

**Recommendations for User-Centered Design of Intelligent Systems in Healthcare**

**Understanding Social and Technological Causes of Medical Data Citizenship**

A Thesis Prospectus  
In STS 4500  
Presented to  
The Faculty of the  
School of Engineering and Applied Science  
University of Virginia  
In Partial Fulfillment of the Requirements for the Degree  
Bachelor of Science in Computer Science

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November 1, 2021

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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## **The Need for Better Design of Medical Artificial Intelligence**

Artificial intelligence (AI) was first conceptualized in 1950, but did not become popularized in medicine until recent decades. Effective medical AI systems must analyze large amounts of data. These datasets, and computer hardware strong enough to process them, were not available until the early 2000s (Kaul et al., 2020). Now, AI is integral to medicine: it can recognize symptoms of disease, assist with online scheduling or check-ins, and support patients emotionally (Amisha et al., 2019). However, the medical field does not have a standard for designing the logic of intelligent systems. Logic refers to algorithms' decision-making processes: the criterion by which a model analyzes its input in order to reach some conclusion (Truemper, 2004). According to Forsythe (1996), improperly designed logic can represent assumptions of its designers that “are not necessarily shared by end-users” (p. 553). Because these beliefs become hidden within the system's architecture, end-users, such as physicians or patients, are unaware of these traits. As Forsythe demonstrates, physicians may then incorrectly diagnose a disease or prescribe treatment without consulting their patients, both of which may risk patient health. Although these systems are intended to empower patients, uninformed design choices can decrease the quality of patient care or limit patients' control over their medical care.

Social scientists employ user-centered design to understand user needs while reducing the effect of their own worldview. This approach promotes working with participants throughout a project's lifecycle so that users remain “squarely at the center” of the product (IDEO, 2015, p. 12). Target communities can continuously provide feedback about a product, resulting in systems that are less biased and more reflective of users' perspectives (IDEO, 2015). Therefore, the technical work of this project will apply the user-centered design framework to the development of medical AI systems. However, even a well-designed model may not be accepted by patients

who are concerned about privacy violations of their medical data. Health records databases can be hacked, or private companies that own these databases may be able to access this data (Dalton-Brown, 2020, p. 116). The STS research of this project will explore significant events or technological developments that have shaped these concerns in order to inform future decisions about intelligent systems' data usage.

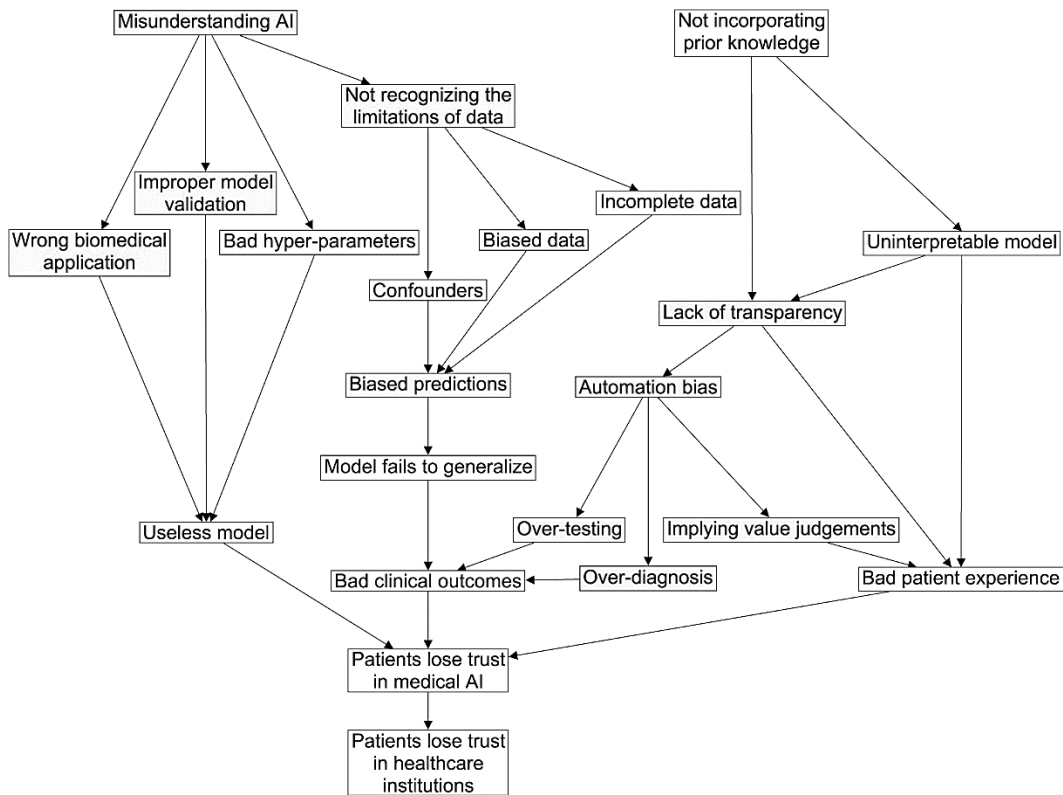
### **A User-Centered Approach to Developing Intelligent Systems**

User-centered design involves both quantitative and qualitative methods of study. Examples of quantitative evaluations include surveys or questionnaires, which acquire responses using sets of predetermined answers (Moran, 2018). Qualitative methods involve interviews, observations, or workshops. Furthermore, Newell et al. (2011) notes that “standards and guidelines are less than successful” in user research, so user-centered design should be viewed as a mindset to use while conducting research (p. 238). The goal of this approach is to develop a robust understanding of users' experiences, so designers should use the qualitative and quantitative studies that best fit their participants.

However, engineers who construct AI systems often do not engage in user research. Instead, this responsibility is delegated to social scientists or ethnographers on the team (Forsythe, 1996). Meanwhile, the developers focus on translating relevant human knowledge into a logical form that computers can understand and efficiently process (Truemper, 2004). Because engineers do not work with their participants, they may unintentionally incorporate their own worldviews into the product. For instance, Straw (2020) notes that some mental health apps have not been trained on culturally diverse datasets and so only recognize Western “expressions of suffering,” which prevents patients of marginalized communities from accessing proper care (p. 2). Other mobile apps that identify melanoma skin cancer via imaging software are prone to false

negatives or false positives, which increases patient worry and dermatologist workload and delays much-needed diagnoses (Mikkelsen et al., 2019).

Continued development of such systems will cause increasing harm to patients, which “could erode public trust in medical AI” and healthcare itself (Quinn et al., 2021, p. 890). Figure 1 exemplifies this idea, showing that developers’ invisible assumptions (lack of transparency) and design choices such as ranking treatment options (implying value judgements) negatively impact patient experience, which affects patients’ trust in these models.



**Figure 1. Sources of poor design of medical AI systems and their consequences.** Continued development of these systems will damage trust in healthcare (Quinn et al., 2021, p. 891). Figure has been adapted by Author to remove node colors.

Prior research has proposed different ways of applying user design methods to AI development, or has studied the effect of such work in specific contexts. Falco (2019) suggests using participatory design in the form of a virtual ledger that city officials, AI developers, and

residents contribute to during the design phase (p. 156-157). Quinn et al. (2020) proposes involving three different groups throughout the lifecycle of an intelligent system: a multidisciplinary team for its development, a team of validators for continuous auditing, and operational staff who use and understand these systems. Forsythe (1996) highlights a failed attempt to incorporate ethnography into the development of an informatics system for migraine sufferers. Tsiourti et al. (2018) used focus groups, interviews, questionnaires, log files, and diary entries to design and evaluate a virtual daily life companion for older adults living alone. This project builds on these studies, and on the overarching principles of user-centered design, to develop a framework for developers to take a user-centered approach to building medical AI systems. To ensure the recommendations will be relevant and easily applicable, the study will focus on systems that patients or physicians directly interact with, such as health evaluation tools.

### **Understanding Social and Technological Causes of Medical Data Citizenship**

As mentioned above, AI systems have many different applications in healthcare: decision support for diagnosing disease, administration and clinic management, and patient monitoring or support (Amisha et al., 2019). In order to fulfill these roles, medical AI systems must be able to access patient data, which can range from electronic health records to clinical images (Amisha et al., 2019; Kaul et al., 2020). However, electronic records are vulnerable to hacking, and the rules around data ownership are ambiguous (Dalton-Brown, 2020). As a result, some patients do not consent to having their data stored electronically (Hannon, 2018). Recently, Australia implemented “an opt-out record-keeping system,” increasing patients’ right to protect their data (Dalton-Brown, 2020, p. 116). Bartoletti (2019) terms this increased desire for control over one’s personal information “data citizenship,” and states that this movement has been popularized due

to increasing awareness of the ways in which data can (and has been) misused (p. 7). Now, the public is less trustful of “the way private and public organizations handle ... data,” especially medical data (Bartoletti, 2019, p. 8). When patients are distrustful of intelligent systems, or are unwilling to have their data stored electronically, AI models cannot be used to their full benefit. In this sense, the success of intelligent tools is dependent on their perceived trustworthiness and benefit.

Therefore, when designing future AI systems, developers should have a better understanding of the reasons behind these concerns. This project will investigate significant social or technological events that have contributed to rising concerns of medical data privacy. Figure 2 demonstrates that searches for the term “medical data privacy” have spiked at certain times since January 1, 2004. The project will consist of a comprehensive study to correlate these spikes with relevant events that may have contributed to them. This research will be limited to events that occurred in the United States from 2004 onwards.



**Figure 2. Search interest for “medical data privacy” from Jan. 2004 to Oct. 2021.** Searches for the term have spiked multiple times over the years, and the frequency of spikes has increased since 2014 (Google Trends, n.d.).

As Bartoletti (2019) mentions, privacy is “culturally bound” and ideas of privacy vary depending on the “territories, generations and backgrounds” one is examining (p. 7). In accordance with this idea, this historical evaluation will align with sociotechnical systems thinking, which relates technology to its users and their cultures. In addition, Nass et al. (2009) conducted a study to determine how perceptions of the importance of medical data privacy have evolved in recent decades and correlates some of these statistics to events such as the passing of the Health Insurance Portability and Accountability Act Privacy Rule (p. 79). This work, and others that it cites, will be used as a guide for the study. Furthermore, the project will examine news articles or other sources of historical information that discuss events related to medical data privacy.

**Intended Outcomes of Project**

The technical work of this project will deliver a set of recommendations for a user-centered design approach to developing the logic of intelligent systems. These recommendations will discuss ways to define project requirements and user needs, and to ensure development remains focused on the end user. Furthermore, these suggestions will be targeted toward developers on

the design team. By following the proposed framework, future systems' logic will better represent the needs and perspectives of their users, making models more reliable and improving patients' quality of care.

The STS research of this project will provide a better understanding of how concerns about medical data privacy have evolved in the past two decades. After a comprehensive historical study, the result of this work will be a timeline denoting significant events and their effect on the rise of data citizenship. This contextual information will allow developers to identify trends or themes that affect data privacy concerns. Such knowledge can then be used to adjust future systems' data usage in order to increase trust and acceptance by users.



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