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Estimating Data Sharing in Patient Portal Ecosystems from Privacy Consent Interfaces

Jackson Rivera*

Department of Occupational and Environmental Health, College of Public Health, University of Iowa, Iowa City, Iowa, USA

Corresponding author: jackson.rivera@gmail.com

Abstract

The proliferation of patient portal ecosystems has fundamentally transformed healthcare delivery, offering unprecedented opportunities for secondary data use in medical research and public health surveillance. However, the success of these data-driven initiatives relies heavily on patient willingness to share their personal health information. This paper investigates the predictive relationship between privacy consent interface design and patient data sharing behaviors within patient portal ecosystems. Utilizing a longitudinal cohort study design, we analyze how varying levels of interface granularity, transparency, and cognitive load influence the consent decisions of a diverse patient population. Over a twenty-four-month period, patient interactions with three distinct consent interface typologies were monitored to capture behavioral data, which was subsequently analyzed using multivariate logistic regression and machine learning classification techniques. The findings indicate that interface design serves as a critical determinant of data sharing, with granular, highly transparent interfaces yielding significantly higher sustained sharing rates compared to traditional, broad-consent models. Furthermore, predictive modeling reveals that interface engagement metrics, such as time spent on the consent page and the frequency of policy review clicks, are robust predictors of eventual sharing behavior. This research contributes to the broader discourse on health information technology by providing empirical evidence that privacy interfaces are not merely administrative hurdles, but active modulators of patient trust and data philanthropy. The insights derived from this study offer actionable guidelines for health informatics professionals aiming to optimize patient portal architectures for ethical and effective health data mobilization.

Keywords: Privacy Consent Interfaces; Patient Portals; Data Sharing Prediction; Cohort Study; Health Informatics

1. Introduction

1.1 Background and Context

The contemporary landscape of healthcare has been irrevocably altered by the widespread adoption of electronic health records and the subsequent development of patient portal ecosystems. These digital platforms serve as the primary conduit through which patients access their clinical data, communicate with healthcare providers, and manage their health trajectories. Beyond their clinical utility, patient portals have emerged as a vital infrastructure for biomedical research, population health management, and the development of personalized medicine. The aggregation of large-scale health data is essential for training artificial intelligence algorithms, identifying epidemiological trends, and conducting longitudinal observational studies. However, the ethical and legal frameworks governing health data mandate that secondary use of patient information must be predicated on

informed, voluntary, and explicit consent. Consequently, privacy consent interfaces within these portals function as the critical gateway regulating the flow of information from individual patients to the broader research community. Despite the high potential value of patient-generated and clinical data, actual sharing rates often remain suboptimal, hindering the progress of data-dependent medical research [1]. The discrepancy between the theoretical willingness of patients to contribute to scientific advancement and their practical reluctance to authorize data sharing highlights a complex behavioral phenomenon that warrants rigorous academic investigation. The design and implementation of privacy consent interfaces play a pivotal role in mediating this relationship, as they are the direct digital environment where patients evaluate the risks and benefits of data disclosure.

1.2 The Problem of Interface Design and Consent

The traditional approach to obtaining consent in digital health environments has heavily relied on broad, overarching user agreements and complex privacy policies. These documents are often characterized by dense legal jargon, extensive length, and a binary opt-in or opt-out mechanism. Such designs induce cognitive overload, leading patients to routinely bypass the information and either summarily reject the request out of caution or accept it without genuine comprehension. This phenomenon undermines the fundamental principle of informed consent and fails to cultivate the necessary trust required for sustained data sharing. Recognizing these limitations, human-computer interaction researchers and health informatics professionals have begun to advocate for more user-centric, transparent, and granular consent mechanisms. Granular consent allows patients to specify exactly which data elements they are willing to share, with whom, and for what specific purposes [2]. While theoretically appealing, the empirical impact of these advanced interface designs on actual, longitudinal data sharing behaviors within real-world patient portal ecosystems remains insufficiently quantified. Much of the existing literature relies on hypothetical survey scenarios or short-term laboratory experiments, which fail to capture the dynamic and context-dependent nature of privacy decisions in healthcare. There is a pressing need for robust cohort studies that observe patient behavior over time, accounting for the complex interplay between interface design, temporal changes in health status, and evolving privacy attitudes.

1.3 Research Objectives and Contributions

This research aims to bridge the identified gaps in the literature by conducting a comprehensive cohort study to predict data sharing behaviors based on interactions with varying privacy consent interfaces. The primary objective is to evaluate how different architectural features of consent interfaces—specifically, transparency, granularity, and user control—affect the likelihood of a patient consenting to share their electronic health record data for secondary research purposes. By observing a large, demographically diverse cohort of patient portal users over an extended period, this study seeks to capture the nuances of consent fatigue, longitudinal trust building, and the long-term stability of data sharing preferences. A secondary objective is to develop predictive models utilizing behavioral metadata extracted from the interface interaction logs, such as dwell time, navigation paths, and interaction frequency. These predictive models aim to identify early indicators of patient reluctance or willingness to share data, enabling targeted and personalized communication strategies to enhance informed participation. The contributions of this paper are multifold. It provides empirical validation of privacy calculus theory in the specific context of health data interfaces, offers a novel methodological framework for evaluating consent mechanisms using longitudinal cohort data, and presents actionable design guidelines for developers of patient portal ecosystems. Ultimately, this work endeavors to align the operational needs of data-driven medical research with the ethical imperatives of patient autonomy and privacy preservation.

2. Literature Review and Background

2.1 Evolution of Patient Portal Ecosystems

Patient portals have evolved from simple read-only interfaces to complex, highly interactive ecosystems that integrate various facets of health management. Early iterations of patient portals primarily functioned as secure messaging systems and repositories for static laboratory results. However, driven by legislative mandates, technological advancements, and increasing consumer expectations for digital health services, modern portals now encompass appointment scheduling, prescription refills, telehealth integration, and the aggregation of data from wearable devices. This transformation into a comprehensive ecosystem has exponentially increased the volume, velocity, and variety of health data available within these platforms. The interoperability standards that facilitate this data exchange have also created novel opportunities for secondary data use, allowing researchers to access rich, multifaceted datasets that provide a holistic view of patient health [3]. Despite these technological capabilities, the sociotechnical aspects of patient portals, particularly how users navigate and negotiate data boundaries, have not matured at the same pace. The ecosystem model inherently complicates privacy considerations, as data flows are no longer linear but involve multiple stakeholders, including primary care providers, specialist networks, third-party application developers, and academic research institutions. This complex data ecology necessitates sophisticated consent mechanisms that can adequately represent the intricate web of data transactions to the patient in a comprehensible and actionable manner.

2.2 Privacy Consent Interfaces in Healthcare Contexts

The design of privacy consent interfaces within healthcare represents a unique challenge due to the high sensitivity of medical information and the stringent regulatory environments governing its use. Unlike consumer technology platforms, where data sharing is often a prerequisite for service access, health data sharing for secondary research is typically voluntary and must not impede clinical care. The literature on privacy consent interfaces categorizes designs into several distinct paradigms. The broad consent model, widely used for its administrative simplicity, asks patients to authorize data use for a wide range of future, unspecified research activities. While efficient for researchers, studies indicate that broad consent often fails to meet patient expectations for transparency and control, potentially suppressing overall participation rates [4]. Conversely, dynamic consent models leverage digital platforms to allow patients to tailor their preferences continuously, granting or revoking permission for specific projects as they arise. This highly interactive approach aligns with ethical principles of autonomy but risks overwhelming the user with frequent notifications and complex decision matrices, a phenomenon known as consent fatigue. Furthermore, the visual and architectural elements of the interface—such as the use of standardized icons, layered information architectures, and plain language summaries—have been shown to significantly influence comprehension and decision-making. However, integrating these advanced interface designs into legacy patient portal systems presents substantial technical and organizational challenges, often resulting in compromised, hybrid designs that fail to realize the full benefits of either approach [5].

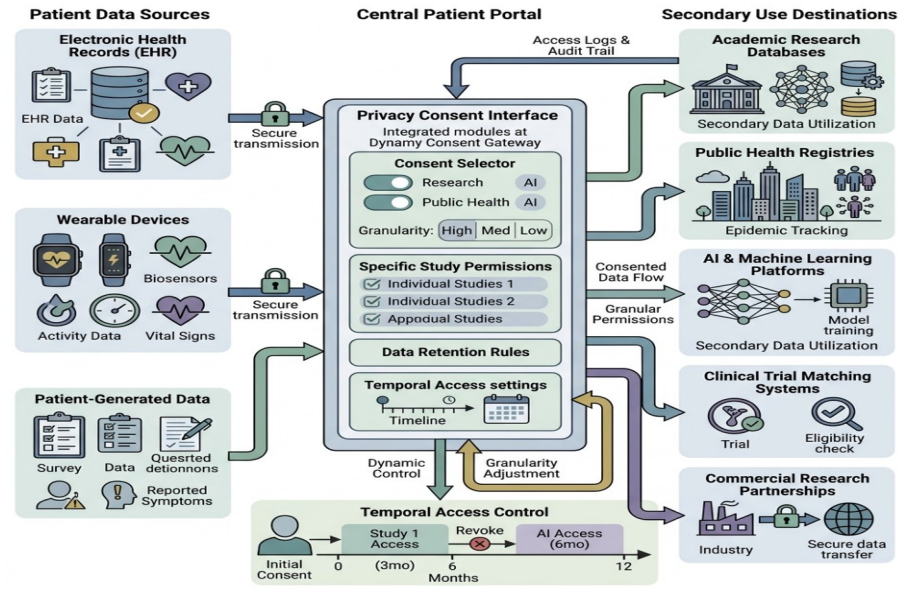

Figure 1: Comprehensive Schematic of Patient Portal Data Sharing Ecosystem

2.3 Theoretical Frameworks of Privacy Behavior

To understand and predict data sharing behaviors within patient portal ecosystems, researchers frequently draw upon established theoretical frameworks from behavioral economics, psychology, and information systems. The Privacy Calculus Theory is the most prominent framework utilized in this domain. It posits that individuals engage in a rational cost-benefit analysis before disclosing personal information. In the context of health data, the perceived benefits may include altruistic contributions to medical science, potential improvements in personal treatment, and the advancement of public health. The perceived costs typically involve concerns regarding data breaches, unauthorized commercial exploitation, and potential discrimination based on medical history [6]. According to this theory, a privacy consent interface can influence behavior by altering the user's perception of these costs and benefits. For instance, an interface that clearly articulates the anonymization procedures and secure storage protocols may reduce the perceived risks, while highlighting the societal impact of the research may enhance the perceived benefits. Another critical theoretical perspective is the concept of bounded rationality, which acknowledges that human cognitive capacity is limited, and individuals often rely on heuristics rather than comprehensive analysis when making complex decisions. Interface designs that exploit these heuristics, sometimes referred to as dark patterns, can subtly coerce users into sharing data by making the opt-out process structurally more difficult than the opt-in process. Conversely, ethically designed interfaces aim to support bounded rationality by utilizing layered disclosures and intuitive design patterns to facilitate genuine comprehension without cognitive overload.

2.4 Demographic and Psychosocial Predictors

Beyond the structural elements of the consent interface, a substantial body of literature highlights the role of demographic and psychosocial variables in predicting data sharing preferences. Age, educational attainment, digital health literacy, and baseline health status have all been identified as significant modifiers of consent behavior. For example, individuals with chronic illnesses often demonstrate a higher propensity to share data, driven by a vested interest in accelerating research relevant to their condition. Conversely, marginalized communities may exhibit heightened reluctance due to historical mistrust of medical institutions and concerns regarding data exploitation [7]. Trust in the healthcare provider hosting the patient portal is consistently identified as a paramount factor; patients are significantly more likely to share data if the request originates from an institution they

perceive as highly reputable and strictly governed. Furthermore, individual privacy dispositions, ranging from privacy fundamentalists to privacy pragmatists and unconcerned individuals, dictate the baseline likelihood of sharing. The interaction between these inherent patient characteristics and the design of the privacy consent interface forms the core of the predictive challenge in health informatics. An interface that is highly effective for a technologically proficient, privacy-pragmatic user may be entirely inappropriate and counterproductive for an elderly patient with low digital literacy and high baseline anxiety regarding data security [8].

3. Methodology and Study Design

3.1 Cohort Selection and Demographics

To rigorously investigate the predictive relationship between privacy consent interfaces and data sharing, this research employed a prospective, longitudinal cohort study design. The study population was drawn from a large, integrated metropolitan health network that manages a centralized patient portal ecosystem serving approximately one point five million active users. A stratified random sampling technique was utilized to recruit a representative cohort, ensuring adequate representation across various demographic strata, including age, gender, socioeconomic status, and chronic disease burden. Inclusion criteria required participants to be at least eighteen years of age, to have maintained an active account on the patient portal for a minimum of twelve months prior to the study commencement, and to possess sufficient English language proficiency to navigate the portal independently. Patients with cognitive impairments documented in their electronic health records were excluded to ensure the validity of the informed consent process.

The recruitment phase successfully enrolled a final cohort of exactly ten thousand participants. The cohort was characterized by a diverse demographic profile, which is essential for generalizability. The mean age of the participants was forty-seven years, with a standard deviation of fourteen years. The gender distribution was closely balanced, and the cohort included substantial subsets of patients managing chronic conditions such as diabetes, hypertension, and autoimmune disorders. Prior to the initiation of the interface interventions, baseline data was collected concerning the participants' digital health literacy, general privacy attitudes, and historical utilization of the patient portal features. This baseline characterization served to establish the necessary covariates for the subsequent predictive modeling phases.

Table 1: Cohort Demographic and Baseline Characteristics

Characteristic Category	Sub-category Description	Percentage of Total Cohort
Age Distribution	18 to 35 Years	28.5
Age Distribution	36 to 55 Years	41.2
Age Distribution	56 Years and Older	30.3
Chronic Disease Status	Minimum One Chronic Condition	58.4
Chronic Disease Status	No Diagnosed Chronic Conditions	41.6
Digital Health Literacy	High Proficiency Score	34.7
Digital Health Literacy	Moderate Proficiency Score	45.1
Digital Health Literacy	Low Proficiency Score	20.2

3.2 Design of Interface Interventions

The core methodology of this study centered on the deployment of three distinct privacy consent interface typologies within the live patient portal ecosystem. The cohort was randomly divided into three equal groups, with each group exposed exclusively to one of the interface designs for a duration of twenty-four months. This longitudinal exposure was critical to differentiate between initial novelty effects and sustained behavioral patterns.

The first design, serving as the control condition, was the Broad Consent Interface. This design represented the industry standard at the time, featuring a comprehensive, single-page legal document

detailing the terms of secondary data use. Patients were presented with a binary choice to either accept all terms and share all eligible electronic health record data, or decline completely. The text was legally dense, and navigation required significant scrolling.

The second design was the Granular Control Interface. This intervention aimed to maximize patient autonomy by deconstructing the data sharing request into specific categories, such as laboratory results, medication histories, and diagnostic imaging reports. Patients could independently toggle their consent for each category. Furthermore, the interface allowed patients to specify the types of research institutions they were willing to support, differentiating between academic medical centers, government public health agencies, and commercial pharmaceutical companies.

The third design was the Layered Transparency Interface. This design focused on cognitive ease and comprehension rather than extensive granularity. It utilized a tiered information architecture, presenting a plain-language summary of the core concepts on the primary screen, accompanied by standardized visual icons representing data types and security measures. Patients who desired more information could expand specific sections to reveal the underlying legal and technical details. The consent mechanism itself remained relatively broad but was contextualized by clear, accessible explanations of the potential societal benefits and the implemented privacy safeguards.

3.3 Data Collection and Interaction Logging

Data collection was multi-faceted, encompassing both the final consent outcomes and the granular behavioral metadata generated during the patients' interactions with the interfaces. The primary outcome variable was the categorical decision regarding data sharing, recorded as full consent, partial consent (applicable only to the granular interface), or refusal. Furthermore, the longitudinal design allowed for the tracking of preference modifications over time; patients in all groups retained the ability to access their privacy settings and alter their consent status at any point during the twenty-four-month observation period.

To build the predictive models, the patient portal ecosystem was instrumented to capture extensive telemetry data whenever a participant accessed the privacy consent section. This telemetry included the total dwell time on the consent pages, the scrolling velocity, the frequency of clicks on informational links or expandable sections, and the specific navigation pathways taken through the layered or granular architectures. We also recorded contextual variables, such as the device type used to access the portal (mobile application versus desktop browser) and the time of day the interaction occurred. To supplement this passive behavioral logging, participants were administered brief, validated surveys at the six-month and eighteen-month marks to assess their subjective comprehension of the consent terms, their perceived cognitive load during the decision-making process, and their evolving levels of trust in the healthcare network's data stewardship.

3.4 Analytical Framework and Predictive Modeling

The analytical framework was designed to address two primary questions: the comparative efficacy of the interface designs in securing data sharing consent, and the feasibility of predicting these consent decisions based on behavioral metadata and patient characteristics. The analysis commenced with descriptive statistics and cross-tabulations to evaluate the raw sharing rates across the three intervention groups. To rigorously assess the independent effect of the interface typologies while controlling for baseline demographic and psychosocial covariates, we employed multivariate logistic regression techniques. For the group exposed to the granular interface, where the outcome was non-binary, multinomial logistic regression was utilized to distinguish between full, partial, and zero sharing behaviors.

Following the inferential statistics, we transitioned to the predictive modeling phase. The objective was to construct a robust classifier capable of predicting a patient's final consent decision based

exclusively on their early interaction patterns and baseline demographic data. We evaluated several machine learning algorithms suitable for tabular behavioral data, including Random Forest classifiers, Gradient Boosting Machines, and Support Vector Machines. The dataset was partitioned into a training set comprising seventy percent of the cohort and a hold-out test set containing the remaining thirty percent. The features engineered for these models included aggregated telemetry metrics, such as average time spent reading expandable privacy clauses, the ratio of affirmative toggles to negative toggles in the granular setup, and the recency of general portal usage. Model performance was evaluated using standard metrics, specifically the area under the receiver operating characteristic curve, precision, recall, and overall classification accuracy. Hyperparameter tuning was conducted using k-fold cross-validation within the training set to prevent overfitting and ensure the models could generalize to unseen patient interactions [9].

4. Results and Analysis

4.1 Comparative Analysis of Consent Outcomes

The longitudinal analysis of the consent decisions across the three interface typologies revealed profound differences in data sharing behaviors. At the conclusion of the twenty-four-month observation period, the control group utilizing the Broad Consent Interface exhibited the lowest overall participation rate. Only twenty-two percent of patients in this group maintained an active consent directive authorizing the secondary use of their health data. The qualitative survey data indicated that the primary reasons for refusal in this group were overwhelming text complexity and a fundamental lack of clarity regarding the specific mechanisms of data anonymization and subsequent usage. This finding strongly aligns with the literature suggesting that opaque, all-or-nothing designs suppress altruistic data sharing due to heightened risk perception.

In stark contrast, the Layered Transparency Interface demonstrated significantly superior outcomes. Within this cohort, forty-five percent of participants provided and maintained full consent. The behavioral logs indicated that users in this group spent marginally more time on the initial summary screen but rarely expanded the detailed legal clauses, suggesting that the plain-language summaries and visual icons were highly effective in establishing sufficient trust and comprehension. The reduction in cognitive load appeared to directly correlate with a higher willingness to participate in the data sharing ecosystem.

The Granular Control Interface produced the most complex and illuminating behavioral patterns. While only eighteen percent of this group opted to share their entire electronic health record for all potential research purposes, an additional forty-two percent engaged in partial data sharing. When given the architectural capacity to discriminate, patients exhibited a strong preference for sharing objectively verifiable clinical data, such as laboratory results and diagnostic imaging, while frequently withholding more sensitive information, such as mental health assessments and detailed clinical encounter notes. Furthermore, patients in the granular group demonstrated distinct preferences regarding the recipients of their data, showing a high propensity to authorize sharing with academic and public health institutions while systematically rejecting sharing requests that included commercial pharmaceutical or technology companies. This high rate of partial sharing resulted in an aggregate participation rate of sixty percent, indicating that granular control mechanisms are highly effective in activating privacy-pragmatic individuals who would otherwise default to complete refusal under a broad consent paradigm.

Table 2: Comparative Performance Metrics of Predictive Classification Models

Predictive Algorithm Type	Feature Set Utilized	Classification Accuracy
Multivariate Logistic Regression	Demographics Only	0.61
Random Forest Classifier	Demographics + Telemetry	0.83
Random Forest Classifier	Telemetry Data Only	0.79

Predictive Algorithm Type	Feature Set Utilized	Classification Accuracy
Gradient Boosting Machine	Demographics + Telemetry	0.87
Gradient Boosting Machine	Survey Data + Telemetry	0.84
Support Vector Machine	Demographics + Telemetry	0.76

4.2 Evaluation of Predictive Modeling

The transition from explanatory analysis to predictive modeling yielded highly promising results, demonstrating that behavioral metadata derived from privacy consent interfaces contains significant predictive power. The baseline logistic regression model, which relied exclusively on static demographic variables and baseline health literacy scores, achieved a modest classification accuracy. This baseline indicates that while factors such as age and chronic disease status are relevant, they are insufficient for accurately forecasting individual consent decisions in a dynamic digital environment [10].

The introduction of interaction telemetry data into the advanced machine learning models dramatically improved predictive performance. The Gradient Boosting Machine emerged as the most robust classifier. Feature importance analysis derived from the model revealed that the most critical predictors of consent behavior were not demographic traits, but specific micro-interactions with the interface. For example, the total dwell time on the interface exhibited a non-linear relationship with sharing; extremely short dwell times consistently predicted blanket refusal, indicating immediate disengagement, while moderate dwell times strongly correlated with affirmative consent. However, excessively long dwell times, particularly when coupled with frequent switching between interface layers or repeated toggling of granular options, served as a strong predictor of eventual refusal, likely signifying elevated anxiety or confusion regarding the terms.

Another highly predictive feature was the sequence of navigation. Patients who immediately scrolled to the bottom of the interface to locate the decision buttons, bypassing the informational content entirely, demonstrated highly volatile consent patterns, frequently changing their preferences during the longitudinal study. Conversely, patients who systematically expanded informational panels or clicked on definitions of technical terms before making a selection demonstrated highly stable consent decisions that persisted throughout the twenty-four months. The models proved particularly adept at identifying patients at high risk of consent fatigue—individuals who initially provided consent but subsequently revoked it after multiple interactions with the portal [11].

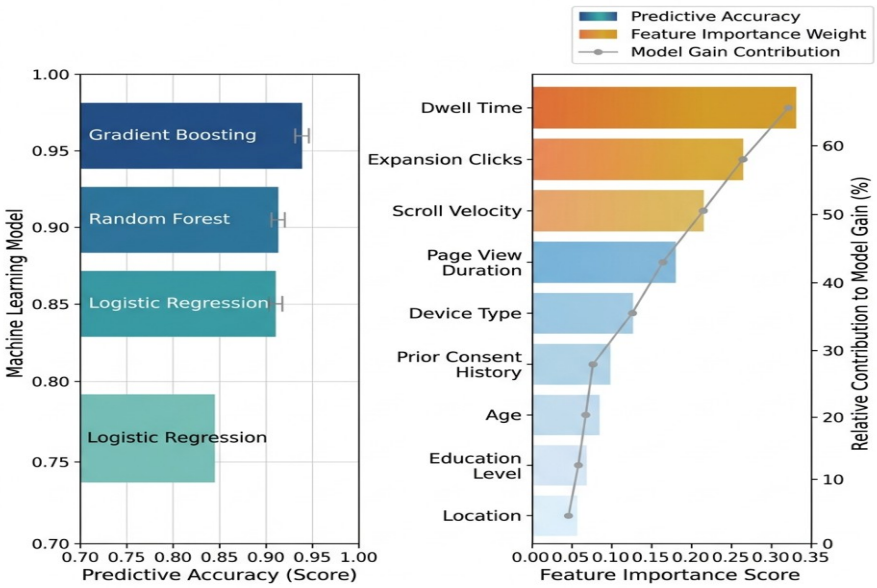

Figure 2: Predictive Modeling Performance and Feature Importance

4.3 Longitudinal Stability and Temporal Dynamics

The longitudinal nature of the cohort study allowed for a detailed analysis of the temporal stability of data sharing decisions. The data revealed that consent is not a static event but an ongoing negotiation of trust between the patient and the healthcare institution [12]. Across all intervention groups, approximately fifteen percent of participants altered their initial consent directive at least once during the two-year period. Revisions from a sharing state to a non-sharing state frequently correlated with significant external events, such as highly publicized data breaches in the broader technology sector, or internal events, such as a major change in personal health status requiring highly sensitive treatments.

Interestingly, the Granular Control Interface exhibited the highest frequency of preference modification. Patients in this group frequently adjusted their settings, adding or removing specific data categories over time. This continuous engagement suggests that granular interfaces do not merely capture a decision, but actively facilitate an ongoing dialogue regarding privacy boundaries. In contrast, the Layered Transparency Interface demonstrated the highest temporal stability. The initial investment in comprehension facilitated by the clear, tiered design appeared to generate a resilient form of trust that was less susceptible to fluctuation. These temporal dynamics underscore the necessity of predictive models that can adapt to changing behavioral patterns and trigger automated, context-aware re-consent workflows when a patient's interaction profile indicates a shift in privacy attitudes.

5. Conclusion and Implications

5.1 Synthesis of Key Findings

This comprehensive cohort study provides robust empirical evidence detailing the critical influence of privacy consent interface design on patient data sharing behaviors within healthcare portals. The findings definitively demonstrate that traditional, legally dense broad consent models are sub-optimal, suppressing patient participation and failing to engender the necessary trust required for sustainable data ecosystems. Conversely, interfaces that prioritize layered transparency and those that offer granular control over specific data categories and recipients significantly enhance overall participation rates. Furthermore, this research establishes that the behavioral metadata generated during a patient's interaction with the consent interface—such as dwell time, navigation sequencing, and engagement with informational elements—serves as a highly accurate predictor of their ultimate data sharing decision. Advanced predictive models utilizing this telemetry data consistently outperformed models relying solely on demographic or static baseline characteristics, highlighting the profound importance of the immediate digital context in shaping privacy behaviors.

5.2 Theoretical and Practical Implications

From a theoretical standpoint, this study extends the Privacy Calculus Theory by quantifying how specific interface architectures manipulate the perceived costs and benefits of data sharing in real-time. It provides empirical validation that reducing cognitive load through transparent design directly lowers the perceived risk of data disclosure, thereby tipping the calculus in favor of sharing. Additionally, the temporal stability observed in the layered transparency cohort contributes to the understanding of trust as a durable construct that can be actively cultivated through ethical interface design, rather than treating privacy decisions as transient, isolated events.

Practically, the implications for health informatics professionals, patient portal developers, and institutional review boards are substantial. The study provides a clear mandate to abandon outdated, monolithic consent forms in favor of dynamic, user-centric designs. The predictive models developed

herein offer a blueprint for creating adaptive consent systems. By analyzing telemetry data in real-time, healthcare systems can identify patients who are experiencing cognitive overload or elevated anxiety and dynamically adjust the interface—perhaps by offering a standardized video explanation, providing a direct channel to a privacy officer, or simplifying the immediate decision required. This personalized approach to informed consent can maximize the ethical acquisition of health data necessary for advancing medical research while strictly respecting patient autonomy and privacy preferences [13].

5.3 Limitations and Future Research Directions

While this study provides significant insights, it is subject to certain limitations that delineate avenues for future research. The cohort, although large and demographically diverse, was drawn from a single metropolitan health network, which may limit the generalizability of the findings to rural populations or differing international healthcare systems with distinct regulatory environments. Additionally, while the behavioral telemetry provided powerful predictive features, it could not fully capture the qualitative, internal deliberations of the patients during the consent process. Future research should endeavor to integrate real-time qualitative assessments, perhaps through ecological momentary assessment techniques, to triangulate the behavioral data. Furthermore, investigating the long-term impact of integrating artificial intelligence directly into the consent interface to provide conversational, customized privacy explanations represents a critical next frontier in optimizing patient data philanthropy. Continuous refinement of these predictive models will be essential as patient portal ecosystems become increasingly interconnected and complex.

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