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The Un-Mattering of People: The Present and Near-Future of Surveillance Capitalism and the Fate of Care in Healthcare

Victor M. Montori
Juan P. Montori
Victor Montori V

Carr-Ryan Center
Discussion Paper

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Capitalism and the Fate of Care in Healthcare**

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Publication design by Kyle Faneuff

Victor M. Montori, MD

Technology and Human Rights Fellow, Carr-Ryan Center for Human Rights Policy;
Robert H. and Susan M. Rewoldt Professor, Mayo Clinic, United States
Chair, The Patient Revolution, Minnesota, United States

Juan P. Montori, MA

Victor Montori V, BA

Knowledge and Evaluation Research Unit, Mayo Clinic, United States

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...And whatsoever I shall see or hear in the course of my profession, as well as outside my profession in my intercourse with men, if it be what should not be published abroad, I will never divulge, holding such things to be holy secrets.

–Hippocratic Oath¹

We have never been allowed to lose sight of the fact that the main purpose to be served by the clinic is the care of the sick.

–William J. Mayo, MD²

ABSTRACT

The encroachment of surveillance capitalism into healthcare takes place as healthcare becomes increasingly industrialized. The industrialization and datafication of healthcare create a receptive environment for firms that concentrate the means of computation—companies that have grown thanks to technologies of surveillance and remote behavioral actuation.

In healthcare, Big Tech finds a massive business opportunity as it becomes fundamental to infrastructure and an unavoidable mediator of medical services. Also, Big Tech can now capture the missing piece in its quest to harvest, control, and use the complete human experience as raw material for their business interests. Central to this encroachment is the misguided notion that the problems of care are problems of information. Big Tech is best situated to address problems of information using powerful data platforms and artificial intelligence systems. Care, a practice by which a human sets out to solve the problematic situation of another human, is replaced by the processing of their data. Care becomes depersonalized, dehumanized, disembodied.

Evidently, advances in information technology can make significant contributions to the project of offering careful and kind healthcare to every person. And yet, the realization of this vision would require outlawing Big Tech's parasitic practices as they commodify humans to advance these firms' anti-human and anti-democratic project of domination.

Abolishing surveillance capitalism and its contribution to corrupting the mission of healthcare may help ensure that information technologies can be harnessed to advance the core mission of healthcare: the care of people.

1. WHAT IS HEALTHCARE FOR?

“The chair.” This was reportedly the answer given by Spanish physician and humanist Gregorio Marañón when asked to name the most important advance in medicine. “The chair enables us to sit with the patient, listen, and explore.”³

The possibility of cures is a relatively recent advance, allowing medicine to shift a patient’s trajectory from a likely adverse outcome to another one in which full health becomes possible. Today, medicine can sometimes cure, fix, and repair. The wise use of implantation, transplantation, extirpation, reconstruction, gene editing, chemotherapies, and antibiotics can restore lost health. Many, though, are left alive but living with the sequelae of disease and treatment.

Most adults, particularly as they age, will live with one or more ongoing health conditions. Some of these conditions make people ill, while others act only as risk factors for other diseases that can cause disability and death. Medicine cannot cure these conditions, affecting one in two middle-aged U.S. adults and nearly all U.S. adults over 65.⁴ And yet, medicine today can offer helpful means of minimizing their effect on health and thus reduce the risk of long-term complications and premature death.

Even though most of healthcare is involved in the longitudinal care of patients with ongoing chronic conditions, spectacular cures dominate headlines, imaginations, and healthcare budgets.

People living with chronic conditions must attend healthcare visits, participate in periodic laboratory and imaging testing, and enact self-management practices involving daily diet and activity habits, self-measurement, and medication administration. Patients in need of cures have traditionally lain in bed while healthcare professionals worked on them, performing procedures to them whereas chronic care demands working with patients, co-creating testing and treatment plans, and delegating their implementation to patients and their communities of care.

To care well, clinicians must cultivate a disposition to notice and respond to health needs. Motivated perhaps by a moral obligation, they must develop expert practices to see patients in high definition, understanding with enough detail what may be wrong (and right) about their body, how is it that life and living contribute to how disease is expressed and experienced, and how ongoing and potential treatments can both enable the life patients desire and disrupt it.

Tronto posits an ethics of care⁵ that starts with noticing. Attending with curiosity to both “biology and biography” should prompt

an emotional recognition and a decision to respond, engage, and participate in improving the situation.⁶ Caregiving expresses caring for, about, and with the patient. It mobilizes both compassion and competence: the carer must attend to the emotional dimensions of the situation and ensure responses do more good than harm. Care receiving completes the act of caring: patients assess the extent to which the care received is pertinent, adequate, and desirable. The goal of this dance, which Pugh calls connective labor,⁷ is for the clinician to respond to the patient’s problematic human situation and for them, together, to form care that is maximally responsive to this situation, maximally reflective of the patient’s priorities and aspirations, and minimally disruptive of the patient’s life and the lives of their caregivers.⁸

To care well, thus, requires the work that people do together. Responding with competence and compassion to the problematic situation of the patient tends to enhance both clinician and patient, elevating them both as they recognize humanity in each

other; in care they know that they matter to each other.^{7,9} Patients get better not only due to technically correct responses but

also because of the strength and quality of the collaborative relationship that made those responses possible.

Cures, as in fixing problems, must be enacted with accuracy and precision, with efficient reliability, with first-time perfection, without unnecessary variability or avoidable gaps in quality. Care, as in solving problems, demands something different: dancing together, exploring with curiosity and kindness, trying ideas on, recovering from disappointment (including those emerging from cures that did not work as expected), drawing from experience, expertise and creativity, and self-management support. Care must exhibit all the necessary variance needed to sensibly respond to each person with care that fits well.^{8,10}

The purpose of healthcare is therefore to advance the problematic situation of people suffering threats to their health, sometimes by curing, and always by caring. To care is to invest technical resources in the betterment of people; it is a kindness we extend each other to help people flourish. If you are reading this, it is only because someone at some critical point in your life chose to care for and about you. This human commitment to mutual care¹¹ finds its zenith in healthcare, where it mobilizes to remove or reduce disease and disability as hindrances to the realization of people’s potential capabilities. To care is to participate in the mattering of people: to matter as a worthy recipient of care, to matter as trusted giver of care. Healthcare—the systems of applied knowledge, technologies, built space, policies, and procedures—is for supporting the caring work of people, as only people can care. To care is human and healthcare offers us the chairs.

"The purpose of healthcare is therefore to advance the problematic situation of people suffering threats to their health, sometimes by curing, and always by caring."

2. THE EVOLUTION OF HEALTHCARE: INDUSTRIALIZATION AND THE CORRUPTION OF HEALTHCARE'S MISSION

2.1. How Healthcare Industrialized

American healthcare transformed dramatically from the early 20th century, shifting from a system of house calls and small solo practices to an industrialized model. This evolution was driven by advancements in testing (imaging) and treatment (surgery, pharmaceuticals), the specialization and technification of medicine, coupled with reforms in medical education and the emergence of insurance plans. This resulted in ballooning costs that resisted efforts to be controlled by an equally formidable expansion in administrative personnel and regulatory red tape. Hospital growth in size and complexity accelerated through consolidation and added to the bureaucratization of medicine and nursing while attracting investors to their ownership. The place of care moved from the home to the hospital and to the outpatient office. Physicians cured and nurses cared until they ended up working side-by-side in hospital wards with an expanded array of other professionals and technicians.

This evolution proceeded with different pace and speed in other high-income countries. Most of these kept costs under better control than the U.S. through the negotiated and deliberate introduction of cost-effective tests and treatments, public employment of healthcare professionals including physicians, a highly regulated environment for private participation, and a much higher public health-to-healthcare ratio in public investment.¹²

In the early 90s, healthcare professionals had begun to recognize that many of its practices, including the most expensive, persisted because of tradition, the experience and authority of a senior clinician, and the unwarranted extrapolation of low-quality scientific evidence.¹³ Evidence-based medicine emerged, calling for a patient-centered approach that drew from the best available body of research evidence, prioritized highly reliable experimental evidence in humans, and used this evidence to form care after carefully considering the clinical circumstances and the values and preferences of each patient.¹⁴ Evidence-based medicine democratized clinical authority and devalued the authority of experience alone.

The adoption of evidence-based medicine led to the formulation of clinical practice guidelines that adhered to its principles.¹⁵ Recommended “right answers” enabled the identification of wasteful and harmful variations.^{16,17} Quality-of-care parameters based on these recommendations sanctioned what ought to be done with patients presenting with particular diagnoses. This fostered a movement to improve quality of care, improve the safety of hospitals and clinicians, and reduce unwarranted variations in care.¹⁸ Aggregated data from administrative datasets and clinical records became central to the enterprise, as did systems engineering and quality improvement methods.

The increased administrative and medical complexity of healthcare resulted in its increased industrialization, with the introduc-

tion of forms of scientific management, division of labor, and total quality improvement drawn from other industrial sectors. Within the healthcare industrial sector, some entities were particularly effective at drawing massive profits, including hospitals, physicians, pharmaceutical and medical technology companies, and private insurers.¹⁹ Clinicians spent more time justifying care to payers than giving it, shifting focus from patients to paperwork. Consolidation not only proceeded horizontally but also through vertical integration, always under the promise of efficiency but mostly resulting in private profits without improving access, patient experience, or costs.^{20,21,22,23} Meanwhile, publicly funded systems experienced challenges as countries implemented policies of austerity to their social welfare programs. In poorer countries, constrained public budgets, incompetently managed facilities, and corruption limited the resources available at the point of care and shifted patient demand to private sector offers. These often exploited both the rich and the poor with tests and prescriptions they neither needed nor wanted.^{24,25} Value extraction and profiteering, severe and sustained austerity without service reform, and incompetent and dishonest management all led ultimately to the universal erosion and eventual corruption in the mission of healthcare: healthcare became industrialized. It stopped caring.²⁶

"Care itself became the fat to trim. The result was not a lean and effective care system, but an industrialized machine that became increasingly unsustainable."

2.2. The Acceleration of the Industrialization of Healthcare

Industrialization accelerated in response to political and economic forces. These forces pressured systems to improve access to care services and to deliver such services efficiently and at lower costs to payers. Healthcare responded with streamlined services, briefer appointments, and better and more thorough documentation to justify larger reimbursement payments. Care itself became the fat to trim. The result was not a lean and effective care system, but an industrialized machine that became increasingly unsustainable.

Financially, healthcare became a budgetary black hole drawing resources from social welfare programs, education, and public health. In the U.S., healthcare organizations are now often the main employers and the top economic engines in many states.²⁷ Healthcare is a major cause of personal ruin and financial debt.²⁸ GoFundMe, a platform to crowdsource charity support, is now a major payer of healthcare services.²⁹ It is also environmentally unsustainable, representing a ma-

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Value extraction and profiteering, severe and sustained austerity without service reform, and incompetent and dishonest management all led ultimately to the universal erosion and eventual corruption in the mission of healthcare: healthcare became industrialized. It stopped caring.

major source of carbon and greenhouse emissions.³⁰ But more importantly for an activity oriented toward the promotion of human flourishing, it has become humanly unsustainable.

Nearly three fourths of clinicians have experienced moral injury, half of all clinicians are burned out, and 40% have cut back on their patient care hours or have left clinical practice.³¹ The numbers are similar for other healthcare professionals. Similarly, nearly 40% of patients living with chronic ongoing conditions are overwhelmed by the tasks that healthcare has delegated to them and to their families.³² Primary care clinicians would need 27 hours each day to practice according to current guidelines.³³ Patients with diabetes and other chronic conditions need to spend 2 or more hours each day to self-manage their condition, negotiate healthcare access, and to receive healthcare services.³⁴ Pressed for time, clinicians process patients quickly, unable to notice the patient in high definition. With lack of clarity about the problematic situation they bring, the clinician focuses on matching diagnoses with guideline recommended treatment pathways and meeting quality metrics. This results in treatment that feels generic, appropriate for people like this rather than for this person. When patients have multiple chronic conditions, a situation that is most common among the most disadvantaged and aged,⁴ these treatments and the work to access and use them accumulates and becomes unsustainably burdensome. When patients miss appointments or cannot fully implement treatment plans with high fidelity, the response from healthcare professionals is to label them as “noncompliant” and to deny future services, a cruelty.³⁵

Industrialized healthcare is, therefore, an unfortunate development, one that has transformed the care of the sick into the efficient and depersonalizing processing of people. This system can still produce miracles of cure thanks to its investments in the latest technologies and in the hyper-specialization of its technicians. Care, conversely, is no longer the core purpose of healthcare organizations, but a rare accomplishment. Industrialized healthcare can indeed produce precious moments of care, but these are not efficiently facilitated by sophisticated systems of organization but rather demand that patients and clinicians go out of their ways to connect with each other through acts of disobedience and procedural deviance.

The leviathan is not sated; it needs to continue to grow and get faster, to become more efficient, to do more for less. To do so, industrialized healthcare must enter its next phase and become increasingly “data-fied.”

3. FROM INDUSTRIALIZED TO “DATA-FIED” HEALTHCARE

3.1. The Emergence of the Electronic Health Record

The clinician’s written account of clinical encounters has been a part of modern medicine for over a hundred years. Henry Plummer, a physician and polymath and one of the early partners at the clinic founded by the Mayo brothers in Minnesota, is attributed the invention of the integrated medical record in 1907.³⁶ This paper record accompanied the patient at the hospital and the outpatient clinic, through surgery and rehabilitation, and over time and across visits. Medical records accrued handwritten notes, slips with laboratory and imaging results, and all relevant correspondence. Sharing this record required personal letters and requested copies.



a medic updates patient medical records. Image: Flickr - Georgia National Guard

In the latter half of the 20th century, healthcare systems slowly adopted an electronic record. Electronic Health Records (EHRs) had substantial advantages over paper records: they are more legible (notes were dictated or directly typed onto them), accessible, and comprehensive. Electronic orders and decision support functions were soon added, enabling safer prescription of drugs. Federal incentives and legislation accelerated the adoption of the electronic records in the U.S. since 2004, and particularly since 2008.³⁷ Over the next 8 years, EHR systems became increasingly interoperable, in part through market consolidation. A particularly dominant vendor, Epic, currently holds records for over 40% of hospitals in the U.S. and over 260 million patients; more than 90% of U.S. medical students are trained to care for patients in Epic systems.³⁸

Despite their value as tools to improve patient care and support healthcare research, clinicians struggled to adopt EHRs. The structure and function of this tool changed clinical visits because their setup did not necessarily reflect the natural flow of the encounter.³⁹ The adoption curve for clinicians was steep, with point-and-click interfaces (a method used to increase the proportion of extractable structured data) that required looking at the screen even after clinicians learned to type while maintaining eye contact with the patient. Clinicians

turned into clerks, visits into structured datasets. The use of this tool also produced an increasingly obvious complication illustrated by the disposition of Marañón's chairs in the office: while the patient is facing the clinician, the clinician is facing the computer screen nearly 40% of the time.⁴⁰

The care schedule of professionals bled outside office hours as clinicians struggled to keep up with caring for more and more patients and with documenting their care.⁴¹ With documentation tied to reimbursement and liability protection, clinicians wrote, cut-and-pasted, and clicked their way into ever expanding notes. These bloated notes sought to elicit maximum reimbursement and to overcome insurer's pre-authorization requirements.⁴²

Lost in the bloat, errors could remain undetected and propagate easily as fewer clinicians had the time to read the notes in the medical record (or any confidence that doing so will help them care better for the patient), even though these notes were increasingly the only method of inter-professional communication. Documentation emerged as a key cause of physician dissatisfaction and a target for efforts to palliate the crisis of professional burnout.⁴³

"A robust policy solution at the time, HIPAA was inadequate to contend with the incursion of surveillance capitalism in healthcare."

3.2. The Healthcare Data Trove

The EHR enabled a massive project of collection of patient-related information for purposes largely exceeding the care of the patient. Private and public payers also accumulated healthcare utilization data from billing records, which were increasingly integrated with laboratory and medical record data. In today's information economy, these systems represent a treasure trove of data to be bought, sold, analyzed, and exploited.

Since 1996, healthcare's data in the U.S. has been protected by the Health Insurance Portability and Accountability Act (HIPAA), limiting access to patient data to professionals participating in the patient's care and to entities paying for healthcare services.⁴⁴ Special provisions give data access to researchers authorized by Institutional Review Boards, and to third-party vendors through data use agreements. More recently, patients (and their designees) have also gained full and immediate access to all their medical record.⁴⁵ Access to their own records helps patients get care across healthcare systems, keep records accurate, and enact self-management plans.⁴⁶ A robust policy solution at the time, HIPAA was inadequate to contend with the incursion of surveillance capitalism in healthcare.

3.3. Surveillance Capitalism Meets Healthcare Data

The expansion of the electronic realm within healthcare lagged but eventually merged with an earlier, broader, and faster secular trend outside healthcare due to the birth and expansion of: the Internet and the ability to search through the web dominated by Google (with health and healthcare searches always among the most common, and "Dr. Google" emerging as a common source of first and second opinions);⁴⁷ portable and wearable sensors (designed to capture location, activity, mood, vital signs, and more complex behaviors and their patterns, such as diet and sleep);⁴⁸ mobile phones-cum-ubiquitous computing platforms; and mobile apps to support healthy behaviors and self-management of chronic conditions, themselves often connected with wearable sensors and eventually to the electronic health record.⁴⁹

Many of these entities—including Google, Amazon, and Meta—became massively profitable, not through their primary service offering, but mostly by claiming private human experience as free raw material without regulatory guardrails or users' informed consent. They then used these materials to make predictions about individual behavior for sale into behavioral futures markets.⁵⁰ Prediction products became more valuable the more detailed their input data, and more so after these companies realized they could use these data to affect the behavior of their users beyond purchasing decisions. Prediction became remote behavioral actuation, also shaping political positions, stoking violence against a target group, and inciting specific moods. Their power became unprecedented as platforms expanded their user bases and honed their interfaces, increasing adoption by society to the point of becoming essential for the conduct of everyday personal activities, disrupting civic life and democracy. This is the dawn of the era of surveillance capitalism.⁵¹

Health data, however, remained among the most private and sensitive information yet to be integrated with the increasing array of profiles about individuals collected and appropriated by technology companies. These extractive and integrative activities took place initially as a by-product of users interacting with their services to connect with others (Facebook), search the web (Google), or buy anything (Amazon), only to later become their *raison d'être*. However, one of the few places Big Tech's panoptic gaze couldn't reach was the health record.

Zuboff recognized healthcare as an attractive target for surveillance capitalism from early in its inception.⁵¹ Surveillance capitalists understood both the importance and richness of healthcare data and the vulnerability of people when they interact with healthcare due to illness, uncertainty, and despair. And yet, this massive business opportunity remained largely out of reach. As Eric Schmidt, then CEO of Google, recognized in 2017, "[h]ospitals have enormous amounts of data, which is inaccessible to anyone except themselves."⁵²

" Under 'datafied' healthcare, the patient, presenting as a blur— seen by their clinician only as a diagnostic label or as a test result—, is no longer a pathology of care."

By 2018, the challenge of healthcare as an industry, and of caring for patients, had increasingly been framed, discussed, and approached as a problem of information, a problem of data. Through multiple public statements leaders, such as Schmidt, proposed that to enable excellent healthcare, organizations must harness data they currently ignore either because it was not collected or was not analyzed. In this view, hospitals should take stock and curate the data already collected and setup pervasive sensors to obtain the rest.

Healthcare data, a record of vulnerability and hope, became the ultimate behavioral surplus. These data, connected with the "behavioral exhaust" left behind from people's actions on- and offline can then be used to determine which patients to admit to the hospital, who to dismiss from care early, who can do well staying at home, and who is following lifestyle intervention plans and adhering to therapy. Not only would this panoply of surveillance enable more "precise" care but also avoid wasteful care in those who are not contributing to their own improvement and direct more care toward those in whom doing so is likely to improve outcomes and reduce costs.



Google CEO Eric Schmidt speaking at a tech conference. Image: Flickr-TechCrunch

Based on these premises, more sales pitch than ground truth, Schmidt proclaimed in 2018 that medicine was really a science of information.⁵¹ This framing maneuver was no accident. It justified Big Tech's encroachment: if care is about data then data giants must own care. This self-fulfilling prediction became pervasive, making it impossible to imagine good healthcare without state-of-the-art data and the computational infrastructures and software to handle it. With problems of care turned into problems of information, Dr. Google joined the hospital staff.

The harvesting and processing of personal health data and its availability to various actors at the point of care, and increasingly outside of healthcare, and at the patients' point of life,

signaled that industrialized healthcare was already evolving into a new form: "datafied healthcare."

3.4. Healthcare "Datafied"

Under "datafied" healthcare, the patient, presenting as a blur—seen by their clinician only as a diagnostic label or as a test result—, is no longer a pathology of care.⁵⁵ Rather, the notion of having to appreciate the patient's situation in high definition comes to be defined more narrowly. The patient themselves—their past, future, hopes, joys, and fears—stays a blur, remaining unexamined. It is the collection of genes, proteins, and functions that are seen in high definition. Bespoke medications can then be designed, selected, and administered to reflect and respond to each person's precise biology.

Alongside this hunger for biological precision, datafied healthcare remains oblivious to each patient's life circumstances even when these circumstances—past (as in trauma and experiences with professionals and treatments), present (competing personal, family, community, and work demands, complicating circumstances, and contributing supports), and future (goals and priorities for life, care, and health)—shape the emergence of disease, its manifestations, approach to accessing and using care, selection of treatments, fidelity to the treatment program, and its tolerance and safety.

Datafied healthcare demands increasingly more data, extracting broadly and deeply from all available sources until it has mapped the whole human "info-nome." Problems of care, turned now into info-problems, demand that everything possible about a patient must be known to fix them. If industrialized healthcare merely depersonalized people as they were efficiently processed, turning individuals into "patients like them," datafied healthcare atomizes the patient entirely, moving from responding to each person's needs to focusing instead on processing their collected bits of data to determine how to fix what is wrong.

An intermediate step in this evolution is the quantification not only of biological processes but also of measures of a person's quality of life.⁵³ To the extent that these patient-reported figures enter the estimations, care may be considered patient-centered, even as stories are no longer shared, patients do not get to determine how their experience is represented or analyzed, or even what counts as the qualities of one's living, individually and as members of their communities. "I am the mate and companion of people, all just as immortal and fathomless as myself," wrote the poet Walt Whitman in his "Song of Myself."⁵⁴ "Am not contain'd between my hat and boots," he proclaimed. "I am large, I contain multitudes."

3.5. Big Tech's Scheme in Data-fied Healthcare

Ozalp and colleagues have described the evolution and mechanisms of Big Tech's incursion into healthcare.⁵⁵ They describe this process as the "digital colonization" of a highly regulated industry. Industrialized and datafied healthcare makes demands of healthcare organizations that quickly and largely exceeded their own health information technology capabilities. Big Tech, on the other hand, is fit for the task, offering the infrastructure and computational capacities necessary to support datafied healthcare.

Schmidt and others called for all health information about everyone to be uploaded to the "cloud."^{52,56} Moving healthcare data to the "cloud" completed the liberation of healthcare information from the paper record in the filing cabinet at the clinician's office to the access-anywhere-anytime capabilities provided by massive server farms. Cloud services also reduced the risk for cyberattacks or failed servers. Amazon, Microsoft, and Google certified their cloud services (AWS,⁵⁷ Azure,⁵⁸ and Google Cloud,⁵⁹ respectively) as HIPAA compliant in the early 2010s. These three platforms represent the majority market share for cloud computing and storage in healthcare. These services became essential because, in datafied healthcare, clinicians cannot take care of patients effectively when data becomes unavailable.

With this beachhead, Big Tech reduced the need for IT expertise and workforce in healthcare organizations, which became increasingly dependent on these companies for conducting these, now, fundamental functions. Big Tech's entry into healthcare, however, goes beyond infrastructural support. As analyzed by Rikap, Google and other firms engage, through acquisitions, academic collaborations, and platform participation, in "a quest for conquering new knowledge and data to perpetuate their intellectual monopolies."⁶⁰

Enabled by data use agreements to access healthcare activities and data, Big Tech offered "solutions" not just for back-office functions, but also for point-of-care activities. These included drafting and summarization of notes based on surveillance of clinical encounters.⁶¹ In addition to EHR companies (including Epic working with Abridge, an 'e-scribe' startup founded in 2018), Big Tech, including Amazon (Transcribe Medical, Solventum-3M), Google (Augmedix), and Microsoft (DAX Co-Pilot Nuance, one of Microsoft's largest acquisitions),⁶² offered competing services and vied for e-scribe market dominance.

Again, this arrangement seems mutually beneficial: healthcare receives additional capacity and capability to treat patients, freeing up physicians from one of the most burdensome as-



An Amazon One Medical clinic in Bethesda, Maryland. Image: Wikimedia Commons - Harrison Keely

pects of their jobs, and tech companies get to test new technologies-as-services. Perhaps most importantly, it positions Big Tech as essential for the provision of care, creating the illusion that the provision of care is impossible or impractical without Big Tech, enabling these firms to extract value from all healthcare activities in perpetuity. HIPAA, designed to protect privacy, became increasingly obsolete in this new paradigm as data use agreements allow tech companies to directly harvest healthcare interactions.

One thing is to be a tool for the provision of care, and another is to directly offer care services, an opportunity rendered possible by the advanced of datafied healthcare. Amazon Clinic, a service to connect patients with third party physicians through Amazon apps, was made available across the

United States in 2022.⁶³ Big Tech's move into healthcare raised well-founded concerns and legislative scrutiny.⁶⁴ Would Big Tech exploit protected health information—as they have previously used faces, behaviors, relationships, beliefs, moods, and media—as free, raw material for their commercial activities?

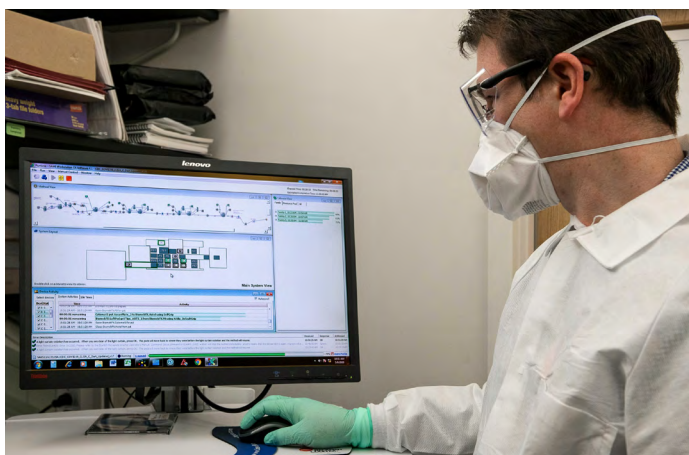
The scope of these activities, however, may not be limited to the commercial, since, as Zuboff has noted, data captured by Big Tech is often accessed and analyzed in service of state policing and surveillance.^{50,51,65} The addition of healthcare data to all other data under their control expands the scope of collaboration, however implicit, between Big Tech, the healthcare organizations they enable, and state agencies. Together, they are better able to identify and prosecute people seeking reproductive services, abortion, or gender affirming care, or to contribute to sophisticated attacks against opposition activists or politicians.^{66,67} Healthcare has a history of such collaborations.⁶⁸

"Their scheme demands the commodification of healthcare data. And yet, trust, a key ingredient in healing relationships, suffers when personal data [is exploited]."

For example, consider the apprehension of undocumented immigrants when they attend hospitals for care, or the participation of healthcare professionals in the interrogation, torture, and execution of prisoners.⁶⁹

Healthcare organizations cannot possibly live to the expectation of producing optimal value to payers without data-driven innovations. Indeed, in time, even patients may come to expect that the “best” hospitals are the most data-driven ones. Those best suited to begin offering tech-driven innovations to hospitals are those who offer tech-driven innovations to the rest of the world: large technology companies. Their scheme demands the commodification of healthcare data. And yet, trust, a key ingredient in healing relationships, suffers when personal data collected for care is used for other objectives. This reveals the special nature of healthcare information. This is the enduring promise made in the Hippocratic oath’s section that epigraphs this report. It is essential that when a patient and a clinician sit together that the questions, concerns, symptoms, disabilities, treatments, confessions, and struggles they shared stay secret.

Nonetheless, Big Tech’s scheme advances. Artificial intelligence systems’ accelerating accrual of capabilities marks the next evolution of healthcare. It also furthers healthcare’s dependence on Big Tech. Industrialized and datafied, healthcare must move to a new form, artificial “healthcare.” If industrialization depersonalized care, and datafication dehumanized it, this new stage may completely do away with Marañón’s chairs as nobody would have to take a seat.



A doctor showing AI models for accurate mapping of endometriosis. Image: Endo Excellence Center

4. THE ADVENT OF “ARTIFICIAL CARE”

4.1. Artificial Intelligence and Clinical Care

Much has been made of the extraordinary capabilities of artificial intelligence systems to detect patterns and power algorithmic predictions. In healthcare, AI systems have been able to determine personal factors—age, sex, race, socio-economic status, etc.—and estimate risk for diseases and complications from material that was not understood to encode enough data to make such determinations. Chest x-rays, for example, inadvertently code the socioeconomic status of a patient.⁷⁰

Alternatively, less powerful but very useful methods exist to detect and prognosticate without data mining. Clinimetric scores,

"Automation bias doesn't just displace judgment—it destroys the ability to develop clinical expertise."

such as the Apgar score to assess the health of a newborn, relies exclusively on directly observed features. These tools are widely and freely accessible, are sufficiently accurate, and consume very little data, computational power, and energy. Furthermore, when compared with sophisticated prediction models, human judgment often is on par with or better in its discriminating ability; when based on intuition, it is also much faster and more efficient.⁷⁰ This performance is even better when “brains” collaborate, as in medical rounds at hospitals, tumor board discussions about cancer treatment, and family conferences at intensive care units.⁷¹

Nonetheless, it is the flaws of human-powered approaches that are emphasized to make the case for artificial intelligence in clinical care, adding to the technological imperative to commodify humans (patients and clinicians), adopt AI solutions to solve problems, and depend on them.

And yet, the development and demonstration of AI’s capabilities has been on datasets that exclude most humans who live and receive care.⁷² People not from largely White, educated, industrialized, rich, and democratic nations are missing from the training datasets for AI algorithms. The consequences of this marginalization, and other errors, cannot be appraised, as AI systems, particularly those that are most complex, are increasingly opaque and resist examination.⁷³ When these black-box AI systems make a recommendation, users often choose to follow it, even when the recommendation contradicts their own lived experience and expertise.^{74,75}

This so-called automation bias erodes human actors’ sense of agency while simultaneously augmenting their reliance on black-box recommendations for action. It also means novices that come into healthcare don’t get to work (and won’t need to work) on refining their intuitions and honing their judgements because they will always be too unreliable when compared to AI. Trained on AI prompts, novices never learn to calibrate their instincts and the clinical encounter becomes a call center script.

Automation bias doesn’t just displace judgment—it destroys the ability to develop clinical expertise. This expertise is crucial for the practice of evidence-based medicine, as it allows clinicians to consider AI recommendations as just another form of evidence to be appraised and integrated, alongside the patient’s situation, into a clinical decision.⁷⁶ Without this expertise, the inexperienced clini-

"The ability to predict behavior or, better yet, to shape it, is quite attractive when care is defined as something healthcare does to people, rather than with them."

cian cannot hope to stay in the loop; the only expert in the room is the algorithm, and the clinician is reduced to a moral crumple zone, someone upon whom to pin the blame when something goes wrong.

Obfuscation by AI emerges as a new moral injury perpetrator: users cannot appraise or rationally object to "objective" AI determinations. Furthermore, AI offers a useful "accountability sink" to decision makers.⁷⁷ UnitedHealthcare, the insurance giant, blamed a faulty AI algorithm for its determinations to cut rehab short for older patients, despite patients' and clinicians' appeals.⁷⁸ Two years later, the same company announced it was developing an AI algorithm to determine how sick patients are, and to use this determination to "risk-adjust" its reimbursement to clinicians and healthcare systems.⁷⁹ Once again, the reasons behind these risk adjustments—patient benefit or profit making—will remain hidden within the layers of a neural network.

4.2. Artificial Healthcare Is Surveillance Capitalism

Predictions about the biology of people are enticing. The ability to predict behavior or, better yet, to shape it, is quite attractive when care is defined as something healthcare does to people, rather than with them. In pursuit of an apparent consensus of what constitutes a healthy life⁸⁰—consider actions like drinking water, being active, consuming fruits and vegetables, etc. – wearable devices, virtual assistants, online shopping data, and medical records can be combined to not only predict but to nudge, market, and induce behavior change toward healthier habits. Amazon Clinic's "personalized health recommendations" mirror Amazon's product ads:⁶³ both exploit vulnerability to maximize the company's profit, not the customer's health. This is care perverted: instead of clinicians responding to patient needs, algorithms enforce corporate-defined wellness.

Assembling data into highly specific personal profiles in order to change behaviors is central to the surveillance capitalism business model, as exemplified by the Cambridge Analytica-Facebook partnership to shift political views, or how Amazon presents products and recommendations to induce purchases.^{50,51} As healthcare seeks to become more effective at promoting health and preventing disease, then these activities must take place within the total human data collection hardware (sensors, wearables, cameras, computers, phones) and computation capability of Big Tech.

Healthcare's ability to care and generate value become, in these ways, fully dependent upon and embedded within systems that can only be provided and supported by Big Tech because they have the means of computation, the data centers, the energy to power them, and the programmers and engineers to build and

deploy them. Healthcare's parasitic dependency on Big Tech enables the unresisted human commodification at this very last frontier of intimate privacy.



A person checking their smart watch exercise data. Image: rawpixel.com

Consider an example. Systems that listen to how clinicians and patients care can save clinician time and effort in writing clinical notes and documenting care by summarizing the encounters.^{81,82,83} This is a welcome antidote to the burden of clinical documentation, but does nothing to address the root causes of that burden. Automatic documentation systems leave documentation requirements unchanged (furthering the dependency of clinicians on AI systems) and reduce the cognitive and emotional value of writing clinical notes as exercises in reflection and synthesis. They exclude note crafting as a method to remember patients, detect errors and omissions in clinical thinking, learn, and develop a sense of satisfaction and mattering in the lives of their patients and change the nature of clinical notes, for example, by excluding biographical elements that the system deemed "irrelevant."⁸⁴ The knowledge of being constantly listened to and recorded, or the perception that this may be possible, may be highly detrimental to people in psychologically precarious states.⁸⁵ Accidental use of or adversarial attacks on AI systems trained with encounter data could reveal these intimate clinical interactions.⁸⁶

With less user control, no information about who gets to listen to and exploit every utterance and action (and who decides who does), wearables and sensors everywhere, and extremely sophisticated black-box advice systems and behavior modification technologies, such as virtual assistants, how can patients be confident they made care decisions with their clinicians, when perhaps choices were already made, even before the patient arrived for care, by a faceless, pulseless, omniscient system?

**“
Personal health data should not be under the control of the technology systems that extract, process, store, and analyze it, but rather be given, by law, the protected status that patients and clinicians have always assumed it should have.**

While these risks are brushed aside as other arguments—clinician wellbeing, productivity gains, and better reimbursement—fuel the adoption of AI-powered ambient scribes and other agents, the true usefulness of these systems may lie in the data they collect and use to optimize its services: the totality of the clinical encounter interaction. If notes continue to be used as the basis of reimbursement for payers, then AI listening systems can offer value to healthcare organizations by including details in the notes that command higher payments, drowning out those details needed to support collaborative problem solving with the patient and with other colleagues.

Just as in searching using Google, purchasing via Amazon, or sharing pictures via Facebook, the production of clinical documentation via AI is also producing behavioral surplus, in this case about doctoring with patients. In addition to the knowledge base of medicine, encounters provide the behavioral and therapeutic raw data from interpersonal care interactions. This material is most valuable to third parties interested in changing the nature of clinical discussions, for example, to promote the adoption of new tests and treatments (when the clients are pharmaceutical and device companies), to foster healthcare nonconsumption (when the clients are payers for healthcare services such as insurers or parties set in the abolition of abortion, vaccinations, or gender affirming care),⁸⁷ or to unlawfully prosecute individuals because of what they disclose in the sacred and protected space of healthcare.^{67,88} This is traditional surveillance capitalism in healthcare.

While unauthorized access violates legal, ethical, and societal norms and expectations about this most privileged communication, Big Tech has learned that apologies followed by a change in norms help establish what before was unacceptable and illegal as the only way in which users can experience the benefits of the system.

In a legal void, Big Tech not only replaces healthcare functions but also its institutions and professionals, who are no longer able to “care” with the low-cost “perfection” that their AI systems can. As Satya Nadella, CEO of Microsoft, stated in 2019, “AI is technology’s most important priority, and healthcare is its most urgent application.”⁸⁹ Under artificial care, there is no healthcare without complete data expropriation and complete human commodification, there is no healthcare without AI, there is no healthcare without Big Tech, there is no care.

4.3. The End of Clinical Encounters

With access to complete data streams across all human activities past and present, and with near infinite computational capabilities, artificial healthcare systems can constantly scan humans for “abnormalities”—what today are diagnoses and prognostic threats that demand a clinical response—and trigger overt or covert interventions to “correct” these abnormalities without patients seeking care or attending a consultation. This will render history taking and physical examination—the reasons for the clinician to pull up a chair and sit by the patient’s side—obsolete. Instead, AI agents can scan and remotely act on the patient’s body or their environment “therapeutically.” Perhaps before

they do so in some fashion, we will enter a transitional period in which AI clinical bots will conduct “visits.”

In an article in *The Lancet*, the top general medical journal, Topol and colleagues propose a path to certification of AI agents as medical practitioners. This process culminates with a certification for autonomous practice, for generalist AI clinical bots.⁹⁰ AI bots will ape clinicians’ actions, and will draw from medicine’s knowledge base and the totality of the patient’s “info-nome,” to “care.” During the consultation, these bots will extract whatever is missing from the complete human database of all human actions (and, eventually thoughts)⁹¹ that Big Tech has already harvested in both the actual and virtual worlds.



World Health Organization in Geneva, Switzerlandx. Image: Flickr - World Health Organization

Couched within the trappings of medical consultations and assumptions of confidentiality, privacy, and secrecy, AI bots, armed with the latest psychological techniques and personal information, can be very persuasive.⁹² This privileged access can be sold to the highest bidder, a core practice of surveillance capitalism. Instead of (or perhaps in addition to) serving ads, AI bots at the point of care can integrate all that is known about a patient in addition to their in-the-moment “cadence, politics, vocabulary, age, gender, preferences for sycophancy, and so on, in concert with brokered bids, to maximize the likelihood of achieving a given behavioral aim.”⁹³ The World Health Organization has already alerted state members about this threat.⁹⁴ In healthcare, ads become ad-vice.

If healthcare corrupted its mission when it became industrialized and stopped caring, the subsequent datafication and shift toward artificial “healthcare” would place healthcare provision within the services offered by Big Tech. If the evolution of platforms like Google, Meta, or Amazon are any indication, the extent to which patients and their health would be better off because of their interactions (or pervasive always-on connection) with artificial healthcare systems may stop mattering altogether. What would matter is that those with all the knowledge about humanity and all the power to shape human action—Big Tech—will have now entered patients’ homes under the pretense of giving care only to also expropriate their most holy of secrets.

A key development to consider is the apparently unending capacity of AI systems to offer sensory experiences that seem real but have no reality in the material world. The possibility of care becoming artificial, in the sense of the word that means fake and inauthentic, may turn out to be a blow to the dignity of people seeking care, a cruelty for them that their suffering is undeserving of attention from fellow people, and an insult to trust, a key ingredient in clinical care. The pervasiveness of detection and behavioral actuation appears as an innovation that offers 24/7 “care,” a redefined form of care rendered fake without accompaniment.⁹⁵ Unable to “step inside patients’ experiences and accompany them through the worst moments with empathy and expertise,” artificial care abandons the patient, who, casting about for a caring hand, now sits alone.

There will be technological solutions to ensure that what patients and AI systems present is real, perhaps solutions that will demand further intimate disclosures to allow these systems to offer some form of verification by triangulation. This solutionist approach may never fully best the uncontroversial reality, not just visual and verbal, but also of touch, smell, and time together of two people facing each other, sitting in real conversation.

5. A WAY FORWARD

5.1. To Care Is Human

Finding the way forward must start with the assertion that to care is human. Every person reading this report is able to do so because, at a critical moment, someone chose to care for and about the reader. Care starts from a moral obligation and is sustained from the realization that the patient, who needs care, matters enough to someone else to deserve their attention and to motivate the caregiver’s choice to respond to their needs and to act. While the quality, competence, and compassion of the care offered may not always be especially good, when crafted with care, it makes the patient and the clinician special to each other.⁷ The caregiver discovers through caring that they matter too.

When addressing the crisis of care, and of financial, environmental, and human unsustainability, two responses emerge as plausible. One response assumes that this is a crisis of organization, efficiency, information technology, and scale. That response calls for organizations to operate at scales of speed and reach that are only possible through Big Tech’s “artificial care,” when the idea that only people can care is abandoned.⁶ This response recalls the ouroboros, as the pursuit of health through artificial care requires more consumption of data, medications, and technologies that end up consuming resources that deprive other pro-health activities, e.g., education, and further undermine planetary health. Technological solutionism cannot address what is at stake.⁹⁶ The alternative response is to see this as a crisis of care in and of itself.⁶

5.2. On Information

Information plays a supportive role in most forms of care, but the problems of care are rarely problems of information. Most patients presenting for primary care don’t present with a diagnostic dilemma. Most treatments offered do not demand consideration of a patient’s precise prognosis or life expectancy. The complete decoding of the human genome and the provision of detailed radiological imaging have not brought about the end of disease.⁹⁷

“Care starts from a moral obligation and is sustained from the realization that the patient... matters enough to someone else to deserve their attention and to motivate the caregiver’s choice to respond to their needs and to act.”

The benefits of efforts to self-monitor and self-manage behaviors linked to health, the combined effect of education on these behaviors, promotion of wearables and apps, and the expansion in healthcare technologies and treatments pale in comparison with the effect of socioeconomic deprivation on healthy life expectancy—a 12-year difference between the most and least affluent.⁹⁸ This difference can be attributed to the effects on people’s biology and biography of politically modifiable determinants, such as social connection, adequate food and housing, clean air and water, equitable opportunities and income, and working conditions.⁹⁹ Addressing these determinants to enable people to achieve the capabilities that lead to good health is a problem of moral action, not of information.^{100,101}

A clearer understanding of care and caregiving, and of the role of information as supportive but not essential for caring, should lead us to reject the notion that healthcare is an information science, as stated by Schmidt, and instead embrace healthcare as connective labor. As described by Pugh,⁷ this is the collaborative work people do in relationship and in proximity. It is work that demands emotional recognition and resonance. It is work that changes both the giver and the receiver of care.

The pursuit of perfection in healthcare draws attention not only to the ability of automata to continuously complete tasks without flaw, but also to human limitations and fallibility. These challenges to humans caring should not call for their replacement with imitation-clinicians, but instead should call for promoting conditions that enable human-clinicians to care well.¹⁰² These conditions include developing organizations in which leaders value clinicians and their work, clinicians control their own work

"Technology can support, not just efficient, but elegant care, in which care is offered without waste and without haste"

conditions, teamwork and mutual care are enabled, and chaotic and hurried workflows are eliminated.^{35,103}

Where healthcare is lacking because of a lack of investment and an unfair and inequitable distribution of its resources, technology must be seen as a weak and temporary replacement, regardless of its capabilities. Investments should be directed instead toward reducing disparities in access to good care, lest we acquiesce to a world in which human healthcare is only for the privileged, and artificial "healthcare" is for the rest.¹⁰⁴

5.3. On Technology

Technology and information do play, however, a major role in supporting care. The broad and equitable availability of these technologies may enable the conduct of robotic interventions everywhere when perfect healthcare is highly desirable, i.e., when there is a correct, safe, and effective way to cure a problem. This may be the case with radiotherapy or surgical treatments.



X-ray of a hand, with automatic calculation of bone age by a computer software. Image: Wiki Common - Setzner1337

The role of technology is more delicate, however, in the care of patients with chronic conditions, in whom a cure is not possible, and the best approach depends largely on patient-specific interactions between their biology and biography. Information systems can collect and analyze patient data and offer tailored estimates of the likelihood that alternative courses of action may produce expected benefits and undesirable harms. They can bring forward facts in the patient's history that may be helpful in deciding what to do, such as the patient's prior experience with a medication or about unsafe treatment-treatment or treatment-disease interactions.

Technological solutions can support communication among clinicians and between clinicians and patients, and schedule encounters at the appropriate time and with adequate duration given the needs and communication styles of the parties. In these and other ways, technology can reduce the effort, time, and attention necessary to access and use healthcare, reducing the burden of treatment.^{105,106} Technology can also eliminate wasteful processes, not only for the healthcare system, but also for the patient and family.^{107,108} Technological solutions can ensure that there is continuity of care, that the consultations are not interrupted, and that the encounters in which clinicians and patients co-create responsive care are unhurried.^{109,110} In these ways, technology can support, not just efficient, but elegant care, in which care is offered without waste and without haste.

Rather than the accumulation of information, wealth, and power in the hands of those who own the means of computation, what underlies all these scenarios is the subjugation of healthcare technology to the main purpose of healthcare, which is to care, and the recognition and celebration, warts and all, of the unique role humans must play in caring.

5.4. We Need Laws to Abolish Surveillance Capitalism in Healthcare

The central role information plays in healthcare in the "imaginarium" of Big Tech must be dismantled, not just conceptually, but also operationally. That healthcare and medicine should learn, improve, innovate, and respond well to patient dilemmas with patient data processed by increasingly sophisticated, artificially intelligent, systems should not justify the appropriation of that data and the commodification of humans.

The human unsustainability of industrialized healthcare should inspire its fundamental reform. Instead, we are currently witnessing the further intensification of its datafication and "artificialization" motivated by the incalculable wealth that exists in controlling healthcare data and its use. The re-definition of care as only what technology is able to produce with such data must be rejected to contradict, interrupt, and abolish⁵¹ Big Tech's march toward becoming essential to the provision of healthcare.

A potential antidote to this undesirable progression toward artificial healthcare demands that we exert our power and reject its apparent inevitability:¹¹¹ the future of healthcare need not be artificial. It also demands that we reclaim the sacred nature of personal health data and that we put in place laws that advance that notion, restricting data ownership and control while preserving its useful ability to advance care for all. Personal health data should not be under the control of the technology systems that extract, process, store, and analyze it, but rather be given, by law, the protected status that patients and clinicians have always assumed it should have. To this end, intellectual monopolistic practices seeking all healthcare knowledge and expertise to capture and leverage the whole human info-nome⁶⁰ should

"As we invent the future of healthcare, we must remember that patients are not a cloud of data, care is not processing information, and only humans can care."

be aggressively curtailed. Furthermore, personal health data should not be for sale, and health data brokers and the markets for clinical care data must be outlawed.

This body of laws should draw from a charter of epistemic rights.¹¹² Patients need to be known by those called to care for them and only while in their care; outside of that situation, the patient has a right to not be known, and even forgotten. Participating in healthcare should not be conditional upon citizens waiving their epistemic rights and their privacy.⁸⁸ At the same time, it is in the patient's best interest for science to advance and, therefore, for the patient's data to contribute to discoveries, and for those discoveries to be translated into useful new tests and treatments accessible to all. Patients who give informed consent for the use of their data to advance science should not face their personal commodification as the cost of their altruism.

Companies that use healthcare data to offer and improve tools and services often enter into data use agreements with stewards of patient data, i.e., clinicians and healthcare organizations. Deliberative democracy methods should be mobilized, as is the case with other sensitive and private data such as those contained in biobanks,¹¹³ to formulate legal frameworks that enable intended data uses, e.g., to develop or improve caregiving or care receiving, while forbidding their use for human commodification.

The results of these efforts should be to abolish surveillance capitalism in healthcare and the participation of Big Tech companies in the governance and provision of care. These companies have proven to be, in words and actions,^{50,51} fundamentally anti-human, with their leaders repeatedly expressing disdain for people, and their brand of "longtermism" condemning the wellbeing of those here and now in exchange for better lives for those living in the far-far future.¹¹⁴ Their anti- and trans-humanism is incompatible with the humanistic goals of care, and thus, they don't belong in the clinical encounter. Their participation in healthcare should be curtailed by law to the activities most likely to produce desirable advances in supporting what humans do to give and receive care. In this way, healthcare stands as a critical front in democracy's "death match" against surveillance capitalism.⁵¹

5.5. Mattering Is the Way Forward

One does not need to be anti-technology to protect the fundamentals of care from the transmutation of this most human activity into its depersonalized, dehumanized, and disembodied replacement. Instead, clinicians and their organizations should act with moral integrity and fulfill the promise to keep patient data in holy secret. Civil society must mobilize its democratic in-

stitutions and methods to define what progress in care ought to be and the epistemically just and legitimate means to achieve it.

Healthcare professionals and patient advocates must add eliminating healthcare's dependence on Big Tech to their revolutionary work towards making care the core purpose of healthcare.²⁶ They must also demand the devolution of healthcare information and activities back to healthcare, and, where feasible, within local governance and expertise.¹¹⁵ Health data utilities, for example, are regional collaborative arrangements between communities and healthcare organizations that exclude Big Tech from their funding or governance. They form platforms for sharing and integrating data from health and healthcare sources for public good, not for commodification.¹¹⁶ Health care utilities offer another alternative for large healthcare organizations to innovate in this space according to their needs and not the imperatives of surveillance capitalism.¹¹⁷

What is at stake, however, is far more than the governance of healthcare data and activities. Ceding control of healthcare to Big Tech as it fuses with autocracies, and as behemoths such as Palantir build "to dominate"^{118,119} rather than to foster human flourishing, may very well represent the last front in the accumulation of their omniscient, global power. This must be opposed with a different vision for humanity, one based on democratic policies of care,¹²⁰ with care as the work we-the-people do to maintain, repair or improve the world—of our bodies, our communities, our planet—so that the we can live better in it.¹²¹

As we invent the future of healthcare, we must remember that patients are not a cloud of data, care is not processing information, and only humans can care. We ought to remember Marañón, and work for a future in which we find people sitting in those chairs, unhurriedly caring; mattering to each other.



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**Carr-Ryan Center for Human Rights
Harvard Kennedy School
79 JFK Street
Cambridge, MA 02138**

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79 JFK Street | Cambridge, MA 02138
carr-ryan-center@hks.harvard.edu