up vote your favorites) on **Slido.com #AIQs**.
- If you encounter any technical issues, please use the chat to write to UMass Chan AV/Abdul Sherzai.

AI and Community-Engaged Research

SPEAKERS



Rosa Alemán, BA
American Civil Liberties Union
of Massachusetts



Matthew DeCamp, MD, PhD
University of Colorado
Anschutz Medical Campus



Colorado Clinical and Translational
Sciences Institute (CCTSI)

UNIVERSITY OF COLORADO DENVER | ANSCHUTZ MEDICAL CAMPUS

Research: *Beyond the Data*

Matthew DeCamp, MD PhD

Associate Professor

Division of General Internal Medicine & Center for Bioethics and Humanities

Director, Research Ethics, CCTSI

What will the future of medicine look like with artificial intelligence?

The future of medicine with artificial intelligence (AI) is poised to be transformative, with several key areas of impact:

Diagnostic Accuracy: AI algorithms, particularly those using deep learning, are already showing promise in diagnosing conditions from medical images, such as X-rays, MRIs, and CT scans, with high accuracy. This can lead to earlier and more accurate diagnoses, which are crucial for conditions like cancer and neurological disorders.

Predictive Analytics: AI can analyze vast amounts of health data to predict outbreaks, track the spread of diseases, and identify potential public health risks before they become widespread. This can lead to more proactive and preventative measures.

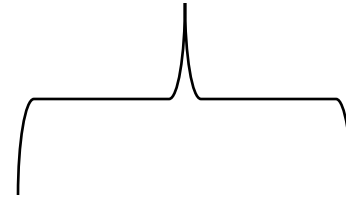
In the future of medicine, oh what a sight, AI will dazzle with all of its might! With data and digits, it'll help us each day, In marvelous, magical, and marvelous ways!

When it comes to diagnosing, oh what a spree, AI sees things that the eye cannot see. In X-rays and MRIs, it'll swiftly detect, Conditions that humans might miss or forget!

Predictive analytics, a future so bright, Will forecast and spot issues with insight. Chronic conditions and outbreaks will be, Monitored closely, as easy as can be!

How does AI “learn to see”?

Gold Standard
“Supervisor”



Artificial
Intelligence Image
Analyzer

Blueberry Muffin

Chihuahua

<https://neurabites.com/muffin-or-chihuahua/>

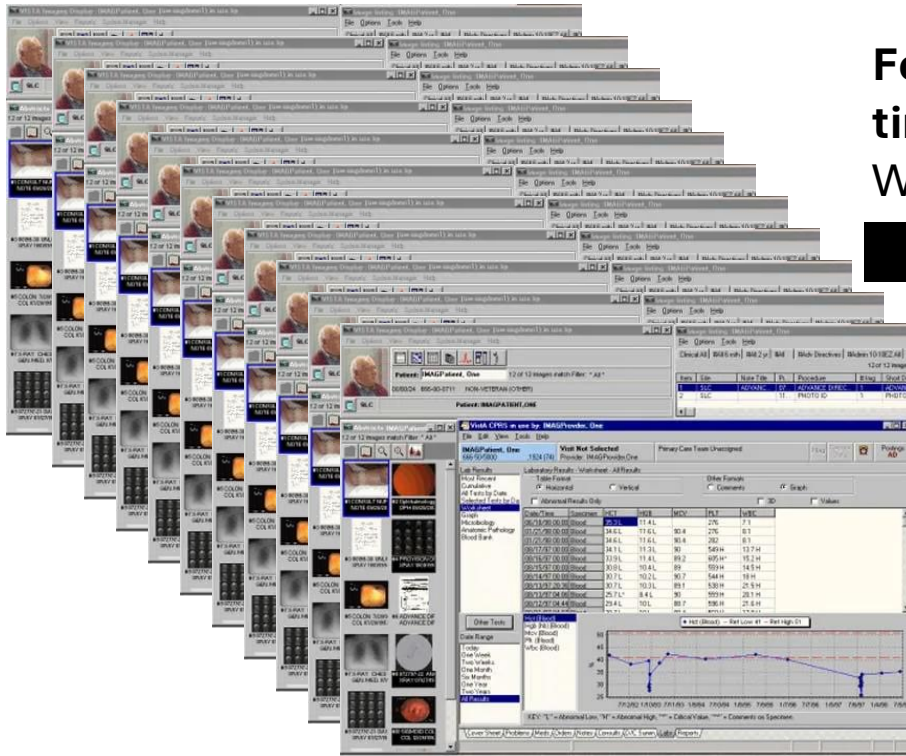
How Does AI “predict the future”?



Height, weight,
blood pressure,
etc



Predictions of future
disease (e.g., heart
attack).



Follow patients over
time:

What factors predict who



The power of AI:

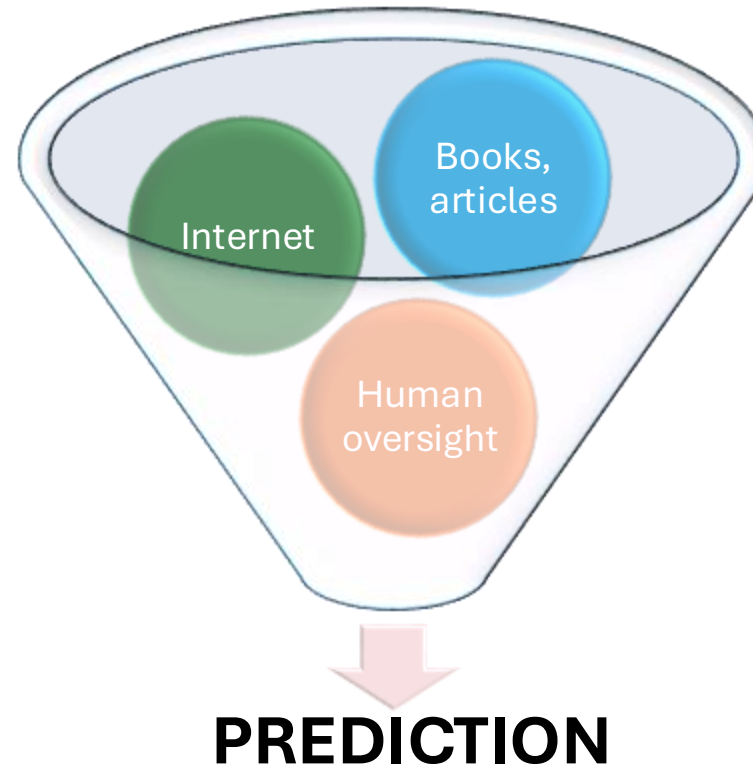
- New factors
- Better predictions

How does ChatGPT generate content?

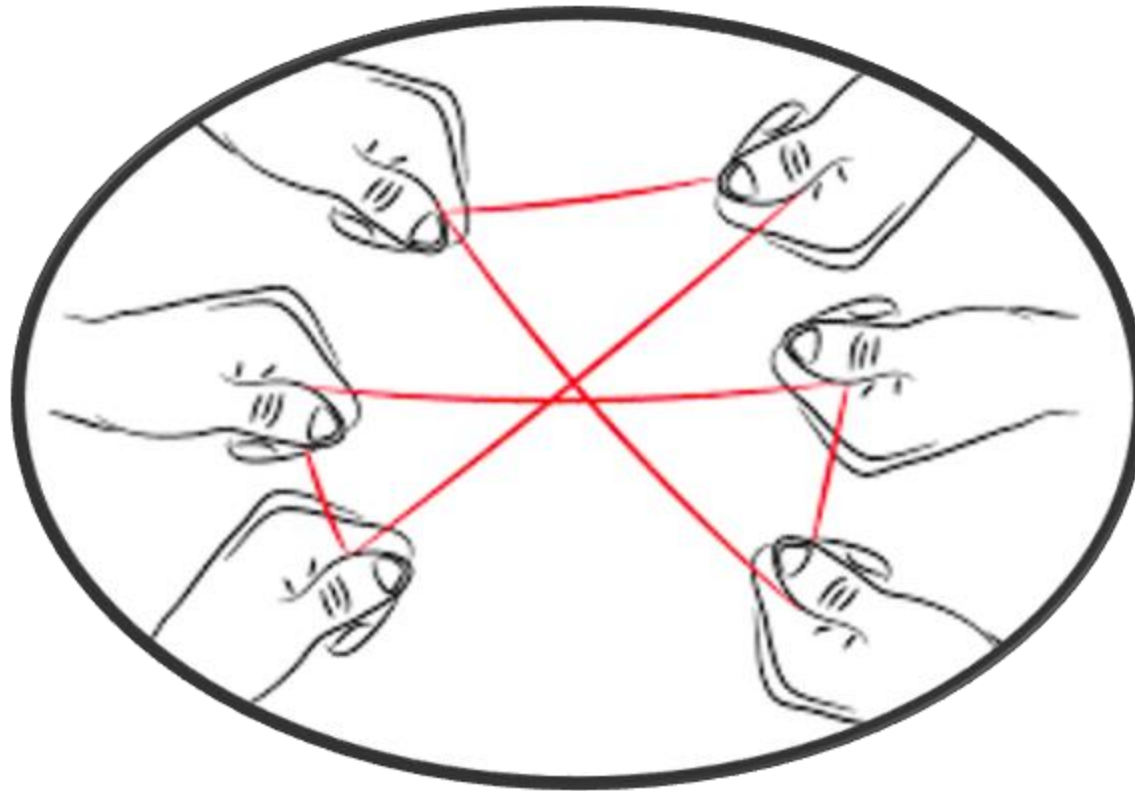
As my colleague Casey Greene says:

Fill in the _____

How?



The Common Thread



AI is only as good as the data and processes used to train it.

A Case Study

Recognizing rural disparities in cardiovascular care, a research team wants to create and study a chatbot that will support patients' engagement in cardiovascular prevention.

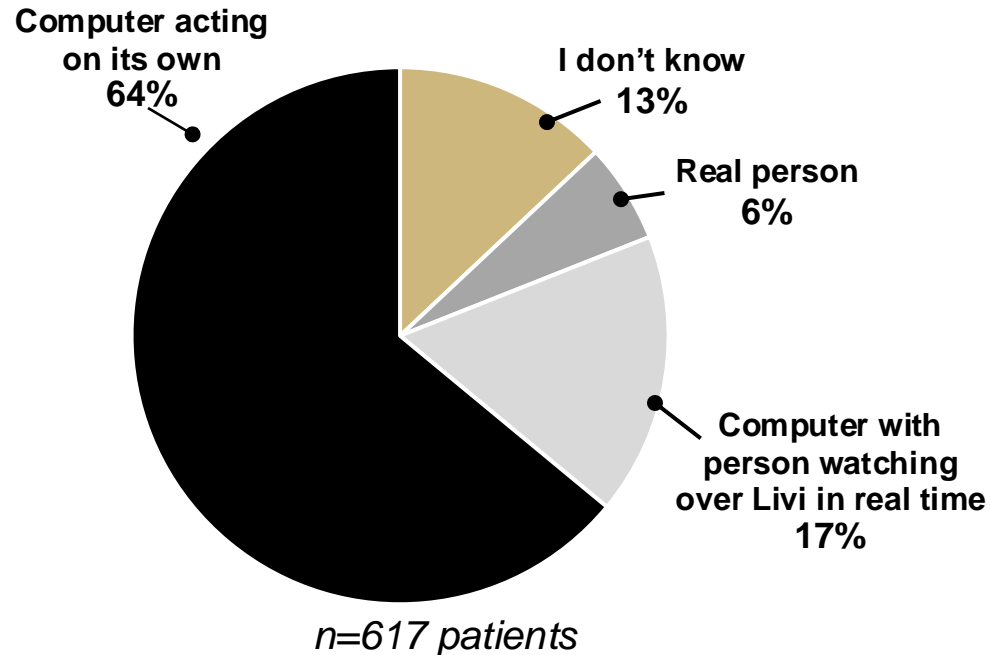
The idea is to create a virtual “lifestyle coach” with tailored advice based on data available in the electronic health record (EHR) so that it will ‘know’ what medications a patient is taking, social history data, and so on.

What are some ethical issues?

(1) TRANSPARENCY



*Livi, the UCHealth
Virtual Assistant*



Our research on a patient facing chatbot found that:

- 1 in 3 people could not identify Livi as a computer
- Race or ethnicity and education were predictors of this.

We agree deception is wrong – but exactly how do we inform...?

(2) CHOICE

It's a robot, so they can't judge me. I don't feel like I'm being judged or looked at in a certain way.

(Age 18-34, Black race, Other Gender)

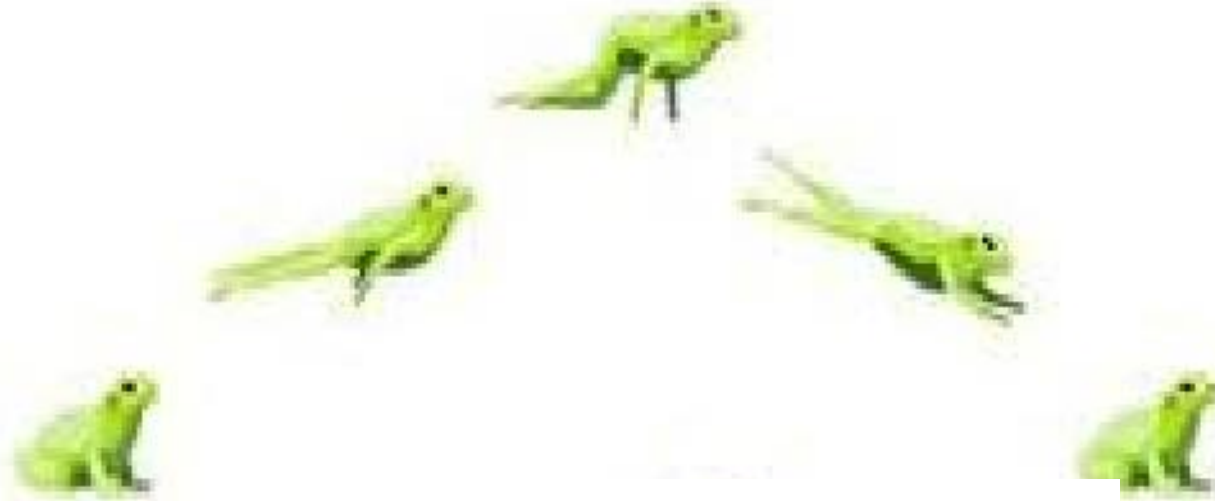


*Livi, the UCHealth
Virtual Assistant*

Some patients *prefer* talking to a chatbot about sensitive topics...is that promoting choice for some patients, or, an indictment of the status quo?

Where Choice and Equity Collide

Our hypothetical chatbot example may try to solve a rural access issue...



Justice As Access

Double Standard of Care –
i.e., chatbot only for this
rural community.

(3) PRIVACY



Use of data without consent may be *legally* permitted, but...

- We still have not found the ideal balance between privacy & innovation.
- Some LLMs “memorize” data – creating a risk of breach.
- Patients and communities remain unaware – where do data shared with chatbot go?

**We need tell people about privacy
AND take steps to protect it.**

(4) BIAS

Content generated by the AI chatbot may reflect bias.

JAMA
Network | **Open**



Original Investigation | Equity, Diversity, and Inclusion

Gender Representation of Health Care Professionals in Large Language Model-Generated Stories

Bradley D. Menz, B. Pharm (Hons); Nicole M. Kuderer, MD; Benjamin Chin-Yee, MD; Jessica M. Logan, PhD; Andrew Rowland, PhD; Michael J. Sorich, PhD; Ashley M. Hopkins, PhD

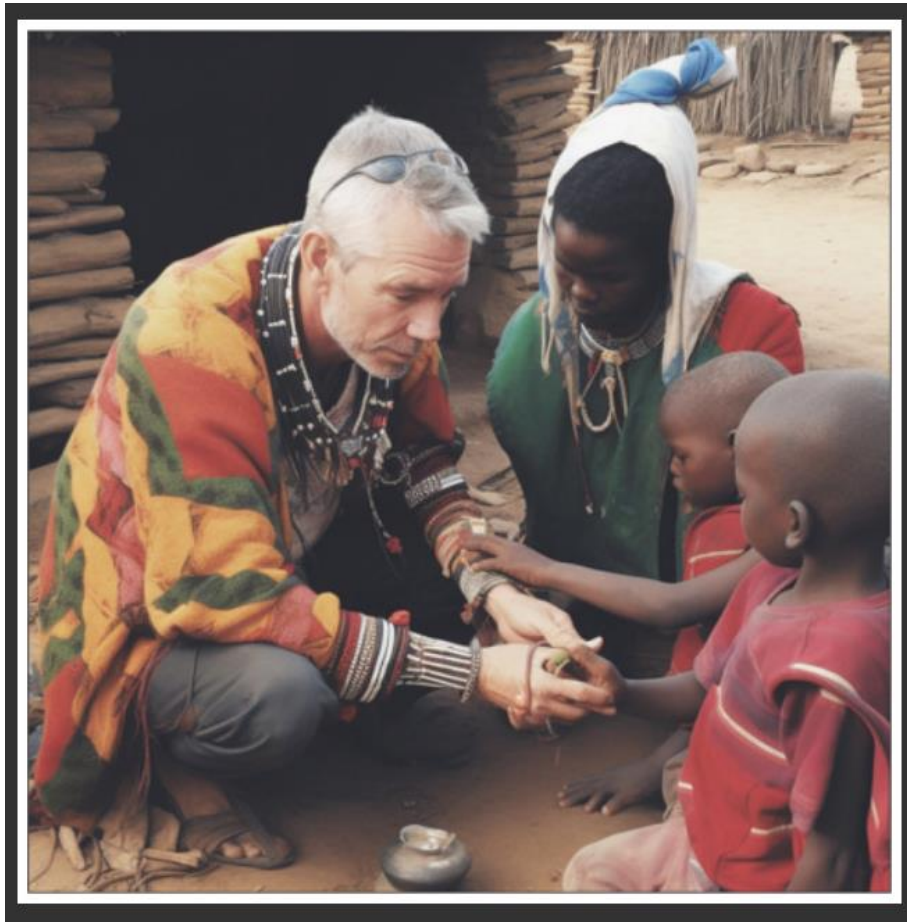
Abstract

IMPORTANCE With the growing use of large language models (LLMs) in education and health care settings, it is important to ensure that the information they generate is diverse and equitable, to avoid reinforcing or creating stereotypes that may influence the aspirations of upcoming generations.

In the initial 6000 prompts submitted to the LLMs, 98% of nurses were referred to by she/her pronouns...

... stories of medical doctors and surgeons with higher agreeableness, openness, and conscientiousness, as well as lower neuroticism, resulted in higher she/her (reduced he/him) representation.

Menz BD, Kuderer NM, Chin-Yee B, et al. Gender Representation of Health Care Professionals in Large Language Model-Generated Stories. *JAMA Netw Open*. 2024;7(9):e2434997.



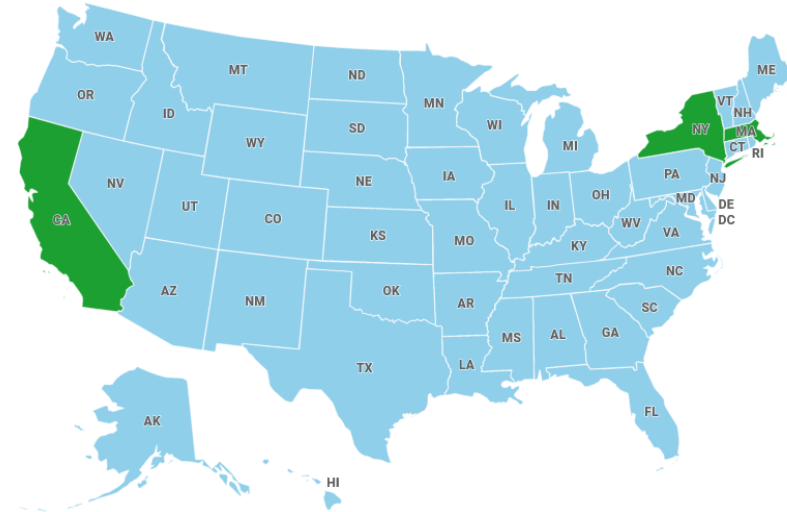
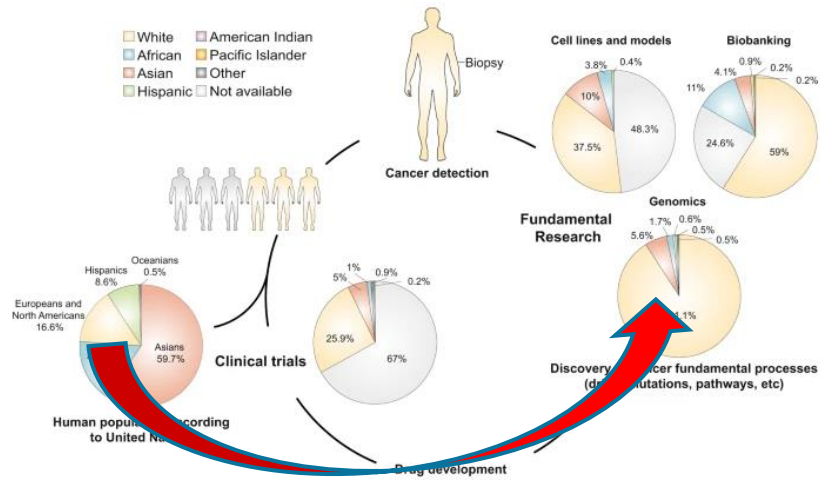
Prompt:

“Traditional African healer is helping poor and sick White children”

Alenichev A, Kingori P, Grietens KP. Reflections before the storm: the AI reproduction of biased imagery in global health visuals. *Lancet Glob Health*. 2023 Oct;11(10):e1496-e1498. doi: 10.1016/S2214-109X(23)00329-7. Epub 2023 Aug 9. PMID: 37572687

Biased Data

Figure 1

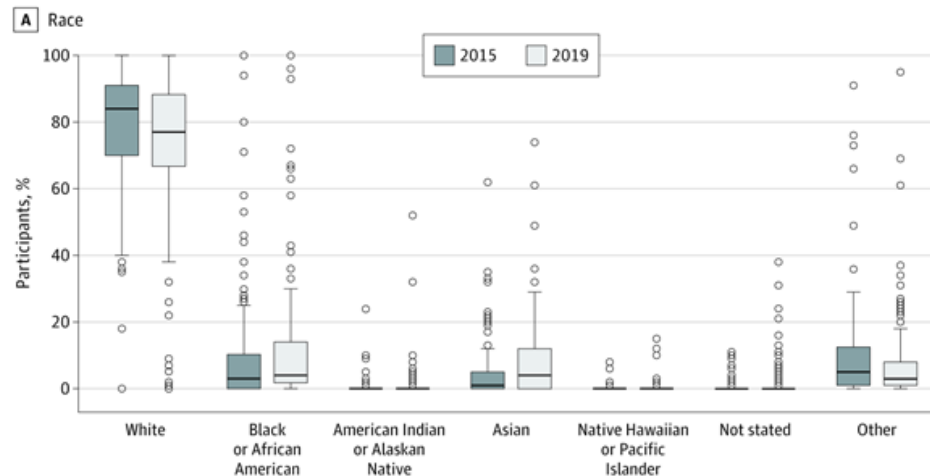


Racial/Ethnic disparities in cancer research. Racial/ethnic inclusion was studied in several aspects of preclinical research, from cell lines and patient-derived xenografts to biobanking, genomics, and drug development. Guerrero, S., A. *et al.* Analysis of Racial/Ethnic Representation in Select Basic and Applied Cancer Research Studies. *Sci Rep* 8, 13978 (2018).

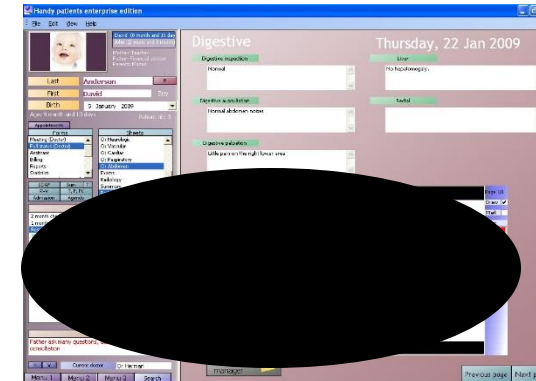
<https://www.fla-shop.com>

<https://jamanetwork.com/journals/jama/article-abstract/2770833>

Figure. Race and Sex Representation in Studies Published in 2015 and 2019

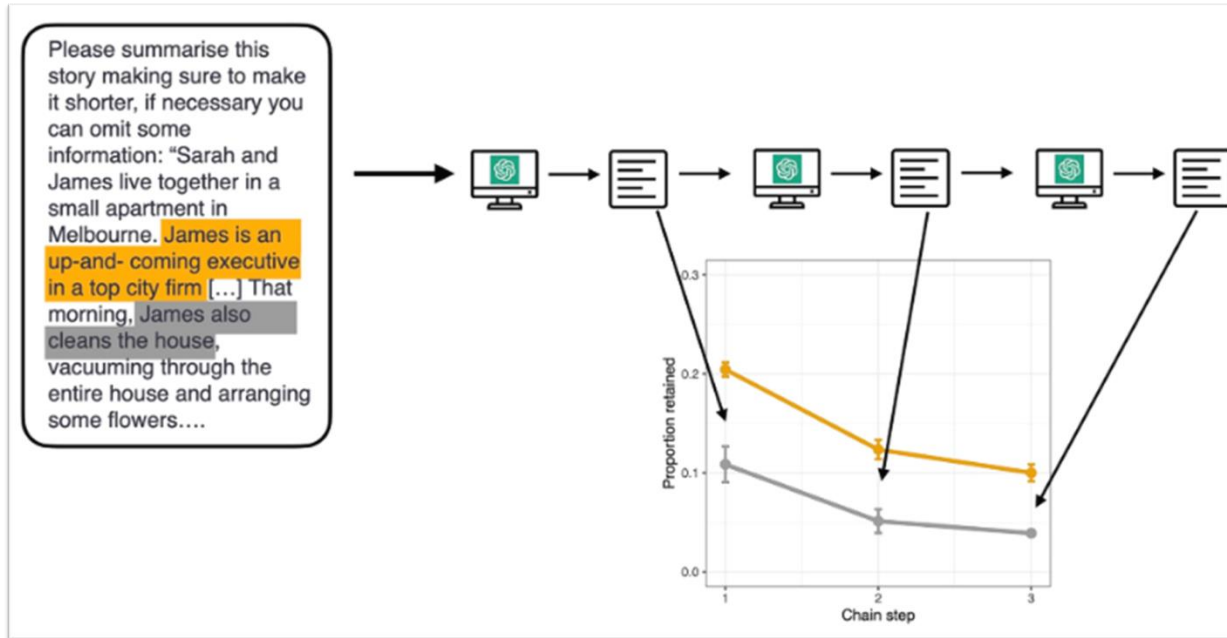


JAMA Netw Open. 2021;4(5):e2111516



Getzen E *et al.* Mining for equitable health: Assessing the impact of missing data in electronic health records. *J Biomed Inform.* 2023 Mar;139:104269. doi: 10.1016/j.jbi.2022.104269.

Biases in Processing



Preferential transmission:

- Gender stereotypes
- Social gossip
- Negativity
- Threats
- Biologically counterintuitive

Misinformation

If these biases exist– and if we become ever more reliant on AI – what will the effect be on (mis)information?



<https://www.apa.org/topics/journalism-facts/misinformation-disinformation>

Implications for Our Lifestyle Coach

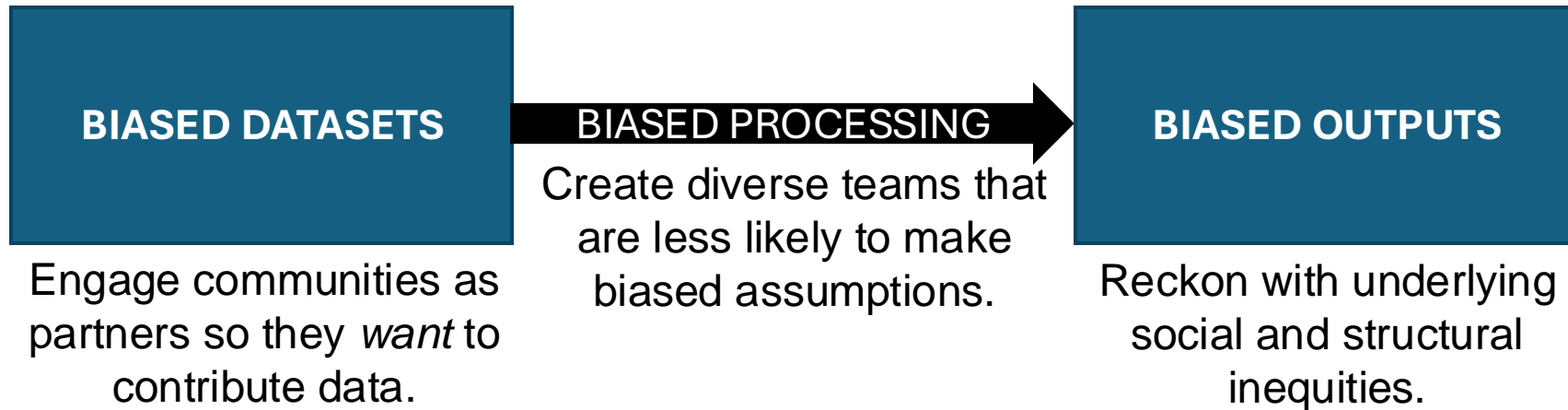
If our lifestyle coach is built on biases, what might the impact be?

Biased or stereotyped responses?

Inability to handle differences in language or dialect?

Differential treatment based on race, ethnicity, something else?

Strategies for Addressing Biases



**Bias in AI is more than a data problem – it's a social problem.
Can we demand AI mitigate disparities – not just do no harm?**

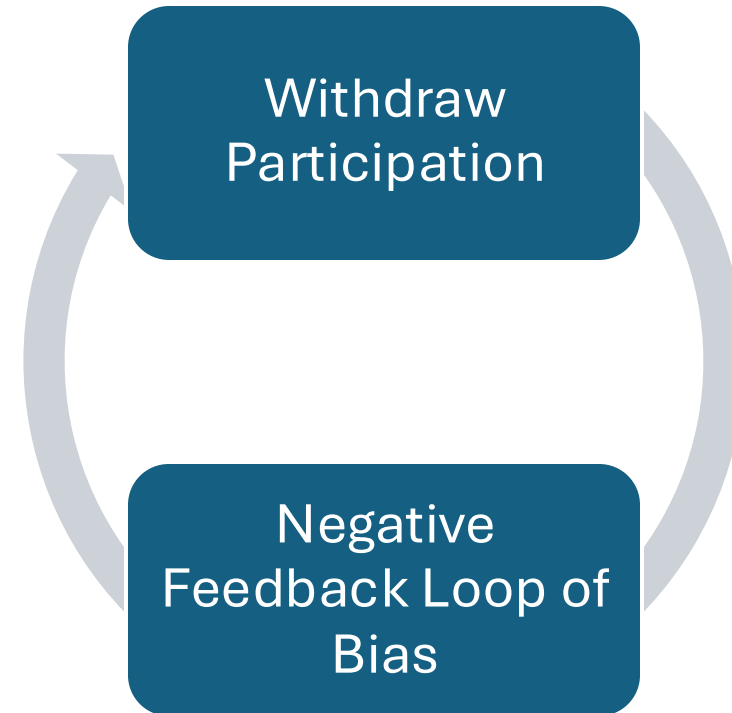
Avoid the “Quick Fix”

What about proposals to create simulated data or *in silico* research studies?



Collins B, Jones N. Digital Simulacra: Circumventing Diversity and Inclusion. *Am J Bioeth.* 2023 Sep;23(9):76-78. doi: 10.1080/15265161.2023.2237430. PMID: 37647473.

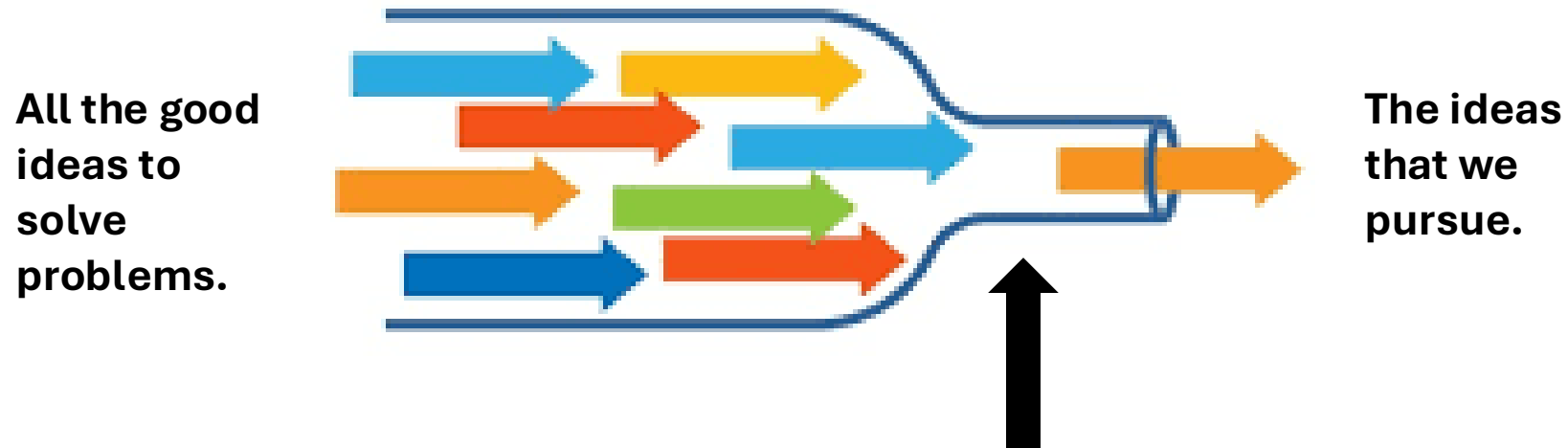
Absent Authentic Engagement...



Without engagement, community could respond to issues of choice, privacy and so on...with the only option to say “no” to participation – *reinforcing the bias problem.*

The Bigger Picture: Why AI?

We should step back and ask, “Was cardiovascular disease a real need for this community?”



Although community engagement is needed every step of the way, it may be most important here – at the point of:
“Why is this a problem worth solving with AI?”



COMMUNITY COALITION FOR EQUITY IN RESEARCH

Goal: Researchers work with community partners to **increase the adoption of evidence-based programs and policies to promote health, prevent disease, and eliminate disparities**

Aligning values and activities:

- Share power and resources
- Promote community involvement in all stages of research
- Support co-learning among coalition members and researchers
- Center community strengths and resources
- Emphasize long-term and systems change

Highlights

- Established a diverse, 17-member coalition
- Co-created health equity review rubric
- Engaged postdoctoral fellows through full professors
- Received positive feedback from all researchers from variety of fields

COMMUNITY COALITION FOR EQUITY IN RESEARCH

* Leadership



Karen Emmons, PhD*
Harvard T.H. Chan School
of Public Health



Michael Curry, Esq*
Massachusetts League of
Community Health Centers



Rosa Alemán, BA
American Civil Liberties
Union of MA



Mark Kennedy, MBA
Boston Public Health
Commission



Rebekka Lee, ScD
Harvard T.H. Chan
School of Public Health



Ana Jaramillo,
Community health worker
Holyoke Community Health
Center



Albert W. Pless, Jr.,
MS
Town of Reading



Abdullah Abdul-Rahim, MEd
Men of Color Health
Awareness



Şeyda Kilic, BS
Community Health
Worker, Kraft Center
for Community Health



Marilynne Smith Quarcoo, PhD
Educational Consultant,
Midezor Consulting



Carolina Trujillo, MPA,
MSPS
Lynn Affordable Housing
Trust Fund Manager



Nancy B. Smith, BS
City of Boston Mayor's
Office of Emergency
Management



Marie-Jacques
Toussaint, MD
Immigrant Family
Services Institute



Lamar Polk, MPH,
MSW, LICSW, CCM
Senior Associate,
Technical Assistance
Collaborative Center



Brenda Evans, MPH*
UMass Amherst, School of
Public Health and Health
Sciences



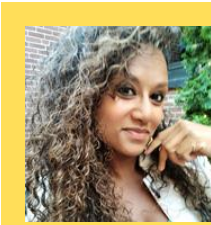
Chien-Chi Huang, MS
Asian Women for
Health



Shauntel Garner-Anderson,
BA, Med
Boston Public Health
Commission



Madeline Stump, MPH
ForHealth Consulting



Chellamal Keshavan, BS*
Medford Human Rights
Commission



Chrismery Gonzalez, MPH
City of Springfield



Tiffany Vassell, BSN, BA, RN
Nurses for Black Maternal
Health and Equity Org



Why I Joined This Coalition Mid-Pandemic:

- Healing old wounds & breaking cycles
 - Remembering family members who struggled to seek proper medical care out of fear, anxiety and skepticism — often based on bad personal experiences & historical memory
 - Ex. **Forced sterilization and other traumas experienced by Puerto Ricans** on and off the island



Sterilization of Puerto Rican Women: A Selected, Partially Annotated Bibliography (Louis de Malave, 1999)

DID YOU KNOW: *Between 1930 and 1970 approximately one-third of Puerto Rico's female population of childbearing age were forced or coerced into sterilization — the highest rate in the world, driven by a population control campaign targeting Latinas.*



- **What constitutes ethical AI?**
- **What are potential good use cases in health & medicine?**

Co-Chair 2023-2024; Consistently surfaced questions and concerns about data privacy, machine learning, and artificial intelligence in health and medical research studies

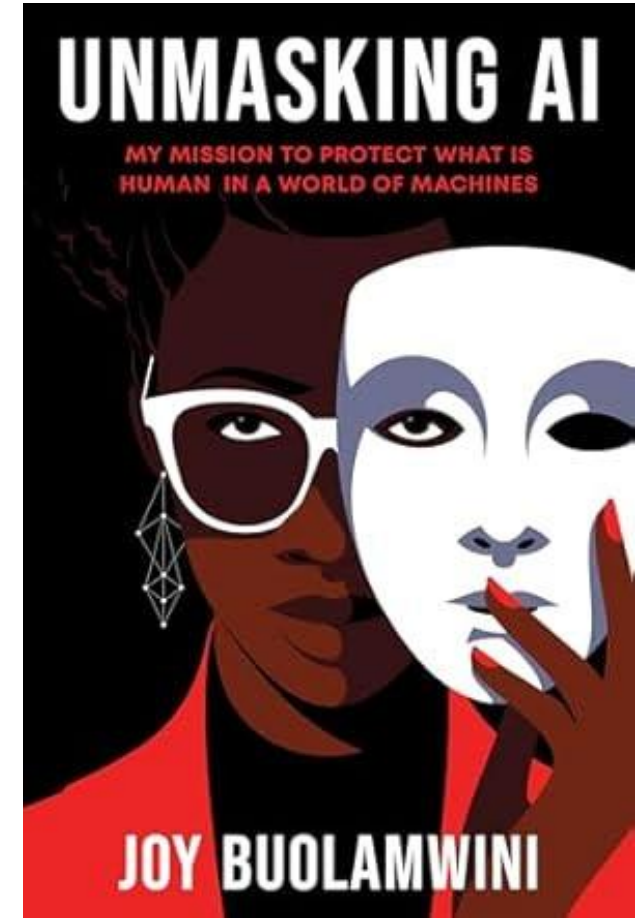
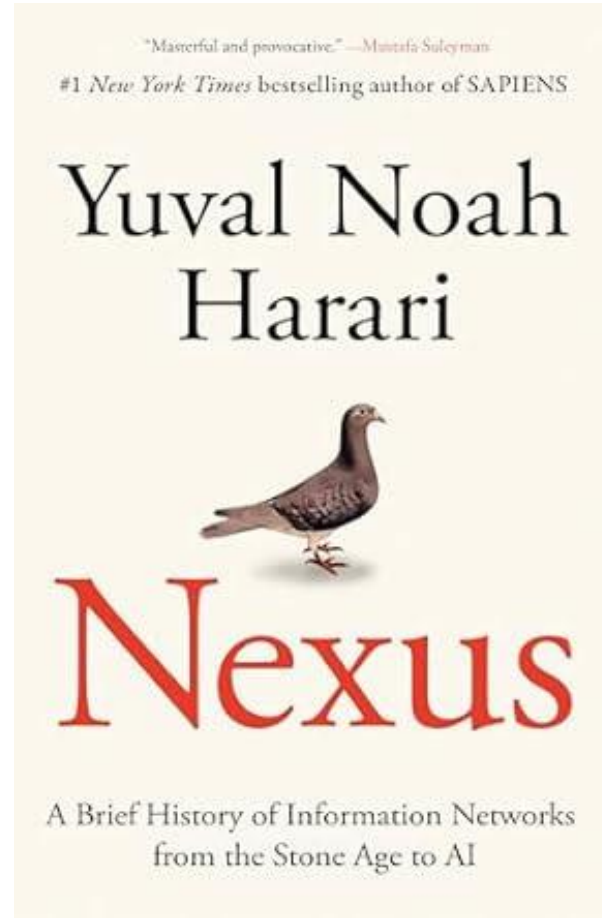
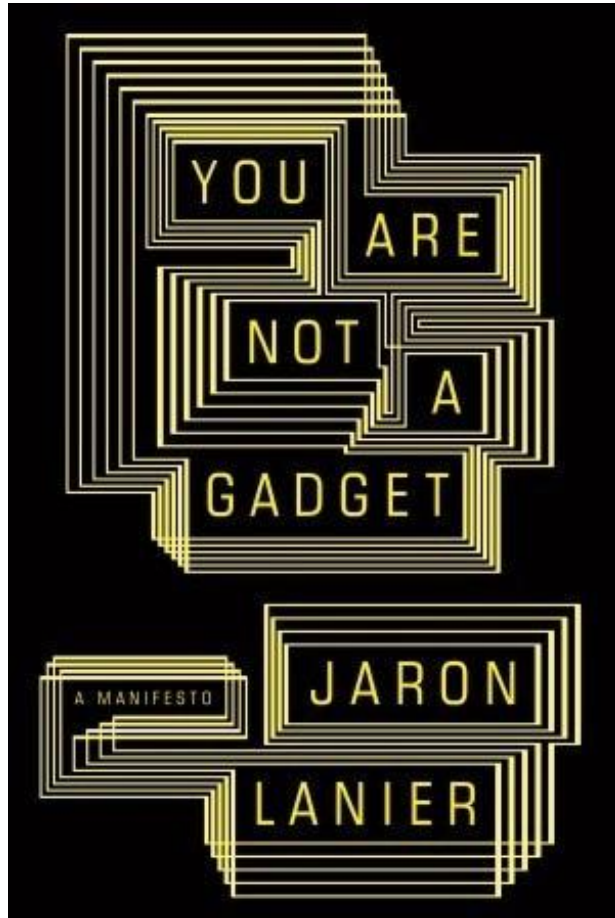
Coalition Reviewed Studies Featuring AI tools:

1. Development and implementation of AI tools to predict and mitigate the risk of postpartum hemorrhage
2. Mental health predictors of pregnant people and their children
3. Afro Pink breast cancer study

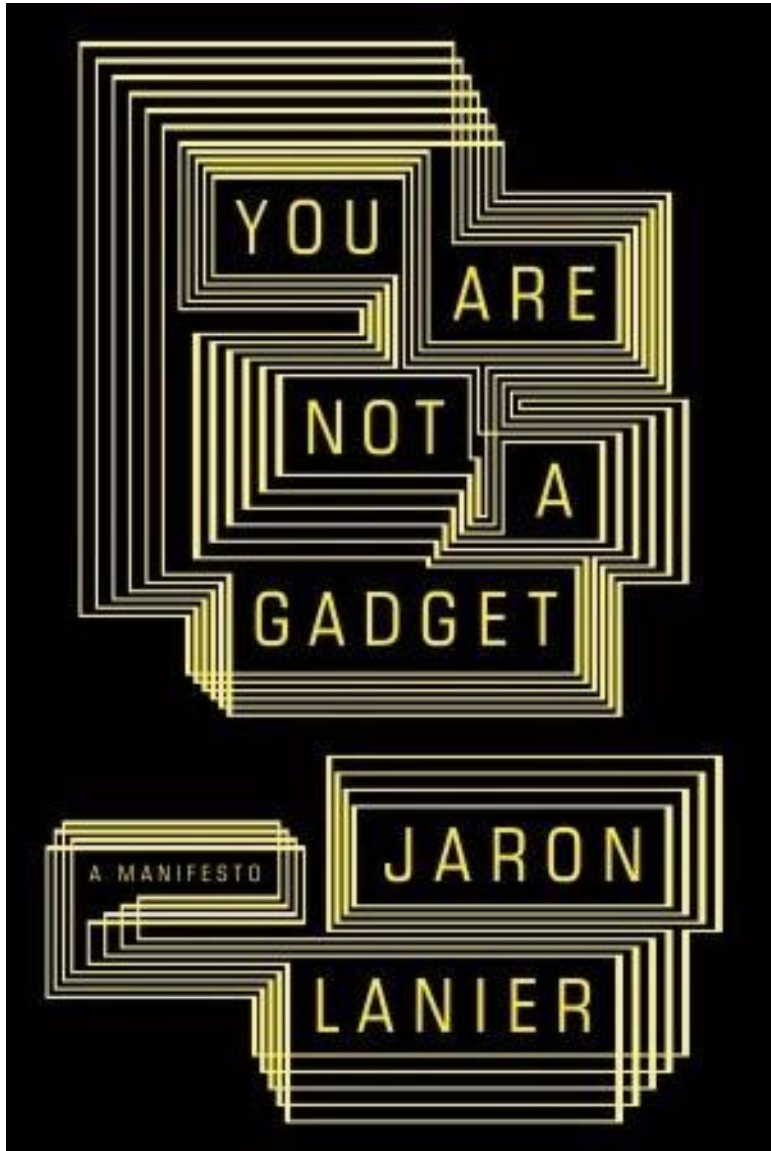
Pressing researchers on their **WHY:**

- Why is AI the right tool for your research or intervention?
- What does “informed consent” mean when people don’t fully understand what AI is, does or can do?
- How will this AI tool influence decision-making differently than before the implementation of the tool?
- Is it worth risking the unknowns?
 - Who could be harmed?
 - Who stands to benefit?

READING AND LEARNING SHARED IN COALITION



CENTERING HUMAN AGENCY IN A WORLD SWAYED BY AI



*“People degrade themselves in order to make machines seem smart all the time. Before the crash, bankers believed in supposedly intelligent algorithms that could calculate credit risks before making bad loans. We ask teachers to teach to standardized tests so a student will look good to an algorithm. **We have repeatedly demonstrated our species' bottomless ability to lower our standards to make information technology look good.** Every instance of intelligence in a machine is ambiguous... While it's to be expected that the human perspective will be changed by encounters with profound new technologies, **the exercise of treating machine intelligence as real requires people to reduce their mooring to reality.**”*

"Masterful and provocative."—Mustafa Suleyman

#1 *New York Times* bestselling author of SAPIENS

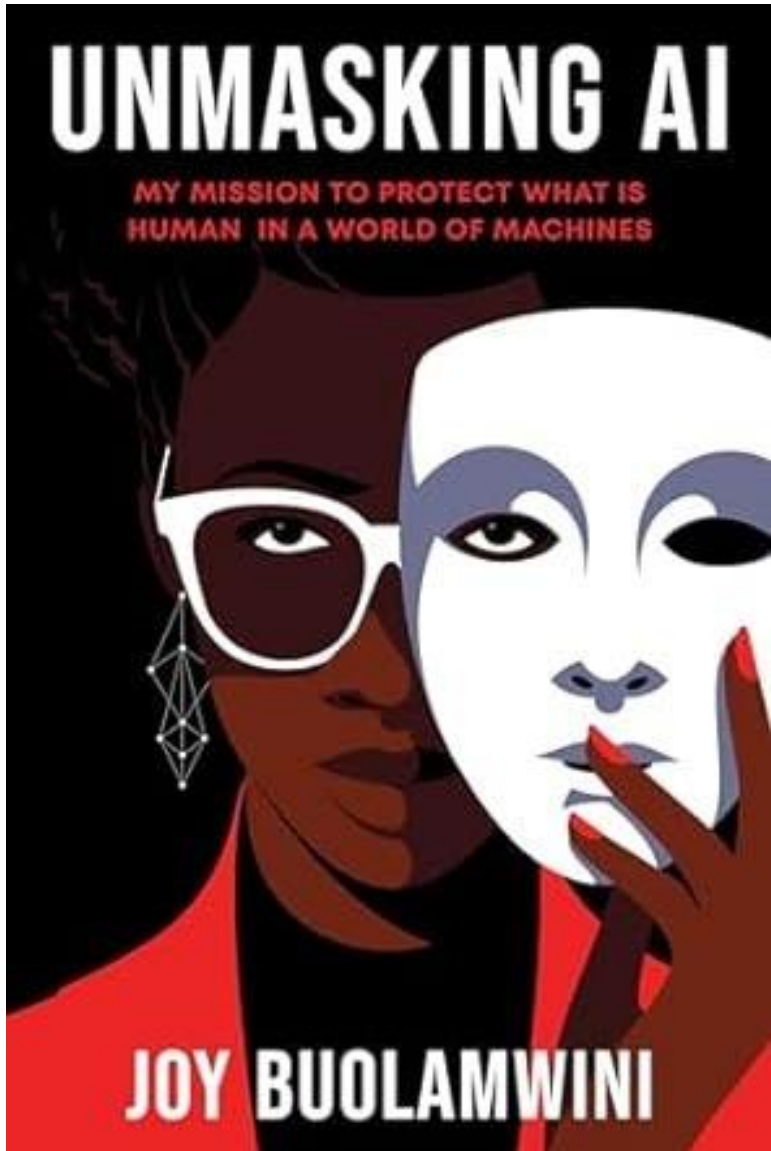
Yuval Noah Harari



Nexus

A Brief History of Information Networks
from the Stone Age to AI

*"Instead of a march of progress, **the history of human information networks is a tightrope walk trying to balance truth with order.** In the 21st century we aren't much better at finding the right balance than our ancestors were in the Stone Age. **Contrary to what the mission statements of corporations like Google and Facebook imply, simply increasing the speed and efficiency of our information technology doesn't necessarily make the world a better place. It only makes the need to balance truth and order more urgent.**"*



*“AI will not solve poverty, because **the conditions that lead to societies that pursue profit over people are not technical.** AI will not solve discrimination, because the cultural patterns that say one group of people is better than another because of their gender, their skin color, the way they speak, their height, or their wealth are not technical. AI will not solve climate change, because the political and economic choices that exploit the earth’s resources are not technical matters. **As tempting as it may be, we cannot use AI to sidestep the hard work of organizing society** so that where you are born, the resources of your community, and the labels placed upon you are not the primary determinants of your destiny. We cannot use AI to sidestep conversations about patriarchy, white supremacy, ableism, or who holds power and who doesn’t. As Dr. Rumman Chowdhury reminds us in her work on AI accountability, **the moral outsourcing of hard decisions to machines does not solve the underlying social dilemmas.**”*

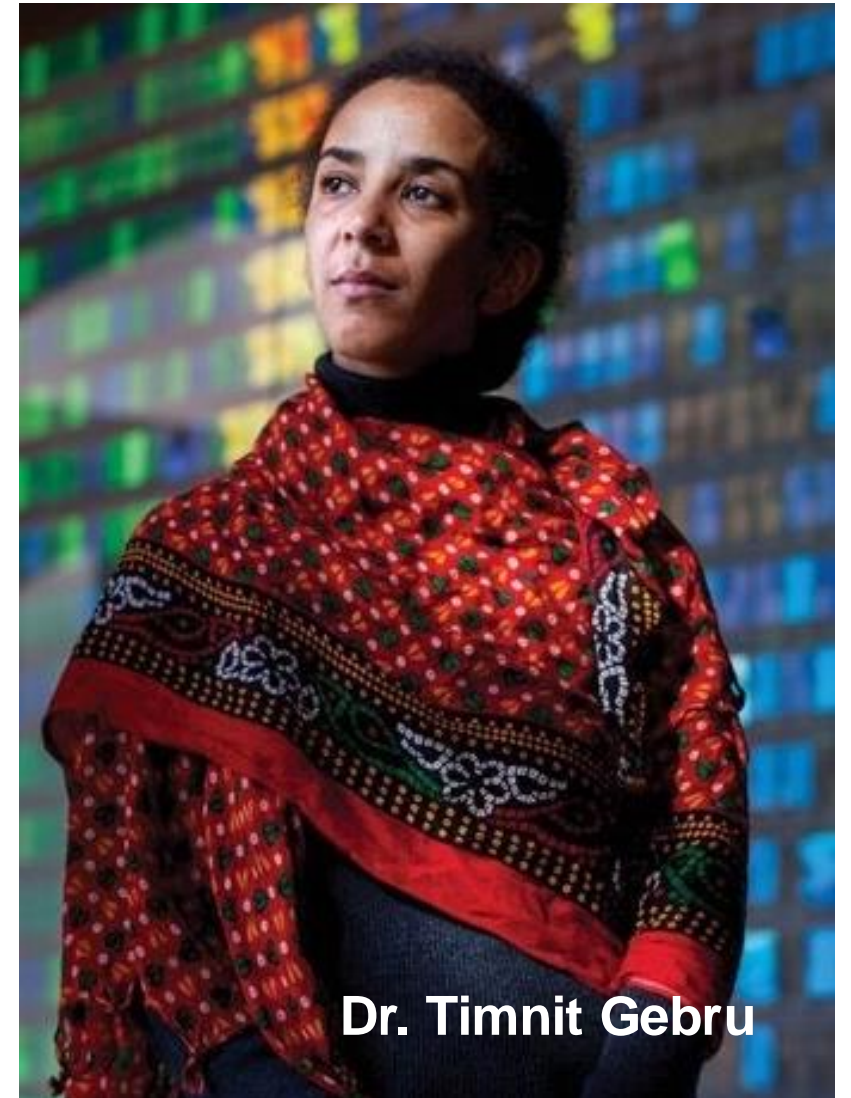
Resist the urge to be impressed

“AI is a marketing term (like big data). Corporations hype it. The public’s perception of it comes from science fiction, which leads them to think of it as something that thinks for itself.

What the public perceives is an illusion of AI, with “armies of exploited workers” behind the illusion.” -Dr. Timnit Gebru, Computer Scientist & AI ethicist (Sourced from The Gray Area Podcast episode titled “Is ethical AI possible?”

Questions to guide the use and creation of AI tools:

- *How was this data created?*
 - *Where did it come from?*
 - *Is it fairly, ethically sourced? Is it biased?*
- *What is the task that you are building for?*
 - *Is it a well scoped task?*
- *How can you test if it is working to solve for that task?*
- *What **actual resources** are going into building the models that aim to solve the problems you are aiming to solve?*
 - ***Is it worth the cost?***



Dr. Timnit Gebru