



# Implementing partnership-driven clinical federated electronic health record data sharing networks



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## ABSTRACT

**Objective:** Building federated data sharing architectures requires supporting a range of data owners, effective and validated semantic alignment between data resources, and consistent focus on end-users. Establishing these resources requires development methodologies that support internal validation of data extraction and translation processes, sustaining meaningful partnerships, and delivering clear and measurable system utility. We describe findings from two federated data sharing case examples that detail critical factors, shared outcomes, and production environment results.

**Methods:** Two federated data sharing pilot architectures developed to support network-based research associated with the University of Washington's Institute of Translational Health Sciences provided the basis for the findings. A spiral model for implementation and evaluation was used to structure iterations of development and support knowledge share between the two network development teams, which cross collaborated to support and manage common stages.

**Results:** We found that using a spiral model of software development and multiple cycles of iteration was effective in achieving early network design goals. Both networks required time and resource intensive efforts to establish a trusted environment to create the data sharing architectures. Both networks were challenged by the need for adaptive use cases to define and test utility.

**Conclusion:** An iterative cyclical model of development provided a process for developing trust with data partners and refining the design, and supported measurable success in the development of new federated data sharing architectures.

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## 1. Introduction

The broad adoption of electronic health record systems (EHRs) and efforts to align data across disparate EHRs have led to advancements in research to improve public health. But barriers to establish effective data sharing systems range across technical, motivational, economic, legal, political, and ethical issues [1]. Data sharing has an integral role in reducing the lag between research and clinical knowledge, products, and procedures that can improve human health [2]. Bi-directional data sharing between clinical care and research environments is crucial to advance improvements in patient care and overall population health and essential to a Learn-

ing Healthcare System [3]. But creating data sharing systems is complex and difficult.

Technical and methodological frameworks and guidelines for providing and integrating data sharing infrastructures across multiple distinct and disparate clinical environments can advance the ability for translational and comparative effectiveness research, and lead to meaningful use and sharing of medical data [4]. However, there are no systematic efforts to develop processes for creating data sharing architectures in public health environments [1]. Published accounts addressing builds of data sharing infrastructures lack any systematic application of well-established software development models. At present, implementation of data sharing systems are often supported by grant funding and require the development of broad engagement strategies between disparate environments. Sustainability of these systems often becomes a challenge after initial investments support creation [5]. Software

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model applications to architecture builds may lead to better sustainability.

### 1.1. Background and significance

Previous efforts in developing methods and tools to support clinical data sharing for research lack access to high quality data sources [6–8]. Centralized approaches to data sharing are limited by the scope of the data that network partners typically authorize for sharing and the difficulty with keeping these data up to date [4]. Historically, limitations have also included uneven common terminology expertise, challenges of trust and feasibility, and concerns for privacy and security [4,9–17]. Storing data locally at partner sites and using federated approaches to support data sharing is attractive because they simplify privacy and security issues and clarify trust relationships [18]. However, no standard use of terminologies and other semantic alignment issues remain a challenge, regardless of a centralized versus federated model [19]. To date, large scale federated data sharing networks remain relatively scarce, though successes have been increasing in domain-specific networks such as Regional Health Information Organizations and cohort discovery pilots [19–22]. Growing concerns of enhanced HIPAA privacy laws may further limit data sharing efforts [23].

The expanding use of health information technology, driven through efforts such as the 2009 HITECH act and the meaningful use requirement of health information exchanges, has created the need for effective data sharing methods across organizations to target evaluation and implementation of evidence based, patient-centered clinical practices [24–26]. Methodological approaches to developing federated data sharing networks need to be testable and generalizable to multiple domains, users, and stakeholders. The NCATS Clinical Translational Science Award (CTSA) consortium has provided a fertile environment for building federated data sharing networks across a range of heterogeneous institutional and community based clinical environments with a focus on translational science.

### 1.2. Objective

We partnered across two network teams to implement and evaluate a software development model for building federated electronic health record clinical data sharing architectures. We describe the use of a common spiral model and the experience of developing two distinct architectures. Implementation of the spiral model centrally incorporated partnership building across different clinical data environments and addressed the crucial role of partnerships and disparate electronic medical record platforms and workflows.

## 2. Methods

### 2.1. Network development pilot projects

The common goal of our network pilot projects was to implement architectures for federated networks that could support research queries through a common set of terminologies and business processes. The Data QUery, Extraction, Standardization, Translation (Data QUEST) project focused on data sharing across primary care based electronic health record (EHR) data domains (i.e., demographics, visits, problem lists, medications, labs, diagnoses, tests, various medical metrics and findings, etc.) across six primary care organizations in Washington and Idaho [27]. Data QUEST is aimed to provide tools for sharing both de-identified and identified data in aggregate form and at the patient level. The Cross-Institutional Clinical Translational Research (CICTR) project

targeted sharing five broad data domains (i.e., demographics, medications, labs, diagnoses, and disposition data), with a common domain of diabetes across acute care settings at three academic institutions (University of Washington, University of California, San Francisco, and University of California, Davis) with a focus of sharing de-identified aggregated data [28]. Both projects used HIPAA guidance to define privacy handling of data prior to allowing research querying. Both projects supported approaches that describe and document the data provenance.

### 2.2. Procedure

Three primary categories of software models have been identified (free/open source software (FOSS), plan-driven, and agile) with little progress made at creating comprehensive reconciliation across these models [29]. However, recommendations for selecting an appropriate model include achieving a balance between agility and discipline [30]. The strength of FOSS lies in allowing stakeholders to address and refine a system based on individual priorities and resources. This model did not provide a feasible approach, given our partner sites must share resources and technical solutions to remain scalable in a diverse health data sharing architecture environment. Plan-driven or waterfall models lack iterative processes for achieving stakeholder engagement across cycles of development that provide flexibility, buy in, and adaptability. Agile methods are iterative but rely on quick “sprints” through the phases of development to produce working systems for evaluation, which require intensive development resources and evaluation resources (clinical and technical) from our partners that they did not have.

To balance agility and discipline, we chose Boehm’s spiral model, used across many commercial and defense projects, which included a focus on using a cyclic approach to grow a system’s degree of definition and implementation while laying out anchor point milestones to ensure stakeholder commitment to the defined solutions [31,32]. The spiral model was used to provide clear process to guide our architecture development and included cycles for iteration, incremental development, and the right level of risk management and cultural compatibility for our environment. We analyzed project activities, milestones, stakeholder priorities, and project documents using themes from Boehm’s spiral model of development, which included four main phases in the software development lifecycle, to define additional emerging themes. Each team, in partnership with project stakeholders, then reviewed and iterated on the emerging themes and charted the history of the project across the theme areas to develop initial project specific content for a draft spiral model. The resulting model was adopted within the Data QUEST and CICTR project teams, guiding biomedical informatics work within the projects. The model provided a frame to report and assess both individual project and cross project successes and challenges.

## 3. Results

### 3.1. The partnership-driven clinical federated (PCF) model

#### 3.1.1. PCF model description

A generic spiral model for partnership-driven clinical federated (PCF) data sharing, based on Boehm’s spiral model for software development [31,32], emerged from our iterative and qualitative based methods (Fig. 1). This model identified four themes to anchor the iterative process of development: (1) developing partnerships, (2) defining system requirements, (3) determining technical architecture, and (4) conducting effective promotion and evaluation.

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