## Perception is Reality: Significant and Novel Events Alter Patients' Attitudes Toward Electronic Health Records

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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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#### Introduction

Since its conception in 1950, artificial intelligence (AI) has become integral to medicine. It has many broad applications across the field, from recognizing symptoms of disease to assisting with scheduling or check-ins and emotionally supporting patients (Amisha et al., 2019, p. 2329). In addition, well-trained AI is extremely effective at using medical images or lab data to diagnose patient diseases (Dalton-Brown, 2019, p. 115). For example, Dalton-Brown states that a Japanese AI system that analyzes endoscopic images for cancerous growths is 94% effective (p. 115). In order to achieve these levels of results, AI models need to be trained on millions of data points, which can come from electronic health records (EHRs) or clinical images (Kaul et al., 2020). However, according to Shah et al. (2021), "our medical imaging datasets are on the order of hundreds of subjects" due to medical data privacy regulations that protect patients (p. 1).

The availability of patient medical data could further decrease as patients want more control over how their private data is stored and used. For example, in 2019, Australia allowed patients to opt-out of its electronic health record system; in less than a year, about 10% of citizens eligible for Medicare (at least 2.5 million people) had opted out (Dalton-Brown, 2019, p. 116; Knaus, 2019, n.p.). When patients are unwilling to have their data stored electronically, AI models cannot be used to their full benefit. Using improperly trained AI models to make medical decisions puts patients' health at risk. For instance, Mikkelsen et al. (2019) report that many mobile applications that use image analysis to identify melanoma skin care are prone to false negatives, which delays diagnosis. In addition, Straw (2020) found that mental health apps that have not been trained on culturally diverse datasets only recognize Western "expressions of suffering" (p. 2). Without representation of their cultures and behaviors, patients of marginalized communities could go undiagnosed and may not receive the mental health support they need.

This project argues that patients opt out of electronic health record systems when their concerns are not properly addressed. Past events have challenged systems' perceived trustworthiness, resulting in increasingly negative views of EHRs. This work presents a timeline denoting significant events and their effects on public perception of EHRs. To categorize attitudes, this project uses the model presented by Kerschner and Ehlers' "A Framework of Attitudes towards Technology in Theory and Practice" (2016).

# Problem Definition: Current Concerns Center Around Security and Confidentiality of Patient Medical Data

Currently, patients are most concerned about the privacy and security of their electronic records. For example, Smee (2018) suggests that Australian patients may have opted out of the country's health record system after an announcement that "third-party access arrangements would allow medical and public health researchers [including those working for private pharmaceutical companies] access to de-identified [medical] data" (n.p.). When companies do not inform patients about third-party usage, patients lose trust in the system that is meant to protect their data. As a result, Fox (2020) reports that patients have "strong concerns regarding unauthorized secondary use, malicious access, and lack of control" over the distribution of their records (p. 1025). Some insurance companies purchase risk scores generated from patients' health records and charge a higher rate to "riskier" patients (Madden, 2018, p. 35). Madden (2018) denounces these acts: "The current Wild West environment... further exacerbates inequalities in our society" (p. 35). Although patients' information is de-identified, the lack of consent creates a harmful environment where the lines of privacy are blurred.

Patients wish to be informed about how their data is being used, especially when it comes to their medical data. When describing using a clinic's new patient portal, Madden (2018) states that "there was no explanation of how [her] data would be stored or protected once it entered [the clinic's] system" (p. 34). In addition to a desire for information, patients also wish to control who can access their medical records. In a study with 30 participants, Caine and Hanania (2012) found that "all participants preferred granular control" when sharing their medical records (p. 10). Granular control refers to the ability to share portions of one's medical records with a care provider, rather than the whole record at once. Yarborough and Stumbo (2021) conducted a survey investigating whether patients would allow machine learning models to use their data to identify individuals at risk of suicide. As Figure 1 shows, most respondents believed that "people should have to give permission... for their electronic health information to be used for suicide risk identification" and "nobody but a member's trusted clinician should have access to [the patient's suicide risk] information" (p. 35). Caine and Hanania's (2012) results also reveal that patients prefer that their medical information is only "used for their health benefit, [and] otherwise prefer it to remain private" (p. 14). Therefore, patients are largely reluctant to agree to secondary uses of their health records, especially unauthorized uses.

#### How much does providing consent matter to you?

Consent refers to giving permission to use electronic health data for suicide risk identification.



#### How much does privacy matter to you?

Privacy refers to someone in the health system other than a trusted clinician seeing your suicide risk information.





Online platforms also use nonmedical data for unauthorized (and, until recently, unpublicized) purposes. Bartoletti (2019) reports a "public awakening regarding the malicious use of data for microtargeting, online manipulation and behavioral advertising" (p. 8). Consequently, the public is less trustful of the ways in which organizations use data. As a result of this awareness, members of the Senate have introduced the Algorithmic Justice and Online Platform Transparency Act. Under this bill, online platforms that customize content based on a user's data must inform users of what data they collect and how the data is used (Algorithmic Justice and Online Platform Transparency Act, 2021). Due to publicized violations of people's private data, the public is now seeking to have greater control over their data and how it is used. Moreover, recent studies have found that patients tend to perceive technology as emotionless or lacking human nature. In the same study conducted by Yarborough and Stumbo (2021), one participant asked, "Who wants a spy in their house?" and another commented, "This number [a patient's suicide risk score] describes who you are as a person" (p. 33). These remarks demonstrate that patients feel that technology lacks emotional human characteristics, such as empathy. In addition, Hassol et al. (2004) reports that patients whose test results are abnormal do not want to receive this information electronically, where only an automated message is attached to the results. Rather, patients prefer informative emails or in-person discussions with their care providers (p. 510). Thus, it is evident that patients do not feel that electronic medical systems provide the same emotional support as more personalized engagement with their doctors.

Further research must be done to understand what specific events have led to these concerns about security and confidentiality. For instance, there have been recent recurrent instances of hacking or data misuse. In September 2021, HIPAA Journal reported a 23.7% month-over-month increase in reported healthcare data breaches (September 2021 Healthcare Data Breach Report, 2021, n.p.). Figure 2 depicts the number of healthcare data breaches month-over-month since October 2020. Of the 47 breaches that occurred in September 2021, 34 were due to a hacking or IT incident.





This paper seeks to identify major, specific events that have altered public perceptions of EHRs. The scope of the project was limited to the United States from 2004 onwards, when the federal government began to promote the adoption of EHRs in earnest. The search was informed in part by Google Trends data, which depicts the frequency of specific search terms over time, used on terms relevant to electronic records and medical data. Furthermore, Kerschner and Ehlers' (2016) techno-attitude model was used to categorize the public's changing attitudes toward EHRs as a result of these events, as discussed in the following section.

#### Methods: Using Techno-Attitudes Framework to Map Patient Perceptions Over Time

In the article "A Framework of Attitudes toward Technology in Theory and Practice" (2016), Christian Kerschner and Melf-Hinrich Ehlers present a model for classifying attitudes toward technology. Specifically, the authors propose four categories representing attitudes that are positive, negative, or ambivalent. The framework was originally designed for evaluating researchers and teachers, but can be applied to statements that are recorded in articles or surveys. The framework was developed by categorizing the articulation of one's attitudes, and can thus be applied to anyone's written or recorded communications. Kerschner and Ehlers analyzed attitudes toward technology (also referred to as techno-attitudes), which represent how people perceive and respond to technology and its advancement (p. 140). Under their framework, technology is defined as "the making and using of artifacts". In addition, Kerschner and Ehlers argue that techno-attitudes are not dichotomous; rather, ambiguous attitudes are becoming increasingly prevalent due to a greater variety of historical, socio-psychological, and theoretical contexts that influence how people perceive the world. Thus, the two authors present four techno-attitudes: enthusiasm, determinism, romanticism, and skepticism. These attitudes are not exhaustive or exclusive, but instead represent a spectrum. The four attitudes are presented below in Figure 3, along with their subcategories.





In the framework, enthusiasm represents optimistic views of technology: the belief that "technology is ... inherently good and its misuses accidental" (p. 144). Technological enthusiasts believe that technology can overcome any obstacle, and that humans will eventually be able to control the world surrounding them. For example, one of the presentations analyzed by Kerschner and Ehlers mentions that technological innovation is driven by optimization, by which technology improves incrementally and produces greater economic returns. Under this view, new technology is always desirable.

In comparison, romanticism stands "between technological enthusiasm and skepticism," thus representing ambiguous views of technology (p. 145). Romantics are uneasy toward technology; they are aware of its benefits as well as its complexity, fragility, and moral implications. For example, technology that benefits humanity may at the same time carry risks of failure and hazards such as toxins. This attitude is largely a result of harmful technology, including nuclear weapons and environmental pollution. Thus, romantics may view different technological projects in different lights depending on the context of each.

Determinism also represents ambiguous views of technology. This attitude is generally concerned with the inevitability of technology. Kerschner and Ehlers present three sub-categories of determinism: automatic, social forces, and evolution. Under the automatic sub-category, technology evolves "independently from social, economic and political forces" and cannot be controlled by human means (p. 146). Eventually, technology will replace nature. The social forces attitude argues that society and technology evolve together, with one affecting the other in turn. This sub-category, along with the evolution sub-category, state that technology (and its advancement) is unavoidable because it is beneficial to human survival. As the "diversity of natural ecosystems" increases, the need for technology also increases (p. 146). Across the three sub-categories, perceptions of technology can have either positive and negative tendencies.

Finally, technological skepticism represents pessimistic views of technology. Skeptics focus on the "negative social, environmental, and economic impacts of technology" (p. 147). Under this perspective, technology is antithetical to society, and will eventually lead to the fragmentation of community by emphasizing individualization and eliminating jobs. Technology also damages the environment via pollution and the removal and exploitation of natural resources.

This paper adopts part of Kerschner and Ehlers' own methodology to apply the framework to the evidence gathered (p. 141). First, a literature review was conducted to gain a broad understanding of people's perspectives toward technology. Google Trends was used during this step; the frequency of the terms "electronic medical record" (as a search term), "medical data breach" (as a search term) and "electronic health record" (as a search topic) were found. The month and year corresponding to significant spikes in search frequencies were identified. Then, scientific databases were searched to find news or journal articles addressing these same terms that were published around the same time of the spikes. The scope of the review was limited to 2004 to the present. Next, a qualitative content analysis was conducted on the data from the literature review. This paper used statements gathered from the articles to infer the attitude of the speaker or those they represent. The attitudes used in this investigation were drawn from those developed by Kerschner and Ehlers. Figure 4 illustrates the steps undertaken in this project.



Figure 4. Flowchart depicting the methodology used in this paper, with each step informing the next (Created by Author).

Although originally developed to analyze the attitudes of researchers and teachers of technology, Kerschner and Ehlers' framework can be applied to statements of patients or members of the general public regarding EHRs. As described earlier, this paper identifies events that have altered public perspectives of EHRs, as well as statements recorded publicly that express these sentiments. These pieces of evidence can be used as indicators of the public's general attitude toward EHRs. Then, specific events can be "measured" by the magnitude of the shift in attitudes that they cause. The result of this analysis is a better understanding of how perceptions of EHRs are affected by events that are either directly or indirectly related to the medical field.

## Results: Techno-Attitudes Are Affected by the Magnitude and Novelty of Technological Events

Google Trends highlighted several events that impacted public perception of EHRs, as shown in Figure 5. For instance, searches for "electronic medical record" were highest in May 2004, the same year that the federal government began to advocate for electronic records with the Health Information Technology Plan. Searches for "medical data breach" spiked significantly at three different times: July 2015, September 2017, and June 2019. The July 2015 spike occurs a few months after the 2015 Anthem data breach. 2017 and 2019 correspond to the occurrence of the Equifax data breach and Quest data breach, respectively. Of the three, the Anthem data breach most influenced public attitudes and is the only data breach discussed in detail in this section. Finally, searches under the topic "electronic health record" significantly spiked between December 2008 and February 2009. The latter date is when the Health Information Technology

for Economic and Clinical Health Act, which increased the prevalence of EHRs, was signed into law.



The events mentioned above altered public perception or awareness of EHRs. When EHRs were first promoted by the federal government in 2004, they were a novelty to the public. Unfamiliar with the negative consequences of health information technology, the public's attitude was technophilic. However, as EHR adoption grew, so too did the prevalence of their harmful effects. Between 2004 and 2015, the public attitude shifted toward ambiguous appropriation, then to ambiguous aversion. However, the severity of the 2015 Anthem data breach resulted in a wave of negative and pessimistic opinions, and the public attitude became technophobic. Due to system and regulatory changes that have occurred recently, the public perception has shifted back toward ambiguous aversion. Figure 6 provides a summary of the results discussed in the rest of the section.



Figure 6. Timeline of significant events and shifting techno-attitudes from 2004 to the present. Attitudes were at first largely positive, then shifted negative due to increasingly harmful consequences (Created by Author).

### Timeline of Significant Events and Their Effects on Public Attitudes

EHRs were not widely used until the early 2000s due to high cost (of both the computer systems and the transition to electronic records) and limited portability (of the computers). The hospitals and offices that did use EHRs mostly used them for billing and scheduling rather than recording patient medical information (Net Health, 2022, n.p.). By 2004, Evans (2016) reported that only 13% of surveyed offices were fully transitioned to an EHR system (p. 551).

In his 2004 State of the Union address, President Bush mentioned the potential of EHRs: "By computerizing health records, we can avoid dangerous medical mistakes, reduce costs, and improve care" (Transforming Health Care: The President's Health Information Technology Plan, 2006, n.p.). This statement indicates a highly positive view of EHR capabilities. During the same year, the President introduced the Health Information Technology Plan, which sought to achieve a nationwide adoption of EHRs within the next decade. The language of the plan reflected confidence in the technology, stating that these records would "dramatically" change the national healthcare system. Due to the heavy focus on the benefits of these records, the federal government's attitude is evidently enthusiastic and can be assigned to the technophile sub-category. Since EHRs were not yet widely adopted, President Bush's statements can represent how the general public felt about EHRs at the time.

Although limited literature is available regarding American patients' stated perspectives on EHRs, studies conducted in other countries can be used to infer these ideas. For example, Zurita and Nøhr (2004) investigated Danish patients' opinions of electronic records. The researchers concluded that patient attitudes were largely positive, but did question the data's security and confidentiality (p. 1335). Pyper et al. (2004) conducted a similar study with British patients accessing their electronic records for the first time and made the same conclusions (p. 42). As the American public was gradually being exposed to the features of electronic records, it is likely that they expressed similar feelings. These largely positive attitudes can be categorized as ambiguous appropriation, and were prevalent from 2004 to 2012.

In 2009, President Obama created the Health Information Technology for Economic and Clinical Health Act (HITECH), which greatly spurred the nationwide adoption of EHRs by providing incentives to providers that met certain criteria of using EHRs (Atherton, 2011, p.

188). By 2014, 81% of physicians and 97% of hospitals had transitioned to EHRs (Blumenthal, 2014, n.p.). However, during subsequent years, the harmful risks of EHRs became more apparent. Clemens (2012) reported that poorly designed systems resulted in "dosing errors, failure to detect life-threatening illnesses, and delaying treatment... [that] led to serious injury and death" (p. 47). In addition, some patients became concerned about facing stigma if their general providers accessed their mental health records. Furthermore, EHRs faced cybersecurity challenges: over a period of 2 years, almost 12 million Americans' records were breached, and the Department of Defense was sued for \$4.9 billion dollars. These increasingly negative effects indicate a change in the public attitude. Patients were apprehensive of serious medical consequences, to the point where their concerns outweighed the perceived benefits of EHRs. However, patients were not yet fully opposed to the use of health information technology. These largely negative attitudes can be labeled as ambiguous aversion.

In 2015, patient attitudes shifted dramatically. During that year, Anthem, a health insurer, was subjected to an attack that exposed 80 million accounts, "by far the largest breach in the industry" (Abelson & Creswell, 2015, n.p.). Some members of the public questioned whether the attack was indicative of a rising trend of attacks on the medical industry and wondered how the stolen information would be used. Others doubted that their medical providers could appropriately protect their personal and medical data; an advocacy group encouraged the boycott of an Anthem-built database containing Californians' medical records (Terhune, 2015, n.p.). This event demonstrated the fears surrounding technology and the safety of data that had been growing since 2004. The public's severe criticism of Anthem, including the call for a boycott, indicates that they believed the risks of electronic records were too great to allow their use to continue. Due to the magnitude of the data breach, attitudes shifted toward technophobia.

Although healthcare databases remain the target of cybersecurity attacks today, more action is being taken to minimize the chances and consequences of a breach. Databases and electronic record systems alike have "matured" in recent decades, especially following major events such as the ones outlined above. Therefore, their safety and reliability has increased. In addition, members of the public are taking action to ensure their own confidence in technological systems, such as by introducing the Algorithmic Justice and Online Platform Transparency Act discussed earlier (Algorithmic Justice and Online Platform Transparency Act, 2021). Thus, it is evident that belief in the potential and trustworthiness of medical technology is once again increasing. Zanaboni et al. (2020) investigated Norwegian patients' opinions of their country's fully implemented EHR system. Responses were largely positive, with only a minority of patients expressing concerns about security and confidentiality. Therefore, if the American public's attitude in 2021 was ambiguous aversion, one may hope that with continuing improvement of EHRs, they will shift towards the ambiguous appropriation attitude that Norwegians achieved.

### Conclusion

Across the 16 years of this investigation, patients were consistently concerned about the security and confidentiality of their data. During the early years of EHR adoption, these risks had not been realized in significant ways, so patients were willing to use EHRs. However, patients lost trust in electronic systems as a result of increasingly dangerous events. Because their concerns had not been properly addressed, patients saw opting out as the only way to protect their data. Therefore, future development of EHRs should focus on improving their security and trustworthiness. More importantly, patients should be made aware of (or even a part of) these

changes. If patients witness or contribute to the improvement of systems that dictate their personal wellbeing, they will be more willing to use these systems. Increased trust will result in increased utilization. Medical AI can be trained on a greater amount of user data, including more representative data, which will further improve the quality of patient care.

This information can be used by those who make decisions about how medical data is used, distributed, and stored. For instance, legislators can use these findings to inform future regulations as they will better understand the origins of patients' concerns. Engineers or organizations who maintain health records databases can also use this research to prioritize areas to strengthen or improve in order to increase trust in their systems. Finally, engineers who develop intelligent systems that use health record data can use these findings to understand where they should improve their systems' transparency or adjust their systems' data usage.

This work is limited by the amount of data available concerning patient attitudes. Many studies have investigated physicians' feelings about electronic records. In comparison, studies that involve patients typically involve specific use case scenarios or record systems, rather than investigating their general opinions. This study extrapolated public attitudes based on available material. These conclusions are inherently variable, as the public is too diverse to be able to soundly generalize. However, as they stand, these results are a strong foundation for future analysis that is more specific. For instance, a statistical analysis could investigate the techno-attitudes of different populations based on age, gender identity, socio-economic status, ethnicity, and more. Furthermore, opinions about technology are dynamic. The COVID-19 pandemic likely increased the use of EHRs while also bringing more visibility to their risks. Research should be done to understand how the pandemic has affected public opinion and what the future of EHRs looks like.

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