

# **HEALTHCARE INNOVATION AND PATIENT TRUST IN THE UNITED STATES**

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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## **HEALTHCARE AND THE CURRENT LANDSCAPE OF PATIENT TRUST**

Secure healthcare depends upon the physician-patient relationship, the security of personal information, and the affordability of care. Billions of dollars in government funding goes to the healthcare system as a whole each and every year, being divided amongst innovation, research, infrastructure, and essential services to the US population. Healthcare expenses occupy 17% of the national GDP, and are expected to grow 5.1 percent from present time to 2030 (CMS, 2023; Kaplan, 2021). With such rapidly advancing infrastructure, it is certain to say that medical technology infrastructure growth has provided the opportunity for successful treatment of previously incurable ailments. Medical technology has yielded major developments such as lab-grown cartilage implants for severe joint injuries (OSU, 2015, n.p) and neural network HR tracking for fitness recommendations (UCSD, 2019, p.3), but it has also complicated realms in security, patient rights, care efficacy, and equity. The advent of online record keeping, wearable health tracking, and technology/medicinal developments for just about every complication are just some of many related subjects that show effectiveness despite carrying unique issues. With online storage and personal tracking comes security and privacy concerns, and with any development comes distribution, accessibility, and pricing concerns. These innovations come at a time where the debate within healthcare is already controversial, with any deficit affecting patient trust. For example, researchers at the University of Chicago found that one third of physicians and patients distrust the US healthcare system (NORC, 2021, n.p). Healthcare has been well established as an issue that extends care ethics, becoming one of the most debated political standpoints in recent times. The pandemic continues to bolster the issue, with the advent of COVID contributing to a decrease of 10% regarding trust in the Center for Disease Control (CDC), critical infrastructure within the United States government (Pollard, 2021, n.p).

Rising care costs and health data vulnerabilities can compound distrust. Present issues within communication through the healthcare system and the growing divide between patients and their care providers leave many confused, isolated, and without proper help and guidance. Divisive controversies in healthcare, such as public health responses to coronavirus and the overturning of *Roe v. Wade*, exacerbate the problem. Like with any industry, the insurance of resilience within new systems is paramount to productivity and safety of subjects involved. When considering healthcare, system infrastructure, and the ramifications of innovation within the current economic structure in the US, millions of lives are truly on the line each day. With the uncertainty of healthcare in the U.S, how much are current healthcare system implementations contributing to patient dissatisfaction? This paper will explore this topic through utilizing actor-network theory to identify internal and 3<sup>rd</sup> party influence on healthcare development infrastructure, specifically within medical treatment, physician care, research, and emergency services. Understanding the level of involvement of each party and their interactions within healthcare is crucial to understanding where to properly enforce policy for the benefit of patients and their treatment options. Issues will be explored through the lens of cost, accessibility, human rights, and care ethics.

### **COST AND AFFORDABILITY DISPARITIES IN TREATMENT**

Debates within the true presence of accessible healthcare in the US is controversial, with contending opinions. The American Association of Retired Persons (AARP) contends that “older Americans need affordable health care services and prescriptions”; which advocates for public policy that would reduce insurance premiums and drug costs for old people (AARP, 2017, n.p). For those uninsured, the affordability gap only widens. The cost effects have sometimes caused personal bankruptcies, even among the insured (Institute of Medicine, 1991; Himmelstein et al.,

2009). In the tradeoff between expensive, state-of-the-art medicine for the well insured and affordable healthcare for all, the U.S. healthcare system has favored expensive care. According to Dr. Madara of the American Medical Association (AMA), “The lack of transparency in health care pricing and costs is primarily the result of a health care financing system that depends

largely on the complex arrangements between and among employers, third-party payers, providers and patients” (Madara, 2018, n.p). Within the greater healthcare system, a complicated network of users populates the indoctrination process of emerging technologies on both the private and public stage. This is outlined in Figure 1 utilizing the Actor Network Theory (ANT) to illustrate interactions between

each sector, allowing ease of visualization for investigating primary causes into systemic communication issues (Cresswell, 2010, n.p). ANT

outlines both objects and concepts to explore relationships and interactions, typically within a transient network framing. Actors are those within the system that directly affect and interact with the model being explored, within this context being an emerging technology for record keeping. The example used shows development, testing, and adoption of a simple medical

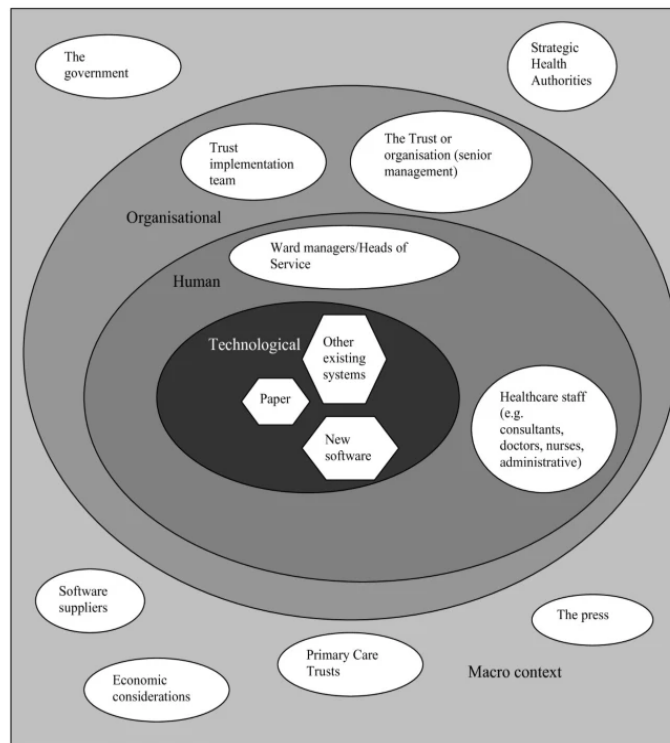


Figure 1: Actor Network Model: The detailed contexts of analysis within the development, review, research, and distribution of emerging healthcare technology. This model further explores these relationships by providing those involved within general realms of concepts, highlighting the multidimensionality and complexity of the process (Cresswell, 2010, n.p).

records network. Context and implication are explored within the multiple dimensions of operation, with a macro context outlining use cases and distribution of technology. Using this model, organizational context actors can be identified as partial influence on pricing, access, and implementation. A similar rollout and process model would be followed for implementation of my technical capstone project, involving both data storage for human chronotype preferences, scheduling, and private general health and heart rate information constantly transmitted and stored. An example of this is a current advocacy point making its way into public healthcare, price transparency: especially within contexts of hospitals and emergency treatment. However, complications arise with further considerations of external motivation and interest, resulting in roadblocks. Mandatory price transparency was imposed in 2021, but according to Patient Rights Advocate (PRA) only 14 percent of hospitals comply with the new standards. According to PRA, “This acceptance of the failing status quo is offensive” (PRA, 2022; Lyons, 2022). This shows the interaction and coupling of the organizational sub-context being influenced by factors such as economic motivation, care trusts, press, and internal human systems such as healthcare staff, which possibly contends hospital willingness to publish full pricing transparency.

## **DATA SAFETY AND SECURITY**

While healthcare is considered critical infrastructure to the US Government, it operates continually as the highest category for data breach cost (IBM, 2022; Ponemon, 2022, p.36). The study additionally notes that 22% of participants within the study noted human error as cause for breaches and 25% reported IT issues as cause for loss of private patient information (p.36). Separated from internal issues, criminal attacks have become the number one cause of data breach in healthcare, according to a 5-year trend study (Ponemon, 2022, p.1). Another notice from the Federal Bureau of Investigation (FBI) found that “53% of connected medical devices

and other internet of things (IoT) devices in hospitals had known critical vulnerabilities” (FBI, 2022, p.2). If patient data is subsequently breached in any of these circumstances, possibilities such as financial fraud, identity theft, and harm to both organization and patient reputation have significant chances of occurring. Residual effects of these events include the waning of patient trust in the overall system, frequently associated with non-disclosure of vital health information out of fear of violated privacy and/or confidentiality. A large contributing factor to this situation is the use of legacy systems in medical infrastructure for record keeping. Legacy systems as mentioned are used long term due to their cost efficiency and lack of need for transitioning labor and compliance, at the tradeoff of security vulnerabilities due to outdated software and hardware. As hardware in healthcare systems have revolving lifespans of 10-30 years of use, attacks taking advantage of this security risk have sharply risen. As more and more patients are affected, more continue to lose trust in healthcare providers’ ability to keep them and their information safe. According to a 2020 study, it is found that “patients with higher trust in provider confidentiality have significantly lower likelihood of reporting having ever withheld important health information and lower likelihood of thinking it is important to find out who has looked at their medical records" (Lott et al., 2020, p.1). Additionally, those using legacy systems are hesitant to upgrade their technology, as the difficulty and cost of transition, training, and integration of new systems outweighs the present risk in economic contexts.

## **CONFLICT OF INTEREST AND DATA ACCESS**

Third parties additionally can threaten the privacy of patient information. Health devices such as fitness watches and trackers store substantial personal health information but remain unregulated. Since Roe v. Wade was overturned in June 2022, patient advocates have stepped up their demands for privacy. Data from phones and other personal devices can yield evidence of an

intention to seek an abortion. According to the Center for Democracy in Tech (CDT), “most data can be ‘reproductive health data’ if it is used for such purposes, even if it appears unrelated on its face.” CDT demands data encryption to protect the public (Lapperuque et al., 2022, p.1). This information can then be accessed via third-party selling or subpoena, increasing the opportunities of harm for marginalized communities. Daly Barnett, staff technologist at the Electronic Frontier Foundation (EFF), calls for data security following the overturning of Roe, warning that “patients, their family members and friends, doctors, nurses, clinic staff, reproductive rights activists, abortion rights counselors and website operators, insurance providers, and even drivers who help take patients to clinics may face grave risks to their privacy and safety.” According to Barnett, “other legislation that does not depend on deputizing ‘bounty hunters,’ but rather criminalizes abortion, presents even more significant risks” (Barnett, 2022, n.p). This instance provides an example of how sensitive personal data can truly be, and the significance in extending privacy rights to personal data especially within the medical context. Legal implication tied to personalized health data is a red herring for citizens who value preservation of individual rights and freedoms, therefore reducing their willingness to seek proper medical consultation for legitimate issues as discussed above. Additionally, government access with legitimate consequence creates a power disparity within technology access, serving to bolster mistrust in care systems in fear of malicious intent. A written statement for the House Judiciary Committee hearing on U.S. government data access states, “By entering voluntary contracts with data brokers, without a court order or probable cause warrant, U.S. law enforcement and intelligence authorities are moving in a direction that enables monetary purchases of bulk data troves from private information aggregation services with significantly less judicial oversight and public transparency” (Chin, 2022, n.p).

## **DISTANCING OF PATIENT-PHYSICIAN RELATIONSHIPS**

Another unexpected byproduct of the combination of technology and circumstances brought about by the pandemic was the advent of telehealth and alternative sources of at-home healthcare. This form of tele-health has provided great opportunity and access to needed health related services, however continue to carry the reputation of being less legitimate than medical practice facilities. Understanding and trust in a healthcare provider's competency is proven to be a key component in patient willingness and trust, and many organizations fail to recognize its importance, leaving a lasting impression for the industry's general reputation. According to a 2017 study on health outcomes, there is a significant correlation between trust and patient satisfaction, with trust in healthcare professionals additionally contributing towards high ratings of wellness and quality of life (Birkhäuer et al., 2017, p.1). While this form of healthcare has significant capability to help close disparities within healthcare access, attention needs to be given to providing foundational reassurance in proper care when compared to traditional care facilities. An additional consideration is the range of accessibility within telehealth and technology ownership. As COVID-19 greatly affected healthcare in-person and served as the tipping point for remote health to become dominant, "challenge of the sudden need for massive expansion of telemedicine services and clinical challenge for the physicians and patients to adapt to this new modality appear to be important" and would have greater complexity and implications when dealing with lower- and middle-class income groups (Ghosh et al., 2020, n.p).

## **INDUSTRY INFLUENCE AND MOTIVATION**

Motivations and conflicts of interest within the healthcare system are deeply complex and multifaceted even excluding the present threats that unchecked technological innovation brings about. As the need for additional data collection, research, testing, and integration occur for life-



saving technologies, risk grows without the proper safeguards in place. However, human interest plays a role as conflict in this measure for resilience, as the financial structure of healthcare has shifted towards personal interest. A 2004 study postulates that “a common theme across markets was that harsh business realities had left physicians feeling financially beleaguered, forcing them to become more business-oriented” (Pham, 2004, p.1). This presents an ethical dilemma between ensuring guarantee of resources for needed innovation, while keeping the best interests of the patients that require care. Ensuing possibilities within this thesis will use the three frameworks to orient solutions: Utilitarianism, Virtue Ethics, and a Principle-Based Approach. Utilitarianism is defined as the viewpoint that “the morally right action is the action that produces the most good” (Stanford, 2009, p.1) which shares orientation with the healthcare industry as a service built to ensure the health and safety of its constituents. With this framework, policy and safeguards shall focus solution-based practice on healthcare accessibility and equity, while ensuring that constituent rights, privacy, and security are maintained through the development and funding process. This framework conflicts with financial motivations of the healthcare industry however, as the shift towards favoring expensive treatment options continues to grow with health insurance policies allowing providers to charge significantly more. This heavily contributes towards the \$88 billion of debt owed in health expenses alone, leaving 22% of Americans in debt (CFPB, 2022, p.1). When considering accessibility through safety concerns with regards to data and patient trust, principle suggests that it is important that patients receive autonomy over their private health data for the sake of their safety and reputation, so that they continue to trust healthcare systems to get the care they require. Lastly, Virtue Ethics, the act of performing benevolent acts for the express purpose of aid, assists those in healthcare positions to build additional trust with patients (Stanford,

2003). This presents itself within communication, continued treatment, and increasing care equity through initiatives for those unable to afford care. Privatization additionally exacerbates the issue of differing interests within healthcare, as they are not bound by the same regulations. Dr. DeWolf in an ethical review of healthcare as a human right states, “private actors may not always have the incentives to deal with externalities that affect the availability, accessibility, acceptability, and quality of health care services; they may not be in a position to provide “public goods”; or they may operate under imperfect information” (DeWolf & Toebes, 2016, p.1). Within the research community, the prevalence of private review boards for research and drug development approval is a rising issue despite their efficiency of operation and approval. There is a present concern for ulterior motivations within these review boards for their “for-profit” methodologies, which allows for outside influence (Gilbert, 2022, p.5).

## **PIVOTING IDEALS WITHIN HEALTHCARE INNOVATION**

Utilizing the frameworks discussed above and with technical ideology as assistance, it is imperative that the healthcare industry centralize around several principles when pivoting towards benefiting patients in the US. Providers have inherent responsibility to take measures to build patient trust through security, accessibility, transparency, and adequate communication and personalization. This entails a full-scale reinforcement of both policy and infrastructure resilience for patient confidence and quality of life post treatment.

With context related to security purposes, a reframing of the need for profit management needs to be considered when addressing technology and data security. Upon findings of the FBI, it is recommended that organizations prioritize asset management, vulnerability management, and employee training to reduce risk. Policy on higher

turnarounds, employee training, and tech transition may mitigate the risk of security issues being as present (FBI, 2022, n.p). A greater emphasis on increasing research into cybersecurity practice and system resilience as a whole would greatly benefit the healthcare system, or at least assist efforts in risk analysis and management when addressing new system implementations. Regulations should be put into place to enforce this level of security and technological quality on both private and public bodies within the healthcare system.

With security from third-parties being a large consideration in data security, it is significantly paramount that attention is brought to protection and policy defending private user health data, especially from legal implication and investigation. The use of HIPAA is outdated in many terms, and doesn't account for identifiable health data within tracking technology in other contexts. For this in the context of the greatest good, HIPAA should modernize their policies to recognize identifiable health information as its own protected class of data (Healthaffairs, 2019, p.1). This benefit provides confidence and clarity to patients who are concerned about their data use and viewership, leading them to trust the system and seek needed medical assistance. As data and consumerist based analytics grow in our everyday lives, it is important to ensure that health data receives growth parallel to the ethical considerations going into controlling regular data privacy.

In terms of financial disparities within health insurance and care, the framework at which care quality is compared to cost savings and effectiveness should be reworked. If looked through the scope of both virtue ethics and utilitarianism, it would be postulated that ideally healthcare providers would innovate towards accessibility in tandem to effectiveness. Framework focus towards early detection and treatment heavily reduces future costs and expenses for both patients and healthcare providers in the long run, while also increasing

odds of treatment success. Additionally, sanctions on the privatization of international review boards for research will allow greater focus on ethical review on developing medicine, technology, and practice, ensuring the best interests of patients and their needs. Finally, to ensure greater communication, greater enforcement of price transparency policies within hospitals for treatment and infrastructure. These qualities from a financial standpoint will greatly assist in maintaining trust from the general US population, as medical innovation and technology development continue to surge. These changes and further progression in all facets strive to restore patient trust in the greater healthcare system, allowing them to have access to needed treatments of all severity.

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