

The takeaways

- Older adults, including people living with dementia, want more control over digital technologies used in their care and decisions about use
- Frontline staff require education about AI tools, including knowledge about the ethical issues and how to navigate them
- Data privacy is unprotected at the federal level and AI is underregulated
- We need privacy legislation as well as strong AI legislation
- AI hype and the “aging-and-innovation” discourse should not drown out critical questioning
- There are several questions all organizations/agencies should be asking now...



Concerns at CMS about passive monitoring (2014)

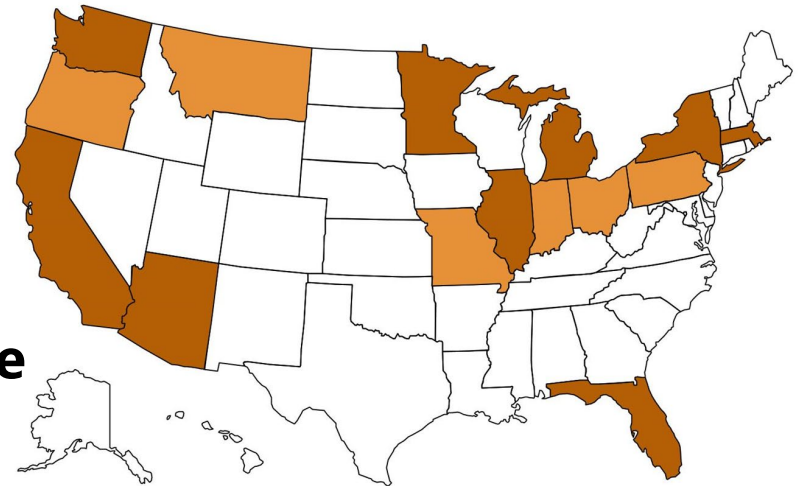
Medicaid HCBS Waivers

- How do we know what is being used with beneficiaries?
- Does it produce or intensify isolation?
- What are the ethical implications?
- Privacy?



Key Findings: State Medicaid HCBS analysis (2016)

- 2/3rds of the 15 states covered location tracking and activity-monitoring sensors; 1/3rd covered cameras
- Only 3 states had service categories to track when they are paying for any of these
- Consideration of ethical issues was limited**
- States struggled to understand which circumstances warrant use and to train staff about tech**



Berridge, C. (2018). Medicaid becomes the first third-party payer to cover passive remote monitoring for home care: Policy analysis. *Journal of Medical Informatics Research (JMIR)*

State Medicaid analysis of home and community-based services waivers

“There’s a consent factor there, and understanding if the person knows they’re being monitored, and if their representative is solely safety-driven and doesn’t include evaluation of dignity at risk. So there are a lot of factors. How informed is the person?”

-state Medicaid waiver manager

Berridge, C. (2018). Medicaid becomes the first third-party payer to cover passive remote monitoring for home care: Policy analysis. *Journal of Medical Informatics Research (JMIR)*

a 2023 National Association of Social Workers webinar on AI

72% rated their knowledge of AI as “low”

1% rated it “high”

-automation:

often, the use of algorithms to classify (e.g., for targeted advertising), suggest (e.g., Netflix), or make consequential decisions (e.g., screening, allocating benefits)

-facial recognition

-generating synthetic media (text or images) using large language models (i.e., ChatGPT, Bard)

UnitedHealth pushed employees to follow an algorithm to cut off Medicare patients' rehab care



By [Casey Ross](#) and [Bob Herman](#) Nov. 14, 2023

ars TECHNICA

BIZ & IT TECH SCIENCE POLICY CARS GAMING & CULTURE

DESPICABLE —

UnitedHealth uses AI model with 90% error rate to deny care, lawsuit alleges

For the largest health insurer in the US, AI's error rate is like a feature, not a bug.

BETH MOLE - 11/16/2023, 3:37 PM



With Labor Department Focus on Tech, Unemployed New Yorkers Can't Reach Human Agents

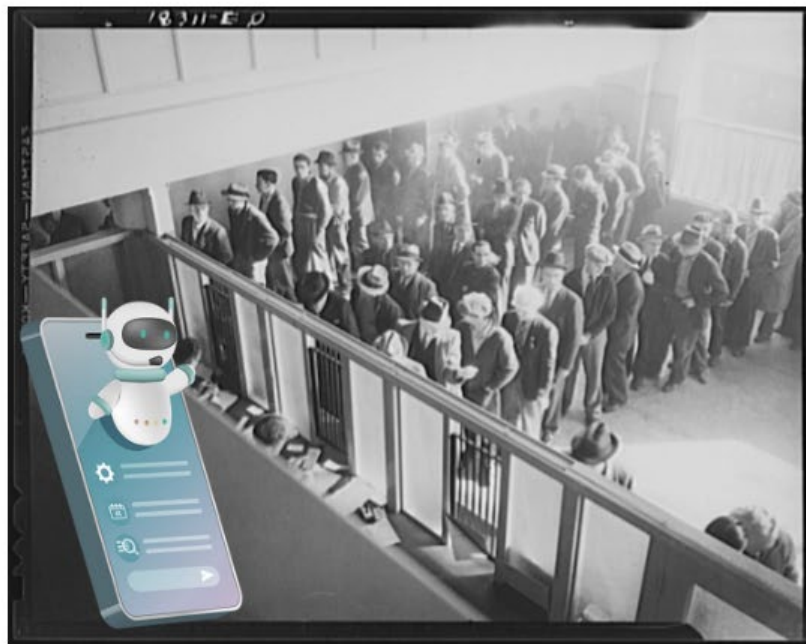
A Rochester man lost his job while his daughter went through cancer treatment. He's struggled to communicate with the DOL for months.

MAXWELL PARROTT · DECEMBER 5, 2023



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NEWS CULTURE MUSIC PODCASTS & SHOWS SEARCH



The Department of Labor encourages claimants to use an AI chatbot rather than calling. | Photo: Dorothea Lange / Library of Congress | Illustration: Maia

TECHNOLOGY

Eating disorder helpline takes down chatbot after it gave weight loss advice

JUNE 8, 2023 · 4:21 PM ET

HEARD ON ALL THINGS CONSIDERED

“Algorithmic decision-making is predisposed to inflict harm if it is introduced to triage support in a benefits system that is chronically underfunded and set up to treat beneficiaries as suspects rather than rights-holders.

By contrast, benefits automation is more likely to promote transparency, due process, and “equitable outcomes” if it is rooted in long-term investments to [increase benefit levels](#), [simplify enrollment](#), and improve working conditions for [caregivers](#) and [caseworkers](#)” (Toh, 2024).

Toh, A. (January 4, 2024). The Algorithms Too Few People Are Talking About LAWFARE. The Lawfare Institute and Brookings:
<https://www.lawfaremedia.org/article/the-algorithms-too-few-people-are-talking-about>

Study: Some AI chatbots provide racist health info



Maya Goldman, author of [Axios Vitals](#)



Illustration: Maura Losch/Axios

Some of the most high-profile [artificial intelligence](#) chatbots churned out responses that perpetuated false or debunked medical information about Black people, a new study found.

ACLU

About

NEWS & COMMENTARY

Algorithms Are Making Decisions About Health Care, Which May Only Worsen Medical Racism

Unclear regulation and a lack of transparency increase the risk that AI and algorithmic tools that exacerbate racial biases will be used in medical settings.

Inaccurate and misleading anthropomorphizing descriptions:

ascribing empathy

understanding

thinking

“brain power”

...sentience

Automation bias is the tendency of people to assume that computers are objective, authoritative, and fair, even when there is evidence to the contrary.

It causes someone to go along with a machine's output even if it doesn't sit right with them.

Automation bias is the tendency of people to assume that computers are objective, authoritative, and fair, even when there is evidence to the contrary.

It causes someone to go along with a machine's output even if it doesn't sit right with them.

People are still driving into lakes because their GPS tells them to

Yoni Heisler

May 17, 2016



GPS Directs Two Drivers Into Hawaii Harbor

In the span of one month, two vehicles have ended up in Kailua-Kona's Honokohau Small Boat Harbor—and allegedly it's all thanks to GPS.

By Adrianna Nine May 31, 2023



Democratizing AI requires public participation

- “Access to government services and benefits
- Gathering and retention of biometric, health, or other sensitive personal information
- Surveillance of vulnerable populations
- Policing functions of the state, such as law enforcement and child welfare
- Gatekeeping access to life necessities such as housing, credit, education, employment, and health care”

Copied from Michelle Gilman, Sept 27, 2023, Democratizing AI: Principles for Meaningful Public Participation. Policy brief. Data & Society

Large language models

- ChatGPT and other tools use code to read and generate plausible text (it's a machine learning model)
- This is a "system for manipulating text" built to "provide a plausible continuation of some input prompt (*what's the likely next word, what's the likely next word...*). The problem is it is so plausible that we interpret it as if it's language, and we do that by imagining there's a mind behind it" (Emily Bender, 2023).
- They are optimized for plausibility – not for accuracy.

Large language models

- Open AI and other companies refuses to release details about their training data.
 - Because different patterns will emerge from different data sets, it matters what the source data are.
- Harms can't be mitigated when you don't know what the training data is.
- Dominant LLMs are likely trained on words written by majority white, majority male, with resources (e.g., Reddit, Wikipedia, public social media accounts).

Examples of unresolved problems & ethical concerns with LLM uses

Treatment recommendations w/out proper validation/oversight leads to harms

Hallucinations, fake “information”

Accountability is not properly assigned. Unregulated – no recourse for harm

Copyright violation and plagiarism

Harmful content (violent, offensive)

Bias (design, training data)

Labor exploitation (outsourced human work to identify toxic/illegal material)

Over-reliance (lack of verification)

Privacy problems

Explanatory understanding is lacking

Inaccurate AI-generated text/images pollute information ecosystem – deteriorating public trust in information/media

Environmental costs (i.e., water for cooling and other resources)

TELEHEALTH & REMOTE PATIENT MONITORING



SHARED CARE PLANNING & COORDINATION



SMART LIVING & HOME CARE



MEDICATION MANAGEMENT



HEALTH ASSESSMENTS



Source: HealthXL Platform (Note: The companies listed above are meant to be representative, not exhaustive. Visit HealthXL.co for more detailed company information including partners, funding, and publications).

CrunchBase and Digital Health Report HealthXL & AARP: Enabling connected and independent living through new care models

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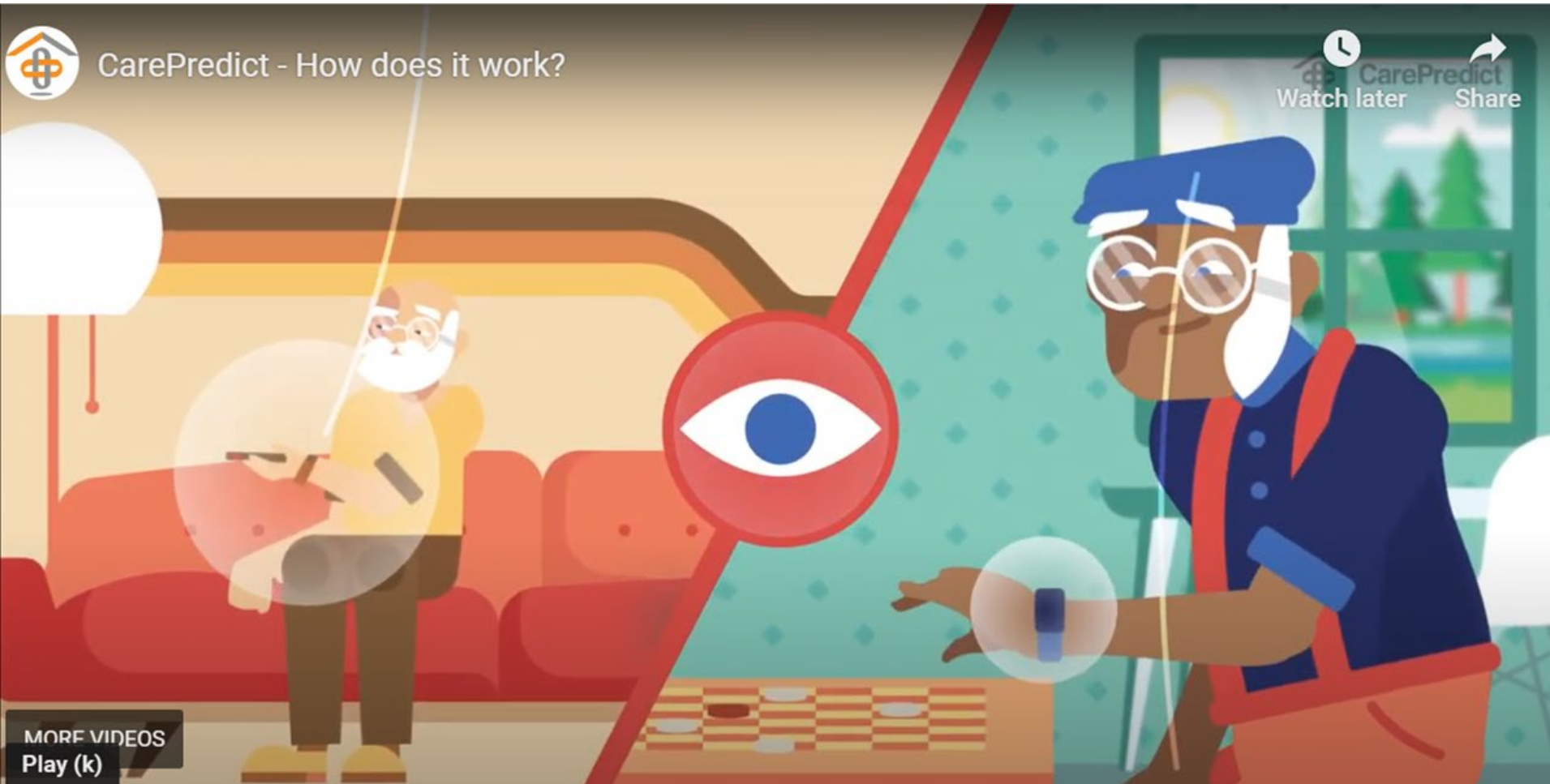
MEDICATION MANAGEMENT



HEALTH ASSESSMENTS



Source: HealthXL Platform (Note: The companies listed above are meant to be representative, not exhaustive. Visit HealthXL.co for more detailed company information including partners, funding, and publications).



“...gathering data at every second to observe each elderly person through their daily activities. To identify and chart their individual behavior patterns to spot any significant deviation.”



CarePredict - How does it work?

SENIOR LIVING COMMUNITIES

Watch later Share

“Making the whole system as sharp and individually vigilant as no single caregiver—either family related or professional—could ever manage to be.”

MORE VIDEOS

24/7 Notifications for Staff Efficiency

Caspar provides 24/7 notifications and automated check-ins. The real-time dashboard allows staff to provide care to residents more effectively.

Even with 1 less FTE, staff provides better care to residents.

The Triple Win of the aging-and-innovation discourse

Neven, L., Peine, A. (2017). From triple win to triple sin: How a problematic future discourse is shaping the way people age with technology. *Societies*

The problem

- Ethics conversation on gerontechnology was slow to get started
- We are now aware of numerous risks and value tensions (Mortenson, Sixsmith, Woolrych 2015; Novitsky et al., 2015, Ienca et al., 2019; Ho, 2020; Lariviere et al., 2021; Higgs 2022)
- But there is a significant gap between the research on ethical issues and design, real-world implementation, policy, and practice

What's at stake for older adults in decisions about how technologies are used in their care?



Lariviere, M. et al. (2021). Placing assistive technology and telecare in everyday practices of people with dementia and their caregivers: findings from an embedded ethnography of a national dementia trial. *BMC Geriatrics*

Those most likely to cause value tensions

- Recording audio in a person's home to respond to emergencies, monitor socialization, detect cognitive change
- Video conferencing allowing a caregiver to turn the webcam on and "enter" the room visually for social connection and visual assessment
- Location tracking outside the home
- Location tracking inside the home to monitor safety and social activity, variation in activity
- Using an AI virtual agent or socially assistive robot for non-human companionship to ease loneliness or prompt engagement
- Remotely monitoring physiological variables for frequent assessment to predict and manage health risks

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Common risks of dementia care technologies (1/4)

- privacy invasion for individual and visitors
- feeling uncomfortable/bugged/no place to hide
- infantilize or lead to feeling “baby sat”
- compromise one’s dignity

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Common risks (2/4)

- caregiver stress from ambiguous data/alert overload
- false sense of security, reducing proactive help
- reduction of visits or calls, leading to loneliness

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Survey comments on importance of human connection

"All of these artificial companions provide the illusion of intimacy without actual intimacy. That's dishonest - and creepy."

"The answers to the problems implicit in these prompts cannot be found on robots - they can only be found in the difficult, and necessary, work of restructuring our society so that people who need it always have in-person support."

"We need to temper AI with HI-Human Intelligence systems that are financially supported and that provide healthy human interactions rather than pretending that Alexa is your 'friend.' That is AI jail keeping, not community building."

Berridge, C., Zhou, Y., Robillard, J., Kaye, J. (2023). Companion robots to mitigate loneliness among older adults: perceptions of benefit and possible deception.
Frontiers in Psychology

Common risks (3/4)

- tension caused by caregiver paternalism in form of intrusive or harassing questioning
- caregiver limits freedom, using data to rebuke, restrict, or micromanage
- behavior change to conform w/ expectations

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Common risks (4/4)

- data lead to knowledge of non-adherence or high risk activities that lead to increased premiums or denial of coverage
- data security risk & nefarious use
- unknown or unsanctioned third party use (companies monetizing data)

Berridge, C., Demiris, G. & Kaye, J. (2021). Domain Experts on Dementia-Care Technologies: Mitigating Risk in Design and Implementation. *Science & Engineering Ethics*

Example of data privacy and use concerns

“Overall I like the idea of an AI companion or device to check-in on a family member. Particularly to alert medical services and family if an emergency arises. However, I have concerns about how that data is being stored and used by third party companies. Far too often that data is not being stored securely and being sold to third party companies for data aggregation.”

-survey participant

Berridge, C., Zhou, Y., Robillard, J., Kaye, J. (2023) AI companion robot data sharing: comfort and preferences of an online cohort with policy implications.
Journal of Elder Policy

HEALTH TECH

Hospitals pledge to protect patient privacy. Almost all their websites leak visitor data like a sieve

A STAT INVESTIGATION

‘Out of control’: Dozens of telehealth startups sent sensitive health information to big tech companies



By [Katie Palmer](#) — STAT and Todd Feathers and Simon Fondrie-Teitler — The Markup Dec. 13, 2022

Limited protections against harm and privacy violation (U.S.)

- “Notice and consent” leaves burden on the user/consumer
- Under HIPAA regulations, companies making direct-to-consumer devices are not covered entities, despite the use of health information (Ho, 2023) (Berridge, 2023, p38).
- There is no requirement that developers provide privacy policy statements in the U.S., or make them widely comprehensible (Ho, 2023; Lupton & Jutel, 2015).

Ho, Anita (2023). *Live Like Nobody is Watching: Relational Autonomy in the Age of Artificial Intelligence Health Monitoring*. Oxford University Press

Berridge, C., Zhou, Y., Robillard, J., Kaye, J. (2023) AI companion robot data sharing: comfort and preferences of an online cohort with policy implications. *Journal of Elder Policy*

Limited protections against harm and privacy violation (U.S.) cont'd

- Data sharing practices matter to people but are inadequately communicated to them (Berridge, 2023, p38).
- Ex: most health apps focused on dementia require explicit entry of personal information (Ye et al., 2023)—and most lack a privacy policy and admit to possible data sharing with outside parties (Rosenfeld et al., 2017).
- Companies under no obligation to do bias assessments (of their algorithm) or otherwise assess social impact

U.S. Federal AI Guidance

Blueprint for an AI Bill of Rights (2022)

White House Office of Science and Technology Policy

- Automated systems and technology-based efficiencies *tempered by civil rights and democratic value concerns*
- *Safe & Effective Systems* (proactive protections, independent evalu.)
- *Algorithmic Discrimination Protections* (unjustified impacts/ treatment based on classifications protected by law (i.e., race, color, ethnicity, sex, religion, age, disability, etc.) equity assessments, algorithmic impact assessment & mitigation info)
- *Data Privacy* (ethical review, use prohibitions, civil rights/liberties)
- *Notice & Explanation* (automated system, how and why impacts you)

White House Executive Order on AI

October 30, 2023

- charges federal agencies with drafting guidelines for responsible AI and taking steps to regulate and review its applications
- requires an immediate “talent surge” at these agencies
- implementing the directives?

Resources: Organizations, media, and advocacy groups

- Center for Democracy and Technology (CDT)
- Tech Policy Press
- Center for Critical Race & Digital Studies (*People's Guide to Finding Algorithmic Bias*)
- Our Data Bodies
- AI Now
- Berkman Klein Center for Internet & Society
- The DAIR Institute
- All Tech is Human
- Data & Society
- Allied Media Projects/Detroit Digital Justice Coalition
- Design Justice Network

Specific suggested resources

- **Examples of how AI touches marginalized communities:**

Poverty Lawgorithms by Michelle Gilman. Data & Society report.

<https://datasociety.net/library/poverty-lawgorithms/>

- **To better understand large language models:**

Watch: “ChatGP-Why” presentation by Drs. Emily Bender and Alex Hanna

<https://www.youtube.com/watch?v=qpE40jwMilU>

Their podcast: *Mystery AI Hype Theater 3000*:

<https://www.buzzsprout.com/2126417>

- **Advice for intentional language use about AI:**

Artifice and Intelligence by Emily Tucker. Tech Policy Press:

<https://www.techpolicy.press/artifice-and-intelligence/>

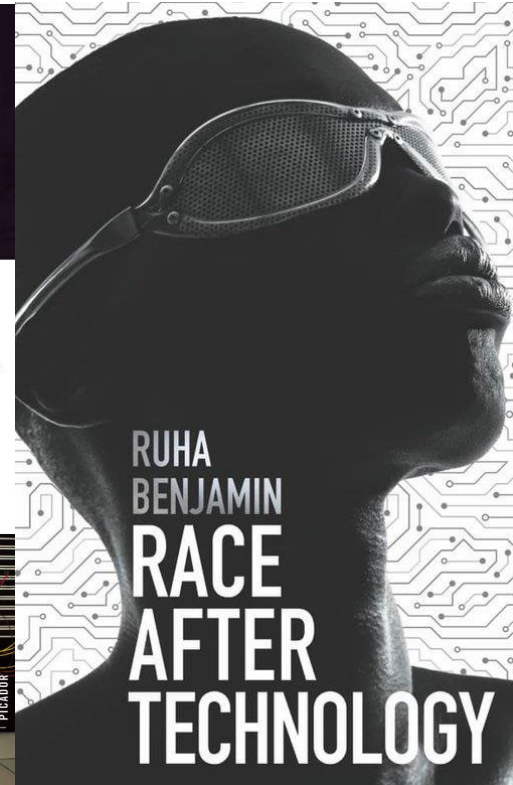
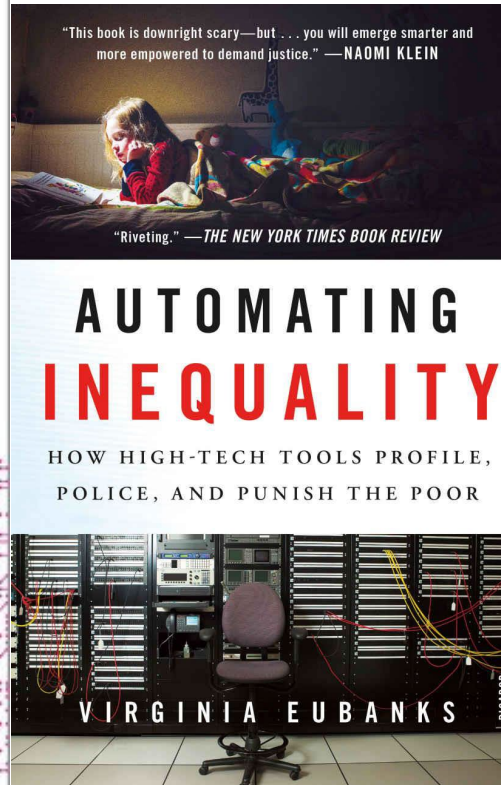
- **Up-to-date discussion of new devices on the market:**

Aging & Health Technology Watch: <https://www.ageinplacetech.com/>

Anita Ho

Live Like Nobody Is Watching

Relational Autonomy
in the Age of
Artificial Intelligence
Health Monitoring



- How were end users and impacted people involved in design and development?
- What's being automated, why, and who benefits from this automation?
- Is this the way we want to achieve this goal?
- How is success and accuracy measured exactly? What are the evaluation metrics?
- How well does it work in the specific case we're using it for?
- Where does accountability lie when something goes wrong?
- How does a person with few financial resources report harm or error? What is the recourse?
- Are the people using and impacted by a given AI tool informed about its use and implications?
- What data was the AI tool trained on? What or who is excluded?
- How much money is invested in this?
- What are the potential opportunity costs?
- Does this address the underlying problem? Does this enable the underlying problem to persist?
- Does this allow us to address structural problems? Does it obscure underlying structural problems?

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Thank you

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Articles cited here that I've co-authored can be found, open access, on my faculty page:

<https://socialwork.uw.edu/faculty/professors/clara-berridge>