# Redefining Power Structures Surrounding Healthcare and Data Privacy

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**Abstract:** The following paper dives into the implications of the growing presence of the Internet and other technologies in our daily lives, especially in relation to handling healthcare data and privacy. In each section, the paper explores the associations of technologies to knowledge, power, and control in the field of healthcare. Ultimately, it warns against the increasingly exploitative nature of today's technology products which oftentimes trade personal information for usage and convenience. In addition, it discusses the benefits and potential consequences of current healthcare privacy laws. To transition into practical applications and world systems, examples such as the Mexican healthcare system are presented as case studies of how technology companies and producers can adapt their policies and products to best cater to the needs and wants of marginalized communities and populations.

**Keywords:** healthcare privacy, data, technology, knowledge, power and control

## 1. Introduction

The most misleading illusion the technology companies today can generate is the perception that their products come at no cost. What they claim may be partially true — simply accessing the Internet or creating a social media account usually has no monetary cost — yet an exorbitant cost comes in the form of users' brains and bodies in a metaphysical, unquantifiable way that transcends the material and monetary world. Google searches come at no cost because users — the searchers — often become searched themselves. Facebook and other social media accounts are often free because the product is not the platform but the users themselves.

As the Internet further increases the ubiquity of access, the largely exploitative features of technology can no longer be regarded as trivial. Especially in the context of healthcare, technology can decide a life or death issue. Technology like our smartphones or smartwatches can not only track users' every movement and conversation, but also predict their future behavior and events in their lives. This paper will focus on applications to healthcare, wherein technologies can make assumptions about individuals' health history and outcomes before we even notice them. Doctors, nurses, and other healthcare workers are no longer the only ones in control of our health. Rather, extensive networks — invisible to most — store patient healthcare data, raising serious questions regarding the privacy of patient information. Rather than combing through mounting files of paperwork about an individual, companies can utilize a simple search algorithm to cue up almost anything about a patient's health history for their advertising wants or to be "abused by a malicious insider" (Diaz and Gurses 2012). Almost everyone covered under a major healthcare provider, such as Kaiser or Sutter Health, receives care through their online system, where patients both interact with their doctors, make appointments, receive test results, and much more. Those oblivious to the data collection subject themselves to a progressively exploitative framework — sensitive information and personal data sold for large profits and positive margins with no compensation to the creators of the information themselves. The proliferation and collection of personal data and knowledge churn an overwhelming profit in an economic model known as surveillance capitalism. Surveillance capitalism, originally coined by Shoshana Zuboff, a professor emeritus at Harvard Business School, can be defined as the exploitation of privacy to churn profit (Zuboff 2019). With increasing data exploitation and surveillance capitalism, networks built through grassroots community efforts demonstrate a promising approach to reclaiming the right to healthcare privacy.

## 2. Knowledge is Control

As a whole, privacy warrants and protects knowledge as a precursor. The age-old saying declares that knowledge is power. As such, knowledge can mean predictive power over a consumer's actions, behaviors, and even thoughts — which, in turn, provides the means to control. Knowledge may never be fully defined as it requires a knowledge of knowledge itself, of which is limited through human understanding. So much is yet unknown about knowledge that ontology serves as the field of study surrounding the means of expressing and articulating knowledge (Srinivasan 2018). The basis of surveillance capitalism for big technology companies, and by consequence their source of profit, is knowledge — the more they know about their consumers, the more they can target advertisements and other marketing schemes to influence their behavior. For instance, the popular game Pokémon Go created a mass experiment that essentially herded players through specific locations and provided guaranteed footfall for establishments who paid the game to feature their businesses as hotspots (Zuboff 2019). Unsurprisingly, Google executive John Hanke incubated the game as its chief investor (Zuboff 2019). In relation to the classic framework between the state and the war machine, technology completely reshapes the two actors' interactions (Delueze and Guttari 1986). With the advent of the Internet, the war machine no longer localizes and moves between individual bodies but instead exists as an extension of the very body itself. In modern society, the war machine can be likened to big technology companies whose sole purpose is to exploit and extract. For large companies, physical territories and borderlines have been rendered useless to their efforts through accessible networks that do not require an existence in material space (Deleuze and Guttari 1986).

## 3. Knowledge Applied to Healthcare

In the field of healthcare, knowledge revolves around science and patient data. In the Enlightenment era of the 17th and 18th centuries, science became increasingly popularized as universities, societies, and other academies emerged as centers for individuals to deepen their scientific knowledge (Srinivasan 2018). At the time, however, the so-called "centers for public knowledge" limited access primarily to rich white males who uncoincidentally wielded the most power in society (Srinivasan 2018). Today, science itself represents a local knowledge body conducted in different places by different people of different backgrounds that cannot be fit into a one size fits all model. Scientific knowledge extends beyond its common associations with Western medicine, which can sometimes demonstrate apparent contradictions with healthcare knowledge generated by communities (Verran 2002). The scientific method may provide general guidelines for how an experiment should be conducted and how results should be analyzed, but the limits of scientific exploration are endless.

In the scope of the medical field, knowledge is also limited to Western standards in the United States. Western medicine rarely incorporates the herbal medicine used so commonly in the East, regarding treatments such as acupuncture almost as an entirely different branch of study (Lam 2001). Furthermore, healthcare knowledge still exists within the sovereignty of the few. While doctors' expertise can prove essential for the general public, the rest of the general population, specifically those who do not regularly attend doctor's appointments, are left out of the loop. The definition of health, albeit primarily liminal and existing within a fluid jurisdiction, largely adheres to medical advice and parallels medical training. Especially in low-income communities and racial minority populations, there exists an inherent mistrust of the medical system and healthcare providers due to "continuous and repeated discrimination, racism, and harmful experiences" throughout history (Bogart et al. 2021). Most notably, the U.S. Public Health Service's Syphilis Study at Tuskegee conducted in the mid-1900s left lingering feelings of animosity toward the healthcare system in communities of color. Especially as participants and their families were only compensated $37,500 or less, communities of color remain wary of the healthcare system repeating the practice of exploiting minorities and conducting unethical experiments on them for profit and knowledge without their knowledge or consent (Bogart et al. 2021). As a result, they feel more hesitant to receive medical treatment and follow doctors' advice, from the COVID-19 vaccine to following healthy lifestyles such as regularly exercising (Bogart et al. 2021). On the other hand, they may be more receptive to alternative forms of medicine such as herbal treatments or natural remedies from Eastern practices, especially as they have been reliably used for hundreds of years (Lam 2001).

## 4. Introduction to Healthcare Privacy

The gravity of responsibility of knowing a patient's health history and habits, of having a patient confide in them, lends itself to the intensive training doctors must undergo. The most uncomfortable moments of a doctor's visit may be the answering of lifestyle-related screening questionnaires, which ask personal questions that one's parents may not even want to be privy to: Do you drink? If so, how much alcohol have you consumed in the past week? Do you have a history of sexual intercourse that could put you at risk of sexually transmitted diseases? Have you had adverse childhood experiences in the past? Oftentimes, doctors may ask the patient directly during an appointment. Within the walls of a hospital room, where patients are given the option to have a parent leave, the conversations foster a sense of confidentiality between physician and patient. But what happens when computer networks can extend information past the confines of a building?

The increasing shift to online data collection of patients' health history, test results, and other data raises a longstanding ethical question about individual rights to privacy. When individuals share personal healthcare information with doctors, which later becomes stored in medical records and databases, who else should be able to access the information? Privacy hinges particularly on society and social norms. In the United States, the Health Insurance Portability and Accountability Act (HIPAA) of 1996 currently sets the guidelines for what can and cannot be shared about an individual (U.S. Department of Health & Human Services 2000). In total, it lists 18 identifiers that are known as personal health information (PHI), such as names, Social Security numbers, and medical record numbers.

Online medical systems, although much more convenient and accessible to the common user, come with a dangerous sacrifice: privacy. What happens when private information becomes theoretically available to anyone who can bypass a system's security firewalls? What is the value of secrecy or privacy in a world where it seems to be gradually shrinking in significance? What does it mean to reclaim one's right to privacy, especially in regards to one's own body?

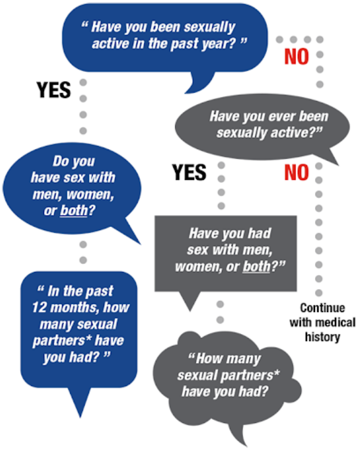
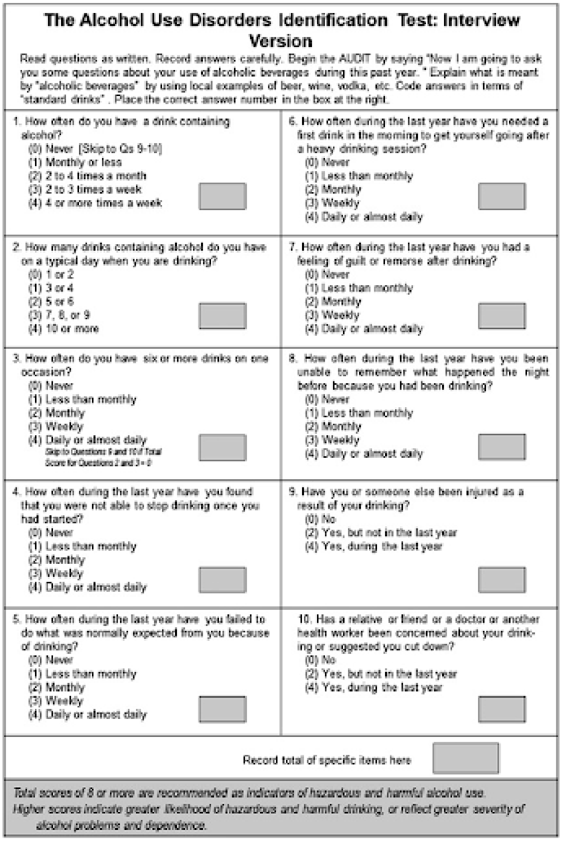

" Have you been sexually active in the past year? "
YES
NO
Have you ever been sexually active?"
Do you have sex with men, women, or both?
YES
NO
Have you had sex with men, women, or both?"
" In the past 12 months, how many sexual partners* have you had? "
Continue with medical history
"How many sexual partners* have you had?

**Figure 1:** A flowchart provided by the Center for Disease Control and

Prevention that delineates how doctors can approach questions about sexual history (Center for Disease Control and Prevention 2018).



**The Alcohol Use Disorders Identification Test: Interview Version**

Read questions as written. Record answers carefully. Begin the AUDIT by saying "Now I am going to ask you some questions about your use of alcoholic beverages during this past year." Explain what is meant by "alcoholic beverages" by using local examples of beer, wine, vodka, etc. Code answers in terms of "standard drinks". Place the correct answer number in the box at the right.

1. How often do you have a drink containing alcohol?
   (0) Never [Skip to Qs 9-10]
   (1) Monthly or less
   (2) 2 to 4 times a month
   (3) 2 to 3 times a week
   (4) 4 or more times a week
   □

2. How many drinks containing alcohol do you have on a typical day when you are drinking?
   (0) 1 or 2
   (1) 3 or 4
   (2) 5 or 6
   (3) 7, 8, or 9
   (4) 10 or more
   □

3. How often do you have six or more drinks on one occasion?
   (0) Never
   (1) Less than monthly
   (2) Monthly
   (3) Weekly
   (4) Daily or almost daily
   Skip to Questions 9 and 10 if Total Score for Questions 2 and 3 = 0
   □

4. How often during the last year have you found that you were not able to stop drinking once you had started?
   (0) Never
   (1) Less than monthly
   (2) Monthly
   (3) Weekly
   (4) Daily or almost daily
   □

5. How often during the last year have you failed to do what was normally expected from you because of drinking?
   (0) Never
   (1) Less than monthly
   (2) Monthly
   (3) Weekly
   (4) Daily or almost daily
   □

6. How often during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session?
   (0) Never
   (1) Less than monthly
   (2) Monthly
   (3) Weekly
   (4) Daily or almost daily
   □

7. How often during the last year have you had a feeling of guilt or remorse after drinking?
   (0) Never
   (1) Less than monthly
   (2) Monthly
   (3) Weekly
   (4) Daily or almost daily
   □

8. How often during the last year have you been unable to remember what happened the night before because you had been drinking?
   (0) Never
   (1) Less than monthly
   (2) Monthly
   (3) Weekly
   (4) Daily or almost daily
   □

9. Have you or someone else been injured as a result of your drinking?
   (0) No
   (2) Yes, but not in the last year
   (4) Yes, during the last year
   □

10. Has a relative or friend or a doctor or another health worker been concerned about your drinking or suggested you cut down?
   (0) No
   (2) Yes, but not in the last year
   (4) Yes, during the last year
   □

Record total of specific items here □

*Total scores of 8 or more are recommended as indicators of hazardous and harmful alcohol use.*
*Higher scores indicate greater likelihood of hazardous and harmful drinking, or reflect greater severity of alcohol problems and dependence.*

**Figure 2:** An example of the Alcohol Use Disorders Identification Test (AUDIT), a screener for alcohol disorders.

## 5. The Importance of Privacy Concerning the Body

Technologies like the cellphone have become increasingly omnipresent in one's everyday life. For instance, a 2019 Pew Research Center study found that 96% of Americans own a cellphone of some kind

(Pew Research Center 2019). Due to their portable nature, cell phones and other technologies go wherever their owners go. As technology increasingly manifests as extensions of ourselves and our bodies, what it means to be human and what it means to be in control of our bodies have simultaneously evolved (Deleuze and Guttari 1986; Mbembe 2017). Just as one's life story can be gleaned from "permanently available" social media profiles through a readily accessible Google search, so too can one's biological makeup and function be predicted from one's online health profile (Solove 2015). The tradeoff with social media tools, which can "simultaneously support grass-roots political mobilizations as well as government surveillance and human rights violations," applies to online healthcare tools as well (Coleman 2010). The frequent calls for transparency pervade today's society, whether it be about politicians or large corporations. They can be equated to "wars on secrecy," but little regard goes toward the implications of such endeavors (Mbembe 2018). What is sacrificed when secrecy becomes abolished and transparency of the body becomes widely circulated? What power does that accord to those aiming to exploit and extract the very means of movement? When technologies can reveal our bodies in full transparency, it also exposes the very essence of who we are and the "truth of who we are" that is oftentimes "hidden inside our bodies" (Mbembe 2018). The continual erasure of privacy concerning our bodies parallels the erasure of the distinction between humans and objects as technologies constitute more and more of our daily lives (Mbembe 2017). While the blurring of lines between humans and objects can be regarded as almost emancipatory, there also exists a perennial devaluation of privacy, which may be worth more than millions to innovators of technology. Little would distinguish a list of human traits from mere descriptors that can also be applied to animate or inanimate objects. At the root of it all, giving up privacy also means giving up the "liberal individual" who could be the "subject of democracy" (Mbembe 2017).

The loss of democracy and declining privacy of our bodies lends itself to a serious collective action problem that nevertheless still has the potential to be reversed through law and democracy (Zuboff 2019). Individual privacy is largely provided by societal norms which dictate against intrusions, such as peeking into a neighbor's window or into people's data files, as society recognizes that it would be "suffocating" without privacy protection (Solove 2015). The widespread storage of biometric and sensitive healthcare data by companies and government systems raises serious ethical questions. When it comes to storing sensitive information, such as health history, identifying information, and taking extra privacy measures, only HIPAA acts against doing so. Societal norms value the appearance of privacy despite technologies increasingly threatening the status quo, adhering to how "the law should protect privacy not because we expect it, but because we desire it" (Solove 2015). When it comes to the hacking and mishandling of biometric data, the law should protect privacy beyond the surface because it is necessary.

## 6. What Privacy Does HIPAA Provide?

A combination of HIPAA and the 2009 Health Information Technology for Economic and Clinical Health Act (HITECH) attempts to protect personal healthcare information from organizations that can capitalize on the data for marketing or other purposes (Burde 2011). Combined, they stipulate regulations on what health providers and health insurance companies can share with other organizations. HITECH expands upon HIPAA in the realm of sharing electronic PHI (ePHI), extending HIPAA's restrictions to businesses in partnership with healthcare-related companies or providers (Burde 2011). In addition to physical safeguards of patient data, healthcare entities must also create technical safeguards such as firewalls and encryption to protect electronically stored data. Under HITECH, patients requesting access to their data must be granted access within thirty days (Burde 2011). The primary purpose of the HITECH Act, however, was to persuade healthcare providers to transition to ePHI recordkeeping to "improve the quality and efficiency of care delivered" (Adler-Milstein and Jha 2017). As a result, hospitals adopted electronic health records at nearly 15% annually, a staggering increase from 3.2% before the passage of the act (Adler-Milstein and Jha 2017).

Even though the HITECH Act reinforces previously lax HIPAA stipulations with penalties that can go up to $1.5 million in total, businesses can still find ways to fly under the radar and bypass compliance to continue their practices of surveillance capitalism (Burde 2011). Nevertheless, the Human and Health Services seems to be moving toward incentives over punishments. For instance, a recent amendment to the HITECH Act passed in January 2021 will award more favorable ratings to businesses in compliance with HIPAA regulations (Hartsfield 2021).

## 7. When Data Storage and Systems Go Wrong

What HIPAA and its amendments cannot protect, however, are several surrounding loopholes and calamitous instances of cyberattacks. When privacy becomes violated and knowledge rests in the wrong hands, healthcare systems can be severely compromised. When hospitals and other clinics rely on online databases to operate and store patient data, they become extremely vulnerable to criminal activity that interferes with their systems (RSI Security 2020). It is no longer localized to one or a few facilities but a vast network of interconnected healthcare facilities across the globe. For instance, Universal Health Services found themselves the victims of a ransomware attack worth $67 million in losses in September 2020 (Lyngaas 2021). Scrambling to take back the reins of their system, information technology employees were forced to reroute ambulances to competitor hospitals and delay patient billing and other information for a few months (Lyngaas 2021). Although no system, online or physical, can be completely impenetrable, it is alarming that one of the largest healthcare providers so easily lost control of its computer networks. With the data breach, not only did the health network lose much of its revenue, but it also leaked treasure troves of data to the hackers responsible. The Universal Health Services attack represents simply one out of the many cyberattacks that have transpired and will transpire in the future. While robberies of physical files likely occurred just as often as that of electronic information, the large-scale databases can be extracted in a matter of seconds (RSI Security 2020). Society's collective behavior will tell which side will ultimately win out in the security race between those enforcing security and those looking to crack it.

## 8. Approaching Privacy Protection

Objects subject to the natural laws of entropy inevitably break and wear down over time. With material foundations, Internet technology also constitutes objects that gradually wear down physically (Srinivasan and Bloom 2020). Code can break, malfunction, and fail to run. In the framework of cyberattacks, code can be manipulated and heavily exploited. Devices such as smartphones, laptops, and tablets can be easily shattered into glass pieces in a moment of ineptitude. In order to approach digital healthcare privacy through the lens of law and societal norms, broken world thinking, which focuses on channeling creativity and innovation toward repair, must be first considered (Jackson 2014). As a result, sustainability is prioritized, and existing technologies can be strengthened through the repair process before creating temporary patches for deeper issues. The HITECH Act embodies broken world thinking; focused on dissolution and change instead of outright invention, the act allows healthcare providers to adapt previously paper-based files onto a digital network without having to create new files themselves. Electronic health records live in a constant state of repair, addition, and repurposing as patient healthcare metrics evolve and are updated (Jackson 2014). In addition, improving current systems of storing electronic health records are oftentimes easier than inventing new systems as a whole.

An appropriate repurposing of a famous quote from Leo Tolstoy's *Anna Karenina* addresses the ever present risk of data breaches in such electronic healthcare systems: "All working technologies are alike. All broken technologies are broken in their own way" (Jackson 2014). Just as no perfect human being or family exists, objectively speaking, no perfect technology exists. Therefore, all existent technologies, especially electronic healthcare systems, represent the latter of Tolstoy's preface into the classic novel.

## 9. The Pitfalls of Imperialistic Thinking

Non healthcare-related issues of privacy that relate to technology generally cloud over issues specific to the healthcare sector. The surveillance capitalistic frameworks that many companies follow must first be prefaced by discussing imperialist attitudes upon which they hinge and severely jeopardize user privacy. Religious parallels are often drawn to technology, likening the Internet to a God or Savior of sorts (Srinivasan and Bloom 2020). When European colonists arrived in Africa on missionary trips to spread the gospel of Christianity, they invoked religion as the primary driving factor for their actions. Yet in addition to preaching about their Savior Jesus Christ, they also largely assumed a savior complex toward the indigenous communities they colonized. The viewpoint of the colonized population as inferior can now be dubbed imperialistic thinking wherein the humanity of communities is neglected and the main modes of interaction involve extraction and exploitation of labor, data, and much more (Crawford and Joler 2018). Stretched even further, imperialistic thinking no longer regards colonized populations as human beings. The same perspective endures today wherein society looks well upon those who donate to developing countries or work directly with poorer countries, even though underlying motives for such ventures may easily bleed into imperialism. For instance, the presence of other major corporations in the area, such as Uber, only take profit and customers away from local businesses, such as the matatu minivan services (Srinivasan 2019). The actual benefit of increased transportation services that Uber provides is little to none. More often than not, introducing new technologies to developing countries does more harm than good to the population — the term "pilotitis" was specifically coined for new technologies that failed past the pilot phase (Srinivasan 2019). Even if approached with non-imperialistic intentions, "sending aid is not always a panacea" (Srinivassan 2019).

Ron Eglash, a professor at the School of Information at the University of Michigan, demonstrates the slippery slope of imperialistic thinking through his study of African fractals. Although having studied the subject for several years, Eglash's work seems to simplify the essence of African culture with a mathematical and algorithmic metaphor. The humanity etched into the "diversity of African cultures" becomes transformed into robotic and objective forms of data collection instead (Eglash 2007). While Eglash only goes so far as to view African communities through the lens of data and algorithms, others directly affect disadvantaged populations through aid-based programs or organizations. For instance, the One Child Per Laptop (OCPL) project aimed to execute exactly what the organization's namesake delineates: to provide access to a laptop per child for lower-income countries (Philip et al. 2010). By selling low-cost laptops at a wholesale price to developing countries and promising a one-to-one model for its donors, OCPL wanted to contribute better technological resources under the philosophy that a "laptop can turn the lives of these children around" (Philip et al. 2010). Although noble in its initial mission, the undertones apparent in one of OCPL's advertisements tells another story. In a chilling video, the organization contrasted the images of "Asian and African children hunched in manual labor" and "an African boy dressed shooting an automatic firearm" with "African boys wearing collared shirts engrossed in the iconically green XO laptop" (Philip et al. 2010). In a mere thirty seconds, the video encapsulated several tropes and negative stereotypes associated with children from lower-income countries. Through the visuals displayed on screen, the OCPL presents the laptop as an all-encompassing savior, just as religious missionaries had proclaimed when colonizing the ancestors of the OCPL's service recipients (Philip et al. 2010). The OCPL broadcasts the message that kids need "the right tools" to thrive and grow in a positive environment but disregards a crucial part of the journey in getting there. Supplying someone with a computer is rendered useless unless they actually learn how to use the device itself, and the OCPL ultimately failed to address how children can take advantage of the new age of “postcolonial computing” to truly effect the “end of colonialism” and the “end of exploitation” (Philip et al. 2010). It is unsurprising that a few years after its initial launch, the project failed to both bolster students’ learning in the classroom as well as turn its laptop and other products into a profitable endeavor (Robertson 2018).

The same parallels can be drawn to solutions surrounding healthcare privacy where imperialistic thinking can alleviate surface-level issues in the short-term, but ultimately leave the communities “served” in worse shape than they were before in the long run. It may not be enough to administer healthcare services, collect patient data, and conduct research with populations starved of regular healthcare treatment, but rather impress a more sustainable model of care that the local community can implement itself (Skinner 2019). It is not enough to simply make assumptions about the community and its wants and needs, but rather becoming immersed in the community allows technology innovators and service deliveries to analyze the needs of the community (Skinner 2019).

## 10. Shifting the Focus to Local Efforts: Case Study of the Mexican Healthcare System

Several examples of community-based technological networks demonstrate that they are often the best solutions toward erasing the growing digital divide. As healthcare moves to an increasingly digital format, from telemedicine to online appointment systems, technologies adapted by local communities may prove necessary for improving the quality of care and preservation of privacy. Instead of assuming an imperialistic point of view, those working directly with communities developing technologies need to first understand the complexities of the interactions at play — both the assemblage as a whole and within its individual parts.

For instance, in Australia, the Yolngu Aboriginal Community engages in a specific ritual process for managing the ecological landscape that has been practiced for centuries. Members engage in “worrk,” a practice they describe as “setting fire to a bush and managing that fire” (Verran 2002). In worrk, community members engage in a planning and burning process through “wanga,” as “people-places” or “clans-lands,” that regards people and places as “one entity” (Verran 2002). Although controversy surrounds the efficacy of worrk in the scientific community, worrk has been a practice among the Yolngu Aboriginal community since long before European settlers set foot in Australia (Verran 2002). The scientific counterpart to worrk is commonly known as prescribed burning, otherwise known as scientific land management firing. Prescribed burning follows specific protocols that rely on accumulating data and “applications of generalizations about interactions between plants, soils, fires and weather” from previous scientific studies (Verran 2002). Despite the differences in process between worrk and prescribed burning, both express a “collective memory that embed evaluative witness” and provide a more personal meaning to land management firing (Verran 2002). Both worrk and prescribed burning practices constitute their own ritual processes with different reasonings and justifications that lead to the same outcomes of sustaining the ecological landscape and continuing land management. As a result, worrk should be respected as a valid practice among the Yolngu community and integrated within modern scientific practices (Verran 2002).

Mexico demonstrates another example of prioritizing community needs when developing infrastructure. Neighboring the United States directly to the south, Mexico’s healthcare system exemplifies the necessity of comprehending the ins and outs of the infrastructure of the individuals and communities it serves. Under current president Andrés Manuel López Obrador (AMLO), the country transitioned to a centralized healthcare system called INSABI and eliminated the 2003 Seguro Popular reforms previously in place (Reich 2020). Previous criticisms of Seguro Popular can be summed up in AMLO’s quote, “ni es seguro, ni es popular,” which loosely translates to “neither is it sure, nor is it popular.” Despite promising universal coverage of both the population and of services, Seguro Popular delivered neither, instead resulting in several out-of-pocket expenses and widespread corruption (Reich 2020). On the other hand, INSABI does not require a registration system or any out-of-pocket expenses for the services and supplies covered. However, INSABI does not provide as many services as Seguro Popular did and more specific procedures or services, such as surgeries, chemotherapy, and dialysis, would have to be paid fully out-of-pocket (Vallejo 2020).

The implications of switching to INSABI are far-reaching for rural or poorer communities historically denied adequate access to healthcare and proper treatment. Several barriers to healthcare access exist in lower-income communities and INSABI both helps and harms them. While all Mexican citizens would be covered at no extra cost, those suffering from chronic diseases such as cancer and kidney failure will have to pay out-of-pocket to receive proper treatment (Vallejo 2020). Therefore, further evaluation of INSABI's effects on more disadvantaged communities in Mexico should include direct input from individuals from such communities.

Given the recent COVID-19 pandemic, Mexico has followed suit from other first-world countries and shifted its health services online toward telemedicine efforts under the INSABI framework. Since many from local rural communities in Mexico cannot afford transportation to and from medical facilities, especially as they are often at least 60-90 minutes away, the INSABI network provides coverage for them online (Vallejo 2020). Telemedicine provides access to those without transportation and therefore offers a promising alternative to healthcare treatment. For those with chronic illnesses, it may be essential to saving both money and time from frequent hospital visits. Nevertheless, Latin America as a whole lacks regulation on telemedicine and other digital technologies compared to the United States. Mexico is only one of two countries with an "independent national data protection authority"— its version of HIPAA involves the General Health Law and regulations on other medicine-related supplies and services (Guerrero and Beach 2020). However, the government exacts no regulations over software within digital apps. As a result, features such as location tracking or monitoring real-time information about a user or patient on the app are not subject to any consent requirements or regulatory approval (Guerrero and Beach 2020). The question surrounding privacy resurfaces: what does privacy cost and what does it mean in an unregulated digital age?

## 11. Reclaiming Technologies from Larger Corporations

Recent grassroots efforts, especially among indigenous communities, to restore and reinvent technologies to cater to local populations exemplify a solution that strays away from relying on larger technology. A local community in Oaxaca, Mexico, for instance, built an entirely community-based media framework that broadcasts news and entertainment to villagers (Srinivasan 2019). In Australia, a consortium of five Aboriginal communities collaborated to develop the Outback Digital Network in 1998, also known as the Tanami Network (Sawhney and Suri 2008). The network consists of multiple projects, all of which serve to connect the communities together — for instance, the First Voices project preserves each tribe's language in digital format while the Storyscape project promotes storytelling via audio and videotapes (Sawhney and Suri 2008). Created entirely separate from mainstream technologies, these networks are not subject to the privacy concerns that major search engines such as Google impose on their users. There stand no substantial barriers toward repurposing or expanding the technologies to better healthcare treatment for the communities as well. Indigenous communities in the United States, as well as other disadvantaged populations, can follow the example of the Tanami Network and the one established in Oaxaca to reclaim their own healthcare treatment from the status quo shown to them by larger healthcare providers and companies. Despite losing the centrality of streamlined databases with a more far-reaching healthcare system, the localization of networks has the advantage of being less vulnerable to large-scale data breaches. In fact, doing so may begin to rebuild the trust so irretrievably broken in Hispanic and Black communities who have been historically mistreated and undermined by the American medical system (Bogart et al. 2021).

## 12. Conclusion

Privacy surrounds the accumulation of knowledge about an individual. The gradual lack of privacy from technology-based corporations and organizations, especially in healthcare, has dangerous implications for the future. While much about healthcare technologies can be met with startling optimism regarding privacy, much can also evoke extreme cynicism. Nevertheless, the emergence of practices such as telemedicine and storing health data online is still relatively new, having been popularized only within the last ten years, with even the birth of the Internet itself being less than 100 years old. Surveillance capitalism is "barely 20 years old in the making, but democracy is old" (Zuboff 2020). With such novelty comes the malleability and flexibility to evolve and improve for the better. Transparency should not be seen as the be-all and end-all, but rather a privilege that those with access should tread carefully on. Privacy, on the other hand, should be treated as a right instead of a privilege. Despite its limitations, the HITECH Act exemplifies a promising starting point for laws surrounding the management of digital healthcare information in the United States and other countries like Mexico. Ultimately, studies of local networks provide the best framework for recovering the right to privacy and confidentiality in the realm of healthcare, especially to disadvantaged populations who have been exploited the most. To do so, however, requires a thorough understanding of how local communities function and interact in the first place and a dismissal of imperialist attitudes when formulating solutions.

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