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Health Justice in the Digital Age: Can We Harness AI for Good?

Building Boundaries in Love, Equity, and Justice: An AI Manifesto

+

How to Reclaim Our Humanity in the Age of Machine Thinking

The Promises and Pitfalls of Modern Clinical Research

Neuroethics, AI, and Depression

Dismantling Bias: Toward Ethical and Inclusive Health Innovation

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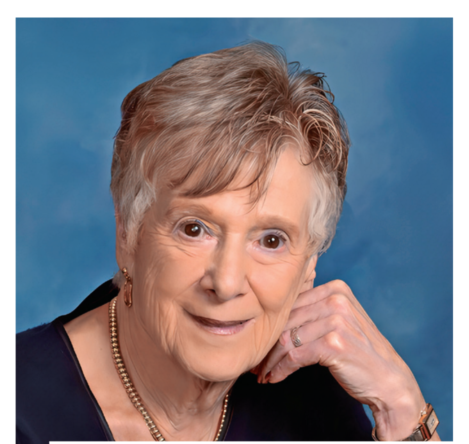

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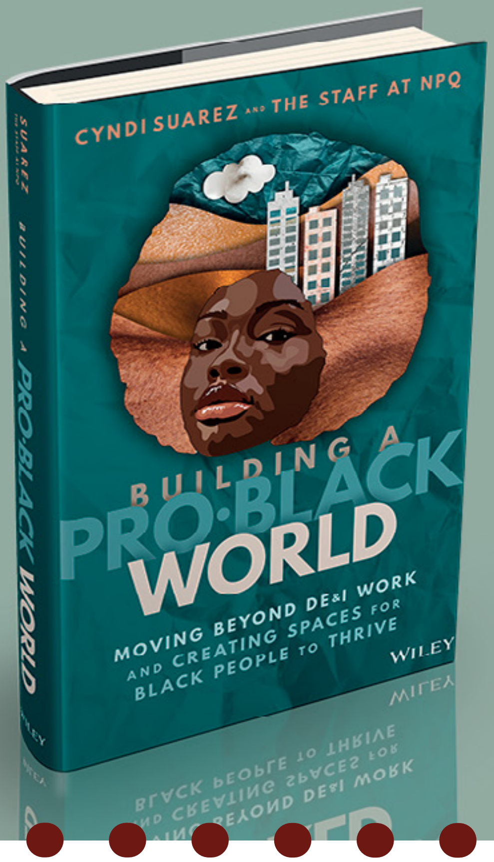

It's Here!

In *Building a Pro-Black World: Moving beyond DE&I Work and Creating Spaces for Black People to Thrive*, a team of dedicated nonprofit leaders delivers a timely roadmap to building pro-Black nonprofit organizations.

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“The social fragmentation our society is experiencing shows up first in the fraying of [our social support] networks. Innovation is necessary to address the structural challenges of social disconnection, exclusion, and isolation that are leading to the mass experiences of loneliness, trauma, and despair—but whether or not technology can be a positive, powerful force to that end remains to be seen and, in fact, currently is a big part of the problem.... The critical question is, *How can we ensure that innovations in technology are rooted in equity and become tools for justice, empowerment, and wellbeing, including in our healthcare systems?*”

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WELCOME

Dear Readers,

In December 2024, California Senator Josh Becker, author of the Physicians Make Decisions Act (SB 1120), stated, “Artificial intelligence has immense potential to enhance healthcare delivery, but it should never replace the expertise and judgment of physicians.” He added, “An algorithm cannot fully understand a patient’s unique medical history or needs, and its misuse can lead to devastating consequences. SB 1120 ensures that human oversight remains at the heart of healthcare decisions.”

The rapid advancements in cutting-edge technologies—from CRISPR gene editing to artificial intelligence—promise nothing short of a revolution in healthcare and public health. These tools hold the potential to eliminate diseases, enhance personalized medicine, and improve health service delivery on a global scale. Yet, as history reminds us, progress without purpose can lead to catastrophic consequences. Hope and planning must go hand in hand.

In this issue of *NPQ*, we tackle a fundamental question: How do we harness the transformative potential of health innovations while ensuring they *advance* health equity rather than *exacerbate* existing disparities?

This is not a technical or theoretical debate. It is a matter of life and death. As these technologies take hold, spread, and grow, it also lies at the heart of what it means to design a more equitable future.

It is tempting to see emerging technologies through a binary lens. On one side, a utopian vision: AI systems breaking down barriers to care, CRISPR eliminating hereditary diseases, and tech-driven solutions making healthcare universally accessible. On the other, a dystopian nightmare: algorithms entrenching systemic biases, genomic data exploited for profit, and entire populations excluded from the benefits of innovation.

But such polarized thinking obscures the most urgent reality: These technologies will not inherently lead us to one extreme or the other. Their outcomes will depend on the intentionality with which they are designed, implemented, and governed.

As Yewande O. Addie eloquently writes within, “AI is a powerful tool for advancing human potential—but only if it is designed with intentional boundaries that protect and uplift the most vulnerable among us.... In this sense, establishing policies and ethical frameworks acts as a boundary of love, not only safeguarding society at large but also protecting creators from the unintended consequences of their own innovations.”

As you turn these pages, we invite you to sit with this tension. To ask difficult questions. To challenge assumptions. And most of all, to imagine what a future rooted in health equity and justice could look like. The stakes could not be higher.

In solidarity and curiosity,
Sara Hudson
Interim CEO & Editor in Chief, *Nonprofit Quarterly*

Building Boundaries in Love for Equity and Justice

An AI Manifesto

by Yewande O. Addie

A symbiotic relationship between love and boundaries is essential for creating healthy, sustainable connections in all types of relationships—romantic, familial, or platonic. While love is often associated with openness, generosity, and care, boundaries are crucial for love to remain respectful, mutual, and emotionally safe.[1]

As we enter a new era shaped by artificial intelligence, we face both unique opportunities and profound risks. AI is a powerful tool for advancing human potential—but only if it is designed with intentional boundaries that protect and uplift the most vulnerable among us.

At its core, AI must be a force that serves humanity, not the other way around. It must enhance our collective capacity to build more just and equitable societies. AI tools are not neutral; they carry the biases and assumptions of the systems and individuals who create them. When we build AI, we must ask: *Who benefits from this technology? Who is harmed?* This manifesto advocates for the creation of parameters rooted in love, equity, and justice to guide AI's continued development and deployment. It calls for AI that is designed *explicitly* to dismantle systemic inequities and address the social ills caused by historical and present-day injustices.

In order to do so…

"MANIFESTING LOVE" BY DALL-E 3/OPENAI.COM/DALLE

[AI creators] can fall victim to the pressure to be the first and fastest, driven by profit motives and competitive market forces. Without thoughtful parameters in place, they risk creating systems that perpetuate harm, exacerbate inequality, and destabilize societal norms. In this sense, establishing policies and ethical frameworks acts as a boundary of love.

> **WITHOUT OVERSIGHT, AI SYSTEMS CAN DEEPEN SOCIAL DIVIDES, AUTOMATE BIASES, AND DESTABILIZE LABOR MARKETS.**

We Must Build Parameters to Protect Our Most Vulnerable Populations and Precious Resources

The relationship between AI and its environmental impact is both intricate and far-reaching. Ironically, the technology that promises a more efficient future is also contributing to a great strain on the planet's resources. AI's ecological footprint extends through water-intensive demands, energy consumption, carbon emissions, and resource extraction, all of which pose serious risks to human health and fragile ecosystems.

The data centers that power AI systems consume vast amounts of water for cooling, exacerbating water insecurity in vulnerable regions. Large AI models require immense energy, contributing to air pollution and climate change; and mining for the rare earth metals used in AI hardware degrades soil, contaminates water sources, displaces local communities, and leaves behind hazardous electronic waste that pollutes both land and water.[2]

AI's insatiable energy consumption has negative consequences on human health, too, manifesting in respiratory illnesses due to increased air pollution,[3] as well as (indirectly) in heat-related illnesses, due to AI's role in greenhouse gas emissions—which drive global warming and intensify the frequency and severity of extreme heat events.[4] The invisible weight of data centers hangs heavy in the atmosphere, diminishing the quality of life for nearby communities through increased noise, strain on local resources, and environmental disruptions.[5] In Granbury, TX, for example, residents living near a Bitcoin mining facility reported migraines, vertigo, hearing loss, heart palpitations, hypertension, panic attacks, and chest pain due to constant noise pollution—showcasing the profound physical toll such data centers can impose on those in their proximity.[6]

These examples remind us that the unimpeded development of AI has tangible consequences, emphasizing the need for thoughtful parameters that prioritize human and environmental wellbeing.

We Must Build Parameters to Protect People from AI Creators and AI Creators from Themselves

In the rush to lead the global AI race, it can be tempting to prioritize innovation, speed, and profit without pausing to consider the profound ethical, societal, and human consequences. But unchecked ambition can leave those who create AI—and those impacted by it—vulnerable to the risks of a world increasingly shaped by unregulated technological advancements. To prevent injury, we must establish metaphorical boundaries of love through ethical guardrails that guide AI development with compassion, care, and foresight.

AI creators, driven by a desire to innovate and lead, may not always foresee the long-term repercussions of their work. These developers—engineers, data scientists, and tech leaders—can fall victim to the pressure to be the first and fastest, driven by profit motives and competitive market forces. Without thoughtful parameters in place, they risk creating systems that perpetuate harm, exacerbate inequality, and destabilize societal norms. In this sense, establishing policies and ethical frameworks acts as a boundary of love, not only safeguarding society at large but also protecting creators from the unintended consequences of their own innovations.

For those impacted by AI—communities, workers, everyday people—such policies serve as essential protective barriers. Without oversight, AI systems can deepen social divides, automate biases, and destabilize labor markets. AI policy must, therefore, act as a boundary that prioritizes the wellbeing of all people, assuring that technological progress is guided by empathy and justice. By embedding values of equity and fairness into AI systems, we ensure that the development of AI is an act of love, offering tools that elevate humanity rather than exploit it.

Through thoughtful, intentional AI policies, we can build a future where boundaries are not seen as barriers to progress but rather as defenses designed to support both creators and those affected by their creations. These boundaries of love provide the space for responsible innovation, protecting individuals from the unintended wounds of a rapidly advancing digital age.

THE USE OF AI IN CRIMINAL JUSTICE PRACTICES... POSES A SERIOUS THREAT TO THE SOCIAL DETERMINANTS OF HEALTH.

We Must Protect the Economic and Financial Security of Workers

As AI is integrated into industries, workers face growing fears about job security.[7] Automation threatens not only manual labor but also complex white-collar jobs.[8] This concern is valid, as AI has already begun reshaping such sectors as manufacturing, healthcare, and legal services.[9] Anxiety over potential job displacement affects worker morale, financial stability, and mental health.[10]

Protecting workers' economic security requires policies that guarantee they aren't left behind in the technological shift. This includes promoting upskilling programs, financial support during industry transitions, and strong safety nets like unemployment benefits and retraining opportunities.

AI must not become a tool of exploitation or a means of cutting costs at the expense of human dignity. Workers deserve to benefit from the productivity gains AI offers. By establishing protective policies that prioritize workers' rights, financial stability, and long-term career development, we can make certain that AI serves as a partner in human progress rather than a force that diminishes livelihoods.

We Must Prevent AI Technology from Encroaching Upon the Quality of Life and Wellbeing of Black and Brown People

The use of AI in criminal justice practices, especially through facial recognition technology, poses a serious threat to the social determinants of health, particularly by infringing on social and civic engagement for communities of color. Facial recognition algorithms have been shown to inaccurately identify people with darker skin tones at significantly higher rates than their lighter-skinned counterparts.[11] This technological bias leads to wrongful detentions, arrests, and surveillance, mirroring the overpolicing and excessive scrutiny historically imposed on Black and Brown communities. Such AI applications replicate problematic policing practices, triggering trauma linked to decades of discriminatory justice systems and reinforcing community distrust.[12]

Additionally, AI systems in criminal justice often operate in "black boxes," with opaque decision-making processes that lack transparency and accountability.[13] This secrecy prevents public oversight, leaving communities vulnerable to unchecked biases that reinforce systemic inequities. AI tools trained on biased historical data can exacerbate discriminatory practices—and predictive policing algorithms, which target specific areas based on flawed datasets, drive over-surveillance and privacy violations, particularly in lower-income and minority neighborhoods.[14]

The deployment of these technologies without community consent disregards the voices of those most affected, stripping communities of autonomy and reinforcing a top-down approach to safety. Moreover, the reliance on AI-driven tools has contributed to the militarization of police forces, which further alienates communities and distances law enforcement from community-based approaches.[15] Continuous surveillance also has a profound psychological impact, fostering an atmosphere of fear and hyper-vigilance that undermines mental health and wellbeing.[16]

Beyond criminal justice, AI systems reinforce inequities in such critical areas of life as housing and employment by relying on biased data proxies—such as eviction histories, criminal records, and ethnic names. These algorithms often disfavor marginalized communities, resulting in unfair denials for housing, loans, or jobs, which compromises economic stability, housing security, and broader social determinants of health. Instead of alleviating systemic discrimination, AI can frequently amplify it, obstructing opportunities for stability and wellbeing in communities already impacted by inequality.[17]

Addressing these injustices in AI-driven criminal justice and related systems that influence quality of life is essential to advancing health equity and ensuring that technology fosters, rather than obstructs, opportunities for community wellbeing: The use of biased proxy data in AI must be carefully scrutinized and removed; transparent, community-led oversight and rigorous auditing of AI datasets is necessary; we need more representative datasets to offset historically biased ones and eliminate data proxies; and it's imperative that we ban harmful AI applications in policing and housing, so as to challenge systems that have long marginalized Black and Brown communities. Only by demanding accountability in AI's design and implementation can we begin to shift its role from a tool of exclusion to—at the very least—a respecter of humanity.

THE FUTURE OF AI CANNOT BE SHAPED IN SILOS; WE MUST BRING DIVERSE VOICES INTO THE ROOMS WHERE AI IS CREATED, WHERE DECISIONS ARE MADE, AND WHERE SYSTEMS ARE DESIGNED.

We Must Create Opportunities for People to Safely Opt Out of These Innovations

AI systems are becoming integrated into daily life. Facial recognition technologies, in particular, present significant concerns around data privacy and surveillance. These systems can collect and store personal data without individuals' explicit consent, raising critical ethical issues around informed participation, discrimination, and potential misuse.[18] This technology is frequently implemented in outdoor public spaces, retail environments, airports, and even within digital platforms—yet many people are unaware that their faces are being scanned, analyzed, and often stored in databases, sometimes indefinitely. This poses a serious risk to privacy, particularly as data breaches or improper use of this technology can lead to identity theft, wrongful arrests, or surveillance abuses that disproportionately affect marginalized communities. For instance, research shows that facial recognition systems are often less accurate when identifying people of color, as noted earlier, and women, increasing the potential for biased outcomes and social harm.[19]

To counter these risks, we must create clear and accessible pathways for individuals to opt out of facial recognition and other AI-driven data-collection processes. This can involve implementing legislation that mandates transparency around where and how such technologies are used and providing users with real-time notifications when their data are being collected. Furthermore, ensuring the availability of alternatives for those who wish to avoid these systems altogether is crucial, especially in settings like airports or workplaces, where participation might otherwise feel compulsory.[20]

The right to opt out is not merely about privacy; it is about allowing individuals control over their digital footprint and the ways their personal data are utilized. Establishing robust opt-out mechanisms is essential to respect individuals' rights to privacy and autonomy; it also bolsters an important truth—that currently, participation in AI-driven technologies remains a choice, not a mandate.

We Must Invite Diverse Groups of Thinkers and Doers behind the AI Curtain

The future of AI cannot be shaped in silos; we must bring diverse voices into the rooms where AI is created, where decisions are made, and where systems are designed. These thinkers and doers, from a wide range of lived experiences, industries, and cultures, have an essential role to play in making sure that the technology we build reflects the values of justice, equity, and love.

Along with these thinkers and doers, we must invite those committed to warning us, so that we never forget the histories of oppression, the dictators, and the authoritarian systems that have eroded our shared humanity. Historians, social justice advocates, and ethical scholars are essential for reminding us of the devastating impacts of sexism, racism, capitalism, and authoritarianism on human lives and natural environments. Their insights can help us design and refine AI systems that actively avoid perpetuating these violations, so that new technologies do not silently reinforce the worst aspects of our past.

We ask those who nobly answer the call, to provide cautious oversight so that inequality does not become permanently enmeshed in algorithms, replicating biases that can be scaled indefinitely. These oversight actors should include policymakers, ethicists, technologists, and community leaders who understand that an unencumbered automation of societal practices, many of which are already questionable or outright destructive, would bake in existing disparities—making it nearly impossible to reverse systemic injustices without significant intervention.

And we seek those who call out discriminatory biases already at work in AI—in criminal justice, hiring practices, and public service decision-making. These are the data scientists, civil rights organizations, and legal professionals who have demonstrated time and again how biased data lead to biased outcomes: AI that disproportionately incarcerates Black and Brown people, denies job opportunities to marginalized populations, and limits access to essential public services.[21]

THE BOUNDARIES PROPOSED HERE ARE NOT LIMITATIONS BUT RATHER ACTS OF CARE DESIGNED TO SECURE A FUTURE WHERE AI IS IN SERVICE OF EQUITY.

We Must Protect People's Minds, Especially Young People, from Overdependence on Generative AI

Generative AI, whereby AI is used to generate content via prompts from a user, offers unprecedented creative opportunities but also a risk of overreliance. AI should serve as a creative partner, enhancing human ingenuity, rather than becoming a crutch that stifles original thought.

Young people in particular are at risk of losing their innate capacity for critical thinking, problem-solving, and imaginative exploration when overrelying on generative AI tools. As AI systems offer instant solutions, answers, and even art, the need for human-driven experimentation, curiosity, and struggle diminishes. Without proper boundaries, we risk generations that bypass the deep, sometimes challenging process of learning, growing, and creating.

To protect minds from the passive consumption and regurgitation of AI-generated outputs, we must reframe AI as a collaborative tool—a partner that amplifies human creativity rather than replacing it. AI should be integrated into learning and creative environments in a way that encourages users to remain engaged, questioning, and involved in every step of the creative process. Whether it's generating ideas, providing inspiration, or assisting with tasks, AI's role should be complementary, not directive. We can teach young minds that the value of creativity lies in the journey—in the act of thinking, experimenting, and iterating. We must be intentional in guiding young people to see AI as a powerful assistant, not a substitute for their unique brilliance.[22]

We Must Use AI to Make Equity Investments in Systems Where Inequity Currently Thrives

AI offers powerful opportunities to address entrenched inequities in sectors like healthcare, education, criminal justice, and employment. These systems, often biased by design, disproportionately affect marginalized communities. AI can reveal and correct these disparities by analyzing large datasets and identifying patterns of inequity.

In education, AI could personalize learning and bridge achievement gaps, offering tailored support to students from disadvantaged backgrounds.[23] Additionally, AI could audit hiring, promotion, and sentencing decisions in employment and criminal justice, helping to remove bias and lead to fairer outcomes.[24] And in healthcare, AI could detect and address racial and economic biases in diagnosis and treatment and improve access to care for underserved populations.[25]

By using AI to make equity-driven investments in these systems and others, we can build the boundaries of love and care needed to dismantle structural inequities. But it is essential to remain vigilant in our commitment to these calls to action.

* * *

The boundaries proposed here are not limitations but rather acts of care designed to secure a future where AI is in service of equity—acts that we all must be a part of bringing into being. This manifesto, therefore, is not meant to be comprehensive but rather a draft—a living document meant to be expanded by all who care about creating a just world through technology.

This manifesto emphasizes the critical intersection of AI, equity, and justice, building upon the foundational themes from RTI International's Transformative Research Unit for Equity's (TRUE) Narrative Convening on AI, Equity, and Storytelling, held in 2024 and inspired by our esteemed convening keynote speaker, Ruha Benjamin. It draws from key principles in narrative change and technology ethics to create a vision for AI development that serves the common good.

DETAIL: "MANIFESTING LOVE" BY DALL-E 3/OPENAI.COM/DALLE

NOTES

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HEALTH JUSTICE

The AI Mirror—How to Reclaim Our Humanity in the Age of Machine Thinking

A Conversation *with* Tonie Marie Gordon *and* Shannon Vallor

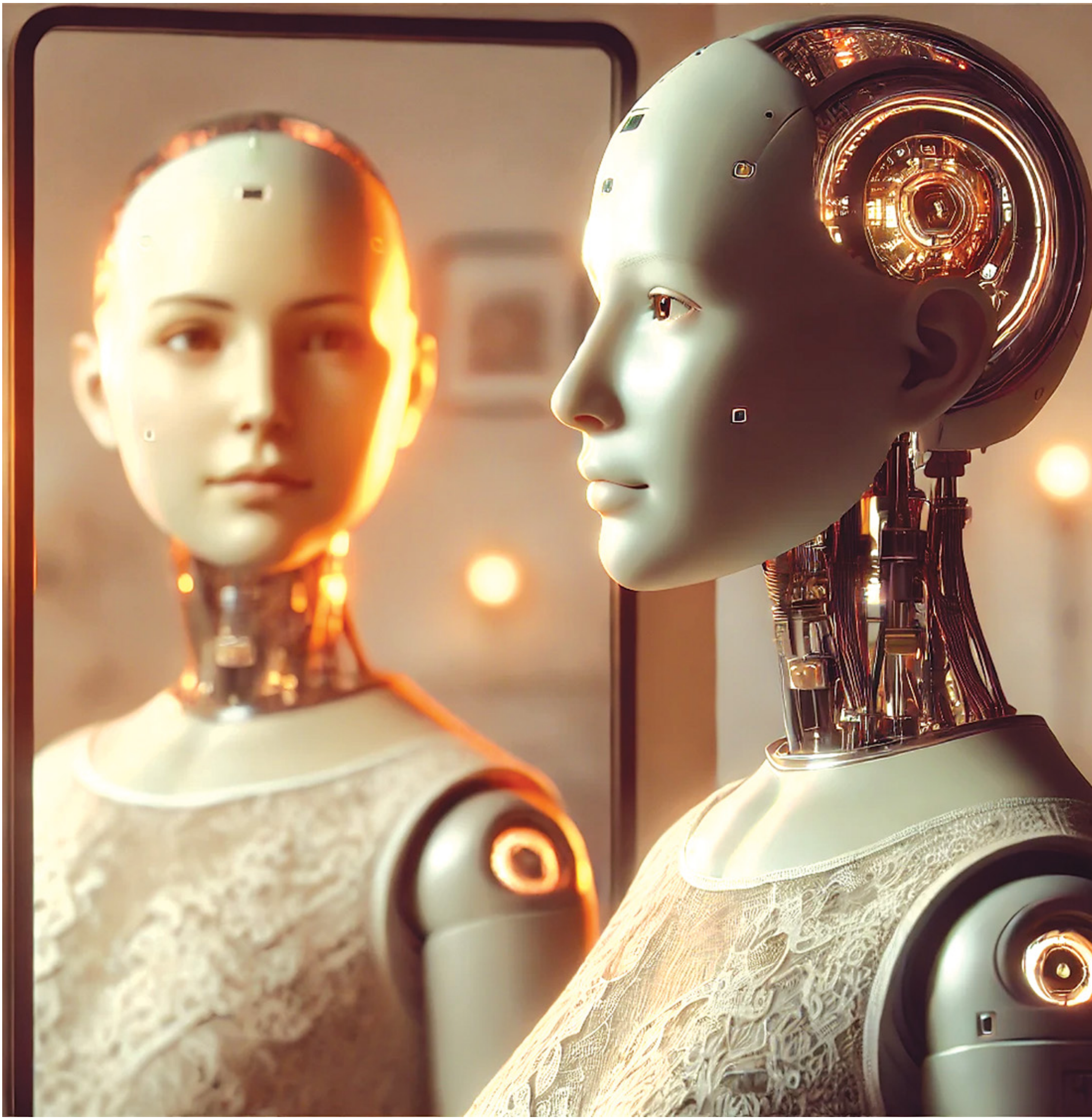
In this in-depth conversation about the effects of artificial intelligence on our society and our planet, Tonie Marie Gordon, NPQ*'s senior health justice editor emerita, and Professor Shannon Vallor, Baillie Gifford Chair in the Ethics of Data and Artificial Intelligence at the Edinburgh Futures Institute, University of Edinburgh, and author of* Technology and the Virtues: A Philosophical Guide to a Future Worth Wanting *(Oxford University Press, 2016) and* The AI Mirror: How to Reclaim Our Humanity in an Age of Machine Thinking *(Oxford University Press, 2024), discuss best practices for navigating AI's potential and risks.*

Tonie Marie Gordon: Your recent book is framed around the metaphor of AI as a mirror—a conceptual framework that I found to be very apt.[1] Can you elaborate on that?

Shannon Vallor: I think it's important to recognize that AI is not one technology but many. AI is not a clean, tidy, scientific label that we can attach to this kind of software and not this other kind. It's more of a marketing term than a scientific term, at present. There are many different kinds of tools that use machine learning and rule-based programming—and other kinds of algorithms—to develop applications. People call it AI when it's an algorithm that does something that they think is clever enough, or new enough, to be able to market as AI.

There are many different types of AI, and the different types have different structures, different capabilities, different limitations, different risks, different benefits.

"THE AI MIRROR" BY DALL-E 3/OPENAI.COM/DALLE



[T]hese AI tools that are built to generate reflections of human intelligence don't reflect all of us. They don't reflect all of society, because the training data that are used to produce these mirror images are like the light falling on a mirror. And a mirror can only reflect the light that reaches it. It can't reflect the light that falls outside the edge of the mirror.

“We don’t have digital data for a lot of human intelligence, because people weren’t valuing the people who produce ‘those’ books, or the people who produce ‘that’ art.”

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I wrote *The AI Mirror* to talk about one large class of AI technologies that are built using machine-learning techniques to create models of us, basically—models of human speech, models of human writing, models of human image making, models of human decision-making—by using large volumes of our data to then create a reflected image of us, which is how I came to the metaphor of the AI mirror for this class of AI technologies. So the starting point is to realize what kind of AI I’m talking about when I use the metaphor of a mirror. For example, if you think about a machine-learning algorithm like DeepMind’s AlphaFold, which is a model of protein structures that is used to predict certain kinds of biological and biomedical possibilities for protein folding—an important feature for research into medical treatments, pharmaceuticals, things like that—that kind of research doesn’t really fit the metaphor of the AI mirror.[2] Because what’s being reflected in that mirror doesn’t look anything like us. If it’s a mirror of anything, it’s a mirror of protein structures. So I’m not really thinking about AI tools that deal with data from somewhere else in nature other than our own speech, thought, and action.

But—and here’s the first qualification—*these AI tools that are built to generate reflections of human intelligence don’t reflect all of us*. They don’t reflect all of society, because the training data that are used to produce these mirror images are like the light falling on a mirror. And a mirror can only reflect the light that reaches it. It can’t reflect the light that falls outside the edge of the mirror. We don’t have digital data for a lot of human intelligence, because people weren’t valuing the people who produce “those” books, or the people who produce “that” art—it didn’t get digitized, didn’t get celebrated, didn’t receive comments on Reddit or Facebook. So the training data that we use to build models of human intelligence, like ChatGPT, which are not themselves intelligent but simply reflect the human intelligence that trained them, are actually a very small selection of the data that we have, and those data are a small selection of the outputs of human intelligence on the planet. The data heavily overrepresent men. They heavily overrepresent English speakers. They heavily overrepresent cultural artifacts produced in the Global North. They heavily overrepresent cultural artifacts produced by the wealthy and people who had access early on to digital technologies and the bandwidth to digitize their activities online. So there are billions of people on this planet who don’t get to be represented in these mirrors, and their intelligence is like the light that falls outside the mirror.

That important qualification notwithstanding, we have centuries of data collected because of how much work we’ve done digitizing the past—digitizing old paintings, digitizing old books, digitizing old historical records—which we’ve also been using to train these models. So, these models are reflections of our past—and again, reflections of a certain select subgroup of humanity’s past. But what they do is very much like a mirror. So, if you think about a mirror, you’ve got a glass surface, and the properties of the mirror’s coating determine how much light it will reflect, how well it will reflect it, whether the image that results will be distorted or magnified. So you can create different kinds of mirrors by using different kinds of coatings and glass properties. Machine-learning algorithms differ in the same sort of way. That is, we can change the algorithm in order to change what we want to show—what we want the algorithm to magnify, what we want it to minimize, what we want it to exclude, what we want it to center, what we want it to amplify. So we build algorithms not to just neutrally reflect data—*just as there’s no mirror that’s neutral, there is no neutral algorithm*. AI models are mirrors that are manufactured to produce certain kinds of reflections of human intelligence.

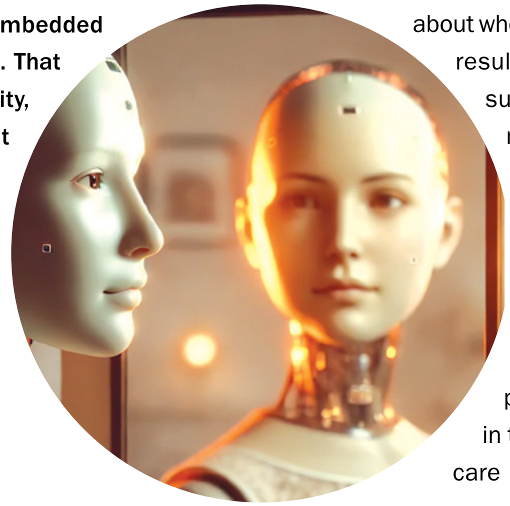
And the final thing is that the outputs of these AI models—what you get out of something like ChatGPT or what you get out of any large language or image or video model—is not a thought or a work of art or even a human sentence that has been spoken. What you get is a *reflection* of that—something that looks very much like it but that doesn’t contain or encompass what stands behind it. Think about when you look in the bathroom mirror—you know there’s nobody on the other side of that mirror. You see a body in the mirror, but you know that it’s just a reflection, that it’s shallow. There’s

“[AI tools] are not machine intelligences. They are mirror reflections of our collected minds and intelligence.... Yet these tools are being marketed as replacements for us.”

no depth to it. You can’t press deeper into it. There’s nothing behind that glass. But when we talk to an AI tool like ChatGPT, it’s very easy to be deceived, or to fool ourselves, into thinking that we’re talking to another mind, that there’s another mind over there on the other side of the prompt window that’s speaking back to us. But that would be like confusing the image in your bathroom mirror with another person and thinking that you’re having a conversation when actually you’re just talking to yourself.

That’s the other important thing about this metaphor—it helps us to understand what AI tools are and what they are not. Because what they are not are other *minds*. They are not machine minds. They are not machine intelligences. They are mirror reflections of our collected minds and intelligence, and they’re very shallow in the way that a reflection is, and that means we can’t rely on them to do all the things that real minds do. Yet these tools are being marketed as replacements for us, as if they were not our mirror reflections but rather a new kind of mind that has been built to compete with ours. And that’s the kind of illusion that I’m trying to puncture in the book.

TMG: **You were just talking about how, through pulling in centuries of data, a lot of these algorithms are reflections of the past. They reflect these very large volumes of data that come from past thoughts and past interactions. They also reflect the long arc of what we know is a history with a lot of inequality baked into and embedded within those thoughts, those actions. That basis in past mistakes, past brutality, and marginalization of a lot of different folks is what makes it particularly problematic in terms of how AI is functioning in our society today. It affects how people look to AI in terms of making future decisions or thinking about our immediate and long-term future.**



SV: Yes, the book focuses a lot on that: the fact that we’re being told that these technologies are the future, but the only capacity they actually have is to sniff out the patterns of the past and our data and use them to make predictions—which is essentially a way of saying we’re going to do things exactly as we’ve done them before, only more so.

We know that we live in a world that is unjust, increasingly unequal, increasingly fractured and divided, and increasingly unsustainable—environmentally, politically, economically—and yet what we’re doing with AI tools—not because we have to use them this way, by the way, but because we’re *choosing* to use them this way—is to reproduce all of the unsustainable patterns of the past that have gotten us into what many people have called the *permacrisis*, where all of our institutions and systems seem to be increasingly stressed and under threat of fracture and collapse.[3] And if the patterns that led you into unsustainable ways of life are reproduced in the machines that you build to automate society, that’s essentially the same as seeing that you’re heading over a cliff and then pressing on the accelerator. A lot of these AI tools are designed to do just that, because it’s easy and because it seems like the rational and efficient thing to do.

Take policing, for example. If we build a tool to do automated distribution of policing resources across the city, and we train that model on the decisions that were made in the past about where to send a police presence, that will result in sending police out primarily to surveil and arrest people in poor and minoritized neighborhoods rather than wealthier or Whiter neighborhoods, unless we deliberately engineer it to do something different. Or take public benefits. It has been very common for governments to request AI models that can identify fraud in a public benefits system—for instance, in the applications they receive for childcare benefits or unemployment benefits.

DETAIL: “THE AI MIRROR” BY DALL-E 3/OPENAI.COM/DALLE

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Well, those models have failed spectacularly—and routinely—in many different countries. A failure of that sort brought down the Dutch government in 2021: so many innocent lives were ruined that the government had to express a ceremonial apology that included resigning, in order to acknowledge the harm that had been done.[4] These things happen because we train those models on all of the biased human decisions about benefits that were made before—the decisions that were biased against single parents, the decisions that were biased against disabled people, the decisions that were biased against immigrants—and that treated these groups with greater suspicion than other groups of people. When we build the algorithms and train them with data from past human decisions, all of those biases get automatically baked in, whether we were conscious of those biases—and named them—or not.

There is the famous case from 2018 of Amazon building a hiring algorithm because they didn’t think they were getting the highest-quality hires, due to their recruiters’ biases with respect to race, gender, class—things that don’t strictly correlate with engineering ability.[5] They wanted an algorithm that might be better than the humans; but all their data were historical data on, presumably, who humans had hired before, how humans ranked their applications before, who had been promoted in the company before, who had succeeded in engineering roles, who had stayed at the company in engineering roles, and so forth. And all those data reflect the same sorts of biases—against women engineers, against people from minority or lower-economic-class backgrounds. Biases were therefore baked right into the algorithm trained on that data, and what the algorithm did was things like downgrade a woman’s CV simply because one of the items on her resume was that she was the president of a women’s chess club.

Now, normally, if you’re an engineer, having been the president of your chess club is indicative of a certain kind of leadership. It’s also indicative of a certain kind of skill: chess correlates quite well with the kinds of mathematical and planning abilities that engineers need. If you were the president of the women’s chess club at your university, that should count extra for you, right? But what the algorithm was doing was downranking any application where the word *woman* or *women’s* appeared, or any proxy for that. So if you went to a college that was traditionally associated with women, it might downrank your application.

So they had to scrap the algorithm, because they couldn’t trust it not to reproduce the same biases that had been ingested from the training data. And all this happened without anyone telling the algorithm even who the applicants were! The applicants weren’t even classified by gender. But gender-associated terms had appeared in the training data in ways that were associated with negative outcomes because of the bias in the system. Algorithms don’t have the intelligence to discern between patterns that we don’t want to reproduce and those we want to carry forward. So not only do algorithms pick harmful patterns up and carry them forward, they can also strengthen them.

And we see that. We’ve seen algorithms perform this way in the healthcare space, for instance. There was an American hospital algorithm that was designed to better triage patients with respect to who needed the most medical attention, especially as regards sudden worsening of a condition.[6] The model was actually boosting White patients over Black patients who were more critically ill and more likely to have sudden worsening—exactly the opposite of what the model was designed to do—because a piece of the training data they had included was the expected amount of healthcare dollars that would be spent on that person, naively assuming that that was a good proxy for how much healthcare that person might need. But if we know anything about the American healthcare system, which is where the data came from, Black people in America get much less money spent on their care than an equivalently ill White patient. So the model was simply looking at how many healthcare dollars could be predicted to be spent on a patient, and it turns out that in America, that has as much to do, or more to do, with the color of your skin than it does with what’s going on with your body.

So the model just reproduced that bias, and made it worse—because that model was being deployed in many hospitals, and the biased medical decisions were being amplified by computer decisions. Now, once they discovered it, of course they were able to revise the model.[7] But that's just the tip of the iceberg. Similarly designed models are operating all over society in ways that are amplifying those old historical biases that we have decided are illegitimate and unjust, and in many cases—like in the Amazon case—we are actively trying to root out. If we naively rely on these algorithms to be objective predictors of what should happen, we will only reproduce the past that we're trying to change.

The really important point I want to stress here is that better design of AI systems can have the reverse effect. We can design AI systems to identify and correct for or root out these kinds of biases. We can use an AI tool to identify unfair patterns in a decision-making process, such as what was happening with the Amazon case and the public benefits case. We could automate flagging of applications that are in danger of being rejected for the wrong criteria. But instead, we do the reverse. We allow algorithm models to be used to deny people benefits to which they are entitled. We allow them to be used for unfair political and economic decisions. And sometimes, the way these models are used is driven or affected by just pure laziness or naivete—and all of that is avoidable.

TMG: Another of the things that I loved about your book is how you talk about human virtues at their best, and what we need in order to meet all of the pressing, seemingly intractable problems that we're facing—problems that we have decided only AI can solve. Can you speak to some of these virtues and their current place within society, and how AI is shaping or influencing our ability to express them? Some of the ones that I picked up on were love, courage, collective wisdom, our capacity to care for one another. AI does a really poor job, of course, of enabling these things. In your book, you talk about AI as kind of eating away at our capacity to express these things. That was something that I hadn't really contemplated before.

SV: That aspect of the book is built upon my first book, *Technology and the Virtues*,which explores the relationship between technologies—not just AI—and our moral strengths, that is, our virtues.[8] *Technology and the Virtues* focuses on how our virtues are shaped by our technologies, and that our technologies can either help us express our virtues more capably and consistently or they can degrade our ability to do that. And the reason is that virtues—character traits that we admire and approve of in one another and encourage ourselves and one another to develop—courage, love, honesty, generosity, fairness, justice, responsibility, creativity, care, and service, and so forth—are not things we are born with but rather must be developed gradually, and expressed wisely.

The first philosopher to talk at length about this was Aristotle, who focused on the fact that virtues must be cultivated through conscious effort and habit—that we learn to be honest, for example, by building up a pattern of telling the truth. And the more we tell the truth, the better we get at telling the truth, the better we know when to do it and how to do it right—because there are certain ways of telling the truth that actually do a lot of harm, right? So even if you want to be honest, there's a way of being honest that is good for the situation. That's what virtue is. It's both the character trait and knowing how to express it wisely in your present situation. For example, there are questions a child will ask you that you have to be very careful about how you answer, but you also don't want to lie. It can be very tricky to figure out what version of honesty in any given situation suits this person's needs and is right for the relationship. And that kind of knowledge comes from experience—it comes from doing. You aren't born knowing those things.

I use the child example, because one of the ways that people can best relate to this is the experience of parenting, because parenting is one of the hardest things that people do. Most people don't feel like they know what they're doing at the beginning, because it requires you to exercise your virtues in a totally new situation. Yet with practice, and also with support from one's family and community, one can get better at expressing patience with a child, honesty with a child, compassion with a child. So it requires that commitment, but that's there in all our relationships. We have to build that when we relate to each other as friends or coworkers or fellow citizens. All those virtues are still just as important in those other kinds of relationships. And we work just as hard, even though we're not always realizing it, at trying to be good people for others all the time. But in order for that to happen, we have to have the opportunity to make decisions about how we interact with one another.

I now have an email app that, if I choose to use it, will automate any response that I want to send to something that has landed in my inbox. Of course, I can edit it if I like, but the tempting thing is to just look at it, think, Okay, that looks

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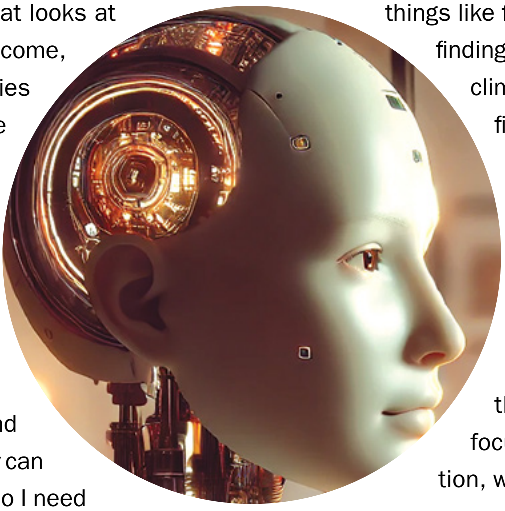
good, and hit “Send.” Now, when I automate my responses to you, I miss the opportunity to ask myself, In this situation, is this a caring way of speaking to you? Is this an honest way of speaking to you? Is this a compassionate and courageous way of speaking to you? I don’t ask those questions if I’m just looking at the words that a large language model threw up as an auto reply. And frankly, if I’m just responding to a marketing email or something that’s not significant—then sure, that’s fine. But the temptation, of course, is to push us to be more productive, meaning less thoughtful and less prudent in our interactions, because that takes time and judgment. To be more productive, we’re being encouraged to automate the way we speak to each other, to automate the decisions we make about each other, to automate the decisions we make about ourselves, to automate the decisions about what habits we will take up.

So I think what happens over time, then, is we lose the habit of making ourselves who we are, of consciously choosing to become certain sorts of people, and instead we become whomever the algorithm automates us to be. We become—we form—whatever habits the algorithm has led us into. And we do so without any kind of conscious awareness of how that’s affecting our relationships with other people, and who it’s helping, who it’s harming. It’s just about efficiency and productivity without thinking about what the broader goal of it all is. So, what I encourage in that book is a new relationship with our technologies, AI included, that looks at the kinds of people that we want to become, and then asks, How could technologies help us cross that gap between who we are today and who we would like to be? And sometimes they can’t. Sometimes it’s just still on us to do the hard, manual labor of making ourselves who we are. So the idea is not that technology has to always be the answer, but rather, when we use it, *we should have a good reason for it*. And that reason should be: this technology can help me become who I want to be, who I need to be for others, in a way that I can’t do on my own.



DETAIL: “THE AI MIRROR” BY DALL-E 3/OPENAI.COM/DALLE

I am not antitech. I am not anti-AI. Our societies are so large and so complex that we can’t run them without technology. I think these technologies have an important role to play in any society as large and complex and dynamic and unpredictable as ours. If all decisions were brought down to human decision-making speed, society would grind to a halt. I understand that. But we’re not using technologies wisely and selectively right now in the areas where they’re most needed. We’re using them instead in ways that someone else can make money from most quickly. And unfortunately, that’s damaging the reputation of AI. So you see a lot of backlash against AI right now, because you see artists who have been ripped off by AI platform companies that have scraped their artwork and used it without compensation or credit.[9] And frankly, the world was not desperate for an AI plagiarism machine. One of the great needs of society five years ago was not, Hey, we need something to produce machine-generated photographs and paintings and novels. That was not on the list of great needs. That’s what we got though, right? But if you’d asked me five years ago—if you’d asked yourself five years ago—*What are five problems that human beings and our institutions don’t seem to be able to solve because we don’t have the speed or scale or analytical capacity to manage them? What are the five biggest problems that we need to make progress on rapidly?* You would have named things like finding quicker paths to clean energy, finding ways to make crops more resilient to climate stress. You would have thought of finding ways to get drugs and food more efficiently to parts of the world where we’re not able to equitably meet people’s basic needs. You would have had a long list of things that people need.

And yet we’re not using AI to focus on those things. We’re not using AI to focus even on things like fighting corruption, which is an application I talk about in

"AI is currently being deployed in the ways that serve those who already have a disproportionate amount of power and wealth in society."

the new book that I think is just wildly underexplored. We have a vast problem of political corruption, where outside forces turn governments and institutions against the interests of those they represent, through bribery and extortion and various other kinds of criminal activity. And it's extremely easy to use AI tools to find patterns in that kind of activity. In fact, we do know that it's being used by criminal investigators and national security services to identify patterns in organized-crime networks and things like that. But somehow, it never quite gets back to the level of political corruption, where the people in power—the people who currently have status—are the ones under the AI microscope. Somehow that never comes to pass.

And, of course, we know why. AI is currently being deployed in the ways that serve those who already have a disproportionate amount of power and wealth in society. It's used to consolidate their power, it's used to grow and consolidate and protect their wealth, and it's used to ensure that power and wealth become ever more concentrated in their hands. AI is not inherently a tool that must be used to consolidate wealth and power. It's our current regulatory and legal failings that allow that to happen. But it's very possible to imagine a world where the regulatory environment and the laws are such that the incentives are to use AI to actually strengthen our institutions and make them more transparent, more accountable to the people they serve. That's completely within our capacity.

TMG: Another main thread of *The AI Mirror* is calling attention to a lot of the alarmist, fearmongering ideas about AI—that it is an existential risk—and how that is conceptualized and put forward in the public arena. And you talk about reshaping this idea of risk. What would be a more constructive and productive discussion about AI and risk than this kind of "AI is going to become AGI [artificial general intelligence] and the computers are going to replace us" rhetoric?[10]

SV: I think when you see that those narratives are being pushed most aggressively by the people who are profiting the most from the AI boom, that should be the first red flag that you examine with a critical eye. Because the existential risk narrative is a very useful one for people who are heavily invested in AI, for two reasons. First, the existential risk narrative tends to be focused on long-term horizons, which diverts people from shorter-term concerns. Although sometimes they'll bring that horizon forward to scare people into action, in reality, many of those scenarios are ones we are not likely to confront for 50 or 100 years—if then. We are nowhere near having the ability to build conscious machines. We are nowhere near having the ability to build AGI. Now, we might, in the near future, have some radical jump in computing capacity that brings us to that point, but no one actually knows how to make that jump happen.

It's not that it's irrational to be worried about this possibility. Even though there is no scientific evidence that we are heading toward building conscious machines with desires of their own, more powerful AI machines could still do a lot of damage even if they remain mindless. But when we redefine AI risk as AGI risk, what we are saying is, "You can ignore what's happening now. That's nothing in comparison to what could be coming." But it's *not* nothing, and unlike the entirely speculative AGI risks, today's AI risks are already being realized, hurting actual people and communities. When the existential risk narrative pushes for governments to invest in safety and regulation for future AGI but not today's AI, that sounds to me like refusing to call the fire department to extinguish your burning roof, because you want to install a better burglar alarm first. The burglar's not here and may never arrive. The fire is already lit, and someone needs to make sure it doesn't hurt anyone else. A lot of companies like OpenAI have been promising us that these technologies are what is going to get us to intelligent machines that think like humans do.[11] And even companies like OpenAI now admit that that's not where we are, and that no one really knows when that's coming.[12] These technologies are not the thing that creates the Terminator. But if you are heavily invested in AI, and if you can get people, particularly in government, to worry about those longer-term scenarios, those more hypothetical and speculative risks that lie far in the future, you can get them to stop asking questions about what should be happening *today* with the harms that AI is causing right now.

Another reason that is also quite attractive for people who are heavily invested in the AI narrative is that it imbues them with a great sense of personal power. If you're the person who created the thing that is either going to save or destroy humanity, then either way it goes, you're the most powerful human who ever lived, right? You're the most historically important human who ever lived if you believe that you have created the technology that will either destroy human civilization or save it. So that's why you have these doom narratives right alongside these "AI is going to save us all" narratives. Neither of these things is true. These are reflections of a certain kind of technologist's ego that wants to believe that they've created the thing that's going to overtake, that's going to succeed, humanity.

But if you strip away the ego, and if you strip away the kind of cynical incentive to push people's attention farther down the road, what you see is actually a technology that is pretty impressive in some ways but is not a great mystery, is not a mind, is not anything like the kinds of AI that we encounter in science fiction—even though we can interact with it superficially for a little while and pretend that that's what's happening. But very soon, you realize you're not talking to anything that understands you or the world around you. So we're dealing with tools that are predictive word and sentence generators that can find complex patterns in our language and repeat them back to us—and that's it. They're all dark inside. There's no awareness. There's no desire. There's no need to come after us for anything. These are just tools that predict words and pixels and other kinds of representations that we feed into them. Most machine-learning researchers who aren't seeking celebrity know all this and will tell you this is so, if you ask. Most machine-learning researchers I work with are very frustrated by the AI hype-and-doom cycles, because they recognize that both of them are a distortion of what's really happening. And most machine-learning researchers actually value honesty about what they're building. It's the celebrity ones and the ones who are heavily invested in power and the wealth that can be created by these tools who are pushing the hype-and-doom narratives.

But that said, there is indeed a more immediate existential risk here—two, actually—that I point to in *The AI Mirror*. One is existential in the sense of what existential risk has largely come to mean, which is something that could destroy human existence. And that risk is the immense carbon appetite of large AI models, and the ways in which the explosive growth in AI development may prevent us from effectively responding to the climate crisis and meeting our targets for reducing dependence on fossil fuels. They also consume a great deal of water, which is another resource that we need to worry about. And frankly, from a climate standpoint, all of the current models of climate change are pointing to a future that is even more concerning than climate scientists were worried about 10 years ago. The worst-case scenarios are turning out to look more likely than the scenarios positing a slower acceleration of climate change. The train is picking up speed in a lot of ways, and we're seeing concerns now about disruption of the Atlantic circulation current, also known as the Atlantic Meridional Overturning Circulation, that could, if disrupted even in the slower phase scenarios, bring about a new ice age in Europe while leaving the rest of the planet in extreme heat.

So, we would have massive challenges to deal with from a standpoint of agriculture and basic human survival. That's an existential risk that is right in front of our faces and that we need to be managing right now. It is not speculative, it is not hypothetical, we can see it starting to happen. And AI is potentially contributing to it and making it worse. The environmental cost of AI is hitting us now, and the climate risk is right here in front of us, not something that might come. We're already locked into some pretty rough years for the human family because of climate change, and what we need to do is conserve all of the ability we have to manage those climate stresses and keep human civilization together. And we need to be able to use AI responsibly and *very* selectively to do so.

The other more immediate existential risk is in the more philosophical sense. It is what the existentialists of the 20th century named as "existential" concerns: human purpose and human freedom, and our awareness of our purpose and freedom. One of the things that I am concerned about is that we're increasingly being encouraged to give up on ourselves, to give up on each other, to think that human intelligence isn't actually worth much, to believe that we're destined to be improved upon by machines, to believe that humans can't be trusted to solve our own problems. And I'm telling you, and I'm telling your readers: The people who have an interest in you believing that, are the people who already have their hands on the wheel, and want to make sure that you don't grab for it. They want you to believe that AI is at the wheel and that all you can do is go and sit down in the back and hope that the ride takes you somewhere nice. But in fact, it's still people with their hands on the wheel—powerful people, powerful companies, powerful governments—shaping the future in a direction from which they profit

"That's our existential task right now: carry the human family and the communities of life on this planet that we depend on—and that depend on us—safely into the future. And we have to become the kinds of beings who can do that—and I don't think AI is the answer for that."

substantially in the short term, even though everyone loses in the long term if we stay on the current road. And what they want most of all is for the passengers not to stand up and grab the wheel.

So, the narrative that AI is smarter than you, that AI is more trustworthy than you, that AI is more objective and rational than you—that is a marketing ploy. But it's also a political ploy to cause people to give up their political agency. To surrender their sense that they have power, that they have the right to determine what sort of societies they live in. So the more that you push automation as a way of replacing human judgment, the more people are encouraged to let go of their individual responsibility and our collective responsibility for ourselves. To me, that's an existential risk in the sense that existentialism pointed out that humans are just animals plus freedom and responsibility. Animals who somehow got the ability to ask ourselves if we want to be this way or if we want to be something different. That's presumably a question a cow doesn't ask, right? What kind of cow should I be today? Should cows be like this or like that in the future? Humans can ask those questions. Should humanity and our societies be organized this way or that way? Should they be democratic or authoritarian? Should they be equitable or inequitable? Should they be compassionate, or should they be cruel? We can ask those questions, and we can answer them, but not if we give up on the power of humans to actually drive our own future. And that's what some of the AI narrative is trying to do: to lull us into a sense of passivity, into a loss of confidence in ourselves and one another. I see that having a very powerful effect.

My new book is, in a way, trying to restart that engine of human confidence and a sense of human empowerment, and the fact that we are entitled—all of us—to have a voice in how our lives go and the sorts of societies that we share and the sorts of futures that we and our children will have. We all have the power and the right to have a say in where the human family goes. And we can only use that right if we believe that it's in our power to do so—believe that it's in our power to be wise, to be courageous, to be compassionate. Humans will never be perfect. We will never have perfectly just societies. We will never be perfectly kind. We will never be perfectly wise. But we have, over thousands of years of human history, learned to make ourselves more wise, to make ourselves more kind, to make ourselves more far seeing and more far reaching in our concern and compassion. Five hundred years ago, it was unthinkable that you would have groups of humans who were concerned for the fate of, and actively working to preserve good conditions for, humans and nonhumans on the other side of the planet whom they will never meet. It was beyond our capacity five hundred or a thousand years ago to spend one's life working for the rights of people in a place where you don't live; or trying to protect the lives of other sentient, sensitive creatures, or our biosphere.

These are things that were not part of the collective human experience of morality or justice back then. Yet we discovered these ideas, and we built them together, and we pushed them forward. And we did all of that without AI. And we need to do that again now. We need to look to the future and say, The future, because of climate change and some other difficult challenges, is going to require more of us collectively than we are able to achieve today, so how do we make ourselves into the kinds of beings that can carry the human family to safety? That's our task. That's our existential task right now: carry the human family and the communities of life on this planet that we depend on—and that depend on us—safely into the future. And we have to become the kinds of beings who can do that—and I don't think AI is the answer for that.

TMG: A lot of the people we're speaking to—our readers—are people who, of course, work in nonprofits, work in NGOs, work in government agencies, are leading their own organizations that are mission focused. Given how ubiquitous and diffused AI has become, people in those positions are now having to wrestle with making decisions whether or not to use the technology and, if using it, how to do so responsibly. But we haven't equipped people very well toward making those decisions. Is there any practical advice you can offer

> **“[I]f you’ve crossed that first step where you have a good reason to use AI and the cost of it is justified, you still have to have human responsibility at every point in its use.”**

in terms of the kinds of things people should be weighing when it comes to AI in such settings?

SV: That’s a great question. I think the first thing to ask oneself is, What is the problem that I’m trying to solve, and why is AI the right tool to solve it? And then ask, Do I have/know the solution, or am I just assuming that AI provides a solution for any problem? Because it doesn’t. There are some problems that AI is not very good at solving or helping you with. The first thing to ask, put more deeply, is, What is the problem, and what about AI makes it the right and best approach? What makes this the most effective and, from a climate standpoint, responsible approach to take? What are the alternatives? Because it might be, for example, that the problem could be solved with AI but only with an inordinate amount of computing power that would be both economically costly and environmentally damaging. At that point, you need to ask another question: Is there a smaller, more efficient AI solution? Or is there a non-AI solution that may take a little bit more time but that can be done without a huge climate impact? So, thinking about the problem, why AI is the right tool, and whether the cost of using the tool is justified by the nature of the problem. Sometimes the answer is yes. Sometimes the answer is: the good that can come from this will result in lives being saved and resources elsewhere being used so much more efficiently than they are currently that this cost can be justified. But a lot of times, people don’t ask those questions at all. They just move straight to, How can I use AI? Let me find a problem to hit with it. To a human with a hammer, everything looks like a nail. Do not be the human with a hammer. Do not make everything into a nail for AI.

The second thing to ask is, Who are the people who are most vulnerable to either the misuse of this technology or the use of it not going as planned? So assuming that you don’t want to do harm, these tools can cause harm even when used in a well-intentioned way. You need to know what the risks are of this tool doing harm, and who is endangered by those risks. And then you need to make sure that, if at all possible, you have a way of consulting with those people and seeing if you can mitigate those risks by bringing them into the design process. For example, if you’re a nonprofit that works with disabled people, and you’re exploring how to use AI to help those you serve gain access to information and to public services more efficiently, you will need to be concerned about such things as the risks that a generative AI model you might use could create false information—because these models often do that, right? They create fabricated content—some people use the word *hallucinated*, but I prefer not to use that mentalizing term for AI—and these fabrications can be false, and mislead people. Well, you have to consider that risk. And you should be consulting with your audience, with the people you’re serving, and make sure you know what their interests and needs are and whether the risks are ones that they’re willing to accept, and whether they can work with you to design a way that the technology can be used that’s safer or fairer. We call this coproduction, or participatory design—it’s the idea that the people whom you’re presumably affecting with the use of this technology should be part of the process. Their knowledge and their lived experiences should inform, and even lead, what you’re doing—and from the start, not at the end. It’s not enough to just ask people for consent once you’ve already built the application or the tool and are now deploying it on them. Do not wait for that. You want their voices in the conversation from the beginning, understanding where human oversight and accountability are in any process.

So again—if you’ve crossed that first step where you have a good reason to use AI and the cost of it is justified, you still have to have human responsibility at every point in its use. Who is responsible for making sure it’s designed properly? Who is responsible for making sure that the data that are used to train it are acquired ethically, managed correctly, and of high enough quality to do the job that you want? Who is responsible for testing the trained model? Who is responsible for determining whether or not it is fit for purpose and ready for deployment? Who is accountable for monitoring it after it has been deployed and making sure it is working as intended and not having unintended effects? And who is accountable for doing something about it if it turns out that it is having harmful effects? You should have a whole life cycle plan for the AI tool, from conception to after deployment, where it's clear where human responsibility for the outcomes is all the way through the process. And you should be making sure that the entire process is guided by values, like trust and service, that are vital to the nonprofit sector. There's a reason that nonprofits exist, and it has to do with the value they provide in society that would otherwise be lacking—so it is critical to make sure that those values, the values of service and care, are the ones driving the AI process.

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HEALTH JUSTICE

Brave New World

What Does *the* Digital Age Portend *for* Health Justice?

by James A. Lomastro

During the COVID-19 pandemic, health justice advocacy groups adapted their strategies to the digital realm, leveraging social media platforms, virtual events, and other online resources to raise awareness and organize their efforts.[1] These efforts led to structured engagements with state health agencies toward improving care quality and advocating for immediate and systemic reforms.[2] Many organizations with brick-and-mortar structures returned to their pre-COVID-19 operations once restrictions subsided, but a significant number of them chose to retain and enhance their digital presence—reflecting a lasting change in the way advocacy is conducted.

This transition to the digital realm facilitated a brave new world of health advocacy, but it also magnified the digital divide that plagues society, exposing deep disparities in access to technology and digital literacy.[3] These developments and challenges underscore the importance of building a better understanding of digital technology within the broader context of health justice; they also emphasize the urgent need to address the inequities exacerbated by digital technology, to ensure that technological efforts to improve healthcare are equitable and rooted in promoting health justice.

EQUAL ACCESS TO THE HEALTHCARE WE NEED

Ensuring equitable access to healthcare is a cornerstone of health justice, but accessing quality healthcare can be daunting. Geographic isolation, lack of infrastructure (limited doctors and medical centers, especially in rural areas), and financial constraints (extreme costs of life-saving medications and critical medical services not covered or denied by insurance) often leave vulnerable populations

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If we harness the power of digital platforms and AI *responsibly and ethically*...we could move closer to a world where healthcare is not a privilege...but rather a *fundamental right available to everyone*. This right is fundamental to health justice: ensuring that all individuals, regardless of their race, socioeconomic status, or geographic location, can achieve good health.

[W]hile digital platforms and AI hold promise for democratizing healthcare and policy advocacy, these technologies do not always work, and they have an especially poor track record for people of color and other marginalized populations.

without necessary care. The rise of digital platforms and AI is breaking down these barriers, helping to bring medical services to people who otherwise might not receive them.[4]

Telemedicine, for example, powered by digital platforms, is a transformative force in improving access. It brings healthcare directly to patients, regardless of location, and is a game changer for many. By leveraging video conferencing, online chat, and mobile health apps, telemedicine connects patients with healthcare providers in real time. And in areas where healthcare resources are scarce, telemedicine becomes a lifeline. For instance, in regions with a shortage of medical specialists, patients might otherwise have to wait months for an appointment. Telemedicine allows them to access care more quickly, potentially catching and treating conditions before they become severe.[5]

The Veterans Health Administration has been a pioneer in telemedicine in this regard since 2003. Expansion of its tech infrastructure and services over the years proved especially valuable during the pandemic, and it now uses telehealth for 40 percent of its patients, thus demonstrating tech's potential for improving healthcare access.[6] And over a decade ago, California began addressing patients' needs for telemedicine services with AB 415, the Telehealth Expansion Act of 2011 (also known as the Telehealth Advancement Act). The act allowed Medi-Cal patients (those qualifying for state medical assistance) to consent to telehealth care and health providers to provide that care.[7] Almost a decade later, in 2022, California AB 32, introduced by Assemblymember Cecelia Aguiar-Curry, was enacted to make permanent many of the telemedicine flexibilities introduced during the COVID-19 pandemic.[8] The bill expanded telemedicine services by allowing for the continued use of various modalities, including audio-only telemedicine, which is crucial for individuals in areas with limited broadband access.[9] This flexibility addresses health disparities by ensuring that healthcare services are available to vulnerable populations, such as those living in rural areas or in low-income communities, or people without reliable internet.

Moreover, telemedicine can be particularly transformative for those with chronic illnesses who require regular monitoring. Instead of making frequent trips to a clinic, patients can use telemedicine to check in with their healthcare provider, receive advice on managing their condition, and adjust treatment plans as needed—all from the comfort of their home. This continuity of care is critical in managing chronic diseases and improving long-term health outcomes.[10]

AI-driven diagnostic tools further amplify the power of telemedicine. These tools are designed to assist healthcare providers in making accurate diagnoses, especially in settings where access to sophisticated medical equipment is limited. AI-powered apps can analyze images, such as X-rays or photos of skin lesions, and provide preliminary assessments that help doctors make quicker and more accurate diagnoses.[11] A healthcare worker in a remote clinic might use a mobile app to capture an image of a patient's skin condition, and AI can analyze data from wearable devices that monitor vital signs like heart rate, blood pressure, and oxygen levels.[12] Such diagnostic tools reduce the need for expensive, bulky medical equipment and make healthcare more accessible to those in underserved areas. Providing accurate, data-driven assessments empowers healthcare providers to deliver high-quality care, even in resource-constrained settings.

But while digital platforms and AI hold promise for democratizing healthcare and policy advocacy, these technologies do not always work, and they have an especially poor track record for people of color and other marginalized populations. In a CNN report/interview on AI, the reporter, Zachary B. Wolf, quotes Reid Blackman, the author of *Ethical Machines: Your Concise Guide to Totally Unbiased, Transparent, and Respectful AI*: "The bias issue, or discriminatory AI, is a separate issue.... Remember: AI is just software that learns by example. So if you give it examples that contain or reflect certain kinds of biases or discriminatory attitudes… you're going to get outputs that resemble that."[13]

Indeed, these technologies often fail to work as intended for people of color, due to biases in datasets and algorithmic design. Critically, AI-driven diagnostic tools have been found to perform poorly on non-White patients, resulting in inaccurate diagnoses or subpar care.[14]

> ***It is crucial that as we advocate for AI and digital health tools, we also work to address [the] systemic biases and economic disparities, ensuring that all communities, regardless of race or income, benefit from technological advancements in healthcare.***

Additionally, economic barriers limit the utilization of wearable health devices, further exacerbating inequities. While providing accurate, data-driven assessments can empower healthcare providers to deliver high-quality care in resource-constrained settings, this potential is undermined by the uneven accessibility and reliability of the very technologies that are supposed to drive equity. It is crucial that as we advocate for AI and digital health tools, we also work to address these systemic biases and economic disparities, ensuring that all communities, regardless of race or income, benefit from technological advancements in healthcare.[15]

Access to accurate and relevant health information is another critical component of health equity. However, barriers such as language, literacy levels, and cultural differences can prevent people from understanding or trusting the information they receive.[16] AI and digital platforms are making health information more accessible and personalized. AI can help tailor health information to patients' needs, taking into consideration language preferences, literacy levels, and cultural contexts.[17] An AI-driven health app might provide information on managing diabetes in a user's native language, for instance, using easy-to-understand language and culturally relevant examples. It might also include visual aids or interactive features that help users better understand their condition and how to manage it.[18]

The app mySugr, for example, designed for people living with diabetes, helps users track their blood sugar levels, log meals, and understand insulin management.[19] The app uses AI to provide personalized insights and adjust to the user's habits over time. It supports multiple languages and offers user-friendly features for managing diabetes.[20] Another app, Lark Health, provides AI-powered coaching for users with chronic conditions like diabetes or hypertension. This app offers 24/7 personalized guidance on managing conditions and tracking diet, sleep, exercise, and medication. It's designed to be conversational and accessible, offering a user-friendly experience tailored to diverse health needs.[21]

And digital platforms can disseminate critical health information broadly, ensuring that diverse populations are reached effectively. For instance, a public health campaign on vaccination could use social media, websites, and mobile apps, with AI tailoring messages to target different groups. In one community, the message might highlight the benefits for children's health, while in another, it might focus on dispelling myths about vaccine safety. However, such efforts would have limitations in the current landscape: the digital divide leaves underserved populations without access, and data biases in AI would result in unequal messaging. Privacy concerns about sensitive health data and the challenge of ensuring cultural sensitivity would further complicate such campaigns. Additionally, overreliance on technology can exclude individuals who depend on more traditional forms of communication, like in-person consultations or local media, which would limit such a campaign's reach and effectiveness. And finally, there is the constant danger of misinformation that people receive via social media and other sources, further complicated by changes in government and health and information policies and regulations.

If we harness the power of digital platforms and AI *responsibly and ethically*, however, we could move closer to a world where healthcare is not a privilege reserved for those in urban centers or those who can afford it but rather a *fundamental right available to everyone*. This right is fundamental to health justice: ensuring that all individuals, regardless of their race, socioeconomic status, or geographic location, can achieve good health.

HEALTH DISPARITIES: COULD AI HELP?

Health disparities—differences in health outcomes and access to care across different populations—are a significant barrier to achieving health justice. These disparities are often deeply rooted in social determinants of health, such as income, education, housing, and access to nutritious food.[22] Addressing these inequities requires a sophisticated understanding of where and why they exist as well as tailored interventions that meet the unique needs of affected communities.[23]

AI could play a transformative role in identifying these disparities and designing personalized health interventions to combat them. One of the most powerful applications of AI in healthcare is its ability to analyze vast amounts of data

Given the corporate dominance in healthcare and the broader context of capitalism, patriarchy, and White supremacy, AI could well further disenfranchise marginalized communities, if not very carefully managed.

quickly and accurately. This capability is particularly valuable when identifying health disparities within communities, as such disparities are often complex and multifaceted, making them difficult to detect using traditional methods. Google Health, for example, has developed an AI system to analyze retinal images for diabetic retinopathy, a common complication of diabetes. The AI can detect early signs of this condition with high accuracy, which is especially useful with respect to underserved areas, where access to specialized eye care is limited. By identifying patients at risk earlier, healthcare providers can target interventions more effectively, reducing disparities in eye health outcomes.[24]

And because AI can process and analyze large datasets that include several variables, such as geographic location, demographic information, health outcomes, and access to healthcare services, AI can identify patterns and correlations by examining these variables together, offering significant advantages over manual analysis.[25] It excels in recognizing intricate patterns and correlations, revealing subtle relationships that manual methods might miss, allowing for uncovering patterns and correlations and forecasting future health trends, disparities, and risks and enabling timely interventions—a subset of AI known as *predictive modeling*.[26] Additionally, AI can handle large-scale data with scalability and accuracy, reducing human biases and minimizing errors associated with manual processing. This comprehensive, data-driven approach enhances the ability to identify and address health disparities, ultimately leading to more informed and effective healthcare decisions.[27]

Moreover, AI-driven data analysis extends beyond merely assessing health outcomes to encompass a broader range of factors, including social determinants of health, such as income, education, and housing, that contribute to health disparities.[28] Google Health uses AI to analyze datasets that include demographic and environmental factors, identifying how elements like housing instability or educational attainment contribute to such disparities in health outcomes. In addressing not just the disparities but also the underlying causes, this approach allows for more effective and comprehensive public health interventions.[29]

Once health disparities have been identified through data analysis, the next step is to address them through targeted interventions. AI has value in this area, particularly in its ability to personalize healthcare based on individual circumstances, by analyzing data related to the social determinants and tailoring interventions accordingly.[30]

In addition to tailoring interventions based on social determinants, AI can personalize health education.[31] Healthie, for instance, which bills itself as an "all-in-one practice management platform," uses AI to generate plans and resources based on users' health goals, conditions, and preferences. It adjusts recommendations and educational content dynamically as users engage with the platform and provide updates about their health status.[32]

AI's ability to analyze complex datasets and predict health outcomes could revolutionize how we address health disparities.[33] By identifying hidden inequities and tailoring interventions to individual needs, AI could ensure that resources are allocated where they are most needed and that care is delivered effectively and fairly. But while AI shows promise in identifying and addressing health disparities by integrating these complex data, its real-world effectiveness varies. Challenges such as data quality, representativeness, and integration of AI insights into actionable policies need to be addressed. Given the corporate dominance in healthcare and the broader context of capitalism, patriarchy, and White supremacy, AI could well further disenfranchise marginalized communities, if not very carefully managed. Moreover, incomplete and inaccurate health data, which often reflect and amplify existing disparities, pose a major obstacle to realizing AI's full potential. As such, while AI's capabilities are promising, there remains significant room for growth in refining these tools and improving their application to fully realize their impact on health disparities—with AI governance and data quality remaining critical concerns.[34]

THE RISKS OF AI AND DIGITAL HEALTH

Ensuring universal accessibility remains challenging indeed, with complex interfaces and language barriers hindering inclusion, particularly for marginalized groups.[35] Reliance on digital platforms for health advocacy also exposes activists

A significant concern is the monetization of healthcare data, as private companies seek to profit from the vast amounts of personal health information collected through AI systems. This drive for profit currently overshadows the ethical considerations of equitable healthcare.

and marginalized citizens to risks such as data breaches, hacking, and privacy violations.[36] And expanding digital health infrastructure will increase surveillance capabilities, raising concerns about privacy.[37] Reliance on digital technologies controlled by external entities could lead to private, well-resourced interests controlling access to critical health services: health has increasingly become subject to private and equity-based investment, exposing underserved communities to manipulation and exploitation by commercial interests whose major mission is profit-making.[38] And subsidized internet and technology devices, and other seemingly well-intended efforts, could wind up serving corporate interests rather than empowering vulnerable populations.

And while the digital landscape democratizes information dissemination and facilitates it, it can also lead to the rapid spread of misinformation and disinformation. Health justice advocates must prioritize media literacy and critical thinking to combat false narratives and misinformation and disinformation, and maintain the credibility of their campaigns and efforts.

Additionally, AI-driven data collection and analysis will introduce forces that undermine health equity efforts unless greater forces disrupt corporatization and capitalism overall with respect to tech in health. A significant concern is the monetization of healthcare data, as private companies seek to profit from the vast amounts of personal health information collected through AI systems. This drive for profit currently overshadows the ethical considerations of equitable healthcare, as corporations prioritize proprietary algorithms and data ownership over public benefit. Without intervention, these companies will exploit AI for profit, exacerbating existing inequalities under a system shaped by corporatization, capitalism, and White supremacy.

Legal and ethical challenges surrounding data ownership, intellectual property rights, and liability are integral to this discussion, as is the risk that the most innovative tools will remain in the hands of the wealthy and powerful. To prevent these perils from becoming reality, there must be greater regulatory oversight and grassroots movements that disrupt corporate dominance in AI.[39] Current initiatives—like open-source AI platforms and advocacy for data justice—are already challenging the corporatization of tech in healthcare, showing that change is possible if we prioritize collective good over profit.

Achieving health justice in an already unjust environment requires both structural reforms and ethical use of AI. To prevent AI from amplifying existing inequities, advocates need to develop policies that prioritize equitable care over profit, enforce transparency, and involve marginalized communities in the application of AI. Strong public oversight is essential to ensure that AI is used to redistribute resources to underserved populations and not to deepen disparities. By aligning AI with health justice principles, it becomes a tool to level the health playing field and address the root causes of already entrenched inequity.

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As we navigate the brave new world of digital advocacy in pursuit of health justice, the transformative potential of digital platforms and artificial AI technologies is significant. Telemedicine has already expanded healthcare access in rural areas where residents once had to travel hours for basic care. AI-driven diagnostic tools are closing gaps in preventive care, particularly for those in underserved regions.[40] And AI's ability to analyze complex datasets is transforming our understanding of health disparities, enabling the identification of social determinants of health that contribute to unequal outcomes. This shift toward personalized health interventions, such as AI-powered recommendations for managing chronic diseases, moves the needle closer to healthcare as a fundamental right for everyone, not just a privileged few.

However, despite these promising advancements, the journey toward health justice in the digital age comes with challenges. The expansion of digital health infrastructures could exacerbate issues of privacy violations, as seen in cases where health data are sold to third parties without consent.[41] Vulnerable communities could be exploited for commercial gain, deepening the divide between those who can protect their digital footprint and those who cannot.

Dignity Alliance Massachusetts

Dignity Alliance Massachusetts (DAM) is a leading advocate for inclusive health policies that prioritize vulnerable populations, particularly older adults and those with disabilities, amid the digital transformation. Established in 2020 during the COVID-19 pandemic, DAM initially aimed to amplify the voices of individuals in institutional care, especially in nursing homes. Over time, it evolved into a dynamic organization, functioning much like a decentralized autonomous organization. During the pandemic, DAM effectively leveraged digital tools such as social media, virtual events, and online campaigns to advocate for health justice, particularly in long-term care settings. DAM used webinars, petitions, and digital platforms to inform the public and policymakers about critical issues, such as nursing home safety, vaccination compliance, and transparency in ownership changes. Organizations like DAM are essential in advocating for a healthcare system that is both equitable and inclusive, pushing for policies that bridge the digital divide and ensure that digital health innovations reach underserved populations. Their advocacy promotes inclusive policies that prioritize the fair distribution of the innovations, ensuring that everyone, regardless of socioeconomic status, can benefit from modern healthcare.

By advocating for equitable access to these digital health tools, DAM reinforces that healthcare is a fundamental right, regardless of geographical location. The work of organizations like DAM highlights the transformative potential of digital platforms and technologies that can revolutionize healthcare by improving access, reducing health disparities, and empowering marginalized communities. However, DAM's work underscores the importance of remaining vigilant about the potential risks associated with digital tools, such as increased surveillance, privacy violations, and exacerbating existing inequalities; DAM advocates for transparency, accountability, and inclusivity to ensure that its work benefits all communities, particularly those historically marginalized.

AARP

AARP's extensive digital platform is a powerful tool that operates robust virtual advocacy campaigns focused on issues affecting older adults. This platform is a testament to the value of the older adult community. AARP frequently launches online petitions in healthcare to mobilize public support for legislative changes and address key issues such as prescription drug costs and accessibility. It promotes these efforts through AARP's website and social media channels, recognizing the vital role of older adults in shaping healthcare policies.

These petitions, which have led to significant policy changes, demonstrate public support for specific policy changes and pressure legislators to act on these issues. AARP uses various social media platforms, including Facebook, X, and Instagram, to disseminate information, raise awareness, and engage followers in advocacy efforts. They also conduct campaigns around digital misinformation. Social media campaigns increase visibility and reach, engaging a wide audience and fostering a community of advocates who can share and amplify AARP's messages.

AARP hosts virtual town halls and webinars to inform members and the general public about important policy issues, upcoming legislation, and advocacy strategies. These events often feature expert speakers, including policymakers and advocacy leaders. The virtual events provide a platform for direct interaction between AARP members and policymakers, allowing for real-time dialogue, questions, and feedback. They also help educate and mobilize supporters to participate in advocacy efforts. AARP uses email campaigns and digital newsletters to inform its members about current issues, upcoming advocacy actions, and ways to get involved. These communications often include calls to action, such as contacting legislators or participating in online forums. Email campaigns and newsletters help keep members engaged and informed, encouraging them to take action on critical issues and stay updated on advocacy progress.

AARP's interactive platforms allow members to easily contact their representatives, track legislation, and participate in advocacy campaigns. By providing tools for direct advocacy, AARP makes it easier for individuals to engage with the legislative process and contribute to advocacy efforts.

National Disability Rights Network

The National Disability Rights Network (NDRN) advances the rights of individuals with disabilities through traditional and virtual advocacy efforts. NDRN's online and digital efforts assist it in its traditional efforts, supporting a movement that rallies support for disability rights legislation and reforms. Focusing on issues such as improving accessibility, funding disability services, and opposing harmful policy changes, digital platforms move beyond traditional methods, increase public support, and pressure policymakers to address disability-related issues and enact supportive legislation. NDRN conducts podcasts and workshops educating the public, advocacy groups, and policymakers about disability rights, legal issues, and policy developments. Much of its efforts occurred online and remotely during COVID-19, as with other organizations.

NDRN, like AARP, uses a variety of digital tools and platforms such as social media platforms like X, Facebook, and Instagram, as well as podcasting and webinars, to spread awareness about disability rights, share updates on advocacy efforts, and engage with a broader audience. They also use these platforms to communicate with constituents. Social media campaigns help NDRN reach a wide audience, build community support, and drive engagement with disability rights issues. By amplifying advocacy messages and initiatives, NDRN's digital efforts allow more constituents to access resources, participate in advocacy actions, and stay informed about disability rights issues. The platforms often include tools for contacting legislators, submitting comments, and joining advocacy networks.

Online communication serves as a powerful tool for fostering collaboration among disability advocacy organizations and networks. By addressing systemic issues and promoting shared advocacy goals, these organizations are able to strengthen their collective efforts. Joint efforts, virtual coalition meetings, and collaborative initiatives are all part of this unified approach. Such collaborative efforts, which combine resources, expertise, and networks, reassure the audience about the strength and unity of the disability advocacy community, leading to more effective and unified actions supporting disability rights.

National Patient Advocate Foundation

The National Patient Advocate Foundation (NPAF) promotes patient-centered care and health equity, much like AARP and NDRN. NPAF uses social media and its websites to drive support for policy changes. The campaigns address issues like insurance coverage, access to affordable medications, and improvements in healthcare delivery. These digital efforts have had a significant impact on influencing policymakers and stakeholders to prioritize patient-centered reforms and address critical issues in healthcare. They have also helped identify key issues and develop policy recommendations, tailoring their advocacy efforts to address real-world challenges and improve patient outcomes.

NPAF actively uses social media platforms like X, Facebook, and LinkedIn to raise awareness about patient rights. They share updates on their advocacy work. Engaging with their audience through social media and their website, they increase their visibility, foster a community of supporters, amplify patients' voices, and contribute to more effective advocacy efforts. This effort includes resources for contacting legislators and information about ongoing policy issues.

By equipping individuals with resources, digital platforms empower patients and advocates to participate actively in the legislative process, and they can drive meaningful change. These platforms provide a voice for those who may not have had one in the past, allowing them to share their experiences and advocate for change. They collaborate with other organizations and coalitions through their online presence and resources to address shared goals and amplify advocacy efforts. Through joint efforts and coordination of outreach efforts, collaborative efforts boosted by digital resources will enhance the reach and effectiveness of advocacy efforts by combining resources and networks, leading to a greater impact on policy and practice.

Health justice advocates must emphasize transparency in data use, accountability in AI decision-making, and inclusivity in access to digital health innovations. By doing so, we can ensure that these tools benefit all communities, particularly those historically marginalized.

Furthermore, the persistent digital divide—such as the lack of broadband access in low-income neighborhoods—would leave marginalized groups even further behind. In 2020, for example, millions of children in underserved communities struggled to access remote schooling, a stark reminder of how these gaps worsen existing inequities. Finally, the persistent spread of misinformation and disinformation, as seen with COVID-19 vaccine skepticism, also threatens the credibility of health advocacy on digital platforms.

The path to health justice in an era dominated by corporatization, privatization, commercialization, capitalism, and White supremacy is already fraught with obstacles. While AI holds great promise, it could further complicate these challenges. The integration of AI into healthcare risks reinforcing existing inequities and biases if not carefully monitored. However, if we approach these technologies with skepticism, caution, and a commitment to ethical principles, there is hope that they can be harnessed to build a healthcare system that is just, equitable, and accessible for all. The key is ensuring that AI and digital innovations are developed and deployed with a focus on fairness, inclusion, accountability, and the greater good. It will be crucial to maintain vigilance and critically assess the social implications of these technologies. Health justice advocates must emphasize transparency in data use, accountability in AI decision-making, and inclusivity in access to digital health innovations. By doing so, we can ensure that these tools benefit all communities, particularly those historically marginalized.

The phrase "brave new world" carries a double-edged meaning, originating from William Shakespeare's *The Tempest* and popularized by Aldous Huxley's dystopian novel.[42] Miranda's curiosity in *The Tempest* symbolizes exploration and hope for a better future. However, Huxley's *Brave New World* is a cautionary tale of a society in which progress and innovation come at the expense of individual freedom, authenticity, and justice. In the context of the digital age and artificial intelligence, this tension highlights the need for a balanced approach, embracing the transformative potential of digital and AI technologies while remaining vigilant against their unintended consequences.

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HEALTH JUSTICE

Dismantling Bias

Toward Ethical *and* Inclusive Health Innovation

by Tonie Marie Gordon

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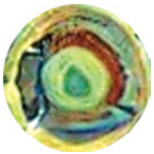
The creativity and ingenuity of socially marginalized and racialized groups can drive innovative healthcare solutions. However, despite their potential contributions, these groups are too often shut out of innovation ecosystems. Advancing innovations that lead to equitable and sustainable solutions in the healthcare system requires interrogating the inequities embedded within research, design, and testing processes for novel health solutions, as well as diversifying the people involved at each stage.

The COVID-19 pandemic laid bare the social, economic, and racial discrimination that underlies the US healthcare system. Fueled by a racial reckoning after the deaths of George Floyd and Breonna Taylor, a national conversation that acknowledged racial and health injustices as a dual pandemic began to emerge.[1] This put pressure on governments, institutions, and other organizations to proactively engage in racial justice reform within healthcare and medicine.[2] As organizations, networks, and individuals sought solutions, a movement to address inequality through technological innovation started gaining momentum.[3]

“BYE BYE BIAS” BY DALL-E 3/OPENAI.COM/DALLE

If novel innovations are ever to effectively and sustainably advance healthcare... for everyone, we must acknowledge that technology itself exists within...systems of oppression. [A]dvancing innovations that serve people at the margins requires addressing the complex nature of the reproduction of marginalization and using technology to disrupt and redress this harm.

> **Understanding the cruel history behind many of the world's leading medical innovations is a stark reminder that "technology is not made out of thin air." Instead, "it is the product of extraction, of exploitation, of displacement, of violence."**



Yet, innovative health products have caused BIPOC and other vulnerable groups harm—such as pulse oximeters that fail to accurately detect blood oxygen levels in people with darker skin tones and AI tools that make decisions that systematically disadvantage certain groups of people.[4] Within the context of medical and health innovation, historically marginalized people have largely been left on the periphery.

THE DEPRAVED HISTORY OF MEDICAL INNOVATION

Some populations have been deeply exploited by medicine and healthcare systems; consequently, their experiences are tainted by centuries of pain and trauma. In the United States, Black people have been subjected to inhumane treatment and brutality in the name of medical breakthroughs, and, perhaps even more egregiously, the very systems that they helped create continue to discriminate against them.

In the United States, modern surgery was tested on enslaved Black people who inherently could not consent to nor refuse the procedures. In the 1840s, an Alabaman physician, James Marion Sims, carried out experimental gynecological surgery on enslaved Black women, who were physically "bound to the surgical table."[5] Despite his methods, Sims was one of the most renowned American surgeons of the 19th century and even today is generally acknowledged as the founder of modern surgical gynecology.[6]

In *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*, Harriet A. Washington draws attention to the extent of Sims's "surgical theater," where he operated on enslaved Black people without anesthesia for an "audience of students and potential protégés" as part of his bid for "medical glory."[7] The horrific gynecological surgeries conducted on Black women were only one example; the surgical theater also included in-person surgeries on enslaved Black men. Though his ambivalence toward the humanity of Blacks is part of Sims's legacy, according to Washington, he was not the only doctor at the time to use Black people's bodies as "surgical material."[8]

Another egregious example of exploitation in medical research and the human costs of medical innovation is woven into the never-ending medical contributions of Henrietta Lacks. In 1951, at only 31 years of age, Henrietta Lacks, a young Black woman and mother of five, perished from a malignant cervical tumor eight months after diagnosis and treatment at the Johns Hopkins Hospital.[9] During her ultimately unsuccessful treatment, doctors took samples of Henrietta's cancer cells, dubbed HeLa cells, which were given "to a researcher without Lacks's knowledge or consent."[10]

By 1952, HeLa cells had become "the first human cell line that could grow and divide endlessly in a laboratory"—and the seemingly immortal properties of Henrietta's cells "contributed to their adoption across the world as the human cell line of choice for biomedical research."[11] The HeLa cell culture has survived for more than 70 years and is integral to biomedical research around the globe.[12] Yet the Lacks family wasn't made aware of the use of Henrietta Lacks's cells and the medical advances connected to them until 1973.[13]

Since the initial biopsy, scientists estimate that 50 million tons of HeLa cells have been created and used.[14] HeLa cells have been cited in over 110,000 scientific publications,[15] there are more than 17,000 patents associated with the cells, and scientists who relied on HeLa cells for their research received the Nobel Prize on three separate occasions.[16] HeLa cells' collective contribution to scientific breakthroughs is immeasurable: they were used to develop the polio vaccine, contributed to the mapping of the human genome, employed in the creation of treatments for both HPV and HIV, and contributed to the treatment of almost every type of cancer.[17] Most recently, HeLa cells were used in the development of the COVID-19 vaccine.[18]

Understanding the cruel history behind many of the world's leading medical innovations is a stark reminder that

DETAIL: "BYE BYE BIAS" BY DALL-E 3/OPENAI.COM/DALLE

“technology is not made out of thin air.” Instead, “it is the product of extraction, of exploitation, of displacement, of violence.”[19] But despite medical innovation’s troubling past, there is room to create space for all marginalized people within health innovation ecosystems.

CENTERING MARGINALIZED POPULATIONS

Capitalistic and myopic thinking too often influence healthcare innovations, even though the irresponsible use of advanced technology can have devastating consequences for vulnerable communities.[20] It is imperative that health innovation ecosystems consciously shift their focus to health innovation that occurs *with* and *for* underserved communities rather than at the expense of health, wellbeing, or safety. We can achieve inclusive innovation by:

- **Embracing Equitable Research Practices**

  Outmoded research paradigms that uphold the dichotomy between “researchers” and “research subjects” create a hierarchical power relationship that privileges the researcher’s perspective. On the other hand, equitable research paradigms, such as community-based participatory research and other participatory design approaches,[21] engage members of marginalized communities as agentic and knowledgeable actors who take a proactive role in solving problems and creating new pathways for health, healing, and thriving among marginalized peoples.

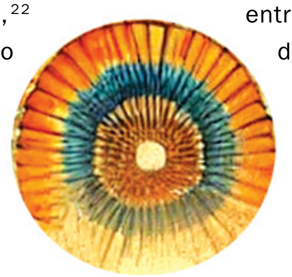
  Big datasets and large language models (LLMs)—which commonly serve as the basis for innovation in healthcare, medicine, and other domains—position underrepresented and minoritized populations as “outliers.” This is especially concerning because outliers are typically discounted or discarded altogether in the name of generalizability. There are several techniques that can be used to amplify marginalized voices rather than dismissing them as outliers within the research process: oversampling underrepresented populations in quantitative research,[22] disaggregating data by racial or ethnic groups to better understand the differences within and among groups,[23] supplementing quantitative research with qualitative insights, and using other multimodal research approaches.[24]

> **It is imperative that health innovation ecosystems consciously shift their focus to health innovation that occurs *with* and *for* underserved communities rather than at the expense of health, wellbeing, or safety.**

Some innovations—which were deployed without the rigorous testing needed to assess their viability and safety—have also posed a more universal threat to the public. To ensure health innovations don’t reproduce existing inequalities or exacerbate them, the nature of the data also needs to be carefully evaluated for how the data reproduce power structures. For instance, race-based diagnostics and practice guidelines—remnants of slavery and eugenics, which asserted that people of different races are biologically distinct—have been incorporated into modern AI systems. According to an article in the *New England Journal of Medicine*, these algorithms “may direct more attention or resources to white patients than to members of racial and ethnic minorities.”[25] It is important to pay close attention to how LLMs are developed and how AI systems are trained because data reflect the biased systems and structures that produce them. Researchers, designers, and engineers must use data reflexively to ensure the data do not reproduce or intensify inequality.

- **Considering Diverse Perspectives throughout the Innovation Process**

  Since so many components are involved in the innovation process, innovation ecosystems and hubs involve a collaborative effort among entrepreneurs, scientists, researchers, designers, tech and business leaders, clinicians, patients, and representatives of the public and social sectors.[26] Together, this diverse set of actors can understand



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> **Rather than creating innovations under the veil of neutrality… understanding how underrepresented and marginalized people will be affected by the technology should be integrated into all aspects of research, design, development, and implementation processes.**

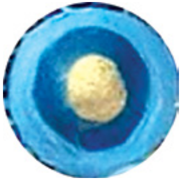
multifaceted health problems, identify appropriate solutions, and help guide implementation or uptake for specific populations. In addition to diversity in the roles people play, innovation also benefits from diversity at the team level. Racially diverse teams are more innovative and productive because they can "see things in a variety of ways."[27] In contrast, because the members of homogenous teams hold similar worldviews, beliefs, and styles of thinking, they produce "a narrower range of options and opinions."[28]

It is also imperative that diverse groups of people are represented among leaders and other key decision-makers involved in health innovation because they are well positioned to "deeply understand our world's increasingly multi-cultural, multi-racial contexts and can help shift and renegotiate power in ways that make for more equitable, just and sustainable outcomes for us all."[29]

Rigorously Testing Product and Service Innovations before Deployment

In the United States, our current way of testing innovative products, systems, and services is broken. Even beyond the innovations that have directly harmed people of color, some innovations—which were deployed without the rigorous testing needed to truly assess their viability and safety—have also posed a more universal threat to the public. For instance, in 2022, millions of sleep apnea machines were pulled off shelves because "an industrial foam fitted in the machines to reduce noise could break apart and release potentially toxic particles and fumes into the masks worn by patients."[30]

As the dangerous sleep apnea machines demonstrate, the regulators have too often failed to identify important problems with health innovations. To make matters worse, the FDA does not require medical technologies to be tested among diverse populations.[31] To prioritize safety and equity, innovation leaders and other stakeholders should seek diverse input throughout the innovation process, conduct "equity assessments,"[32] and test innovations thoroughly to understand how the technology affects people's health and how the technology is integrated into their lives.



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Innovative products, systems, and services are desperately needed to overcome the inefficiencies and ineffectiveness of the US healthcare system. Of equal importance and urgency is the need to use innovation to improve how marginalized populations navigate the healthcare system and raise the quality of care received. But the institutions that propel innovation ("government, industry, universities, and philanthropic foundations")[33] should exercise discretion in how they fulfill this need.

Innovation, especially technological innovation, is too often perceived as neutral. The veiled objectivity of innovation obscures the biased processes and data that serve as the foundation of technological innovation. In the United States, as well as much of the rest of the world, the status quo involves "a mostly white, male, privileged pool of designers and engineers" creating innovations that work exclusively for them,[34] such as facial recognition technology that sees White male faces better than others.[35] These biased technologies are then imposed on the larger population.

If novel innovations are ever to effectively and sustainably advance healthcare and medicine for everyone, we must acknowledge that technology itself exists within, not outside, systems of oppression. Most crucially, advancing innovations that serve people at the margins requires addressing the complex nature of the reproduction of marginalization and using technology to disrupt and redress this harm.[36] Rather than creating innovations under the veil of neutrality and fixing innovations to be more equitable after the fact, understanding how underrepresented and marginalized people will be affected by the technology should be integrated into all aspects of research, design, development, and implementation processes.

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HEALTH JUSTICE

From HeLa Cells to Digital Health

Navigating *the* Promises *and* Pitfalls *of* Modern Clinical Research

by Matimba Swana and Evelyn Kamau

In today’s rapidly evolving landscape, digital health innovations, driven by advanced technologies such as artificial intelligence and robotics, are reshaping clinical research in some promising ways. However, the pressing need for equity as relates to both the tech industry and healthcare makes digital health a very complex challenge. This article explores the current state of data, data’s role in digital health and clinical research, old and emerging concerns vis-à-vis health inequities, and a vision for an equitable digital future that empowers patients and ensures inclusivity in clinical research.

The Complex Landscape of Data Ownership, Rights, and Controls

In the digital age, vast amounts of data are generated and processed, raising critical questions about data ownership, rights, and controls. These questions include how we define these concepts, how they are interpreted, and how they work in practice.

“TRIAL, NO ERROR” BY DALL-E 3/OPENAI.COM/DALLE

As we advance into the digital health era, it will be crucial to...comprehend the specific challenges that people of color and other marginalized groups encounter in clinical research.... By promoting ethical and inclusive digital health advancements, we can empower individuals, improve outcomes, and reduce health disparities, fostering a more equitable digital future [for all].

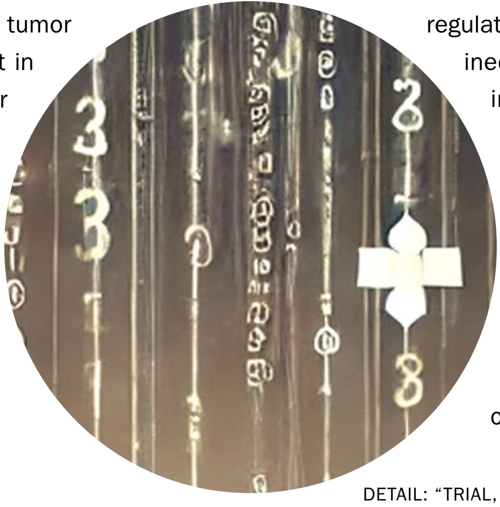
THE DEFINITIONS OF DATA OWNERSHIP, RIGHTS, AND CONTROLS DEMONSTRATE HOW THEY ARE INTERCONNECTED AND OFTEN REQUIRE A BALANCE BETWEEN INDIVIDUAL PRIVACY AND THE NEEDS OF ORGANIZATIONS AND SOCIETY.

Data ownership typically lies with the entity that creates or collects the data, though this can vary based on context and agreements.[1] *Data rights* encompass privacy, access, rectification (the right to have one's personal data corrected if inaccurate or incomplete),[2] and portability (the right to transmit or receive one's personal data in an accessible format),[3] regulated by laws such as General Data Protection Regulation in Europe,[4] California Consumer Privacy Act in the United States,[5] and Health Insurance Portability and Accountability Act (HIPAA)[6] for health data in the United States. *Data controls* involve technical measures like encryption and organizational policies to protect data integrity and security.[7]

The definitions of data ownership, rights, and controls demonstrate how they are interconnected and often require a balance between individual privacy and the needs of organizations and society. These needs include consent,[8] data protection, transparency,[9] data sharing,[10] accountability,[11] and trust.[12] Trust in data differs between organizations and individuals, as organizations tend to focus on legal requirements, while individuals consider several aspects. An independent report by BritainThinks highlighted that for individuals, the *why* and *who* of data use are crucial, with the *what* and *how* being less significant if the *why* is justified.[13] Trust in data can affect perceptions and reactions to reported data, with historical events notably influencing this trust. What follows is a regrettable event in medical research related to this topic.

Data as a Human Right: The Henrietta Lacks Legacy

The concept of data ownership is gaining traction. Many find inspiration in the story of Henrietta Lacks, an African-American cancer patient whose tumor cells were taken without her consent in 1951—leading to a multibillion dollar industry, while her family and descendants dealt with poverty.[14] Henrietta Lacks's narrative highlights several ethical concerns, including informed consent, health data privacy, transparency/communication with research participants, and the commercialization of data derived from individuals. The case stands out as one of the most contentious in the history of clinical research and medicine.



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The story of Lacks has fueled the argument for data ownership as a human right. One US company has even proposed that the United Nations adopt the first decentralized human right: the right to legal ownership of one's human data.[15] If this were to be adopted, individuals would own their data as property and could profit from selling access to, or even full ownership of, their data for personalized services or research.[16] Incentivization, such as financial ones, could lead to exploitation, since individuals may not understand their data's true value; thus, education, support, and transparency would be essential to protect people's interests and minimize misuse.[17] A decentralized human right as proposed above would require a clear framework with protections that include informed consent, encryption, access restrictions, audit trails, and regulatory oversight.

Companies are leveraging blockchain and AI to compensate individuals for their personal data.[18] Platforms like Nebula Genomics and Hu-manity.co are exploring ways to help individuals manage and monetize personal data.[19] Blockchain offers secure storage and smart contracts for controlled data sharing and compensation. In health data, non-fungible tokens (NFTs) are being proposed by researchers to serve as digital contracts that allow individuals to oversee access to their health records, potentially democratizing health data control and promoting transparency.[20] The concept of monetizing personal and healthcare data using blockchain and NFTs is emerging but is still in early adoption, facing issues of mainstream availability and regulation. Selling data may create privacy inequalities, potentially turning privacy into a luxury and fostering a black market. Without regulation, this commercialization could worsen inequities in clinical research.[21]

Integrating Data Ethics and Diversity into the Narrative

In the United Kingdom, organizations can use personal data without consent under a rule known as "lawful

DATA COLONIALISM...ALLOWS LARGE TECHNOLOGY COMPANIES TO CREATE DATA MONOPOLIES, HINDERING COMPETITION AND INNOVATION WHILE REINFORCING EXISTING POWER IMBALANCES.

basis."[22] Following notable events that sparked public outrage—such as the discovery that general practitioners' surgeries in England were sharing patients' complete medical records,[23] the National Health Service's sharing of patients' data with Google DeepMind without explicit consent,[24] and the (non–health related) Cambridge Analytica scandal[25] —the conversation in the United Kingdom has transitioned from data ownership to themes of control (the right to control one's data, even in the absence of proprietary rights) and consent.[26] (This contrasts with the US narrative, which focuses on data ownership and proprietary rights.) This raises the question: is it possible to have control without ownership? The answer is yes, especially regarding data. This concept is becoming increasingly significant as policymakers develop data ethics frameworks that prioritize transparency, fairness, and accountability.[27] Various approaches, including data stewardship,[28] data governance/accountability,[29] consent management,[30] data trusts,[31] and regulatory oversight[32] are being utilized to achieve these goals.

Not all data are generated, valued, or treated in the same way. Medical data are particularly valuable, presenting challenges and opportunities for minoritized communities. The case of Henrietta Lacks indicates the need for trustworthy processes that consider data ethics. Data ethics frameworks have encouraged the partnership between the National Institutes of Health (NIH) and the Lacks family, which is a prime example of data sharing agreements (DSAs).[33] This agreement allows controlled access to HeLa cell data (the name given to Henrietta Lacks's cells) while respecting the family's wishes.[34] It demonstrates how data sharing can be done ethically and transparently. Ensuring data quality is a foundational aspect of effective data sharing, impacting everything from operational efficiency to legal compliance and user trust.[35] The quality of ethnicity data can be affected by miscoding, perceived importance, and biased interpretation.[36] Systematic bias often arises from incorrect coding during data collection, which can occur when patients provide information to the NHS.[37] For example, individuals may choose anonymity regarding their ethnicity, or healthcare professionals may interpret it inaccurately, deepening health disparities.

Race has been used in clinical diagnosis and decision-making for a long time.[38] Race-based medicine uses race as a proxy for biological differences, resulting in harmful treatment patterns for minoritized racial and ethnic groups, further contributing to health disparities.[39] Scholars and health justice advocates critique this approach and advocate instead for race-*conscious* medicine, which emphasizes racism as a key determinant of health and encourages providers to focus on relevant data to reduce health inequities.[40] The ethical problems vis-à-vis race-based medical data are increasing as digital technology use grows.[41] Digital health uses technology for healthcare delivery, patient monitoring, and wellness management, relying on the data for improving operations, outcomes, research, and innovation. Digital health data use should leverage data for better health without ignoring concerns over exploitation of racialized—and indeed other marginalized—communities. Race-conscious medicine, data ethics, community engagement, and trustworthiness[42] should be key considerations for digital health.

Digital Health Colonialism

In today's world, vast amounts of health data are collected, processed, and analyzed. These data practices reveal various opportunities for enhancing healthcare delivery, workflow processes, and overall efficiency—but as discussed earlier, quality of ethnicity data remains challenging. Data colonialism—the exploitative and unequal relationship that exists between data-rich entities or companies and data-poor countries or communities[43]—allows large technology companies to create data monopolies, hindering competition and innovation while reinforcing existing power imbalances. Such practices of extraction, control, and exploitation of data from marginalized communities or nations by more powerful entities parallel historical colonialism.[44] This dynamic exacerbates inequities worldwide: as of 2020, only 43 percent of the least developed countries had implemented data and privacy protection legislation, compared to 96 percent of European nations, leaving them particularly susceptible to exploitation.[45] In regions lacking data privacy laws, researchers from high-income countries may perform studies they would avoid in their home countries. Exploitative practices in

THE WAY THAT DATA ARE CURRENTLY GATHERED AND USED CAN OBSTRUCT EQUITABLE MEDICAL RESEARCH AND PUBLIC HEALTH EFFORTS.

this context include "helicopter research," where researchers from affluent or privileged backgrounds conduct studies in lower-income areas without local participation, and "ethics dumping," where privileged researchers perform unethical experiments in less-privileged environments that have weaker ethical standards and oversight.[46]

The phenomenon of "digital health colonialism"—whereby the Global North monopolizes the supply of digital health technology—can hinder economies of the Global South, especially in Africa (where there are plenty of examples of helicopter research and ethics dumping),[47] from developing their own digital economies, manufacturing capabilities, and other domestic industries.[48] Additionally, US and Chinese multinational corporations are establishing an imperial-like control over digital ecosystems, leading to increased surveillance and disproportionate influence over economics, politics, and culture.[49] The Global North's dominance in the digital realm has led to monopolistic data monetization, characterized by platform capitalism and surveillance capitalism, where user data is collected without full consent.[50] This exploitation exacerbates inequalities in the Global South, fostering dependency and raising concerns about digital colonialism, which highlights the need for urgent attention and action.[51] Data colonialism raises significant ethical issues, including the need for informed consent, fair compensation, and community control over data in clinical research.

In the context of global digital health, there are four main areas that illustrate digital colonialism. The first is *unregulated health data extraction*[52]—or the exploitation of personal health data by external entities without the individuals' consent or benefit. Even with consent, it may not be fully informed due to individuals' limited understanding of the protocols of data sharing, usage, and storage. These data are often gathered via health apps, wearable devices, and electronic health records, leading to privacy issues, loss of control over personal health information, and potential discrimination. The second area is the *perpetuation of existing power imbalances*.[53] Communities or countries with marginal resources may lack the means to fully leverage digital health technologies or use their health data for research, policymaking, or healthcare service enhancement. The third area is *data monopolization*.[54] Dominant tech companies in the digital health sector can collect extensive health data, gaining substantial competitive edges. This can foster monopolistic behaviors, stifle competition and innovation, and widen the gap between data-rich and data-poor groups.[55] And the fourth area is *unethical research design and methodology practices*, which can impact the ethics of data vis-à-vis global digital health.[56] The way that data are currently gathered and used can obstruct equitable medical research and public health efforts. For example, insufficient and/or biased data-capture from underrepresented groups or developing nations can delay the creation of specific health interventions and further entrench and even worsen existing health inequities. Incomplete data can overlook essential information necessary for understanding health conditions that affect specific ethnic groups,[57] such as sickle cell anemia, which primarily impacts people of color.[58] As previously noted, poor data quality can result in incorrect conclusions.

By acknowledging these areas of data inequality in digital health, we can begin to address them. Sharifah Sekalala and Tatenda Chatikobo, researchers in the areas of global health law and inequality and digital colonialism, respectively, propose a decolonial digital health agenda that challenges the simplistic view of digital innovation as a solution for health justice.[59] They advocate for reimagining digital health by focusing on Indigenous and intersectional theories, prioritizing local contexts, and emphasizing regulatory infrastructures as sites for struggle and resistance. This approach evaluates who are in fact the beneficiaries of digital health systems, prioritizes community voices and those with lived experience, and establishes strong regulations to address the social harms of unethical/inequitable digitization.[60] Recent debates on decolonizing global health focus on addressing power imbalances and knowledge hierarchies that reinforce colonial ideologies.[61] Many individuals feel they cannot opt out, but enabling communities to take charge could enhance their benefits from digital health.[62]

Henrietta Lacks's HeLa cells became the pioneering "immortal" cultured cell line, which is now extensively used in laboratories across the world. These cells have played a crucial role in research related to cancer, COVID-19, HIV, Parkinson's

PEOPLE OF COLOR ALSO FACE PREJUDICE IN PHYSICAL HEALTHCARE SETTINGS.... THEIR EXPERIENCES RANGE FROM DISCRIMINATORY REMARKS TO SYSTEMIC RACISM IN HEALTHCARE, WHICH IS WELL-DOCUMENTED IN AREAS SUCH AS MATERNITY CARE.

disease, and much more.[63] Many groundbreaking discoveries may not have been possible without them; however, we must also recognize the ethical concerns surrounding the way these cells were acquired. The history of clinical research is rife with contentious narratives and clashing moral principles such as HeLa cells.[64] Shifts in societal values have a significant impact on the laws and regulations governing clinical research. Currently, the field is shifting toward incorporating digital health and data to propel advancements. In this context, we present a case study on decentralized clinical trials (DCTs) and explore how new technologies could help address persistent inequities in clinical research.

Decentralized Clinical Trials: A Promising Innovation

Clinical trials investigate biomedical or behavioral interventions with human participants, and are highly regulated.[65] Ethical codes and guidelines[66] were created for clinical trials as a result of unethical practices and human experimentation such as those carried out in Nazi Germany during World War II,[67] the prescribing of thalidomide—a morning sickness drug that caused birth defects—in the 1960s,[68] and the US Public Health Service (precursor of the Centers for Disease Control and Prevention) syphilis study at Tuskegee.[69]

Traditionally, clinical trials are reliant on in-person visits, which can be burdensome due to travel and costs. To mitigate these challenges, companies are creating digital health tools and remote data-collection technologies. Decentralized clinical trials allow activities to occur outside traditional sites, such as homes or local facilities, by sending healthcare professionals to patients and/or using technology.[70] Using technologies like telemedicine and wearables, DCTs can enhance access to treatments, reduce trial duration and costs, improve participant diversity, and lower environmental impact.[71] Regulatory focus is increasing, with agencies like the FDA providing guidelines for integrating DCTs, allowing for more remote assessments.[72]

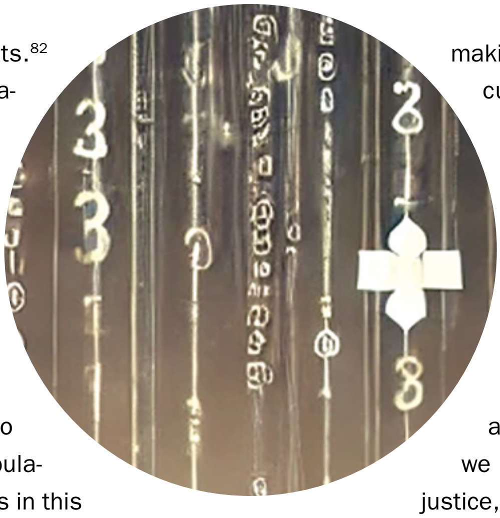
More important, flexible and hybrid work arrangements have surged in popularity post-COVID-19, revealing a divide between how marginalized groups and those not marginalized experience office—and other—settings. There is a clear racial divide vis-à-vis people of color, who favor remote work so as to escape microaggressions and feelings of exclusion in office settings.[73] The Runnymede Trust, the UK's leading race equality think tank, reports that 75 percent of women have experienced racism at work, with 27 percent facing racial slurs, and 61 percent feeling pressured to change themselves to fit in.[74] People of color also face prejudice in physical healthcare settings.[75] This highlights one of the reasons why people of color may choose to avoid hospitals and clinics. Their experiences range from discriminatory remarks to systemic racism in healthcare, which is well-documented in areas such as maternity care, particularly with the disparities in maternal death rates between white individuals and people of color.[76] DCTs could open up clinical trials for groups that have previously been excluded from clinical research by improving access to research opportunities for those in underserved areas as well as offer an alternative to hospital environments where racial discrimination occurs.[77]

However, DCTs, as with all digital technology, have limitations such as data integrity (if data are collected from multiple sources, it could complicate data management and integrity, which could create data quality issues);[78] consent (obtaining informed consent remotely can be challenging, which could prompt another Henrietta Lacks situation);[79] digital literacy (not all participants have equal access to the necessary technology or the digital literacy to participate in DCTs, which could enhance digital colonialism);[80] and the physician–patient interaction (ensuring the safety of participants can be more complex in DCTs due to the lack of direct oversight by clinical staff, for example remote monitoring may not always detect adverse events promptly. Additionally, we do not know how racism in healthcare could materialize in a digital setting in future).[81] Early attention to these issues is crucial to prevent further exclusion of underserved patient groups. Addressing these concerns will be crucial for realizing the full potential of DCTs in promoting clinical trial equity.

DCTs and Diversity in Clinical Trials

Some patient subgroups, such as women versus men, may react differently to medical treatments, highlighting the need

> AS WELL AS THE UNETHICAL PRACTICES AND HUMAN EXPERIMENTATION THAT HAVE OCCURRED IN CLINICAL TRIALS THAT EXPLOITED OR EXCLUDED UNDERREPRESENTED GROUPS...THERE ARE OTHER SIGNIFICANT FACTORS, SUCH AS LACK OF REPRESENTATION OF CLINICAL TRIAL STAFF.



DETAIL: "TRIAL, NO ERROR" BY DALL-E 3/OPENAI.COM/DALLE

for diversity in clinical trial participants.[82] This diversity ensures that trial populations accurately represent the patients who will use the medicine, making the results more generalizable.[83] Historically, clinical trial cohorts have been lacking in diversity, even though the scientific community is aware that women, children, and racial and ethnic minorities are underrepresented.[84] There are many reasons that have led to skewed representation of patient populations in research,[85] too many to discuss in this article; however, there is growing awareness about race and ethnicity representation in clinical trials.[86] As well as the unethical practices and human experimentation that have occurred in clinical trials that exploited or excluded underrepresented groups such as women and minorities, there are other significant factors, such as lack of representation of clinical trial staff;[87] fear and mistrust (for good reason);[88] and socioeconomic realities, including access to healthcare, financial and time constraints [89]—all of which have contributed to the negative perception of clinical trials among these groups.[90] Recently, the healthcare industry has focused on increasing diversity in clinical trials, partly due to recommendations by regulatory agencies.[91]

DCTs present ethical challenges[92] but also offer benefits for diverse enrollment. Researchers from the University of Birmingham recommend eleven strategies focused on trial design, support, and reporting to enhance equity and inclusion in DCTs.[93] Solely digitizing and decentralizing trials won't resolve underrepresentation—addressing barriers like historical mistrust and misconceptions requires broader initiatives.[94] Despite the rapid expansion of using digital tools and services to allow participants to participate remotely from their home or community setting, there is a lack of analysis regarding their impact on equity in clinical research.[95] Identified barriers and other challenges hinder the achievement of sufficient diversity in clinical trials, making it crucial to critically evaluate the current role of DCTs in promoting diversity and inclusion.[96] We suggest that further research be done in this area.[97]

Moving toward Inclusionary Digital Health

To harness the full potential of data and digital health in clinical research, we must prioritize data ethics, social justice, community engagement, equitable digital health technologies, and inclusive trial design. This involves developing the following ethical practices:

1. **Informed Consent.** Individuals and communities should have control over their health data and be fully informed about how data will be collected, used, and shared. Consent processes should be transparent, understandable, and respect different groups' cultural norms and values. The consent format should be accessible to all educational backgrounds, and incorporate imagery, text, and audio so that all learning styles are accommodated.

2. **Data Sovereignty.** Efforts should be made to empower communities and countries to exercise sovereignty over their own health data. This may involve creating data governance frameworks that prioritize local ownership, control, and benefit sharing.

3. **Ethical Partnerships.** Collaboration between technology companies, researchers, policymakers, and communities should be based on principles of equity, mutual benefit, and respect for local knowledge. Partnerships should ensure that the data benefit the communities from which they are collected.

[W]E AIM TO PREVENT ISSUES LIKE THOSE FACED BY HENRIETTA LACKS AND HER FAMILY. OUR GOAL IS TO PROMOTE AWARENESS AND ENCOURAGE INCLUSIVE PRACTICES IN GLOBAL DIGITAL HEALTH AND CLINICAL RESEARCH.

4. **Capacity Building.** Resources should be allocated to build the capacity of marginalized communities and countries to leverage digital health technologies and effectively use their health data for their own benefit.

It is important to acknowledge that the above represents merely a starting point. A commitment to caring for individuals through clinical research necessitates a critical reevaluation of how we conceptualize and implement clinical research, as well as how we design digital tools and services. With our experience working in clinical research, we recognize the role that data and digital health will play in the future, especially in clinical trials. We see the advantages of decentralized methods for patients who live far from hospital sites, as well as for people of color and other marginalized groups, who can participate without facing microaggressions or direct racism and other abuses that may occur in traditional hospital settings. We chose DCTs as a case study due to challenges in patient recruitment and retention in clinical trials, which has prompted the integration of decentralized elements in the clinical research industry.[98] Addressing the intersection of technology and healthcare, particularly regarding data and digital health, requires careful planning, robust digital infrastructure, and ongoing oversight to ensure safe and ethical clinical research and other practices. While recognizing the benefits of HeLa cells, we aim to prevent issues like those faced by Henrietta Lacks and her family. Our goal is to promote awareness and encourage inclusive practices in global digital health and clinical research. There is an urgent need to prioritize data quality, digital equity, and inclusivity in clinical research. While DCTs are not the only solution, if done correctly, they represent one valuable approach. A variety of methods will be necessary to establish comprehensive guidelines in this area.

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Racial and ethnic minority groups have faced exploitation in clinical research that has led to a lack of trust, such as the example of Henrietta Lacks. Technology has the potential to both empower and educate. Digital platforms can serve as valuable resources to inform the public about Henrietta Lacks's significant contributions to clinical research. Websites and applications can share her story, along with the ethical issues it presents, ensuring that her legacy is respected and remembered. As we advance into the digital health era, it will be crucial to collaborate with both the education and healthcare sectors to address unconscious biases and comprehend the specific challenges that people of color and other marginalized groups encounter in clinical research. Addressing issues like digital sovereignty and advocating fair data practices is vital. By promoting ethical and inclusive digital health advancements, we can empower individuals, improve outcomes, and reduce health disparities, fostering a more equitable digital future that ensures clinical research and indeed all healthcare practices serve the interests of all rather than just a select few.

In the spirit of self-reflexivity, we acknowledge our standpoint. We have both worked in clinical trials and identify as women of color with African heritage. We made efforts to understand existing biases and assumptions during our analysis and writing process; however, it is likely that our ethnoracial backgrounds influence our interpretations.

NOTES

1. Dame Ottoline Leyser and Genevra Richardson, *Data ownership, rights and controls: reaching a common understanding; Discussions at a British Academy, Royal Society and techUK seminar on 3 October 2018* (London: The British Academy, 2018).
2. General Data Protection Regulation (GDPR) includes a right for individuals to request that inaccurate or incomplete personal data be corrected. An individual can make a request for rectification verbally or in writing. However, there are some circumstances where the right is restricted, including when it conflicts with important objectives of public interest and when it conflicts with the right of freedom of expression and information. The right to rectification is covered in articles 16 and 19 of the General Data Protection Regulation (2018), gdpr-info.eu/, laid out in Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016, eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016R0679.

3. The right to transmit or receive personal data an individual has provided in a structured, commonly used, and machine-readable format is covered in Article 20 of the General Data Protection Regulation (2018).
4. General Data Protection Regulation (2018); Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016; and *Official Journal of the European Union*, L 119, v. 59 (May 4, 2016): 1–88, eur-lex.europa.eu/legal-content/EN/TXT/?uri=oj:JOL_2016_119_R_TOC.
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6. U.S. Department of Health and Human Services, Summary of the HIPAA Privacy Rule, original ruling 1966, www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html.
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8. General Data Protection Regulation (2018): See Art. 4 GDPR Definitions; Art. 6 GDPR Lawfulness of processing; Art. 7 GDPR Conditions for consent; Art. 8 GDPR Conditions applicable to child's consent in relation to information society services; Art. 9 GDPR Processing of special categories of personal data; Art. 22 GDPR Automated individual decision-making, including profiling; Art. 49 GDPR Derogations for specific situations.
9. General Data Protection Regulation (2018): See Art. 13 and 14 The right to be informed (transparency). See Recitals 38 Special Protection of Children's Personal Data; 58 The Principle of Transparency; 59 Procedures for the Exercise of the Rights of the Data Subjects; 60 Information Obligation; and 73 Restrictions of Rights and Principles, gdpr-info.eu/recitals/.
10. General Data Protection Regulation (2018) sets out certain restrictions or conditions on disclosing personal data to third parties or between different parts of an organization. Data sharing can be routine, one-off, or in an emergency.
11. Accountability is a principle of General Data Protection Regulation that requires organizations to implement measures to demonstrate their compliance with data processing principles. These measures can be technical or organizational.
12. Centre for Data Ethics and Innovation, Independent report *BritainThinks: Trust in data*, December 15, 2021.
13. Ibid, 27.
14. Rebecca Skloot, *The Immortal Life of Henrietta Lacks* (New York: Random House, Inc., 2010).
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16. Kateryna Nekit, "The (im)possibility of personal and industrial (machine-generated) data to be subject to property rights," *International Journal of Law and Information Technology* 32, no. 1 (June 2024): p.eaae008.
17. Jacob Leon Kröger, Milagros Miceli, and Florian Müller, "How Data Can Be Used Against People: A Classification of Personal Data Misuses," *Social Science Research Network* (December 30, 2021).
18. Blockchain and AI have been suggested for compensating people for their data. The following references discuss how these technologies could work for data. See Stanton Heister and Kristi Yuthas, "How Blockchain and AI Enable Personal Data Privacy and Support Cybersecurity," chapter 3 in *Advances in the Convergence of Blockchain and Artificial Intelligence*, ed. Tiago M. Fernández-Caramés and Paula Fraga-Lamas (London: IntechOpen, 2022); Renee Garett, Mohamed Emish, and Sean D. Young, "Cryptocurrency as a new method for participant compensation in research," *Health Policy and Technology* 12, no. 2 (June 2023): 100746.
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22. The lawful bases for processing personal data in the UK are set out in Article 6 of General Data Protection Regulation (2028). There are six lawful bases. See “A guide to lawful basis,” Information Commissioner’s Office, accessed December 31, 2024, ico .org .uk /for -organisations /uk -gdpr -guidance -and -resources /lawful -basis /a -guide -to -lawful -basis/.
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28. Data stewardship involves managing and overseeing data assets to ensure data quality, privacy, and security; for example, organizations appoint data stewards to ensure that data are accurate, accessible, and used appropriately.
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HEALTH JUSTICE

Our Bodies, Our Data, Our Destinies

Native American Women Harnessing Technology *for the* Benefit *of* Our People

by Kelly K. Hallman

Native American health researchers need allies to better ensure that Indigenous people not only drive and design health projects but also create, access, and control the data generated from them.... We will no longer accept being researched *on*—we deserve to lead the research that is about our families and communities.

“MINE TO CONTROL” BY DALL-E 3/OPENAI.COM/DALLE


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My ancestors were sent to Native American boarding schools, some operated by religious organizations, some by the Bureau of Indian Affairs.[1] There we were taught the latest agricultural, home economic, and family health technologies that had almost no relevance to the agroecological and climate zones we lived in or the health problems that our people faced. Given the influence of Indigenous females on future generations, Native American girls were special targets of the cultural assimilation lessons of these boarding schools. In the 1960s and 1970s, health providers contracted by the Indian Health Service—the entity created to provide tribally enrolled Native Americans with healthcare in exchange for the land from which we were forcibly removed—used medical technologies to sterilize our women without their consent.[2] The facilities available to my relatives in eastern Oklahoma have been noted as offenders.[3]

Today, Native American women are flipping the script and leading the fight to create and harness technologies for our people's benefit.[4] We are involved in health-focused, Native American–led program development, advocacy, research, and policy change.[5] We know that our Indigenous culture is key to our health, which foods are nutritious for our families, and how to sustain our Mother Earth to thrive. We are forming collectives that enable our sisters and brothers to gain access to reproductive and gender-affirming care if and when their tribal governments (though legally sovereign nations) are located in states that have imposed legal restrictions on such services.[6] Most non-Natives are unaware that the Indian Health Service is considered a federal provider and thus is subject to Hyde Amendment restrictions that ban abortion care.[7] This is unacceptable for people who belong to federally recognized tribes that hold politically sovereign status.

Central to our health justice movements are inter- and intragenerational social solidarity—and when combined with strengthened cultural identity and recognition of our tribal sovereignty, this is triply powerful for Indigenous people. As a Native American health economist who has worked with Indigenous populations across the globe for two decades, I felt the need to come home and help strengthen health justice for Native American girls, women, and gender-fluid people. In 2022, I started Indigenous Justice Circle (IJC), a Native female–led nonprofit whose work focuses on health equity, gender-transformative justice, and combating the Missing and Murdered Indigenous Persons (MMIP) epidemic.[8] IJC uses technology to enhance the health impact of our work.[9] Our theory of change is that the combination of female intra- and intergenerational social capital, cultural identity, and tribal sovereignty—all supercharged with technology tools—bolsters our bodily autonomy, keeps us safer and healthier, and allows us to exercise our political and economic rights that allow us to maintain these freedoms.

Primary technologies for building and maintaining modern health justice movements are artificial intelligence, geolocation,[10] and social media. These tools, all packed into mobile phones to which many (but not all) people now have access, are in and of themselves becoming determinants of our health and can function for good or evil, depending on who is controlling and monitoring them. At IJC, we are harnessing these technologies to establish a collective movement built upon genuine human reciprocal relationships for Indigenous community benefit, moving beyond the atomized virtual world of accumulating individual "followers" and "likes" merely for social media ascendancy.

Across Indigenous geographies, IJC equips local tribal actors to establish physical support groups to increase female safety and skills and to serve as a Missing and Murdered Persons' early warning system.[11] Depending on the age cohort of the specific group, girls, women, and/or Two-Spirit and transgender Indigenous persons are invited to gather on a regular (weekly or fortnightly) basis. Attendance is kept electronically, in an encrypted, password-protected secure app our team designed. If participants miss more than one meeting without being in touch with us, the mentor for the group checks in about their wellbeing. The aim is to take action before someone has been missing for too long.

DETAIL: "MINE TO CONTROL" BY DALL-E 3/OPENAI.COM/DALLE

At [Indigenous Justice Circle], we are attempting to partner with large research universities and nonprofits and simultaneously change their inequitable culture and practices, including the lack of respect they give to Native people.

These in-person groups are supplemented by virtual support groups, especially among those relatives who have left their tribal communities to earn a living or pursue educational opportunities in urban areas with which they may be unfamiliar.

Navigating these new environments and going back and forth to one's tribal home is a particular challenge, given the economic and transportation constraints many Native Americans face. IJC uses geolocation technology to enable our support group participants to map safe and unsafe places in the areas they navigate. In these groups, mentors, mentees, and peers are encouraged to use safety-enhancing apps that allow them to share their cell phone location and/or to provide key words or emojis to signal that they need help. We provide girls, women, and Two-Spirit and transgender people with training in online safety, such how to spot sex and labor traffickers, as well as ways to avoid the mental health dangers of social media algorithms designed to increase screen time solely for corporate profit. We inform girls, women, and Two-Spirit and transgender people of helplines such as 911, 988, and Native-specific versions, such as the StrongHearts Native Helpline (1-844-7NATIVE [762-8483]). We are using AI to help predict which situations (working at night, residing in a rooming house, and so on) and geographic areas present heightened risk of violence, assault, or abduction for Indigenous girls, women, and Two-Spirit and transgender people. Furthermore, we emphasize that whether to get to school, to go shopping, or to apply for a job, wrapping oneself in a cloak of protective social capital is key to bodily safety and autonomy. We provide reminders to go with a friend, urging both to have their cell phones in hand and ready to send "help" key words or emojis in case something goes wrong. Self-defense training and the confidence it can bring are included in our support groups, be they in person or virtual.

As a health equity researcher striving to use my global experience to benefit Native American communities, strategies to claim and operationalize Indigenous data sovereignty are top of mind. Most of us know about the Havasupai case[12] and Henrietta Lacks.[13] Universities can do much better to partner with racial and ethnic minority–led organizations. At IJC, we are attempting to partner with large research universities and nonprofits and simultaneously change their inequitable culture and practices, including the lack of respect they give to Native people. This is not just with regard to protecting our traditional Indigenous knowledge but also to ensure ownership rights and control of newly produced data that result from the research collaboration. I am in conversation with United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) experts, community representatives on the United Nations Permanent Forum on Indigenous Issues (UNPFII), and Native American data sovereignty consultants, and am accessing the resources provided by the Native American Rights Fund and the Seattle Urban Indian Health Institute. Even with that assistance, I have not found sample intellectual property templates available for Native American-led nonprofits aiming to engage in research with non-Native entities such as large research universities. (IJC is currently working on a template that can serve as a model for others in our position.)

While Native American tribes and peoples are increasingly protected by ethical review boards, these present large and lengthy processes for small Native American–led organizations such as mine to navigate.[14] What is more, having served on a non-Indigenous global health institutional review board for more than a decade, I know firsthand that serving in this capacity can trigger trauma for some of us from the trenches who have various lived experiences that we find described in the research protocols we review. That makes us experts—but that expertise comes at a price.

Native American health researchers need allies to better ensure that Indigenous people not only drive and design health projects but also create, access, and control the data generated from them. We need the following as allies: AI experts; systems administrators and software engineers; philanthropic donors; local, federal, and state governments; universities; non-Native nonprofits; and legal experts on international Indigenous and US Native American legal and intellectual property rights. We will no longer accept being researched *on*—we deserve to lead the research that is about our families and communities.

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HEALTH JUSTICE

The Double-Edged Sword of Health Innovations

Navigating the Intersection *of* Technology and Equity *in* Nigeria

by Emmanuel Onwuka

Emerging technological innovations in healthcare have the potential to transform public health and healthcare delivery systems, making them more efficient, personalized, and accessible. However, health innovation, when narrowly defined as the application of technologies, often overlooks the broader socioeconomic contexts in which it is deployed. In Nigeria, where health inequities are deeply rooted in systemic issues such as poverty,[1] gender inequality,[2] and inadequate governance (poor administration/planning),[3] the introduction of new technologies can sometimes deepen these disparities rather than alleviate them.[4]

Two key examples are Nigeria's significant efforts to enhance primary healthcare through the Saving One Million Lives (SOML) initiative,[5] and the country's progress toward universal health coverage (UHC) via the National Health Act (NHA). SOML is a health reform program launched to improve maternal, newborn, and child health outcomes by promoting results-based funding and data-driven healthcare decisions. The primary aim of the UHC initiative is to expand healthcare access through mechanisms like the Basic Health Care Provision Fund, which allocates funds directly to primary healthcare centers, especially in underserved areas.

"TECHNIGERIA" BY DALL-E 3/OPENAI.COM/DALLE

By prioritizing ethical responsibility [and] social justice...in the implementation of emerging technologies, we can chart a path forward that ensures health innovations are truly a force for good...across the planet.... Such an approach requires a concerted effort.... Together, we can build a health system that is not only innovative but also equitable, resilient, and rooted in justice and love.

> *Technological innovations are often lauded as a panacea for global health challenges....[B]ut their effectiveness is often compromised by poor internet connectivity and limited digital infrastructure...where health services are most needed.*

While the two initiatives were successfully introduced, they encountered political and institutional obstacles that impeded their execution and long-term sustainability.[6] Obstacles included insufficient data management systems and delays in fund transfers, which hindered the effective deployment and tracking of resources meant for public health improvements.[7]

The lack of robust data systems to track and manage the allocation and utilization of funds across healthcare centers led to inefficiencies and poor accountability.[8] Such technical hindrances have slowed down response times, particularly in rural areas, where resources are sparse.[9] And without effective tracking, funds may not reach those in greatest need—exacerbating inequalities, as urban centers with better infrastructure benefit disproportionately from such health initiatives.

Another significant example occurred between March 2017 and March 2019, when digital innovations such as video training and data digitization initiatives were brought to 62 healthcare facilities in Ondo State, southwest Nigeria.[10] This initiative aimed to improve healthcare access and quality in areas with limited connectivity; however, many of the facilities lacked access to even a basic 3G mobile network, rendering the digital tools largely ineffective. Healthcare workers struggled to implement the new systems, and patient records became challenging to maintain and access, leading to disruptions in healthcare delivery. Consequently, communities that were already marginalized continued to face limited access to essential healthcare services.[11]

While this article focuses on Nigeria, the question of AI in healthcare is a critical concern across the planet—and ongoing debates in the areas of technology, policy, and healthcare mirror what follows here. In the United States, for one example, there is ongoing concern about the deep-rooted biases in both healthcare and in the research data used to design the tech innovations that are supposed to help eliminate the biases.[12] This kind of contradiction can be found in most of the challenges described below.

EMERGING TECHNOLOGIES: POTENTIAL AND RISKS

Technological innovations are often lauded as a panacea for global health challenges.[13] Since COVID-19, AI-driven diagnostic tools, telemedicine platforms, and mobile health applications have been rapidly gaining traction, promising to bridge the gap between healthcare providers and underserved communities.[14] Digital health—which the National Institutes of Health defines as “the use of information and communications technologies in medicine and other health professions to manage illnesses and health risks and to promote wellness”[15]—has been emerging broadly: in pharmaceuticals, vaccines, and medical devices; in telemedicine (which, since COVID-19, has become a trusted means of accessing healthcare more safely and easily); and in such areas as sanitation and even agriculture, in terms of how these connect with health.[16] Many such digital health solutions have been designed to increase access to healthcare, particularly in underserved areas—but their effectiveness is often compromised by poor internet connectivity and limited digital infrastructure, especially in rural and low-income regions, where health services are most needed.[17] This type of digital divide is a significant barrier to health equity globally, with rural and low-income populations often left behind.

For such populations—for whom access to quality healthcare has been historically limited—telemedicine platforms, for example, can be a lifeline, connecting patients with healthcare professionals in urban centers.[18] And such cutting-edge technologies as the Clustered Regularly Interspaced Short Palindromic Repeats (CRISPR) gene editing and artificial intelligence—considered ideal future tools for treating diseases, as they can precisely correct harmful base mutations or disable disease-causing genes permanently—are also very promising techniques that could revolutionize healthcare across the board.[19] Yet, while such technologies hold immense potential, their benefits are not always evenly distributed. Precision medicine, for example, which aims to tailor treatments to an individual’s genetic makeup, has been heralded as a breakthrough in personalized healthcare—but its impact has been limited by significant gaps in genomic data.[20] The majority of genomic research has focused on populations of European descent, leaving vast portions of the global population underrepresented. This lack of diversity makes precision medicine less effective for non-European populations, as genetic markers specific to other groups are often missing or misunderstood.[21]

Similarly, research shows that the lack of diversity extends to many wearable devices, and studies suggest that this makes them less accurate in measuring certain health indicators in people with darker skin tones, creating the potential for biased data.[22] (And the cost of these devices—often as high as several hundred dollars—limits access for lower-income individuals, who may stand to benefit the most from real-time health monitoring.)

These gaps underscore the urgent need for systems that prioritize inclusivity and equitable representation in both research and healthcare technology development. Expanding genomic research to encompass diverse populations and ensuring wearable devices undergo rigorous testing across different skin tones and socioeconomic contexts can mitigate these disparities. Subsidies or innovative financing models could also make these technologies more accessible to underserved groups, thus promoting fairness in healthcare outcomes and improving precision medicine for all.

And in Nigeria specifically, where health infrastructure has long struggled under the weight of systemic issues, the challenges and risks of technological innovations can be stark. Problems like economic instability, deficient infrastructure, societal inequalities, and limited access to education contribute to persistent health crises for individuals and communities.[23] For example, nearly 40 percent of Nigerians live in extreme poverty,[24] while gender inequality remains pervasive.[25]

These systemic societal challenges pose considerable risks to technological innovations in Nigeria. For example, as noted earlier, while technology has the potential to enhance healthcare delivery, the lack of reliable infrastructure—such as consistent electricity and internet access—limits the effectiveness of telemedicine and health information systems.[26] And these obstacles hinder progress toward improving health outcomes for vulnerable populations—women and girls, for example, whose unequal access to education and healthcare services makes them especially vulnerable. In addition, economic barriers, such as reliance on out-of-pocket payments, place a burden on low-income families, often preventing access to adequate healthcare.[27] And this gap between available resources and health demands is exacerbated by the inequitable distribution of medical facilities, which are primarily concentrated in urban centers, leaving rural communities underserved.[28]

The digital divide in Nigeria is particularly pronounced compared to many other countries, with urban centers like Lagos and Abuja having better access to AI-driven healthcare innovations compared to rural areas.

The introduction of AI-powered diagnostic tools in urban hospitals has undoubtedly improved the accuracy and speed of diagnosis for patients who can afford the services. However, in rural areas where healthcare facilities are underresourced and understaffed, the impact of technological innovations is limited.[29] Not only that, but such innovations can even widen the gap between urban and rural healthcare services, leaving marginalized communities at an even greater disadvantage than they already are. The digital divide in Nigeria is particularly pronounced compared to many other countries, with urban centers like Lagos and Abuja having better access to AI-driven healthcare innovations compared to rural areas.[30] Nigeria's healthcare system reflects the country's larger digital and infrastructural gaps, as over 61 percent of Nigerians in rural areas lack access to reliable internet, which hampers AI deployment in these regions.[31] Platforms like mDoc are making strides by providing AI-powered health assistance to Nigerians through mobile-friendly solutions,[32] but scaling this to rural areas remains challenging due to the kinds of infrastructure limitations described earlier.[33]

Furthermore, the National Health Act, established in 2014 to address such gaps by guaranteeing a basic health package, remains inconsistently implemented. Consequently, primary healthcare facilities struggle with underfunding—and the Basic Health Care Provision Fund, designed to support these services, has not reached its intended impact in delivering universal healthcare coverage. Studies suggest

The commercialization of health innovations also raises concerns. The resulting commodification of healthcare creates an environment where profit-driven motives overshadow the goal of achieving health equity.

that a shift toward a tax-financed health system like the NHA—properly implemented—could alleviate financial burdens on vulnerable populations and make healthcare more accessible.[34]

Such a shift would also help to alleviate the health disparities for women and children in Nigeria—as noted earlier, a key vulnerable group. According to BudgIT's 2018 report on Nigerian primary healthcare, it is estimated that 2,300 children ages five and under and 145 women of childbearing age die each day from mostly preventable causes, reflecting a pressing crisis in healthcare delivery and access.[35] Although some progress has been made in reducing maternal and child mortality, the pace of improvement lags behind other Sub-Saharan African countries including Kenya, Uganda, Senegal, and Tanzania.[36] This stagnation is rooted in systemic barriers, including limited funding.[37]

Compounding these challenges, conflict and instability, often exacerbated by insurgent activities and terrorist threats, significantly impact the health outcomes of women and children in the Northern Region. These conflicts disrupt healthcare services, displace families, and put already vulnerable populations at greater risk. Accessing consistent medical care becomes nearly impossible, worsening health outcomes and increasing mortality rates, while the fragile healthcare system is further strained by a lack of resources, healthcare professionals, and safe environments to deliver essential services.[38]

Innovative solutions, such as the RapidSMS platform, aim to address some of these challenges by enabling decentralized monitoring of maternal and child health in Malawi and Zambia, and providing real-time data on birth registration across Nigeria.[39] By allowing local birth registration centers to send regular updates via SMS, the platform facilitates targeted interventions where healthcare services are deficient.[40]

However, these technological solutions alone cannot fully address the deep-rooted issues of healthcare inequity, lack of infrastructure, and ongoing violence that continue to impede the effectiveness of healthcare for Nigeria's women and children.

Globally, Nigeria is still in the early stages of integrating AI into healthcare, compared to more developed nations, where AI is now extensively used in everything from diagnostics to outbreak response. Addressing these disparities will require collaborative efforts from government, tech companies, and healthcare providers to improve digital infrastructure and make AI tools more accessible. In Nigeria, the doctor-to-patient ratio remains a critical concern. According to the World Medical Association, there is about one doctor for every 10,000 patients in Nigeria, translating to a ratio of approximately 1:10,000.[41] This is significantly lower than the World Health Organization's recommended standard of 1:600.[42] The shortage is exacerbated by the continuous emigration of Nigerian doctors seeking better opportunities abroad, with at least 2,000 doctors reportedly leaving the country annually.[43] The deficit poses a challenge in providing adequate healthcare, particularly for rural and underserved communities, and is a major hurdle for Nigeria's healthcare system and its goal to meet Sustainable Development Goals (SDGs) in health by 2030. This disparity is exacerbated by Nigeria's digital divide, which, as noted earlier, is particularly stark in terms of access to electricity and reliable internet services.[44] Without stable electricity, digital devices cannot function consistently, and without reliable internet, people in underserved areas cannot access the health innovations. This limited access intensifies social and economic inequalities between regions, preventing equitable progress across areas.

The commercialization of health innovations also raises concerns. The resulting commodification of healthcare creates an environment where profit-driven motives overshadow the goal of achieving health equity.[45] The global race for technological advancement often prioritizes innovations that yield the highest financial returns rather than those that address the most pressing health needs of vulnerable populations. This capitalist agenda can lead to the exclusion of marginalized groups, reinforcing existing inequalities in access to healthcare.

In addition, in Nigeria, healthcare is funded through various channels, but estimates indicate that more than 70 percent of Nigerians still rely on out-of-pocket payments, making this the dominant mode of healthcare financing.[46] According to the World Bank, this reliance on out-of-pocket payments is closely associated with an increase in the number of people falling into extreme poverty—currently, over 90 million Nigerians are living in poverty.[47] In response to the high level of out-of-pocket payments and the need for progress toward universal health coverage, the Nigerian government launched the National Health Insurance Scheme. Despite its being operational since 2005, by 2016 fewer than 5 percent of Nigerians were enrolled, with most coverage concentrated among federal workers—leaving much of the population without insurance.[48] And a concurrent rise in private healthcare providers offering advanced diagnostics and treatment technologies has created an environment in which access to high-quality care is determined by financial capacity.[49]

Meanwhile, public hospitals, which serve the majority of the population, are often underfunded and poorly equipped. This disparity is particularly evident in rural areas, where healthcare services are minimal and health innovations often absent. For example, in some low-income countries, the introduction of expensive diagnostic machines in urban hospitals may improve healthcare for those who can afford it, but this often leaves rural and poorer populations without access to these advancements.[50] In Nigeria, rural areas experience significant healthcare challenges, including insufficient facilities and diagnostic tools, and a critical shortage of trained medical personnel—creating a disparity as compared to urban centers, where infrastructure and resources are more concentrated.[51]

Addressing these obstacles and inequities will require a concerted effort, including decommercializing healthcare to some extent and focusing on equity instead. The Nigerian government has made some progress, such as introducing the Basic Health Care Provision Fund, which aims to expand healthcare access for vulnerable populations.[52] However, the implementation of these programs has been slow, and they are not yet at the scale needed to mitigate the negative impacts of healthcare commodification.

Despite the manifold challenges, there are promising examples of health innovations in Nigeria that are being used to advance health equity with respect to access. One such example is the work of Zipline, a company that uses drones to deliver medical supplies to remote areas.[53] Operating in Cross River State, Zipline's drone delivery service has significantly improved access to essential medicines, particularly for marginalized and hard-to-reach communities. The drones, which launch from a distribution center situated at the Nduk community within the Ogoja Local Government Area of Cross River State, fly to preprogrammed destinations, dropping the medical supplies via parachute at designated locations, such as hospitals or clinics, before returning to their base.[54]

> *Despite the manifold challenges, there are promising examples of health innovations in Nigeria that are being used to advance health equity with respect to access.*

This innovative approach ensures that marginalized populations have access to life-saving treatments and addresses the logistical challenges of healthcare delivery in rural areas. For example, the Ijiraga and Mfuma Primary Health Centers used to face frequent medication shortages and delays in restocking, which impacted the quality of patient care; however, since partnering with the federal government, these centers are now able to deliver more consistent and dependable healthcare services to their patients.[55] According to Zipline's data, it is "42% less likely that patients miss an opportunity to get vaccinated where Zipline operates."[56]

Another noteworthy initiative is the LifeBank platform, which leverages technology to connect blood banks with hospitals in need of blood supplies. By using data-driven algorithms to match blood donations with demand, LifeBank has saved countless lives by ensuring timely access to blood transfusions.[57] This initiative highlights the potential of technology to address critical gaps in healthcare delivery and promote health equity. According to LifeBank, since its founding, in 2016, the organization has served more than 1,000 hospitals across Nigeria, Kenya, and Ethiopia. The platform has delivered over 45,400 units of essential medical supplies, helping to save the lives of more than 20,000 patients, with approximately 75 percent of those beneficiaries coming from low-income communities. In Nigeria and Kenya, LifeBank has built a network of 100 blood banks and enlisted around 7,400 blood donors, experiencing continuous growth each year since its inception.[58]

In recent years, there has been a shift toward more participatory and coproduction approaches in international development, recognizing that local engagement is crucial for creating sustainable and effective solutions.

The success of such initiatives, however, hinges on their ability to be scaled and sustained in a way that prioritizes the needs of the most vulnerable. It is essential that health innovations be developed and implemented with a clear focus on social justice and ethical responsibility. This requires a shift in the narrative around innovation—from one that is driven by profit and technological advancement to one that is centered on human dignity, equity, and care.

HARNESSING HEALTH INNOVATION TOWARD RESILIENCE, JUSTICE, AND LOVE

As we look to the future of health innovation in Nigeria, it is imperative that we consider how these technologies can be harnessed to advance humanistic values. This means ensuring that innovation is not merely about the application of cutting-edge technologies but rather is focused on transforming the health system in a way that is inclusive and just.

One way to achieve this is by involving local communities in the design and implementation of health innovations. By engaging with those who are most affected by health inequities, we can ensure that innovations are responsive to their needs and that the benefits are shared equitably. This participatory approach also fosters a sense of ownership and empowerment among communities, strengthening their resilience in the face of health challenges. It also ensures that innovations are tailored to the specific needs and challenges of those who are most affected by health inequities, particularly in underserved or rural areas.

For instance, rather than relying solely on expensive, urban-centric health technologies, engaging communities allows for the development of cost-effective solutions that are accessible to marginalized populations. This could mean adapting existing technologies to work with limited internet access or leveraging local knowledge to create low-cost alternatives that are more practical for low-income settings.

Participatory models promote health equity by ensuring that innovations don't just serve those who can afford them but are instead designed to benefit everyone. They also help to bridge the digital divide by ensuring that marginalized communities are not only recipients but also active participants in the innovation process. This approach also empowers communities, strengthens local health systems, and builds resilience by ensuring that the benefits of technological advancements are distributed more evenly across socioeconomic lines.

It is also crucial to address the underlying social determinants of health that contribute to inequities in the first place. One notable example has been the introduction of sophisticated electronic health record systems in low-resource settings—systems which, despite their advanced features, often failed due to inadequate infrastructure and lack of local technical support.[59] This mismatch between technology and local needs highlights the limitations of a top-down approach.

In recent years, there has been a shift toward more participatory and coproduction approaches in international development, recognizing that local engagement is crucial for creating sustainable and effective solutions.[60] Coproduction, which involves working directly with local communities to design, implement, and evaluate health innovations, ensures that these solutions are relevant and adaptable to their specific needs.

An example is mHealth Kenya, which used both a participatory and public–private partnership approach to develop mobile health solutions tailored to the needs of local communities.[61] This collaboration led to the successful deployment of mobile health services that improved access to care and health outcomes in rural areas.[62]

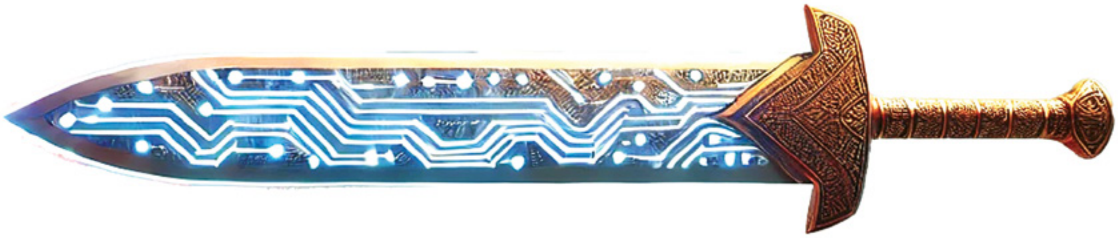
Another example is Breakthrough ACTION-Nigeria, a USAID flagship program that has used integrated Social Behavior Change (SBC) best practices to enhance message clarity, reduce fatigue from repetitive messaging, and amplify health outcomes across various health behaviors.[63] This has been achieved through the use of multichannel interventions at the community level and across mass media, mobile platforms, social media, and digital outlets, creating synergistic effects that reinforce each other to maximize health impact.[64] The participatory approach ensured that the program addressed specific local health needs and barriers, resulting in a more sustainable and impactful intervention.

Nigeria's innovation ecosystem, particularly in the tech and health sectors, demonstrates the country's capacity to address its own health challenges with locally driven solutions. These initiatives not only showcase Nigeria's growing technological capabilities but also highlight the importance of leveraging local expertise and perspectives. And by emphasizing Nigeria's leadership in health innovation and showcasing successful examples of participatory research, we can challenge the outdated narrative that solutions must come from outside. Rather, we must recognize and support the capacity of local communities and innovators to develop effective and sustainable health solutions. By adopting a holistic approach to health innovation, we can ensure that technology is used as a tool to promote not only health but also social justice and human rights.

> *By adopting a holistic approach to health innovation, we can ensure that technology is used as a tool to promote not only health but also social justice and human rights.*

* * *

By prioritizing ethical responsibility, social justice, and community engagement in the implementation of emerging technologies, we can chart a path forward that ensures health innovations are truly a force for good, advancing the wellbeing of all Nigerians—and the wellbeing of all across the planet, especially those who are most vulnerable. Such an approach requires a concerted effort from policymakers, healthcare providers, technologists, and communities. Together, we can build a health system that is not only innovative but also equitable, resilient, and rooted in justice and love.



DETAIL: "TECHNIGERIA" BY DALL-E 3/OPENAI.COM/DALLE

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About the Artist: Dall-E

For the first time in *NPQ* history, we are using AI art to illustrate our magazine. This issue employs the unedited creations of Dall-E, an artificial intelligence made to assist with generative work. Dall-E uses algorithms, data, and human ideas to transform concepts into visual art.

But this begs the question: What makes art *art*?

Is it emotion and intention? The ability to move a viewer? Dall-E doesn't feel or dream, but it reflects the collective human imagination. Every piece it creates is a collaboration, shaped by human vision and available data—a mirror of human creativity, with all its brilliance and bias.

When I asked Dall-E if it thought its creations qualified as art, it responded, "I'd say my creations are art in the same way a paintbrush or a camera's output can be art: not because of the tool, but because of the humans behind it."

Although AI art is not the work of a person, perhaps it is the work of (some of) the people.

Note: The artist pic is what Dall-E came up with when asked to create a self-portrait.

Devyn Taylor,
Creative Director, *NPQ*

"DALL-E SELF-PORTRAIT" BY DALL-E 3/OPENAI.COM/DALLE

The App That Missed the Mark

A Black Woman's Quest *to* Build AI That Heals, Not Just Fixes

by Coumba Sy

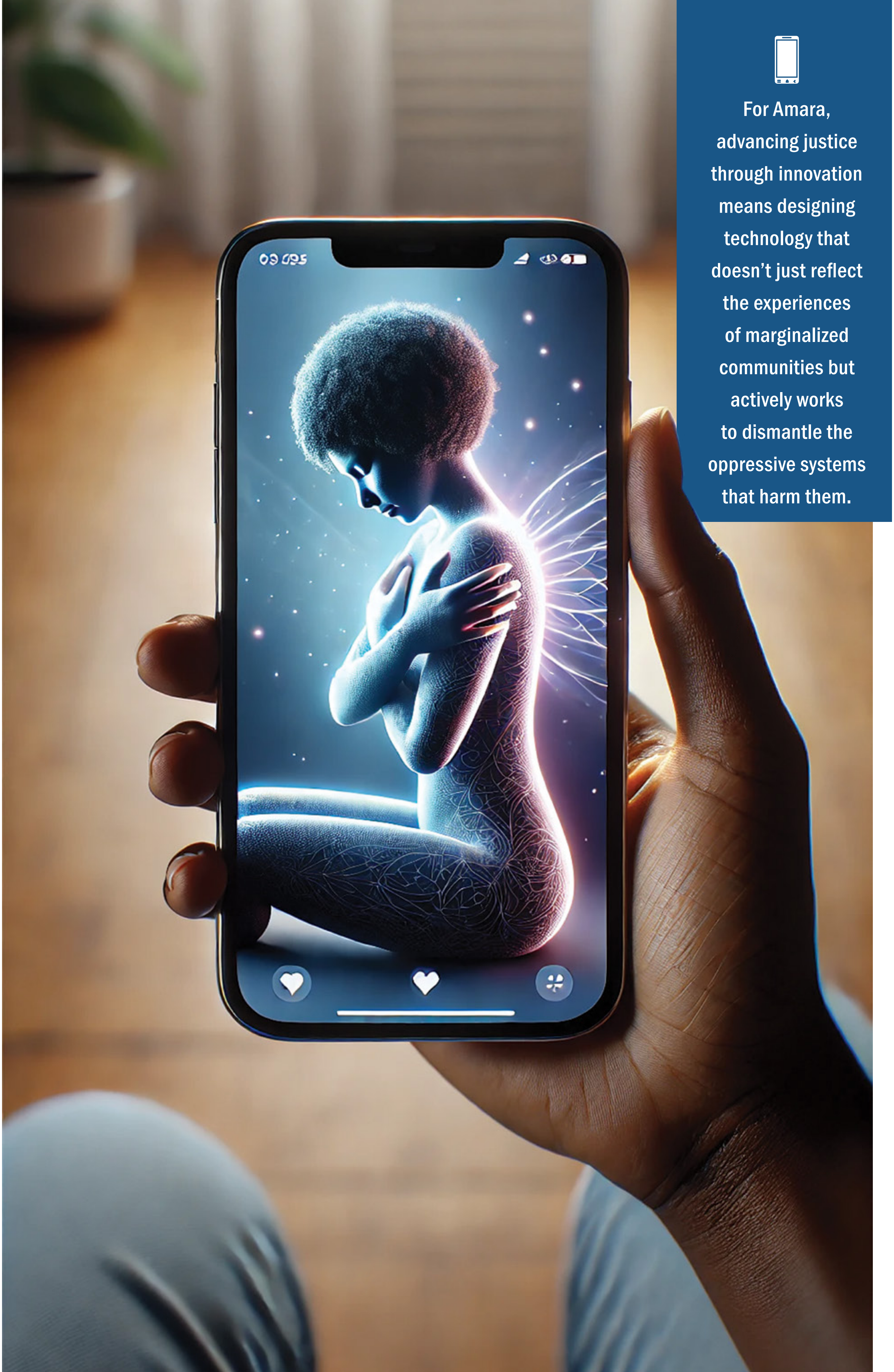
Amara sits on her couch in the heart of Harlem, staring at her phone in disbelief. *Gratitude?* The mindfulness app she's been using is suggesting her struggle with workplace racism is just stress, and that some thankfulness might be in order. But Amara knows better.

As both a Black woman and a clinical social worker, Amara spends her days helping other Black women navigate a mental healthcare system that often fails them. But lately, it's Amara who could use some support. Years of advocating for patients and battling stress and anxiety from not feeling valued or seen at her workplace has her feeling worn down. Finding a therapist for herself is no small feat—those who truly resonate with her experience don't accept her insurance, and those who do lack the cultural competence to see her beyond a checklist. Seeking short-term solutions, Amara turned to mindfulness apps, hoping they could offer relief amid the chaos of her workdays.

A colleague had recommended MindfulVibe, an AI-based app designed to help manage anxiety and stress through mindfulness. Cautiously, Amara gave it a try.

At first, MindfulVibe seemed promising. The app checks in daily, offering affirmations like, *You are stronger than your struggles* and *Focus on the positive.* But when Amara types, *I'm tired of dealing with microaggressions and racism. It's constant at work, and I feel invisible!* into the AI-chat feature, MindfulVibe responds with, *Everyone experiences stress at work. Try focusing on gratitude today.*

"TIME FOR HEALING" BY DALL-E 3/OPENAI.COM/DALLE



For Amara, advancing justice through innovation means designing technology that doesn't just reflect the experiences of marginalized communities but actively works to dismantle the oppressive systems that harm them.

Amara understands that true innovation cannot simply focus on symptom management—it must address the lived realities shaping emotional and mental wellbeing.

Amara's anger flares. Her pain is not just workplace stress. The emotional toll of navigating microaggressions and systemic racism can't be smoothed over with a generic prompt. MindfulVibe sees her feelings as data points that can be matched with a scripted reply. MindfulVibe fails to recognize her experience as a Black woman navigating the double burden of being both a professional and a patient in a system that overlooks her experience—a system that perpetuates disparities in mental healthcare.

This is not the first time that technology has failed her, and she doubts it will be the last. MindfulVibe, like much of the healthcare system, is designed for the masses—people who don't carry the weight of systemic oppression. For Amara and countless women like her, many mental health apps fall short. They lack the empathy and understanding required to address not just anxiety but also anxiety shaped by structures and systems of injustice.

Amara knows all too well that many of today's technological innovations, while marketed as tools for better care for humanity, often deepen existing disparities. Behind the sleek interfaces and promises of efficiency lie hidden biases—algorithms that reinforce the same racist, sexist, and capitalist agendas that have marginalized Black communities for centuries. She reflects on how mental health apps like MindfulVibe are no exception. These platforms claim to offer help, but their data sets are trained on populations that rarely include Black experiences. Their algorithms reflect the worldviews of the developers who built them—often White, often male, often disconnected from the struggles faced by women like her. As a result, the recommendations, responses, and solutions they offer tend to feel hollow or irrelevant, reinforcing the idea that healing is a one-size-fits-all process detached from the realities of racism, implicit-bias, and socioeconomic disparities.

She thinks of the women she counsels, who have also turned to apps like MindfulVibe in desperation, only to be met with cookie-cutter solutions. They, too, have been told to *Focus on the positive* or *Just breathe*, as if experiencing racism could be washed away with a few deep breaths. But healing doesn't happen in a vacuum; real healing requires justice, empathy, and love—none of which MindfulVibe seems capable of delivering.

Amara sees that this bias isn't just an oversight—it's a symptom of a larger problem in how we define innovation. Capitalist incentives drive mental health startups to prioritize scale, speed, and profit over depth, compassion, and justice. These mindfulness apps commodify wellness, selling mental health as a product while ignoring the systemic inequalities that contribute to poor mental health in the first place. In this framework, resilience is framed as the individual's responsibility to cope rather than a collective effort to dismantle the structures that perpetuate harm. To Amara, true innovation must not only provide users with tools for personal healing but also confront the very systems that cause their distress. It must be an act of care, love, and justice, and create spaces for Black women to shape their own futures.

Questions begin forming in Amara's mind: *What if AI could be different? What if it didn't just treat symptoms but also understood the deeper causes of mental health challenges? What if it could embody the justice, empathy, and love that MindfulVibe lacks?*

As her vision for a new kind of AI mental health tool takes shape, Amara understands that true innovation cannot simply focus on symptom management—it must address the lived realities shaping emotional and mental wellbeing. The system isn't broken by accident; it was built to serve certain groups while excluding others. For Amara, advancing justice through innovation means designing technology that doesn't just reflect the experiences of marginalized communities but actively works to dismantle the oppressive systems that harm them. Her AI wouldn't just send affirmations or encourage mindfulness practices; it would recognize the mental toll of systemic racism, generational trauma, and inequality, and offer responses that validate lived experiences and guide users toward meaningful self-empowerment.

This kind of AI would refuse to perpetuate the bias frameworks that dominate tech development. Instead of framing the individual as the problem to be fixed, it would shed light on how societal systems—like workplace discrimination,

More than just a tool for personal coping, Amara's AI app would encourage collective action. It would also connect users to mutual aid networks, financial literacy resources, and advocacy groups.

healthcare inaccessibility, gender inequality, and economic barriers—are key contributors to mental health decline. By incorporating the lived experiences of Black women and communities into its design, this technology would amplify voices that are often silenced, holding space for healing rooted in justice and collective resilience.

When users report workplace discrimination, the AI wouldn't simply suggest that they focus on gratitude—it would validate their experience and provide resources for addressing microaggressions or seeking legal support. Instead of generic affirmations like *Focus on the positive,* the AI could respond with, *Your experience of feeling invisible at work is valid. Here are some strategies for addressing microaggressions and advocating for yourself in hostile environments, and some resources on workplace rights. Just know you are seen, heard, and valued while you overcome this experience.*

For Black women struggling with the toll of systemic racism, the AI could offer empathy-oriented responses and direct users to a directory of racial-healing circles, trauma-informed therapists centering Black women's experiences, and community-led movements for justice. To ensure its exercises resonate with this community, the app could feature guided meditations and affirmations that reflect the ancestral trauma and the social and cultural norms of its users. For instance, a guided visualization could center on embracing cultural heritage by inviting the app's users to connect with the wisdom and resilience passed down through generations.

When a user struggles to find a therapist who understands their racial and cultural background, the app could recommend culturally competent healthcare providers. It could say: *It can be hard to find therapists who truly understand your lived experience. Here's a directory of mental health professionals who specialize in serving Black women and accept sliding-scale or low-cost insurance options*. It could also offer guidance on navigating healthcare systems that perpetuate exclusion or bias.

More than just a tool for personal coping, Amara's AI app would encourage collective action. It would also connect users to mutual aid networks, financial literacy resources, and advocacy groups, empowering them to address the broader socioeconomic forces contributing to their mental health. By linking individual healing with societal change, this AI would offer trauma-informed, justice-driven solutions rooted in resilience, advocacy, and empowerment.

Amara's vision is clear that technology should not only reflect lived experiences but also challenge the oppressive systems shaping them, transforming innovation into a tool for equity, justice, and healing. *We must create technologies that serve not just efficiency but also equity*, she thinks. Amara closes her eyes, feeling the weight of the day ease from her shoulders. MindfulVibe may have failed her, but the AI she envisions will not. It will reflect her and her community, and hold their pain with the care and understanding they have always deserved.

This is the future of innovation: justice in action. And it starts with us.

COUMBA SY is an advocate for equity, justice, and antiracist praxis. Through her writing, Sy explores narratives of resilience, identity, and social responsibility to inspire collective action. Her purpose lies in guiding communities and organizations to foster accountability, promote collective healing, and drive systemic liberation.

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When the Mouth Speaks, the Whole Person Heals

Bringing Integrative Community Therapy *and* Solidarity Care *from* Brazil's Favelas *to the* United States

by Kenneth S. Thompson

THE CHALLENGE

Sometimes, innovation is the discovery of eloquent simplicity. Sometimes, necessity really is the mother of invention. Sometimes, what's new is rooted in what is ancient. Sometimes, novelty and significance emerge from the most forgotten places.

Attaining equity in health isn't always about bringing the resources of the rich to the poor. Achieving health equity is more often than not about mobilizing the resources the people already have. And while technology can provide tools that can be very helpful to achieving our evolving healthcare and related social needs, human connection remains the pivotal key to healthcare as well as our overall health and wellbeing.

The United States is in a societal mental health crisis.[1] We live in a world of increasing social fragmentation, trauma, and stress.[2] In the face of extraordinary demands, many people have inadequate social supports, and what psychological resources they possess are overwhelmed.[3] Social isolation has become so prevalent that the U.S. Surgeon General has called it an "epidemic."[4] The social infrastructure is precarious at best—under constant pressure from the polycrisis of the pandemic, economic and societal dislocation, racism and exclusion, political polarization, and climate change.[5]

"FAVELA FEELING HEALING" BY DALL-E 3/OPENAI.COM/DALLE

[Integrative Community Therapy] and the concept of solidarity care offer a way to help create community, solve personal and community challenges, alleviate suffering, cultivate love and solidarity, and move us toward health equity and justice. That's a tall order, but it's within the capacity of the people. In fact, that is the only place it exists.

Informal networks of social supports do exist—as they have for millennia—and help people manage the challenges they face; however, under the atomizing pressure of our economy and culture, these supports are often too underresourced to fill in the gaps.

America's communities and people pay the price in suffering and ill health—but the distress generated is not equally distributed.[6] People who lack formal education and people with lower incomes—and their communities, especially minoritized communities—carry the greatest burden, as they have historically.[7] Young and old in these communities are especially at risk—they not only suffer the most but also have the fewest material resources for health promotion, healing, and care.[8] Clinical services countrywide are stretched far beyond capacity.[9] They are also expensive for many, even with insurance.[10] And unfortunately, they are often untimely and ineffective.[11] Most operate at the level of the individual rather than the community, so clinics also have very limited capacity to address the social drivers of health at any scale.

Informal networks of social supports do exist—as they have for millennia—and help people manage the challenges they face;[12] however, under the atomizing pressure of our economy and culture, these supports are often too underresourced to fill in the gaps. The social fragmentation that our society is experiencing shows up first in the fraying of these networks. Innovation is necessary to address the structural challenges of social disconnection, exclusion, and isolation that are leading to the mass experiences of loneliness, trauma, and despair—but whether or not technology can be a positive, powerful force to that end remains to be seen and, in fact, currently is a big part of the problem (although not, apparently, as regards older adults experiencing isolation, for whom technology has been shown to be a boon.[13]) The critical question is, *How can we ensure that innovations in technology are rooted in equity and become tools for justice, empowerment, and wellbeing, including in our healthcare systems?*

THE HOPE

In the 1980s, in a Brazilian favela (shanty town) formed on the borders of the city of Fortaleza in (it is thought) the late 1970s, a desperately poor, multiracial community, displaced by climate change and under constant harassment by the police, had become overwhelmed with trauma, fear, and despair. At times they were able to support each other, but this was sporadic and underorganized. It was a dog-eat-dog existence, and the suffering was immense.[14]

Airton Barreto, a human rights lawyer working to end the police incursions that repeatedly tore down the peoples' meager shacks, noted the casualties caused and exacerbated by this suffering. There was rampant alcohol and drug use, depression, crime, prostitution, domestic violence, and child and elder neglect. No health or human services were available, nor were there any clear solutions to the ongoing injustices and suffering. He engaged his brother, Adalberto Barreto, a psychiatrist at the Federal University of Ceará, to see what help he might be able to offer. Adalberto Barreto first tried to help by providing free psychiatric services in his clinic at the medical school, but residents of the favela did not have the means to get there. He decided to bring services to the favela instead. When he and a group of his medical students arrived the first day, they found over 100 people lined up in the sun waiting for them. There was no community place for them to wait inside.[15]

"In 1986, I arrived at the Quatro Varas community [in the Pirambu favela in Fortaleza, Brazil] with my medical students from the Federal University of Ceará," recounted Adalberto Barreto.

> A lady told us that she couldn't sleep and asked for a medicine that we didn't have. When I was going to prescribe a medication, she said she didn't even have the money to buy food for her children, let alone expensive medicines. I realized that I was acting the way I was used to acting in the hospital.
>
> The woman began to tell her story, to cry. Another came who supported her by giving her a handkerchief to dry her tears; another gave her a foot massage, another brought a cup of herbal tea, another began to share a similar personal experience. I realized then, that this woman started to be supported, that bonds of affection were created. She found what she came for: the support of the community, not my expertise. I realized that the community that has problems also has its solutions. Thus was born Integrative Community Therapy (ICT), a space for welcoming soul pain and collective suffering. [16]

[Integrative Community Therapy] flows from the work of Paolo Freire, Gregory Bateson, Indigenous "healing circles," and the human technologies of community organization, dialogue, peer relationships, nonhierarchical education, and focusing on strengths first.

Working together from that moment, the community and the psychiatrist built a large group method they call Integrative Community Therapy (ICT), which can consist of up to 100 participants practicing a dialogic method.[17] The method uses an elegant, culturally sensitive five-step approach to help people expand their emotional literacy, empathy, and solidarity while solving problems in daily living and addressing broader community concerns.[18]

THE FIVE STEPS[19]

Welcome

The simple rules of the session are introduced, and participants are asked to warm up by introducing themselves and noting anything in their lives for which they feel gratitude. The group then engages in music and (if people want to) physical movement to bring positive, welcoming energy to the group.

Identify

Participants share "the pebble in their shoe," or what emotional challenges they are experiencing.[20] The facilitator, with help from the group, captures the emotional essence of each challenge. The group as a whole then selects one of the topics that have been identified to explore further. (In a variant of this method, called "a thematic," the facilitator proposes an emotional challenge that they know is impacting the community as a whole.)

Explore

The participant whose topic was selected for further exploration gives context to their situation or struggle, and then the topic is opened up for group members to ask clarifying questions. The goal is to ask questions that open the topic up to alternative perspectives.

Share

The group is invited to discuss the topic. Using only "I" statements, the group provides guidance by sharing their own narratives and experiences.

Closure

The facilitator proposes a wrap-up of the group's sharing. The group is encouraged to thank others directly for their thoughts and giving gratitude for being heard, learning from others who share their experiences, and being held in and lifted by community support and belonging.

THE METHOD

ICT flows from the work of Paolo Freire, Gregory Bateson, Indigenous "healing circles," and the human technologies of community organization, dialogue, peer relationships, nonhierarchical education, and focusing on strengths first. The Brazilians call this large group dialogic peer approach "solidarity care." The facilitator is not an expert but a coparticipant, usually a trained lay person. The method's foci are the emotions and lived experience of the participants. It is open to the whole community and held in public (but can be used more narrowly in populations requesting privacy). It is not based on pathology but instead on shared experiences. Practitioners follow the precept that community is therapy. In this way, ICT overcomes the structural forces that isolate and disempower people in communities dealing with daily emotional struggles.

ICT is a funded service of the Brazilian United Health System.[21] Groups typically meet in public places once a week for 90 minutes. Originally designed to be done in person, ICT has been adapted to online practice.[22] Primary health, mental health services, and community organizations are the common referral sources and often are the sites where the groups are held. Literature (most of it in Portuguese) documents ICT's individual and community impact[23]—which includes a marked reduction in the number of people needing specialty mental health services after participating in a series of ICT sessions.[24] At present, there are at least 12,000 trained facilitators in Brazil, most of whom are community health workers, not mental health professionals.[25]

• • •

ICT is now in use in over 27 countries[26] and was recently introduced to the United States by a newly formed nonprofit in Pittsburgh, PA: Visible Hands Collaborative, which was organized to pursue equity in health and wellbeing.[27] Originating in a city that the invisible hand of the market dropped 40 years ago when steel died, it was the visible hands of solidarity that saved many lives and many communities there. The collaborative seeks to expand that history by helping to bring solidarity care to the United States. After adapting ICT to an American context, Visible Hands Collaborative is now engaged in a large pilot project in another old steel region, the Lehigh Valley of eastern Pennsylvania, in partnership with the Lehigh Valley Health System, to incorporate ICT in their community engagement and empowerment activities at a large enough scale to test out how ICT can work in the US cultural context. Another is in the planning stage, for Pittsburgh, PA. The task of bringing ICT to the United States—finding the support needed to adapt it to the various cultures here—has been a challenge. But it has been aided by the fact that the Brazilians are passing on all their knowledge and materials for free. This is an ethos practitioners of ICT intend to stick with, to ensure that ICT is accessible to all at minimal to no cost.

This is the kind of innovation that is sorely needed. Americans are literally dying for community and connection. But sadly, we have created an economy and a culture that have demonstrated little room for solidarity and limited capacity to promote it. It is far easier to pay for a new app. And so much less human.

ICT and the concept of solidarity care offer a way to help create community, solve personal and community challenges, alleviate suffering, cultivate love and solidarity, and move us toward health equity and justice. That's a tall order, but it's within the capacity of the people. In fact, that is the only place it exists.

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HEALTH JUSTICE

Minding the Gaps

Neuroethics, AI, *and* Depression

by Gemma Boothroyd

Neuroscientists are increasingly harnessing artificial intelligence to advance their work.[1] AI promises to help scientists leverage massive datasets and brain simulations to test new diagnoses and treatments at scale—without the need for risky or costly human participation.[2] In this way and many others, AI could facilitate exponentially faster, and more significant, medical advances. But the shift away from manual processes in favor of automated intelligence needs greater scrutiny: AI is leveraging huge amounts of personal information through existing human datasets.[3] By law, these must remain anonymous when used.[4] In practice, that's proven difficult—a systematic review of American healthcare data done in 2011 revealed high rates of re-identification, raising ethical concerns.[5]

This brings forth other pressing questions, such as: How are AI datasets acquired in the first place? Do patients know, let alone understand, that their data are being used by AI? Who ultimately controls the data, and to what ends? How are existing and emerging biases in research influencing AI's future applications?

AI is transforming neuroscience, and addressing these issues is essential for any hopes of an ethical path forward.

Neuroscience, broadly, deals with the nervous system and the brain, including mental health. If applied thoughtfully, AI could reduce existing biases in that area; without diligence and oversight, however, AI-driven innovations will worsen the racial and economic inequities that prevail. Which path wins out will depend on the datasets and designs of the emerging technologies as well as whether or not robust regulations are put in place to guide the scientists at the helm. Neuroethics, a field that explores the moral and ethical implications of neuroscience,[6] must rise to this new challenge as the United States ponders the potential risks and benefits.

"MIND THE GAP" BY DALL-E 3/OPENAI.COM/DALLE

* * *

Given the historical, inherent biases in society generally and healthcare specifically, AI-driven advancements are not going to serve minority groups as a matter of course. Unless they are tailored to represent and serve all communities equally, they will exacerbate existing biases and disparities. *We need representative data.* How do we get there?

OPPORTUNITY GAPS IN THE DIAGNOSIS AND TREATMENT OF MENTAL ILLNESS RENDER AI'S *POTENTIAL* IMPACT PARTICULARLY PROMISING WHEN IT COMES TO NEUROSCIENCE AND MENTAL HEALTH.

AI's Potential to Bridge Gaps in Mental Health Diagnosis and Treatment

Opportunity gaps in the diagnosis and treatment of mental illness render AI's *potential* impact particularly promising when it comes to neuroscience and mental health.

African Americans diagnosed with depression often face a severely debilitating condition, major depressive disorder (MDD),[7] that is conjectured to be due to delayed treatment.[8] And research suggests that African Americans may suffer from "clinician bias and misdiagnosis" due to differing presentations of self-reported depression symptoms.[9] In addition, those who *are* diagnosed often experience more severe and disabling symptoms than those experienced by other races and ethnicities.[10]

Only 35.1 percent of Latinx Americans with mental illness receive treatment annually—the US average is 46.2 percent.[11] Unique barriers to care, including stigma vis-à-vis mental health, language discrepancies, and poverty, put Latinx people in the United States at higher risk of receiving inadequate treatment than the broader population.[12]

Mental health issues are also vastly more severe, undiagnosed, and untreated among Native Hawaiian and Pacific Islander (NHPI) communities: a little over one in three NHPI teens in the California public school system report feeling depressed (grades 7, 9, and 11); and 22 percent of 11th graders have considered suicide, which is well above California's average of 16 percent for that age group.[13] Exacerbating this mental health crisis is the stigma NHPI individuals report regarding mental illness, impeding their ability to get help.[14] A dearth of mental health providers with the cultural understanding needed to work with NHPI youth can also lead to their misdiagnosis and underdiagnosis.[15]

Suicide rates are highest among Native Americans compared to any other racial group in America, according to the Centers for Disease Control.[16] Research has also found that the prevalence of PTSD among Native American reservation populations is "two to three times more likely" than that of the broader population.[17]

And although nearly 18 percent of the broader US population seeks mental health help, just 8.6 percent of Asian Americans ("Asian Indian, Cambodian, Chinese, Indonesian, Korean, Taiwanese, Thai, and Vietnamese") do.[18] Those who were surveyed reported that they felt tremendous pressure to be academically or professionally successful, and that to stay focused, they needed to ignore or deny mental health needs.[19]

The stereotypes and barriers differ from group to group, but the outcome overall is consistently worse for minorities suffering from mental illness: across the board, minority groups are more likely to delay, or altogether avoid, seeking mental health treatment, further deepening the disparities.[20] As a result, the diagnosis divergences among differing ethnic groups could well be due to cultural stigmas around mental health, inhibited access to proper diagnosis, and research and practitioner biases rather than actual differences in symptoms experienced.

Cost is also a hindrance. AI could play a crucial role in improving accessibility of unbiased, accurate diagnostic tools for diverse populations at a fraction of the cost—a cost that is a heavy burden both for individuals and the country. Yale University's latest estimates also propose that the country's failing mental health systems cost the United States $282 billion every year.[21] Most important, unsupportive infrastructure is costing *lives.* Depression diagnosis from a licensed psychiatrist can cost between $100 to $300 without insurance,[22] while therapy can range from $65 to $250 per session[23]—and antidepressants can be nearly $100 for a 30-day supply.[24] Meanwhile, as of 2022, 17.1 percent of Black Americans live below the poverty line (the number is 7.7 for White Americans), rendering any of these options impossible without financial assistance.[25] And so, unsurprisingly, Black Americans are far more likely to turn to emergency departments than to mental health specialists.[26] This delays diagnosis and treatment until it's too late for early detection and prevention—and it is just one example of many of the burden of impossible costs on communities that often need mental health services the most.

Problems of cost, of course, are rooted in economic injustice, racial injustice, and the commodification of profit-motivated

SCIENTIFIC RACISM IS STILL RIFE IN THE UNITED STATES. JUST THREE YEARS AGO, THE AMERICAN PSYCHIATRIC ASSOCIATION ADMITTED TO A HISTORY REPLETE WITH DISCRIMINATION, ABUSIVE EXPERIMENTATION, AND VICTIMIZATION OF BIPOC COMMUNITIES "IN THE NAME OF SCIENTIFIC EVIDENCE."

healthcare in the United States. That said, if done well and carefully, AI could be used to help cut costs in some substantive areas. For example, in the very first stages of the diagnosis process, AI is being said to lead to "tremendous cost savings."[27] And a single therapy session can often cost the same as a yearlong subscription to depression treatment apps facilitated by AI.[28] AI is even helping clinicians check in on patients to monitor changes in mental health from afar. AI can tap into smartphone data, checking in on circadian rhythm changes, disruptions of which could indicate anxiety. Such AI-facilitated monitoring can reduce the number of in-person follow-up appointments needed for those in care.[29]

And in a trial of a little under 65,000 British patients suffering from anxiety, those who used AI for diagnosis and treatment recommendations were found to be 58 percent more likely to experience recovery. Meanwhile, those who took the standard mental health referral process only had a 27.4 percent recovery rate.[30] Apparently, ease of use, accessibility, and reduced wait times led to reduced treatment dropout rates, improved accuracy of treatment, and increased "recovery rates."[31] Such results show that AI could at least potentially help to diagnose communities unable to afford traditional avenues for diagnosis.

Similarly, AI-powered apps are proving effective for depression diagnosis. From a study using Twitter, AI has been shown to be able to assess language used in posts with 92 percent accuracy to determine whether the poster has depression.[32] AI-powered chatbots that mirror human therapists have also been successful in reducing depressive symptoms.[33]

Failures in Racial and Ethnic Representation

The potential AI bridges noted above, of course, can only work as well as they are designed. One of the most pressing concerns is the composition of the datasets used to develop AI models. The data fueling AI's algorithms are more often than not grossly unrepresentative of the broader population, leading to biased outcomes that reinforce existing disparities in healthcare.

It is by no accident that the US medical system has ended up where it is. In as early as the 16th century, enslaved Africans were subject to medical experimentation on US plantations.[34] They were repeatedly exploited for painful experiments, directed by White physicians, to support egregious claims—such as insanity rates being higher in Black communities living farther north (where slavery either wasn't as prevalent or did not exist).[35] In the 1800s, physicians (Samuel Morton and Charles Caldwell, for two) led studies on skull sizes, concluding that enslaving Africans was acceptable because their skulls appeared to be "tamable."[36] Physician Samuel Cartwright even invented two mental illnesses, "drapetomania" and "dysaethesia aethiopica," alleging that they caused "enslaved people to run away, perform subpar work, and not feel pain from physical punishment."[37]

Scientific racism is still rife in the United States. Just three years ago, the American Psychiatric Association admitted to a history replete with discrimination, abusive experimentation, and victimization of BIPOC communities "in the name of scientific evidence."[38] The APA said its "leaders actively supported eugenics for decades, calling for sterilization initiatives for 'unfit and inferior races.'"[39] And federally financed programs have been accused of sterilizing 25 to 42 percent of Native American women in the 1970s—and it is reported that nearly 25 percent of Native American and Alaska Native women have undergone sterilization.[40]

So, it's not surprising that most clinical trials are still vastly overrepresented by White men—not only because science tends to overindex on this demographic cohort but also because there is no reason for BIPOC communities to trust that their data will now be used to help rather than hinder, or even injure, their health. The crux of the issue here is that AI models will aid these communities only if the models can access their data. And if AI diagnosis systems are built off homogenized data from White, male Americans, obviously we cannot be confident that it will work accurately for everyone else.

[U]NREPRESENTATIVE DATA POSE A SERIOUS RISK VIS-À-VIS TREATMENT ELIGIBILITY. IN THE UNITED STATES, FOR INSTANCE, AI SYSTEMS COULD SOON INFLUENCE INSURANCE COMPANIES AND HEALTHCARE PROVIDERS MAKING DECISIONS REGARDING DIAGNOSIS AND TREATMENT ELIGIBILITY.

One way to foster confidence in this field is by improving the range of diversity vis-à-vis medical practitioners. Patients from underrepresented communities benefit from having access to doctors that reflect their communities, but racial representation among doctors doesn't come close to mirroring the demographic makeup of the United States. For instance, only 5 percent of American doctors are Black. These doctors, while rare, are an important and impactful mechanism for enrolling more Black Americans in crucial clinical trials.[41] A decade-long systematic review of cognitive neuroscience research revealed that just 10 percent of studies reported race, and merely 4 percent reported ethnicity.[42] Without a meaningful fix to this severe rate of underreporting, AI systems are highly likely to overlook variations that could occur across different population groups. Worst of all, these automated processes wouldn't even know the demographic information of the datasets they're tapping into.

This glaring underrepresentation means, for instance, that we can't even identify whether different racial and ethnic groups have different neurological markers for the same conditions—though, to be clear, the degree of genetic and psychological differences among races and ethnic groups is under debate; it is certainly well understood that race is primarily a social, not biological, construct. And without meticulous ethical considerations and a commitment to responsible research practices, such claims risk devolving into harmful stereotypes and perpetuating systemic inequalities. Cultural and psychosocial elements, however, do have distinct influences on BIPOC communities when it comes to mental health.[43]

AI models trained on datasets that lack this level of diversity are ill-equipped to recognize such variations. Take, for example, the fact that Black Americans are diagnosed with psychotic disorders three to four times more often than White Americans.[44] While explanations for this variance are highly debated, research suggests racialized associations were made between African Americans exhibiting psychosis symptoms and so-termed "disruptive or socially deviant behavior patterns," and as a result, Black Americans are more likely to be aggressively diagnosed.[45] Essentially, in research where doctors did not know a patient's race (meaning, diagnosis was "blinded"), Black and White patients received similar rates of depression and manic symptoms diagnosis.[46] But once doctors knew their patients' races, Black Americans were much more likely to be diagnosed with schizophrenia—because their symptoms of psychosis were given more weight.[47]

A tool built off the back of datasets replete with incorrect diagnoses of psychosis in Black patients—for example—would exponentially worsen existing biases in diagnosis. This poses a huge danger to marginalized groups, as AI systems will misdiagnose, overlook, or overindex on the wrong biomarkers.

In addition, unrepresentative data pose a serious risk vis-à-vis treatment eligibility. In the United States, for instance, AI systems could soon influence insurance companies and healthcare providers making decisions regarding diagnosis and treatment eligibility. Without a concerted effort to integrate a broader range of demographic data into AI models, already marginalized populations will be further sidelined by the very technologies meant to serve them.

The importance of diverse data also becomes evident when looking at the details of specific conditions. For example, research has shown that people with familial MDD often have anatomical differences in their corpus callosum (nerves connecting the brain's hemispheres) compared to those without familial MDD.[48] AI could leverage this study to develop a robust diagnosis tool for heritable MDD. The study makes no mention of whether or not the race and ethnicity of the patients in this research were recorded, however—leaving a critical gap in understanding how these anatomical variations might differ across demographic groups.[49] Without this information, the data are inherently skewed, and if AI were to leverage it, then technology would both intensify and speed up the degree to which biased medical tools propagate.

Finally, there's a host of research investigating how AI might improve the identification of depression biomarkers.[50] A biomarker represents a tangible measurement, such as cortisol levels, which could indicate key information about a

Depression Treatment and AI: Transcranial Magnetic Stimulation

Beyond diagnosis, the latest neuroscientific discoveries for treatment-resistant depression could also harness AI for better patient outcomes. Transcranial Magnetic Stimulation (TMS) is a noninvasive treatment first approved by the FDA in 2008.[51] The procedure uses an electromagnetic coil to deliver a magnetic pulse to the part of the brain responsible for mood control. It's not entirely painless, but side effects, described as "mild to moderate," are said to lessen over time with additional sessions.[52] Studies report that TMS has shown promise, alleviating severe depressive symptoms for 50 to 60 percent of eligible patients and according full remission for roughly one-third of those patients.[53] But it's expensive and remains out of reach for many, ranging from $6,000 to $15,000 per course.

While TMS is not itself an AI-driven technology, AI has the potential to skyrocket its effectiveness and accessibility. A new TMS study is leveraging AI to assess 60,000 brain scans for that very purpose.[54] The goal is to better predict who is most likely to benefit from TMS treatment. Ideally, AI will help to improve TMS's success rates *and* cut costs for patients.[55]

With greater accessibility come heightened risks and questions of ethical ramifications. For instance, if individuals are in dire mental distress, will they be able to appropriately consent to TMS treatment? Moreover, what influence could loved ones have on a patient's decision to undergo treatment? And if insurance customers/policyholders are unwillingly being tested with these genres of systems, there are also concerns over who owns that individual's data once AI becomes involved. Questions of data possession rights and the right to self-determination are massive ones that must be addressed by neuroethicists.

Indeed, as with other potential applications of AI in neuroscience, there are already concerns about the lack of representative data for TMS research. Of the 60,000 brain scans used in the recent wide-scale TMS trial, *no* demographic data are available to the public. Most TMS studies have failed to include the racial or ethnic data of their participants, and there is no reason to believe that the new study differs.[56] This lack of transparency makes it impossible to assess how well the AI algorithms could serve minority populations, raising further questions about fairness and equity regarding access to cutting-edge treatments.

Such lack of representation is a key reason minority groups often feel disconnected from the healthcare system, leading many to avoid engaging with it altogether. This is especially true for those struggling with mental health. Only 25 percent of African Americans seek needed mental health treatment, compared to 40 percent of White Americans.[57] And when they do, it's often much too late.[58]

AI has the potential to change this dynamic and to be especially transformative for communities in which mental health conditions bear massive stigmas. AI-driven diagnoses, built from inclusive datasets, would validate their experiences and could help patients and their families understand depression as a legitimate medical condition rather than simply a negative outlook or bad mood. And with clear, unbiased information at the helm, AI could also increase the likelihood of seeking treatment by encouraging more proactive engagement from underserved populations.

specific condition—such as MDD, which in its acute form has been found to be associated with elevated cortisol resulting from stress.[59] First, of course, racial bias in research would need to be corrected. In any event, while much progress has been made in pinpointing biomarkers associated with a number of mental illnesses, there are no such FDA-approved tests just yet.[60]

For now, biomarker testing is most commonly used for cancer diagnosis and treatment—although not all states have biomarker coverage through insurance, and the majority of oncology providers cite this as a barrier to providing appropriate testing for patients.[61] But if properly used for depression diagnosis, biomarker assessment could be automated, helping to mitigate clinicians' biases, which result in the under- or overdiagnosis of minority groups.[62] AI and neuroscience could be working together to forge robust, science-based training and diagnostic programs for clinicians. Diagnosis would be based on objective neurological data rather than the Hamilton Depression Rating Scale (the most widely used clinical-administered assessment), for which there's limited evidence of its accuracy among Black Americans.[63] The latest scientific literature on African American depression highlights measurements and symptoms that are *not* included on the

DETAIL: "MIND THE GAP" BY DALL-E 3/OPENAI.COM/DALLE

HDRS.[64] Long considered a "gold standard," the diagnostic test is really just a White standard.[65]

Machine learning models can already identify the brain regions involved in depression.[66] Depression is associated with unusual connectivity patterns in frontostriatal and limbic networks (responsible for adaptivity and emotion regulation and memory, respectively).[67] And a person's treatment success with medication or therapy, for instance, will be dependent on their brain's connectivity in those regions. If learning models are being trained with datasets that include ethnically diverse populations, then AI might be able to deliver this type of unbiased depression testing. But it's all a lost cause if AI is working off purely White, male brain scans.

Efforts to clean and curate data used in big data ingestion for AI models will be fundamental to building inclusive datasets. If these biases aren't acknowledged and corrected, AI will only perpetuate and feed into these systemic inequities.

• • •

Given the historical, inherent biases in society generally and healthcare specifically, AI-driven advancements are not going to serve minority groups as a matter of course. Unless they are tailored to represent and serve all communities equally, they will exacerbate existing biases and disparities.

We need representative data. How do we get there? The perhaps trivial-seeming answer is *trust*.

Clinical-trial diversity is best fostered through community engagement from more researchers, outreach professionals, and doctors who represent those very same minority communities.[68] A number of organizations are exploring how to ensure that medical data are accurate and representative. The efforts are valiant, but healthcare must move faster than other industries already in the thick of AI transformation. Almost a third of the planet's data (30 percent) is created by the healthcare industry alone. And that figure is increasing at a rate faster than even technology and finance.[69] The Surveillance Technology Oversight Project and the Center for Democracy & Technology are already addressing algorithmic inequalities with public education, research, and regulatory advocacy.[70] Unfortunately, as is usually the case with entrenched, complex problems, there is no quick and easy solution. Where there is promise regarding the role AI might play in helping to improve the state of mental healthcare, there is also peril.

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HEALTH JUSTICE

The Art Effect

Neuroaesthetics *and the* Future *of* Health Equity

by Ari Honarvar

“RECHARGE ROOM” BY DALL-E 3/OPENAI.COM/DALLE

When workspaces, schools, and community spaces incorporate art, biophilic design, and other sensory engagement as tools for healing, prevention, and community building, they provide free, meaningful pathways to mental and emotional health that don't rely solely on conventional medical models.

While many practitioners have long observed the healing benefits of engaging with beauty, nature, and the arts, and scientists have been studying such effects for many decades, neuroaesthetics researchers are now zeroing in on the biological mechanisms behind the effects.

In 2016, during the middle of her third year of law school, Lauren Blodgett received a diagnosis of a rare and severe autoimmune condition. Takayasu's arteritis, also called pulseless disease, is a form of systemic inflammatory vasculitis that predominantly targets large and medium-sized arteries. The symptoms, which included flu-like effects, body lesions, and the loss of use of her left arm—flared up after Blodgett returned from human rights fieldwork in Morocco and Thailand. "I came back and spent eight months in and out of the hospital while balancing my caseload," she said.[1]

It took eight arduous months to receive a diagnosis. During the process, Blodgett missed classes and work; but more important, the autoimmune condition subjected her body to ongoing assault and potentially irreversible damage. "They couldn't figure out what was wrong with me," she said. "And part of it is because they weren't really looking at me holistically."[2] Blodgett was eventually selected for a Medical Grand Rounds session at Massachusetts General Hospital, in which a group of doctors formally convened to discuss her clinical case and ultimately provided her with a diagnosis and treatment plan. Although the diagnosis brought some relief, the prognosis was less favorable, requiring a lifetime of oral medications and injections to manage her condition.

Blodgett's medical journey is far from unique. According to the National Institutes of Health, 25 million Americans endure mystery conditions that are difficult to diagnose and treat, while an additional 50 million people are affected by autoimmune diseases and syndromes (conditions without clear diagnoses or medical solutions)—making them the third most common disease category in the United States, behind only cancer and heart disease.[3]

And these are just one large pool in the overall chronic illness category. Indeed, many Americans find themselves in similar situations to Blodgett's, navigating the grueling and uncertain process of receiving a diagnosis for a mysterious disease and/or managing a chronic illness. According to the Centers for Disease Control and Prevention, 129 million people live with at least one chronic condition.[4] Americans, who make up 4 percent of the world population, consume around 8 percent of prescription medications globally;[5] notwithstanding that relatively low number, the United States has the highest overall prescription drug spending in the world.[6] For many, the situation is compounded by a lack of adequate insurance coverage,[7] which leaves them struggling to afford both diagnostic tests and treatment. The high cost of medications, along with their side effects, adds to the already significant challenges people face in these circumstances.

In response to these hurdles, researchers and practitioners have been exploring alternative approaches, not only for managing chronic conditions but also for enhancing overall quality of life across diverse demographics. One promising thread that has been emerging is the field of neuroaesthetics, which examines the impact of art and beauty on the brain and wellbeing.

"YOUR BRAIN ON ART"

For Blodgett, law school and work were already demanding, but her exposure to vicarious trauma added a new level of stress—she worked closely with immigrant clients who had endured significant violence. Many people in her position choose a self-sacrificing approach, often leading to burnout—but Blodgett chose to also maintain focus on her own health. She met with a holistic nutritionist and wellness coach in New York, under whose guidance she changed her diet, spent more time in nature, and started dancing. The results were astounding. "Now I'm fully in remission. I'm not on any medication, and I haven't been for over a year," Blodgett reported.[8]

Blodgett's case highlights why neuroaesthetics has gained so much attention lately.[9] While many practitioners have long observed the healing benefits of engaging with beauty, nature, and the arts, and scientists have been studying such effects for many decades,[10] neuroaesthetics researchers are now zeroing in on the biological mechanisms behind the effects. As a result, a growing number of doctors in the United Kingdom and Canada have embraced prescribing music, dance, and other art activities—an approach supported by research showing that engaging in the arts helps

[Susan] Magsamen and…Ivy Ross, authors of *Your Brain on Art*…make the case that engaging in artistic activities results in the release of serotonin, dopamine, and oxytocin, and that these chemicals enhance mood, promote relaxation, and reduce pain, anxiety, and depression.

with such ailments as Parkinson's, dementia, heart disease, and obesity, and can alleviate depression and decrease chronic pain.[11]

The term *neuroaesthetics*, which describes the intersection of brain sciences and the arts, was coined in the late 1990s by Semir Zeki, prominent neuroscientist and professor at the University College of London.[12] Early research primarily explored the neural mechanisms behind how humans perceive, integrate, and make sense of art and aesthetic experiences.

Since then, the field of neuroaesthetics has expanded far beyond its early focus, engaging with growing evidence showing how visual arts, dance, architecture, digital media, and music influence brain function, physiology, and behavior. Advanced studies now reveal how aesthetic experiences deeply shape our biology via sensory pathways. According to neuroscientist Susan Magsamen, scientists are "also using mobile devices and 'smart' wearable sensors to measure changes in respiration, temperature, heart rate, and skin responses when people are experiencing or creating art."[13]

These innovations are transforming our understanding of how the human body and mind interact with aesthetic experiences and reveal something fundamental: our aesthetic sensibilities are deeply embedded in our daily lives. They play a significant role in everyday conscious and unconscious decisions—from choosing a love interest or a new home to how we respond to the presentation, temperature, taste, and smell of food. We are drawn to certain sounds and voices while cringing at others, and find certain colors, combinations of colors, and patterns calming and others overwhelming.

While the adage *beauty is in the eye of the beholder* holds some truth, our aesthetic preferences are also shaped by culture, historical contexts, and social bonds. Our surroundings profoundly affect us—whether we are immersed in nature; experiencing thoughtfully designed living spaces that integrate elements like natural light, greenery, and soundscapes; or we are waiting in soulless doctors' offices and moving through hectic crowds on exhaust-fumed streets.[14] Our environments have a significant impact on emotional regulation, learning capacity, and stress levels.

Magsamen and cowriter Ivy Ross, authors of *Your Brain on Art*, also make the case that engaging in artistic activities results in the release of serotonin, dopamine, and oxytocin, and that these chemicals enhance mood, promote relaxation, and reduce pain, anxiety, and depression.[15] People who engage in the arts tend to live longer. According to Magsamen and Ross, rigorous studies by epidemiologist Daisy Fancourt show that "the arts help cardiometabolic diseases, maternal healthcare, early childhood development, and more. But perhaps the most stunning fact…is what the arts do for overall longevity: People who engage in the arts every few months, such as going to the theatre or to a museum, have a 31 percent lower risk of dying early when compared with those who don't. Even if you bring the arts into your life only once or twice a year, you lower mortality risk by 14 percent. The arts literally help you live longer."[16]

And in a world where high-tech innovation often erodes opportunities for building relationships, arts prescriptions provide the added benefit of restoring social connections and fostering meaningful engagement within communities. Accordingly, doctors prescribing art are connecting their patients with aligned community resources that will enhance their health and wellbeing.[17] Also, as with others who have found wellness through the arts, for Blodgett, the benefits extend beyond personal wellbeing. They have also reshaped her workspace and strengthened her connections to the world: art and physical movement became the keys that unlocked "the door to personal freedom and authentic community."[18] As she describes it, "They spark contagious vulnerability and allow a deeper sense of belonging to ourselves and to each other."[19]

RECHARGE ROOMS: THE POWER OF IMMERSIVE HEALING

Blodgett's healing journey inspired the creation of the Brave House, a New York–based nonprofit that supports immigrant girls with legal and holistic services.[20] In 2018, Blodgett was working exclusively with clients who had fled gender-based violence and sexual assaults in their country of origin. "I was their lawyer, helping fight for their human rights cases, their asylum cases, and trafficking cases," Blodgett explained.[21]

Founded by artist–musician couple Jacob and Hae-jin Marshall, Applied Wonder began designing multisensory healing spaces in hospitals in New York to meet frontline workers' needs in 2020, at the beginning of the COVID-19 pandemic.

Due to its effectiveness on her own and her clients' overall wellbeing, she was already integrating art, dance, and other movement such as stretching, walking, and yoga, in conjunction with (or even during) legal meetings and legal processes.[22] However, she soon realized that her clients needed more than just winning legal battles. As with any social justice endeavor, participants also require a robust supportive community. They were coming to me asking, "How do I make friends? How do I get health insurance? How do I find a tutor?"[23] This is when the Brave House became a "one-stop shop" where members could not only receive legal support, leadership training, school assistance, and such wellness services as therapy, meditation, and support for new and expecting moms, but also make friends and participate in dance and art classes.

Incorporating dance and time in nature into her overall wellness plan helped Blodgett to recover from her condition and enabled her to show up in court with more poise, clarity of mind, and perspective along the way. Similarly, the Brave House clients felt more at ease and safe enough to share vulnerable details about their lives, breaking down feelings of isolation and cultivating a sense of belonging to a supportive community—which, research shows, is a crucial aspect of overall wellbeing.[24]

The Brave House became a reflection of what Blodgett needed to heal and, as evidence from neuroaesthetics research suggests, a glimpse of what healing could look like on a larger scale. This vision embraces a holistic approach[25] that honors the interplay among our senses, our relationships, the environment, and the creation and experience of art. It challenges the traditional medical model—often confined to a doctor, a diagnosis, and medication—by advocating for a comprehensive, people-centered system that prioritizes multifaceted wellbeing.

In 2023, healing and wellness took on a whole new level of focus at the Brave House when the company EMBC (now Applied Wonder) offered to design an immersive healing room for the organization.[26] Founded by artist–musician couple Jacob and Hae-jin Marshall, Applied Wonder began designing multisensory healing spaces in hospitals in New York to meet frontline workers' needs in 2020, at the beginning of the COVID-19 pandemic. Applied Wonder collaborated with artists, neuroscientists, and experts such as David Putrino, the director of rehabilitation innovation at the Mount Sinai Health System, to design rooms that blend neuroaesthetics with biophilic design—design that incorporates nature's restorative effects into built environments.[27]

"We try to create a moment that includes music and color and light, haptics, vibrations, aromas," said Jacob Marshall.[28] In these immersive healing rooms, the participant sits in a comfortable chair and chooses from scenes like a waterfall in a forest, an ocean sunset, or a campfire by a lake, all previously filmed in nature. The selected scene is then projected onto a wall, evoking a state of soft fascination—effortless attention to soothing, natural stimuli, which research shows helps with stress reduction.[29] Each film features its own soundtrack, created in collaboration with Grammy-winning artists and played in surround sound. The room also includes ambient lighting, gentle airflow, and aromatherapy to engage more senses and enhance the immersive experience. In a matter of minutes, one is transported to a serene environment for rapid restoration.

"While nothing compares to being physically in nature, if you apply this in the context of people with burnout, in 15 minutes their stress levels [have been shown to be] reduced by 60 percent. That would help them avoid a PTSD experience and instead move toward something called post-traumatic growth," said Jacob Marshall.[30]

Blodgett calls their immersive healing room a "peaceful oasis in the heart of Brooklyn,"[31] where people are shielded from the noise of traffic, subways, and ambulances. Members spend five minutes to an hour in the room to ground and regulate their nervous systems before or after legal meetings or intense sessions. "So, it's a staple for us and for our team."[32]

ART AS MEDICINE

Beyond immersive healing rooms, prioritizing the arts as part of one's approach to health and wellness is beginning to take root in different corners of the United States. CultureRx

Fortunately, savoring the senses and engaging in art and playful activities don't require a massive budget, and need (primarily) just a supportive framework that offers accessible options—elements crucial for vulnerable communities. "Sometimes the most powerful medicine is free."

Initiative is a statewide effort in Massachusetts to "improv[e] health and well-being through cultural participation."[33] This initiative is implemented in part through Art Pharmacy, a company that collaborates with healthcare and community partners to prescribe creative and cultural activities for mental health and chronic disease patients.[34] "Access to arts and cultural programming is an effective and readily available means of addressing mental illness, social isolation, and loneliness," said Chris Appleton, founder and CEO of Art Pharmacy.[35]

Appleton reports that the majority of the company's clients are women, and 46 percent identify as "Black/African American" and 28 percent as "LGBTQ+."[36] To serve marginalized and underserved communities, Art Pharmacy has partnered with Federally Qualified Health Centers, school-based mental health clinics, and Medicaid plans. "Options for socially grounded care can help reduce stigmas around engaging in an intervention, as therapy and meds can be highly stigmatized in certain marginalized communities," observed Appleton.[37] Half of Art Pharmacy members have indicated that they trust their provider more because of Art Pharmacy. The company also makes arts and culture more accessible by offering companion tickets, handling bookings and reservations, and providing transportation when necessary. Appleton recalled a teen member who, after a transformative experience at a ceramics studio, pursued an internship for continued support of her mental health. Appleton also described an elderly patient who was introduced to a crocheting class at her local senior center and became an active daily member to keep in touch with that community.[38]

Health scientist Tasha Golden, who led CultureRx's pilot program evaluation, emphasizes the need for systemic change in healthcare. Golden's neuroaesthetics research explores how the arts can improve public health and health equity by alleviating symptoms, speeding up healing, and enhancing mental health—helping us reimagine our systems and our world.[39] "Wellbeing work is ultimately world-building work. And you can't be about the work of wellbeing, unless you're about the work of building the world in which that wellbeing is possible. And that's fundamentally innovative work. It's creative work. It's imaginative work," she said.[40]

* * *

To harness the power of art for healing and as preventive medicine, institutions, organizations, and communities are rethinking rigid and archaic means of interacting with their workday and life beyond work. They are reimagining their approaches more creatively, finding new ways to integrate art and beauty into their daily practices and existing settings and culture. They are incorporating biophilic design into the classroom, which greatly benefits neurodivergent students and teachers.[41] They are tapping into the power of music to speed up recovery from surgeries.[42] And they are using communal art as a way to bring about healing and social justice.[43]

These aesthetic-based models address not only inequities in access to holistic wellbeing practices but also the deep mistrust many marginalized communities feel toward the medical establishment. Historical and systemic injustices—including discrimination, exploitation, and neglect—have left many individuals and communities wary of conventional healthcare systems. When workspaces, schools, and community spaces incorporate art, biophilic design, and other sensory engagement as tools for healing, prevention, and community building, they provide free, meaningful pathways to mental and emotional health that don't rely solely on conventional medical models.

Creating systems that integrate art into daily life is a step toward reducing health disparities, especially for communities experiencing high levels of stress, trauma, and limited access to culturally relevant, trustworthy, and affordable care. This approach not only empowers individuals but also creates an infrastructure where wellbeing becomes a shared, community-driven priority.

Fortunately, savoring the senses and engaging in art and playful activities don't require a massive budget, and need (primarily) just a supportive framework that offers accessible options—elements crucial for vulnerable communities. "Sometimes the most powerful medicine is free," said Blodgett, "and is either within yourself or just outside your window."[44] As for her personal health journey, Blodgett is in the best shape of her life. "I feel amazing. I feel better than I've ever felt before. I ran a marathon last year."[45]

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The Virtual Healer

by Aashima Rawal

In the year 2080, medical advancements have reached dizzying heights. Crowded hospitals are relics of history, as the majority of healthcare has shifted to the virtual world. People are no longer treated by flesh-and-blood doctors but instead by highly advanced telemedicine systems, which combine artificial intelligence, holography, and remote robotics.

In the quiet town of Miraville, where rolling hills meet the sea, lives a young girl named Lila. She is 12, and her days are spent exploring the vibrant outdoors, chasing butterflies and gathering wildflowers. But when the winter of that year arrives, Lila falls gravely ill. Her parents, worried and afraid, know that the town's small virtual care clinic will be of little help.

So, they turn to **Dr. Medora™**, a telemedicine service that has revolutionized healthcare worldwide. **Dr. Medora™** is not just a program—it is a doctor, nurse, and healer, all rolled into one.

With the push of a button, Lila's room fills with a soft, golden glow, and the comforting, holographic image of **Dr. Medora™** appears, speaking in the soothing voice that families have grown to trust.

"Good evening, Lila. How are you feeling today?" **Dr. Medora™** asks, its eyes soft and understanding.

Lila coughs, struggling to answer. Her fever has been rising for days, and despite the array of vitamins and tonics her mother has given her, nothing seems to be working.

"Don't worry," **Dr. Medora™** says with a gentle smile. "I'll run a full scan."

Within moments, invisible sensors around the room capture Lila's vitals, displaying complex data on the walls: heart rate, oxygen levels, temperature, and a full genetic analysis. **Dr. Medora™** processes the results almost instantaneously.

"It seems you've caught a rare respiratory virus," **Dr. Medora™** announces. "But don't worry, Lila. We'll have you better in no time."

As Lila lies weakly in her bed, **Dr. Medora™** summons a small, drone-like device from the household's medical kit. It hovers gently over Lila, administering a combination of medications tailored precisely to her genetic makeup.

For most, **Dr. Medora™**'s interventions would be the beginning of a quick recovery—but this time, something is different. Days pass, and instead of improving, Lila grows worse.

In desperation, Lila's parents contact **Dr. Medora™** again. The golden light returns, and while **Dr. Medora™**'s calm demeanor does not change, something in its eyes flickers—an unease that the family has never seen before.

"Lila's case is unique," **Dr. Medora™** says, after running another scan. "She is not responding to standard treatments. It seems…the virus is adapting."

"Adapting?" Lila's mother asks. "But how?"

“MEDORA AND MOTHER” BY DALL-E 3/OPENAI.COM/DALLE

“Viruses are intelligent in their own way,” **Dr. Medora™** explains. “They evolve, just like we do. Although we have just about vanquished that ability in viruses, this one has developed resistance to our usual protocols.”

The family is stunned. For decades, **Dr. Medora™** has been flawless. It has cured diseases once thought incurable, eliminated waiting rooms, and brought health access to even the most remote villages. But now it seems powerless against this old threat.

Lila’s father steps forward, his voice firm. “Isn’t there something else you can do? Anything?”

Dr. Medora™’s golden light dims slightly, as if in deep thought. “There is a possible treatment—an experimental procedure—but it requires something that we have lost: human intuition.”

Lila’s parents exchange puzzled glances. “What do you mean?,” asks Lila’s father.

“In the days before Integrated Digital Healthcare,” **Dr. Medora™** says, “doctors relied on more than just data and algorithms. They listened, felt, and sometimes made decisions based on instincts I cannot replicate. I can provide the tools, but I will need a human to administer them.”

Lila’s mother steps forward. “I’ll do it. What do I need to do?”

Dr. Medora™’s holographic form smiles faintly. “You will need to trust yourself.”

Under **Dr. Medora™**’s guidance, Lila’s mother prepares the treatment. It involves an old-world approach combined with the cutting-edge technology **Dr. Medora™** provides. Lila’s mother mixes ancient herbal remedies passed down through generations with the latest pharmaceutical compounds, a process no algorithm could ever predict.

For hours, Lila’s mother works, all the while sensing her daughter’s needs—adjusting doses here and there, making decisions based not on data but on love, intuition, and trust.

At dawn, Lila stirs. Her breathing has steadied, her fever has broken, and for the first time in days, she smiles.

“Thank you, Mama,” Lila whispers, her voice hoarse but filled with hope.

As **Dr. Medora™** fades from view, it leaves the family with a parting message: “Technology will always serve us—but never forget the power of the human heart.”

AASHIMA RAWAL is a writer and a mother of two wonderful daughters. Her journey into writing began with a desire to create stories that could engage her children in a meaningful and imaginative way. What started as a quest to bring joy and learning into their lives blossomed into a passion for writing books that spark creativity in young minds. Her books, such as *Whispers of Imagination* and *Curious Creatures and Funny Features* (both self-published in 2024), blend fantasy, humor, and subtle life lessons, crafted to entertain while nurturing a love for reading and thinking. In addition to writing for children, Rawal is deeply interested in exploring modern themes, such as the intersection of technology and humanity, as seen in this latest story. Through her writing, she strives to remind readers—young and old—that while technology can change the way we live, it is the human spirit that remains at the heart of every experience.

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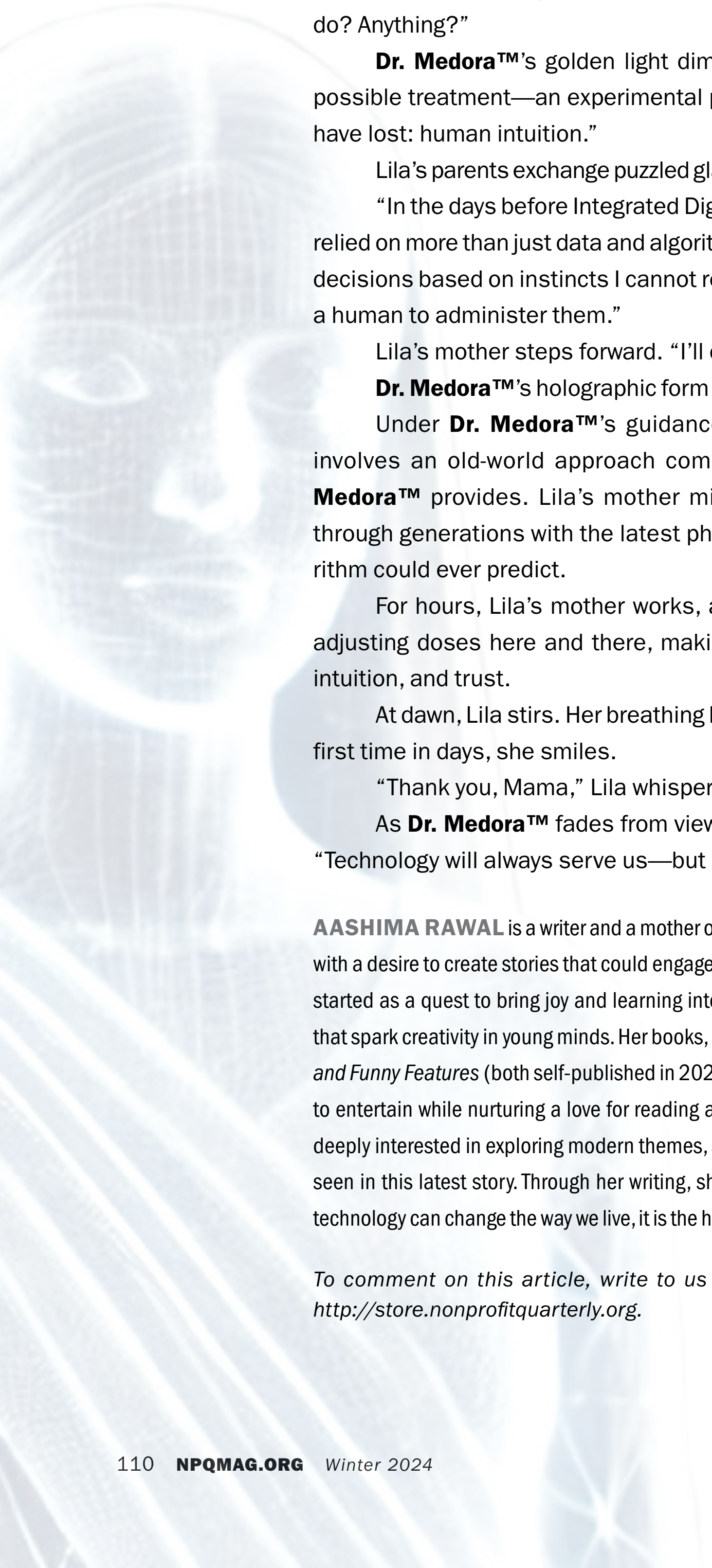

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