JOURNAL OF INTERNATIONAL CRISIS AND RISK COMMUNICATION RESEARCH
ISSN: 2576-0017
2026, VOL 9 , NO 6

Patient-Controlled, Consent-Based Health Record Exchange: Structural Preconditions And Overlay Architecture For Population-Scale Implementation

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Abstract

Fragmentation of patient health records across healthcare institutions remains a persistent challenge in modern care delivery systems, contributing to duplicated diagnostic testing, incomplete medication reconciliation, and delays in clinical decision-making. Although electronic health record (EHR) adoption has expanded significantly, interoperability efforts based on centralized repositories or institutional data-sharing agreements have faced persistent challenges related to governance complexity, cybersecurity concentration risk, data ownership disputes, and workflow incompatibility.

This study examines structural barriers to cross-institutional health information exchange and proposes a federated architecture for patient-controlled, consent-based data sharing. The analysis introduces the Five Preconditions Model, which identifies five structural requirements necessary for population-scale implementation of patient-mediated data exchange: reliable portable patient identity, machine-enforceable granular consent, ubiquitous patient-controlled access channels, interoperable access interfaces, and clinically usable data summarization. The paper further develops the Overlay Moat Stack, a conceptual framework explaining how federated exchange platforms achieve long-term sustainability through infrastructure alignment, workflow integration, consent-network accumulation, and longitudinal intelligence generation rather than centralized data ownership.

Drawing on empirical evidence from health information exchange studies, technology adoption research, and healthcare interoperability initiatives, the analysis demonstrates why previous centralized integration efforts have struggled to achieve sustainable adoption. The findings suggest that overlay architectures—rather than system replacement strategies—offer a more viable pathway for scalable interoperability across heterogeneous provider networks. By aligning technical interoperability standards with patient-controlled authorization mechanisms and existing institutional workflows, the proposed framework provides a structural foundation for implementing secure and patient-centric health record exchange systems at population scale.

Keywords: Health Information Exchange, Patient-Controlled Data Sharing, Federated Architecture, Interoperability Standards, Consent-Based Authorization.

1. Introduction

Fragmentation of patient health records across healthcare institutions has well-documented clinical consequences, including unnecessary duplication of diagnostic testing, incomplete medication reconciliation, unrecognized medication allergies, and delays in treatment. These inefficiencies persist even in healthcare systems with widespread adoption of electronic health records (EHRs), suggesting that the problem arises from fragmentation of information across institutions rather than from the absence of digital records themselves. Consequently, the digitization of health information alone has proven insufficient to ensure effective data sharing and coordinated clinical decision-making.

1.1 Problem Statement

Many interoperability initiatives have focused on national health information technology registries or the convergence of institutional platforms. However, empirical evidence regarding the effectiveness of these approaches remains mixed. A systematic review of 27 studies comprising 94 analyses reported that 57.5% of analyses identified a positive impact of health information exchange on measured outcomes, while 31.9% found no effect and 10.6% reported negative outcomes [1]. Most studies were conducted in the United States (70.4%) and published after 2009 (74.1%). The majority of research settings involved emergency departments (51.9%) and hospitals (25.9%), and the most commonly evaluated outcomes were related to healthcare utilization (71.3%). Other outcomes included healthcare costs (11.7%), quality of care (6.4%), and care coordination (6.4%) [1].

Importantly, methodological differences across studies appear to explain much of the variation in reported outcomes. Among observational cohort studies, 74.1% reported positive effects of health information exchange, whereas only 17.7% of randomized controlled trials and 16.7% of quasi-experimental studies reported similar benefits [1]. Multivariable analysis demonstrated that study design was the only factor significantly associated with findings of overall benefit. Experimental designs were substantially less likely than cohort studies to report positive outcomes (odds ratio = 0.06; 95% confidence interval: 0.02–0.19; $p < 0.001$) [1]. These findings suggest that widely cited evidence of interoperability benefits may partly reflect methodological bias rather than consistent improvements in clinical outcomes.

1.2 Context and Motivation

Beyond technical interoperability challenges, organizational and stakeholder factors also play a significant role in the adoption of health information exchange systems. A three-round Delphi study involving 64 Canadian healthcare providers identified several determinants influencing successful technology implementation, including perceived usefulness, clinician motivation, patient–professional engagement, time and workload constraints, availability of organizational resources, and participation of end users in implementation planning [2]. Health information professionals achieved consensus on 13 of 14 identified factors, whereas managers reached strong consensus on only 2 of 11 factors. Achieving consensus among physicians proved more difficult, with only 8 of 18 factors reaching any level of agreement. These findings highlight the persistent resistance within clinical professions to workflow changes introduced by new information technologies. Across stakeholder groups, privacy and security concerns, workload implications, and human resource constraints were consistently identified as key barriers to adoption [2].

Together, these findings suggest that persistent fragmentation in healthcare information exchange cannot be explained solely by technical limitations. Rather, interoperability initiatives must address both structural constraints and institutional dynamics that influence the adoption and sustainability of data-sharing systems.

1.3 Literature Gap

To address these challenges, this study examines the structural conditions required for patient-controlled, consent-based health record exchange across fragmented healthcare networks. The paper introduces two analytical frameworks designed to explain both the historical limitations of interoperability initiatives and the emerging architectural conditions that may enable scalable patient-mediated exchange. Although the concept of patient-controlled data sharing has long been proposed, such models were historically difficult to implement due to technological and governance constraints. Recent advances in identity management, interoperability standards, and digital access infrastructure suggest that these structural barriers may now be changing.

1.4 Contributions of this Study

This study contributes to the literature on health information exchange and healthcare interoperability in four ways.

First, the paper provides a structural analysis of why centralized health information exchange initiatives have repeatedly struggled to achieve sustainable adoption despite widespread EHR deployment. By examining empirical evidence from prior implementation efforts, the study highlights how governance complexity, institutional autonomy concerns, cybersecurity risks, and workflow disruption have limited the effectiveness of centralized integration models.

Second, the study introduces the Five Preconditions Model, which identifies five technological and organizational conditions required for the implementation of patient-controlled, consent-based health record exchange at population scale. The model synthesizes prior research on identity resolution, consent management, interoperability standards, and clinical workflow integration to explain why earlier implementations were structurally infeasible.

Third, the research proposes the Overlay Moat Stack, a strategic framework describing how federated health information platforms achieve long-term defensibility without centralized data ownership. The framework emphasizes the role of workflow integration, consent-network accumulation, and longitudinal intelligence generation in creating sustainable interoperability ecosystems.

Fourth, the study integrates insights from health informatics, platform economics, and sociotechnical systems design to demonstrate how federated architectures can enable patient-mediated data exchange while preserving institutional data governance and clinical workflow autonomy.

2. Related Work and Methodology

The patient-controlled model for health record exchange is based on the theories of health informatics, organizational economics, and sociotechnical systems design. However, many previous reviews have focused on centralized health information exchange systems, leading to substantial methodological limitations in the literature. Empirical work has been dominated by observational cohort studies, where the benefit appears to be higher than in randomized controlled trials or quasi-experimental studies of similar policies or procedures, indicating considerable selection bias and confounding in the centralized exchange advantage literature. .

To develop our analytical model, this research synthesized the empirical literature on technology implementation, organizational adoption, and patient choice concerning the secondary use of health data. The peer-reviewed systematic reviews of technology implementation literature were examined, national-level datasets of providers' participation decisions, and conjoint analyses of public attitudes toward secondary data use scenarios. The comparison across methodological traditions also allowed some converging findings to be identified as well as limitations in specific designs. .

The Five Preconditions Model synthesized identity resolution accuracy expectations, consent mechanism requirements, access channel availability thresholds, interoperability protocol readiness timelines, and clinical summarization capability limitations, while the Overlay Moat Stack model synthesized network effects, technology adoption curves, switching costs, and competitive advantage mechanisms related to the federated architectures that preserve distributed data ownership but coordinate authorization across institutional boundaries. .

3. Structural Limitations of Centralization and System Replacement

Consolidated health record databases result in concentration risk for cybersecurity vulnerabilities and competitive ambiguity for accurate health record responsibility, record error correction, and responsible record breach liability. Transitioning from legacy systems to unified platforms incurs high costs and extended timeframes, alongside important disruptions to clinician workflows. This tension between integration benefits and the desire to retain institutional autonomy has shaped the progress of health information technology implementation over several decades. .

Six cases were used to develop a framework to understand nonadoption, abandonment, scale-up, spread and sustainability of health technologies: video consultations, tracking people with cognitive impairment with GPS, pendant alarms, remote biomarker monitoring, software to organize care, and integrated case management using data sharing [3]. During the development of the framework, 28 technology implementation frameworks were reviewed for their theoretical perspectives. Similar technology implementation failures were identified due to organizational rather than technological issues. The case studies showed that only a subset of end users had clinical assessments that deemed them suitable candidates for technology use, with many being clinically high risk, unpredictable, or influenced by comorbidities and sociocultural factors [3]. Remote follow-up was low in successful video consultation services, at 20%. Midwifery-led prenatal diabetes services were abandoned, and community-based heart failure services were suspended, as they were incompatible with established multidisciplinary team structures and physical examination requirements [3]. At the 18-month follow-up, 3 of the original 7 agreed to remain on GPS tracking. Again, in line with the attrition that characterizes technology-supported care coordination models [3], those technology programs characterized by high complexity across multiple domains within a given framework rarely achieved a stage of mainstreaming. Clinical staff frequently reported that the technology challenged their professional identity, scope of practice and the quality of professional relationships [3]. .

In the two decades of HIE history, in addition to technology, there have been community health management information systems funded by the Hartford Foundation to seven states in 1990, and lobbying of the Iowa state legislature by physicians resisting data sharing [4]. In the community health information network (CHIN) phase, there were 75 to 500 CHINs in formation or operation during the 1990s. Most did not survive the competition that did not support exchanging information and was unable to show financial returns [4]. Additionally, regional health information organizations required an average of $12 million in startup funding and can require $2 million to $3 million a year in operating expenses, making them difficult to sustain, especially for hospital members [4]. Additionally, this reliance on continued external grant funding suggested poor potential for sustainability and lacked sufficient value propositions for participating organizations.

Table 1: Health Technology Implementation Barriers and Outcomes [3, 4].

Implementation Category	**Key Challenge**	**Quantitative Finding**	**Primary Outcome**
Video Consultation Services	Workflow incompatibility with multidisciplinary teams and physical examination requirements	20% remote follow-up rate achieved	Prenatal diabetes services abandoned; heart failure services suspended
GPS Tracking for Cognitive Impairment	Technology-dependent care coordination attrition	3 of 7 participants retained at 18-month follow-up	High attrition characteristic of technology-supported models
Community Health Information Networks (1990s)	Competitive dynamics limiting information sharing; inability to demonstrate financial returns	75–500 CHINs in formation or operation	Most networks failed to survive
Regional Health Information Organizations	High startup and operating costs creating sustainability challenges	$12 million startup; $2–3 million annual operating costs	Dependence on external grant funding; poor sustainability potential
Technology Framework Analysis	Organizational rather than technological implementation failures	28 implementation frameworks reviewed across 6 case studies	Programs with high complexity rarely achieved mainstreaming

4. The Five Preconditions Model for Patient-Controlled Health Record Exchange

4.1 Model Framework

The Five Preconditions Model explains why patient-controlled federated exchange was not possible without any one of the structural conditions and why implementation at scale was only possible if all five were mature. Historically, implementations of health information exchanges were constrained by the interdependent nature of the basic requirements, with no basic requirement being technically impossible, but practical/real-world constraints preventing the exchange from working until all five were mature.

4.2 Precondition Components

Precondition 1: Reliable Portable Patient Identity
Longitudinal record linkage also requires deterministic or near-perfect identity resolution across institutional boundaries. Likewise, health systems have relied upon local identifiers or probabilistic algorithms, which have insufficient accuracy for population-level deployment. In two hospital patient registries of 6000 record pairs, deterministic algorithms incorrectly linked 4.7% and 9.2% of records when Social Security Number was the only variable. Three types of errors were described: spousal (56% and 39%), typographical (41% and 30%), and unknown etiology (3% and 31%) [5]. 35% of the patient registration records at an institution lacked a Social Security Number (SSN), precluding the single identifier methodology [5]. A Social Security Number in combination with a NYSIIS-phonetically compressed first name, birth month, and gender was optimal to link without false positives. The best combination had a sensitivity of 87% to 88% and a specificity of 100% [5]. Union approaches returned 90% to 92% sensitivity without false links and showed that multi-field deterministic algorithms outperform single-identifier algorithms for patient identification between medical institutions [5].

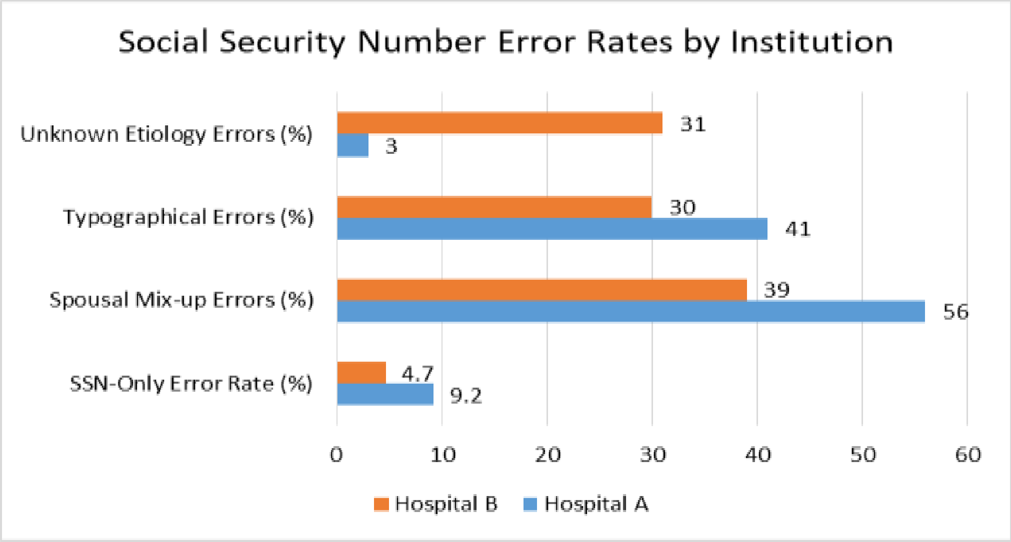
Precondition 2: Machine-Enforceable Granular Consent
The need for consent in health information exchange is specific, time-limited, reversible, and auditable. Static institutional arrangements and paper-based consent procedures cannot support the dynamic information access needs of patients and their care across multiple providers.

Precondition 3: Ubiquitous, Patient-Selectable Access Channels
Patient-controlled exchange requires the patient's acceptance of consent at the time of care and thus assumes high penetration of the smartphone, reliable internet access, and a user-friendly interface with real-time consent.

Precondition 4: Interoperable Access Interfaces
For the exchange to be scalable, these APIs must be standardized to allow federated data retrieval while still maintaining the data sovereignty of these institutions. One example of this is the SMART on FHIR platform, which demonstrated cross-institutional interoperability without the need for centralized storage [6]. The four corporate exhibitors (Cerner Corporation, Intermountain Healthcare, Hewlett-Packard Company, and Harris Corporation) developed prototype implementations that used one or two software engineers for less than two months. None of the vendors had implemented any component of the FHIR API before [6]. The reference implementation of the API server was approximately 3000 lines of Groovy code and implemented all of the FHIR resources, each supporting create, read, update, and delete (CRUD) operations [6]. The active medication list application consisted of 25 lines of JavaScript to instantiate the client, determine the patient context, and have the API retrieve patient demographics and retrieve and output medication [6]. Approximately 60 sample patients with hybrid anonymized and synthesized clinical data were created for testing. Third-party developers were able to port existing applications to the new standard interfaces in one to two days [6].

Precondition 5: Clinically Usable Summarization
Raw health data volumes exceed clinical utility thresholds without appropriate processing or visualization. Unstructured data may overload clinicians' cognitive abilities rather than support clinical decision-making. Tools that automatically summarize clinically relevant information can highlight key elements of longitudinal data for clinicians.

Figure 1: Social Security Number Error Rates by Institution [5, 6].



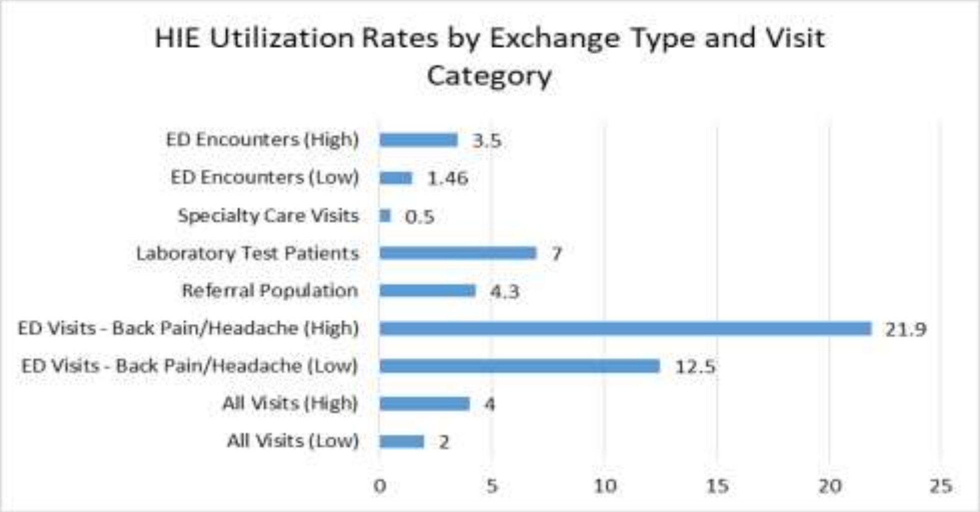
5. Overlay Architecture as a Scalable Design Pattern

In healthcare, systems are rarely replaced, so innovation's durability comes from overlay architectures that build on existing infrastructure. This allows identity, consent, and access semantics to remain consistent while allowing institutions to maintain their own clinical workflows. However, the overriding obstacle to health information exchange is not a technological one but rather the challenges of melding different organizational cultures, liability issues, and workflow, which have stalled centralized integration efforts.

Three types of health information exchanges have been identified. Community exchanges are convened by neutral third-party organizations, enterprise exchanges are convened by large healthcare organizations with affiliated and unaffiliated providers, and vendor-mediated exchanges are eased by electronic health record (EHR) vendors that sell to both sides. Community health information exchanges (community HIEs) have been the most studied, with 119 exchanges identified as having active operations in 2012 and 30% of hospitals and 10% of ambulatory providers participating [7]. In practice, however, actual use seems quite low. Five studies with community exchanges had visits to them in only 2% to 4% of all visits. Visits to emergency departments for back pain and headache ranged from 12.5% to 21.9% [7]. Different results were found for enterprise exchanges, for which outside data on patients was accessed 4. 3% of the time for referrals and 7% of the time for patients undergoing one of eight laboratory tests in two studies for the Clarit health maintenance organization [7]. In vendor-mediated exchanges, such as Epic Systems' Care Everywhere network, the frequency of use was as low as 1.46% of emergency room visits, with 0.5% for specialist visits, and as high as 3.5% of emergency department visits. The lower utilization of vendor-mediated exchanges may result from the integration of mediation with EHR workflows rather than separate portal utilization and security context establishment. Vendor-mediated exchanges received a higher value than other exchange types. They were also rated as more usable than community exchanges but less usable than enterprise exchanges.

According to national survey data on live operational health information exchange efforts, 119 organizations were exchanging clinical information in 2012, a 61% increase from the 75 identified in 2010 [8]. The fraction of hospitals actively exchanging health information more than doubled between 2010 and 2012 (from 14% to 30%), and the fraction of ambulatory practices more than tripled (from 3% to 10%) [8]. Geographic coverage improved as well, with 67% of hospital service areas (2,309 of 3,434) containing an operational effort in 2012 that allowed providers to meet the core health information exchange requirements [8]. However, sustainability remains a challenge. Grants and contracts were the primary revenue source for 52% of operational exchanges, and just fewer than 24% reported being able to fully cover operating costs with participant revenue [8]. Moderate or substantial challenges developing sustainable business models were reported by 74% of all planning and operational exchanges, and fewer than half included payers who could benefit from decreased redundant testing [8]. 82% of exchanges were to transfer results data, followed by summary care records (79%), discharge summaries (66%), and clinical (61%) summaries of the patient's records [8].

Figure 2: HIE Utilization Rates by Exchange Type and Visit Category [7, 8].



6. The Overlay Moat Stack: Defensibility Without Centralization

6.1 Framework Definition

The Overlay Moat Stack theorizes competitive moat strategies for federated health record platforms that have no centralized data ownership. Classic platform strategy assumes that asset accumulation in the form of proprietary data is a sustainable competitive advantage. However, other applications, such as health record systems, that rely on patient-controllable consent do not have this option since consent is always revocable and since data is owned and governed by source institutions; in these cases, defensibility must rely on network density, workflow integration, and intelligence generation from this data.

6.2 Layer Components

Layer 1: Infrastructure Alignment connects distributed source systems through standard protocols. This requires attacking integration engineering in a way that creates switching costs without data ownership lock-in. Technical infrastructure is a necessary but insufficient condition for platform value creation. .

Layer 2: Workflow Integration. Integration of access into the clinical decision process creates use patterns that reinforce the platform value. Data on hospital data exchange behavior (American Hospital Association Technology Survey of 4060 hospitals) showed internal exchange was 68% of hospital data sent, and external exchange with unaffiliated organizations was 17% [9]. Larger hospital systems were positively predictive of internal exchange (odds of internal exchange increased around 2 percentage points for each additional hospital in a system [9]) and negatively predictive of external exchange [9]. The results are consistent with the theory of information silos generated by large hospital systems. Hospitals with Epic systems have a 22.9 percentage point (pp) greater likelihood of internal exchange. Hospitals with Cerner systems have a 16.7 pp greater likelihood. Vendor choice appears to matter independent of organizational characteristics. Non-profit hospitals were 8.6 percentage points more likely to exchange internally, and specialty hospitals were 5.7 percentage points more likely to exchange than general hospitals [9] .

Layer 3: Consent Graph Accumulation builds network effects from patient-to-patient consent relationships across multiple providers/care episodes. Conjoint analysis of selections by 3,336 participants, including 568 Hispanic, 500 non-Hispanic African American, and 2,268 non-Hispanic white, regarding their preferences for secondary electronic health information use [10]. Data use was the most influential variable in willingness to share data, with a mean importance weight of 64.3%.

Identity of the data user had a weight of 32.6%, and sensitivity of data had the lowest weight of 3.1% [10]. Compared with research use, marketing and quality improvement use were associated with a 1.55 and 0.51 point reduction, respectively, on a 10-point Likert scale. Drug company and public health department users were associated with reductions of 0.80 and 0.52, respectively, compared with university hospital users. Hispanic and African American respondents were less likely than white respondents to differentiate between uses, suggesting a need for culturally tailored efforts aimed at improving trust in the use of patient data. .

Layer 4: Longitudinal Intelligence, relies on the synthesis of records from multiple institutions to produce piecing-together insights that would not be available from a single institution's records. Layer 4 is only possible when layer 3 possesses sufficient authorization density and temporal depth to see useful patterns across fragmented episodes of care.

Table 2: Overlay Moat Stack Layer Components and Key Metrics [9, 10].

Layer	Component	Key Finding	Quantitative Metric
Layer 1	Infrastructure Alignment	Technical connectivity through standardized protocols creating switching costs	Necessary but insufficient condition for platform value
Layer 2	Workflow Integration	Internal data exchange predominates over external exchange; vendor selection influences exchange behavior	68% internal exchange, 17% external exchange, Epic +22.9 pp, Cerner +16.7 pp, and Non-profit +8.6 pp
Layer 3	Consent Graph Accumulation	Purpose of data use dominates willingness to share; user identity secondary; data sensitivity minimal influence	Use importance: 64.3%; User importance: 32.6%; Sensitivity importance: 3.1%
Layer 3	Consent Preferences by Use Type	Marketing and quality improvement uses reduce willingness compared to research; drug companies reduce willingness compared to university hospitals	Marketing: −1.55 points; Quality improvement: −0.51 points; Drug company: −0.80 points; Public health: −0.52 points
Layer 4	Longitudinal Intelligence	Cross-institutional record synthesis generating insights unavailable from single-source systems	Dependent on Layer 3 authorization density and temporal depth

Conclusion

Patient-controlled federated health record exchange is a sustainable alternative to centralized integrations, which have repeatedly failed to implement cross-institutional data sharing. The structural preconditions for federated network architectures have only recently simultaneously matured, explaining the longstanding impracticality of conceptually sound approaches to cross-institutional data sharing with self-sovereign systems through decades of digitization. However, overlay architectures will still allow for scalable expansion of existing infrastructure without institutional adoption of standardized technologies or centralized breach liability. This value proposition of federated exchange relies on sufficient density to allow authorized peers to provide meaningful longitudinal context of care rather than ephemeral snapshots of single-instance encounters. In patient-controlled platforms, competitive defensibility will not be maintained through proprietary control of databases. Instead, such platforms will maintain defensibility to the extent that they are able to create integrated, trusted workflows; show the intelligence that is derived therefrom; and build trust through the transparency of authorization processes. Healthcare organizations grappling with investment decision-making on technologies will view community exchanges, enterprise exchanges and vendor-mediated exchanges as complementary channel partners on the road to the emergence of health information networks. The combination of standardized interoperability interfaces, acceptable levels of identity resolution, and ubiquitous mobile devices presents an unprecedented opportunity to finally achieve the long-wished-for use of thorough health information at the point of care across fragmented care delivery systems.

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