



The Continuity of Care Record: A Review of Interoperability, Data Curation, and the "Single Source of Truth"

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Abstract

Background: The modern patient journey generates fragmented data across electronic health records, laboratory systems, and pharmacy networks, complicating clinicians' efforts to compile comprehensive patient information. This fragmentation can lead to medication errors, redundant testing, and potential patient harm, undermining value-based and patient-centered care. The promise of a unified Continuity of Care Record remains largely unfulfilled.

Aim: This narrative review aims to critically analyze the multifaceted challenge of creating a coherent, interoperable Continuity of Care Record. The review proposes a paradigm shift from passive data aggregation to active, multidisciplinary "record stewardship."

Methods: A comprehensive literature search was conducted across PubMed, IEEE Xplore, CINAHL, and Scopus databases for English-language articles published between 2010 and 2024.

Results: The analysis identifies three key pillars for effective Clinical Care Record (CCR): Technical Interoperability, which grapples with syntactic and semantic challenges despite standards such as FHIR; Proactive Data Curation, which requires structured contributions from all care team members for contextual data; and Operational Governance, emphasizing the need for oversight to maintain data quality and integrity. Cross-disciplinary collaboration is crucial to tackle these challenges.

Conclusion: A cohesive Continuity of Care Record is crucial not just technically but as an organizational and clinical necessity. Achieving this requires a shift from viewing interoperability as simply data management to fostering a culture of collaborative record stewardship. A multidisciplinary team, guided by clear governance and current standards, is vital for creating a consistent narrative that offers clinicians a dependable, unified source of truth for clinical decision-making.

Keywords: Continuity of Care, Interoperability, Health Information Exchange, Data Curation, Clinical Documentation.

Introduction

The contemporary healthcare experience is a story told in fragments. A patient's narrative is splintered across primary care clinics, specialist offices, emergency departments, independent laboratories, retail pharmacies, and increasingly, digital health applications (Reynolds et al., 2023). Each encounter generates data, yet these vital pieces of information are routinely trapped within proprietary electronic health record (EHR) systems and siloed databases that communicate poorly, if at all. This

fragmentation creates a profound paradox: in an era of unprecedented data generation, clinicians are often making critical decisions with an incomplete and outdated view of the patient (Irizarry et al., 2015). The consequences are both clinical and economic: missed diagnoses due to unavailable records, dangerous medication interactions from uninformed prescribing, costly and painful duplicate testing, and patient frustration from endlessly repeating their history (Smithman et al., 2022; Temte et al., 2020).

The conceptual antidote to this chaos is the Continuity of Care Record (CCR)—a comprehensive, longitudinal, and portable health summary that follows the patient, providing any authorized caregiver with a coherent "single source of truth." Despite decades of discussion, substantial investment, and regulatory push, this vision remains elusive. This narrative review argues that the failure to achieve a functional CCR stems from a narrow focus on technical "interoperability" between systems, while neglecting the equally critical human and operational processes of data curation and stewardship. True continuity requires that data is not merely exchanged, but meaningfully integrated, contextualized, and maintained.

This review will critically examine the challenge through the lens of the entire care ecosystem, analyzing the distinct but interconnected roles of frontline documenters (nurses, health assistants), data generators (labs, pharmacies), data architects (informatics), and system governors (operations). It proposes that the path forward lies in reconceptualizing the health record as a collaboratively built and maintained asset, requiring a formal model of multidisciplinary stewardship.

Technical and Semantic Hurdles to Interoperability

The foundational barrier to a unified record is the lack of true interoperability. Interoperability is not a binary state but a spectrum, often categorized into four levels: foundational (data transport), structural (data format), semantic (data meaning), and organizational (governance and policy) (Michael, 2018). While progress has been made on foundational and structural levels with standards like Health Level Seven Fast Healthcare Interoperability Resources (HL7® FHIR®), profound challenges persist. Syntactic interoperability, ensuring data can be parsed, is often achieved, but semantic interoperability—the assurance that the receiving system interprets the data precisely as the sending system intended—remains a formidable obstacle (Benson & Grieve, 2016; Ait Abdelouahid et al., 2023). For example, a problem list entry of "HTN" in one system may not map correctly to "Hypertension" or "I10" in another, breaking the continuity of the diagnosis (Chatterjee et al., 2022).

Laboratory results may be transmitted without standardized units of measure or reference ranges, rendering them ambiguous or even dangerous to interpret out of context. Medication data is particularly fraught, with variations in drug names, strengths, and sigs creating confusion that directly threatens patient safety (Vashisht et al., 2023; Dixon et al., 2020).

Furthermore, the current ecosystem is dominated by a document-centric exchange paradigm (e.g., Consolidated Clinical Document Architecture - C-CDA), which often results in the transfer of static, unstructured PDFs or bloated XML documents. These "digital paper" documents must be manually reviewed

and reconciled, burdening clinicians rather than enabling seamless data integration into their workflow (Payne et al., 2010; Cai et al., 2017). The promise of FHIR is its API-based, discrete data approach, allowing for specific data elements (e.g., a latest hemoglobin A1c value) to be requested and embedded directly into the receiving EHR's native flowsheets. However, widespread production implementation of FHIR for broad-based continuity of care is still in its adolescence, hampered by variable implementation guides, security concerns, and vendor-specific customization that recreates silos at a more granular level (Mandel et al., 2016). Thus, the technical pipeline for data movement, while improving, remains leaky and prone to misinterpretation, failing to automatically construct a coherent narrative (Ayaz et al., 2021).

The Human Source as the Frontline Curation of Context and Narrative

If interoperability provides the pipeline, the data that flows through it must be accurate, relevant, and meaningful. This is where the critical, yet often undervalued, role of frontline clinical staff as data curators begins (Campbell et al., 2022). The record is not a passive repository; it is actively authored and shaped at every patient encounter. Health Assistants and medical secretaries are frequently the first to gather and document core information, including social history, family history, and reason for visit (Neadley et al., 2021). The precision and consistency with which they capture this data—using structured templates where possible—set the stage for the entire encounter and feed the longitudinal social determinants of health (SDOH) profile (DeMers, 2022). A poorly recorded smoking status or occupation can have downstream impacts on risk assessment and preventive care reminders.

Nursing documentation is the bedrock of the patient's functional and holistic story. Nurses contribute continuous data on vital signs, pain scores, medication administration, patient education, and, crucially, functional status and care coordination notes. The shift from narrative notes to structured, discrete data fields in EHRs has improved searchability but can sometimes obscure the patient's narrative (Forde-Johnston et al., 2023). The nursing assessment—documenting a patient's ability to perform activities of daily living, their psychosocial concerns, or subtle changes in condition—provides context that lab values and diagnosis codes cannot (Ozonze et al., 2023). This contextual layer is essential for continuity across settings, such as from hospital to home health, yet it is often the most difficult data to standardize and share interoperably. The nurse's role extends beyond entry to verification; they are often the first to identify and correct discrepancies in medication lists or allergy histories, acting as real-time stewards of data accuracy (Zarour et al., 2021). Empowering and training these frontline roles to see themselves as essential curators of the shared record is

a fundamental cultural prerequisite for a trustworthy CCR.

Ancillary Data Streams: Laboratories and Pharmacies as Core Contributors

The patient record is massively enriched by structured data from ancillary services, primarily laboratories and pharmacies. These sources generate high-volume, high-precision data that form the objective core of many diagnostic and therapeutic decisions. Medical Laboratory information systems produce results that are typically highly structured (numeric values, standardized codes like LOINC), making them ideal candidates for interoperability. However, continuity is challenged when patients use multiple lab networks (e.g., hospital lab, outpatient reference lab, point-of-care testing), and results are not aggregated into a single timeline (Adler-Milstein & Jha, 2012). A potassium trend is only meaningful if all potassium results, regardless of origin, are viewable in sequence. Furthermore, lab data without context—such as the medication the patient was on when the test was drawn—loses meaning. True integration requires linking lab orders and results to specific problems and medications within the record (Louch et al., 2022).

Pharmacy data is arguably the most critical for safety and continuity. A comprehensive medication history, including prescriptions from multiple providers, over-the-counter medications, and supplements, is vital to prevent adverse drug events (Zadeh & Tremblay, 2016). Pharmacy benefit managers (PBMs) and retail pharmacy networks hold valuable medication fill history data, which can be accessed via exchanges like the National Council for Prescription Drug Programs (NCPDP) SCRIPT standard for e-prescribing and medication history (Rahman Jabin & Hammar, 2022). Yet, this data often exists separately from the clinical EHR, leading to burdensome manual reconciliation. Pharmacists themselves are expert stewards of medication data; their clinical interventions—documented in pharmacy systems—regarding dose appropriateness, interactions, or adherence, are rarely reflected in the continuity documents seen by other providers (Costello et al., 2023). Integrating these discrete, high-value data streams from labs and pharmacies as structured, coded elements, rather than as scanned documents or manual entries, is a technical and operational imperative for building a complete record (Arnold et al., 2015).

The Informatics Mandate in Structuring, Integrating, and Presenting the Narrative

The disciplines of health informatics and clinical informatics sit at the nexus of the technical and the clinical, with the mandate to structure, integrate, and present data in a way that supports cognition and care. Informatics professionals are responsible for designing the EHR frameworks that guide documentation, implementing interoperability standards, and building the tools that attempt to synthesize disparate data into a useful narrative

(Chiang, 2021). This involves creating logical data models, establishing master data management (e.g., consistent patient identifiers), and developing clinical decision support (CDS) rules that act upon the integrated data (Shortliffe & Cimino, 2006).

A key informatics challenge is information overload. Simply dumping all available data from multiple sources into a clinician's view creates "note bloat" and alert fatigue, obscuring the signal in the noise (Budlong et al., 2018). Informatics must therefore design aggregation and synthesis algorithms. This can range from simple displays, like a timeline graph of lab values, to more complex AI-driven summarization tools that can generate a one-paragraph synopsis of a patient's last hospitalization or highlight the most clinically relevant changes since the last visit (Feldman et al., 2018). Furthermore, informatics governs the user interface (UI) and user experience (UX). The UI must present the curated data from nurses, health assistants, labs, and pharmacies in an intuitive, workflow-integrated manner that tells a clear story. Poor design can nullify the benefits of even perfectly interoperable data. Thus, informatics does not just enable data flow; it is responsible for transforming raw data into actionable information and, ultimately, into the wisdom needed for clinical decisions (Walsh et al., 2019).

Operational Governance as The Missing Layer of Data Stewardship

The consistent creation of a high-quality, longitudinal record cannot be an emergent property of individual workflows; it requires deliberate operational governance. This encompasses the policies, procedures, accountability structures, and quality management processes that ensure data integrity, security, and appropriate use across its entire lifecycle. Governance answers critical questions: Who is accountable for the accuracy of the problem list? What is the process for reconciling medications after a hospital discharge? How often are SDOH data elements reviewed and updated? What are the standards for data entry by different roles? Without clear governance, data quality degrades, interoperability efforts falter, and the record's trustworthiness erodes (Piasecki & Cheah, 2021).

A core governance function is data quality management. This involves ongoing monitoring of key metrics: completeness (e.g., percentage of records with updated smoking status), accuracy (via audits), timeliness, and consistency. Operational leaders must establish data quality dashboards and feedback loops to units and individual contributors, tying performance to a culture of excellence (Weiskopf & Weng, 2013). Furthermore, governance must manage the information lifecycle, including retention policies, archiving, and defining what constitutes the "legal record." In the context of a multi-source CCR, governance must also establish trust frameworks for external data: what external sources are deemed sufficiently reliable to be ingested automatically

versus those that require verification? Operational governance provides the scaffolding upon which the technical and human elements of the CCR are built; it is the function that turns aspiration into reliable, daily practice.

Towards a Model of Multidisciplinary Record Stewardship

Given the interdependencies described, it is clear that no single role or department can singularly own the Continuity of Care Record (Table 1). What is needed is a shift from a siloed, transactional view of

documentation to a shared ethic of record stewardship. This review proposes the formation of formal, multidisciplinary Record Stewardship Teams (RSTs) at the organizational or health network level. An RST would not own the data but would own the processes and quality of the integrated record. Figure 1 depicts the roles of clinicians, nurses, laboratories, pharmacies, informatics, and operations within a Record Stewardship Team (RST), highlighting bidirectional data flows and shared accountability for data quality and clinical narrative integrity.

Table 1: Proposed Composition and Responsibilities of a Multidisciplinary Record Stewardship Team (RST)

Core Member (Discipline)	Primary Focus	Stewardship Key Responsibilities
Clinical Informaticist (Chair)	Overall data integration & usability	Leads RST; aligns technical build with clinical workflow; oversees CDS and presentation layer.
Nursing Informatics Lead	Nursing documentation, care coordination data	Ensures nursing flowsheets and notes support continuity across settings; represents frontline nursing workflow.
Physician Champion	Problem lists, diagnosis accuracy, clinical narrative	Advocates for physician usability; guides policy on problem list management and attestation.
Pharmacy Informatics Lead	Medication data integrity & reconciliation	Oversees integration of pharmacy data (internal and external); manages medication-related CDS.
Laboratory/Ancillary IT Lead	Structured data from labs, radiology, etc.	Ensures reliable, coded data feeds from ancillary systems; manages interfaces and LOINC/SNOMED mapping.
Health Information Management (HIM) Lead	Data quality, integrity, and lifecycle	Manages data quality metrics, audits, chart completion policies, and legal record definition.
Patient/Consumer Advocate	Patient-facing data access and usability	Ensures patient portal views of the CCR are understandable and useful; incorporates patient-generated data.
Operations/Quality Leader	Governance, policy, and performance metrics	Establishes accountability; ties data quality to organizational quality and safety goals.



Figure 1. Multidisciplinary Record Stewardship Ecosystem

The RST's work would be operationalized through regular reviews of data quality dashboards, user feedback on record usability, and proactive management of interoperability projects (Table 2). It would develop and maintain a Record Stewardship Charter that defines data standards, reconciliation protocols, and roles for curating specific sections of the record (e.g., the primary care physician's office is steward of the active problem list, the discharging hospital unit is steward of the discharge reconciliation). Figure 2 illustrates how Technical Interoperability, Proactive Data Curation, and Operational Governance interact to produce a unified, longitudinal Continuity of Care Record (CCR).

Table 2: The Three-Pillar Framework for Achieving a Coherent Continuity of Care Record

Pillar	Definition	Key Components	Enabling Disciplines
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1. Technical Interoperability	The ability of systems to exchange, interpret, and use data.	- Standards (FHIR, C-CDA, USCDI) - APIs & Secure Data Transport - Master Patient Indexing - Semantic Terminologies (SNOMED CT, LOINC, RxNorm)	Health Informatics, IT, Standards Bodies
2. Proactive Data Curation	The human process of capturing, verifying, and contextualizing data at the point of care.	- Structured documentation by frontline staff (HAs, RNs, MDs) - Medication reconciliation - SDOH data capture - Contextual narrative documentation	Nursing, Medicine, Health Assistants, Pharmacy, Social Work
3. Operational Governance & Stewardship	The policies, accountability, and quality management overseeing the record's lifecycle.	- Data Quality Metrics & Audits - Clear Ownership Policies (e.g., problem list) - Record Stewardship Team (RST) - Information Lifecycle Management	Operations, HIM, Quality & Safety, Clinical Leadership



Figure 2. The Three-Pillar Framework for a Coherent Continuity of Care Record

This model acknowledges that the "single source of truth" is not a static document but a dynamically curated resource. The RST ensures the pipes are built (Interoperability), that high-quality content flows through them (Curation), and that the entire system is monitored and improved (Governance).

Conclusion

The quest for a unified Continuity of Care Record is more than a technical challenge; it is a fundamental prerequisite for achieving the aims of modern healthcare: safety, coordination, patient-centeredness, and value. As this review has argued, overcoming fragmentation requires simultaneous and integrated progress on three fronts: advancing technical interoperability beyond document exchange

to discrete data integration; elevating the practice of all care team members as conscientious data curators; and establishing robust operational governance led by multidisciplinary stewardship teams. The HL7 FHIR standard and regulations like the 21st Century Cures Act's information-blocking rules are creating unprecedented technical momentum. However, technology alone is insufficient. Healthcare organizations must invest in the human and operational infrastructure to steward the record. This means providing training and support for frontline data curators, dedicating resources to data quality management, and formally chartering teams with the authority to harmonize practices across departments and disciplines. The Continuity of Care Record, when realized as a collaboratively built and maintained longitudinal narrative, ceases to be just a repository of facts. It becomes the shared cognitive tool that aligns every member of the care team—and the patient themselves—around a common, accurate understanding of the patient's story. In doing so, it finally provides the "single source of truth" upon which truly coordinated, safe, and effective care can be built.

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