Clinical Data Exchange Model: Matching HIE Goals with IT Foundations

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Which IT architecture is best for an HIE? It depends on what the participants want to accomplish. Matching goals with clinical data exchange models is essential to success.

One of many fateful decisions a local or regional health data exchange network makes is the core technical foundation that will enable the actual sharing of clinical data. Several models exist, each with their own benefits and challenges.

Which is best? The answer depends on what the health information exchange (HIE) wants to achieve. To choose the best model, stakeholders must have a clear understanding of their primary purpose, mission, and goal. They may seek to improve continuity of care, decrease cost of patient care, or support clinical research.

HIM expertise can be valuable to this decision. With a comprehensive understanding of how patient data traverses the care continuum, how it should be presented to clinicians, and the need to preserve patient privacy and data confidentiality, HIM professionals offer unique insights into data architecture decisions. By gaining a basic understanding of the models, they can lend their expertise to an HIE's success.

Determining Purpose, Defining Approach

Stakeholders establish their primary goals through several processes. These include defining business level objectives; developing use cases to clarify the scenarios for exchanging clinical data; and describing the types of clinical data to be exchanged. They must define the HIE's data governance, determine the standards to be used in the interoperability of the exchange, and write the integration specifications and implementation plan. They must complete integration testing and define the ongoing quality improvement processes.

Before getting too far down the formation and implementation path, stakeholders must determine their approach to requestor authentication, validation of the patient record being requested (and therefore the record-matching algorithms), and the technical transmission of the actual clinical data (and therefore the data mapping and translation needed). Each of these aspects requires thorough privacy and security policies and procedures.

Stakeholders must think through how a requested piece of clinical data (or report or record) will physically be delivered through the system. This will confirm that users actually gain benefit from the eventual system. Without benefit to the users, adoption of the system will not occur and the HIE will likely falter.

Data Exchange Architecture

Data exchange architecture describes how shared data are processed, stored, and used in a given system. It provides criteria for data processing operations that make it possible to design and control the flow of data in the system. The industry currently recognizes three distinct models: federated, centralized, and hybrid.

Federated is a decentralized approach that emphasizes partial, controlled sharing among autonomous databases. Components (systems) of a federated architecture represent the various stakeholder users, applications, workstations, servers, et cetera. Each stakeholder controls its interactions with others by means of an export and import schema.

The export schema specifies the information that a component will share, while the import schema specifies the nonlocal

information that a component wishes to access. The federated architecture provides a means to share data and transactions using messaging services, combining information from several components, and providing the coordination of data exchange among autonomous components.

Centralized architecture emphasizes full control over data sharing through a centralized repository. Components in a centralized architecture refer to the central data repository and the requestor. The repository authenticates the requester, authorizes the transaction, and records it for audit and reporting purposes.

Hybrid is a combination of the two architecture types used to achieve the actual exchange of clinical data. For instance, pharmaceutical transactions may occur through the use of a federated model, while lab data are shared through a centralized database. Providers in a hybrid architecture may also decide to share patient data through a clinical data repository or via peer-to-peer means.

Hybrid models are generally selected for their attributes normally associated with a consolidated data model, such as standardized terminology, business intelligence, profiling, decision support and quality analysis capabilities, and quick response times

This article builds upon two preceding ones published in the Journal of AHIMA. In September 2007, the practice brief "HIM Principles in Health Information Exchange" provided foundational information on HIE and the key building blocks of a successful RHIO. An appendix summarizes the models side-by-side. "An IT Primer for Health Information Exchange," published in January 2008, offered basic technical terminology related to the electronic exchange of healthcare data. Both articles are available online in the FORE Library: HIM Body of Knowledge at www.ahima.org.

Clinical Data Exchange Models

Typically, the clinical data exchange model is classified according to its degree of centralization. For example, a federated model with shared repositories uses a system of networks connected over the Internet to enable participants to submit clinical data to repository databases that are managed centrally by the HIE.

A centralized master patient index (MPI) allows the HIE to link the records from the various participants. Viewing the clinical data for one patient is achieved by pulling the data from all participating repositories. Regional repositories are interconnected via a centralized MPI or record locator service.

For example, the Veterans Administration has a centralized repository of clinical information, but exchanges data with the Department of Defense through a federated model. This model allows participating organizations to keep their clinical data in their own databases and therefore easily remove it should they withdraw from the HIE. This can be a politically advantageous way to encourage participation.

The Indiana Health Information Exchange also uses this model. Its purpose is to?reduce costs and improve outcomes through improved efficiency and data usability. Its clinical data exchange choice facilitated adoption by stakeholders while still maintaining commitment to the HIE's goals.

A nonfederated peer-to-peer network, also called the co-op model, uses a peer-to-peer network that provides a direct link to participants' individual networks via the Internet. Participants maintain their own network, and there is no centralized repository.

Under this model, there is no national or regional entity maintaining an MPI, and the only technology provided is the network across which the requested data are sent. Each participating organization completes the authentication of its users. This requires all participating organizations to trust one another's security and provisioning practices.

A participating organization sends a request for data on a given patient, and organizations holding information respond. The model is often used for smaller and community-based networks, such as a hospital system and affiliated clinics with point-to-

point communications. Examples include Winona Health in Minnesota and the Brevard County Health Information Alliance in Florida.

Similar to the co-op model is the federated model with peer-to-peer networks. This model features a peer-to-peer network connected through the Internet, individually maintained health information networks, and no centralized repositories. However, unlike the co-op model, a national or regional entity maintains an MPI, which participating providers search to locate their patient.

One version of this model features real-time data request and delivery. Once an organization selects a patient in the MPI, an automated request for clinical data is sent to all participating organizations. This model is being piloted by the Colorado Regional Health Information Organization.

Other versions of the federated model with peer-to-peer networks include a "push" variation, in which clinical data messages are pushed from sending organizations into the HIE. There are no centralized repositories, and the HIE maintains an MPI. Participants send all clinical data messages to the HIE, which then routes the data to designated participating providers, who are identified in the message header or via an index of providers associated to patients. This model is in use by the Santa Cruz RHIO in California and the Quality Health Network in Grand Junction, Colorado.

Federated model with peer-to-peer network models also exist without real-time clinical data sharing. In this model a national or regional entity maintains an MPI, typically a record locator service. Participants search the index, find the patient, and identify all participating organizations where a patient has been treated. They then request clinical data via a separate request for information. MA-SHARE in Massachusetts uses this model.

Under the centralized clinical database, or data warehouse model, HIE participants submit data to one shared repository, which participating providers then query to obtain patient information. The central repository provides a mechanism to link a patient record from one participating provider's system to that same patient's record provided by another contributing system.? The repository also provides role-based access to the stored information and authenticates requestors prior to release of information. This model is used by the Michiana Health Information Network and the Community Foundation of Central Florida.

A health data claims bank features a centralized repository storing claims-related information, such as diagnosis and procedural data on past care, that offers a view of a patient's past medical treatment and conditions. These can be centralized databases, such as the one offered for tracking chronic disease by Cerner in Kansas City, MO, or just a network by which claims data are pushed to the participants, such as in the Utah Health Information Network.

A health data bank is a repository where patients can load clinical and results information and authorize release of this information to specified, authorized providers. It operates as a kind of personal health record. These repositories could be managed by integrated delivery networks or hosted by insurance companies or private companies, which is the case with Aetna's Personal Health Record.

A clinical data exchange cooperative is a consortium of geographically dispersed institutions to provide clinically annotated research specific data. An example is the Cooperative Prostate Cancer Tissue Resource, established by the National Cancer Institute and now managed by the University of Pittsburgh.

Promoting Accuracy

An HIE's success is highly dependent upon the accuracy of the data supplied by participating facilities. HIM professionals play a vital role in helping clinicians and technicians successfully exchange clinical data by understanding the exchange methods of differing models, helping set appropriate policies and procedures, and managing subsequent data exchange.

An HIE's MPI could potentially be populated with intra-organization duplicates or contain a lack of appropriate record linkages across participating organizations. Improper mapping could cause data to be misinterpreted. These inaccuracies could compromise direct patient care. For those HIEs

supporting population health initiatives, inaccurate data could harm efforts related to chronic care management or quality improvement reporting to clinicians.

Mapping the Models to HIE Goals

It is critical an HIE select a clinical data exchange model that tightly aligns with its goals, as each model offers distinct advantages and disadvantages that can ultimately affect the HIE's success.

An HIE seeking to reduce costs and provide results viewing and instant communication between regional hospitals, clinics, physician offices, pharmacies, labs, and imaging centers might choose a centralized clinical database, or data warehouse, model because of its ability to reduce redundancies and inconsistencies in patient care while improving security and data integrity. The model also makes it easier to enforce standards, identify data requirements, and develop data governance. It facilitates personalization of healthcare management processes for patients with chronic diseases.

However, the centralized database model also carries the potential for record acceptance without identity validation, and it can have performance issues due to the volume of data, updates, and requests. It requires significant ongoing investment to keep data maps synchronized. Because data are shared only after provider validation, information may not be the most current available, and upgrades to sending systems could cause data to link or map incorrectly.

An HIE whose goal is to promote patient compliance and improve coordination of care among providers may select a PHR-based centralized clinical database. The model promotes consumer empowerment and enables patients to take an active role in healthcare decisions. Disadvantages include an increased potential for redundancies and inconsistencies, as well as difficulties enforcing standards and securing the data due to the number of facilities contributing to the record.

Maintaining data integrity is more difficult with this model, and data governance will likely require a comprehensive analysis of all participant systems, as well as a gap analysis. HIEs would require reasonable steps to identify data from only reputable sources and cross-reference data against multiple sources, as well as provide consumer access to data and destroy untimely data or convert it to anonymous form, which ensures data integrity.

A federated model with a peer-to-peer network and real-time data request and delivery may appeal to an HIE that is established to enable data sharing among all providers across a region or state with the goal of improving outcomes and reducing duplication of services, healthcare costs, medical errors, and adverse events. The model offers immediate access to requested data, and it allows providers to maintain autonomous systems.

However, there can be delays in response time if multiple participants return clinical data. Because providers search the system directly, the risk is higher that they will select an incorrect record and base care decisions on inaccurate patient data. Participants in this model also must define which clinical data are returned. For instance, in a request for lab or radiology results, should respondents send "recent" results (e.g., within 180 days) or should the criteria depend on test type (e.g., all glucose results in the past 180 days, but all TB results regardless of date)?

For HIEs whose goal is to give small physician practices access to electronic health record systems, a federated model with a peer-to-peer network and pushed clinical data is typically an easier approach. The model does require that physician practices use the same EHR system, however.

It also poses a privacy risk around importing pushed data. In the model, providers receive clinical data (such as a lab result or transcribed document) in their inbox; they accept the transaction if the results belong to one of their patients. The risk comes in the possible blanket acceptance of transactions without review. This increases the potential for unauthorized use of data.

Other HIEs are focused on promoting interorganizational data exchange using standards and administrative simplification. Their goal is to make accurate clinical information available wherever it is needed in an efficient, cost-effective, and safe manner. These networks might employ a federated model with a peer-to-peer network but without real-time data sharing. The model is relatively easy to implement, and it is not dependent upon the individual EHR systems used by participating providers.

The drawback, of course, is that the system does not offer actual exchange of clinical data. The requestor only identifies the facilities where a patient has been seen and does not necessarily know when the patient was seen, the condition presented, or

the treatment performed. To obtain medical records, the requesting provider must complete a second request. Providers may see limited value in this model and decline to join the HIE.

Collaborative HIE efforts to reduce the cost of care by employers, insurers, providers, and consumers typically deploy either the health claims data bank or health data bank models, both with a centralized database. The advantages are the same for both models: healthcare and healthcare coverage becomes more equitable and accessible; employees, employers, and insurers assume active roles in health improvements; and costs for care are reduced.

However, because it lacks clinical data, the claims data bank model does not provide a complete view of a patient's care and a participating organization could draw inappropriate or inaccurate conclusions about the patient's health. Both models also heighten the potential for unauthorized use of data and the potential for employee discrimination based on an individual's health history.

Even for highly specialized HIEs, such as those emerging in response to advances in molecular biology, certain models are more appropriate than others. For example, the co-op model has the potential to transform clinical research by expediting the development of new ways to prevent and treat disease through its ability to share research. However, standards for genomic and proteomic data exchange are still in development, and the value propositions and business cases for each set of stakeholders are still undetermined.

No matter what model an HIE chooses, it should enable the network's stated, predefined purpose. In these pioneering days, it's an alignment that often has been overlooked. HIEs that choose a model without first consulting their goals may find that their goals have been chosen for them.

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