Clinical Data Exchange Models

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For organizations developing regional health information organizations (RHIOs) determining the clinical data architecture and model are critical challenges. A clear understanding of each of the current models is critical to all other decisions that will have to be made. The Healthcare Information and Management Systems Society outlines three different data exchange architectures: federated, centralized, and hybrid.[1]

A wide variation of these architectures currently exist, and these various architectures are used in combination to achieve the actual clinical data exchange (hence the "hybrid" architecture). For instance, public health agencies may use a clinical data exchange model that employs both the federated and centralized data exchange architectures. Immunization database may store immunization-related data centrally in one database, but a federated mechanism may link data about one patient reported from various providers.

AHIMA has developed this document to define the commonly used clinical data exchange models in various RHIOs across the country. The table below provides the definitions and examples of the various clinical data exchange models that exist today. Clinical data exchange models are classified according to their degree of centralization. This document also lists the advantages and disadvantages of the various models.

AHIMA is not promoting or disavowing any of the clinical data exchange models defined below, and readers must be aware that certain models may be advantageous to certain RHIOs. This is why, in its practice brief "HIM Principles in Health Information Exchange," AHIMA encourages RHIOs to clarify early in their development stages the type of clinical data exchange model that will most effectively meet that RHIO's mission and vision.

Clinical Data Exchange Models

Clinical Data Exchange Model	Definition	Examples
Federated model with shared repositories	This model uses a system of networks connected through the Internet. Participants submit clinical data to a centralized regional repository responsible for the data management of patient identification, storage, system management, security, and privacy. The regional repositories are interconnected via a centralized Master Patient Index (MPI) or Record Locator Service (RLS).[2]	Veterans Administration Wisconsin Health Information Exchange (WHIE), Milwaukee, WI

Clinical Data Exchange Model	Definition	Examples
Federated model with peer-to-peer network + real-time, request/delivery of clinical data	This model employs a peer-to-peer network of participant networks connected through the Internet. Participants maintain their own health information network with no centralized repositories. A national or regional entity maintains a RHIO master patient index for the HIE. Using this index, participating providers (authenticated within their participating organization's system) search and find patient in the electronic MPI. When the correct patient is found, the provider selects patient. The selection of patient sends an automated request for clinical data to all HIE participating organizations	Colorado Health Information Exchange (COHIE)
Federated model with peer-to-peer network + clinical data pushed from sending organization	This model employs a peer-to-peer network of participant networks connected through the Internet. Participants maintain their own health information network with no centralized repositories; however clinical data is pushed from sending organization. HIE maintains a master patient index and previously associated providers to patient. Participating providers send all clinical data messages to HIE, which then routes clinical message/result to designated participating providers. Designated providers are identified by providers indicated in message/result header or via an index of providers associated to patients.	Santa Cruz RHIO Quality Health Network (Grand Junction, CO)
Federated model with peer-to-peer network–no real-time clinical data sharing	This model employs a peer-to-peer network of participant networks connected through the Internet. Participants maintain their own health information network with no centralized repositories. A national or regional entity maintains a master patient index (typically an RLS) for the HIE. Participants search the index, find the patient and identify all participating organizations where patient has been treated. Participant then requests clinical data/medical records from the other participating providers via a separate request for information.	MA-SHARE (MA-SHARE uses a RLS and currently no automated clinical data sharing occurs.)

Clinical Data Exchange Model	Definition	Examples
Non-federated peer-to-peer network (co-op model)	This approach uses a peer-to-peer network of participant networks connected through the Internet. The network may be smaller and more community-based (e.g., a hospital system and affiliated clinics with point-to-point communication). Participants maintain their own health information network, and there is no centralized repository. All communications are direct from participant to participant. There is no national or regional entity maintaining a master patient index for the HIE, so a mechanism to identify the location of records (i.e., ascertain which participating provider has medical records for the patient) is required.	Winona Health, Winona, MI Brevard County Health Information Alliance (BCHIA)
Centralized clinical database or data warehouse	All HIE participants send patient demographic and clinical information to one shared repository. Participating providers query the centralized repository to obtain patient's clinical results and other information. Central repository often stores key patient identifying information including name, date of birth, gender, SSN, and other demographic data such as address and telephone number. It may also store all lab results, radiology results, allergy information, medications, patient's problem list, and past medical/surgical history and could store insurance and other benefit information. The central repository provides the mechanism to link one patient's record from one contributing system (i.e., participating provider's system) to that same patient's record that is provided by another contributing system. The repository also provides role-based access to the stored information and authenticates requestors prior to release of information. All requests and releases of information are audited.	Indiana Health Information Exchange (IHIE) Michigan Health Information Network/South Bend, IN The Community Foundation of Central Florida Good Health Network, Inc.
Health data claims bank	Centralized repository storing claims related information. Diagnosis and procedural data on past care received by patient is stored providing a comprehensive view of the patient's past medical treatment and conditions.	Utah Health Information Network (UHIN) Healthe Mid-America

Clinical Data Exchange Model	Definition	Examples
Health data bank	PHR-type repository where patients can load clinical and results information and can authorize release of this information to specified, authorized providers. These repositories could be managed by IDNs, insurance companies, professional associations, or private companies	AHIMA's MyPHR Aetna's Personal Health Record
Clinical data exchange cooperative	Consortium of geographically dispersed institutions to provide clinically annotated research specific data.	The Cooperative Prostate Cancer Tissue Resource (CPCTR)[3]

The purpose, mission, vision, and goals of RHIOs vary as greatly as the models by which clinical data is currently, or will be shared. The table below provides examples of the purpose, mission, vision, and goals for some existing RHIOs and HIEs and the clinical data exchange model that RHIO selects. (This table is not meant to recommend a particular clinical data exchange model for the purpose or mission of the RHIO.) It is an attempt to stimulate discussions around the mapped mission, vision, and goals to the advantages and disadvantages that could affect the RHIO or HIE's successful implementation.

Mission, Vision, Goals of HIE

Mission/Vision /Goals of HIE	Clinical Data Exchange Model	Advantage/Disadvantages
Monitor outcomes and target interventions to improve health status in the region. Immunization and public health initiatives.	Federated model with shared repositories	**Advantages** ♦ Improve public health disease surveillance ♦ Improved communication ♦ Improved homeland security ♦ Empowers consumers through access to healthcare information **Disadvantages:** ♦ Interfaces between systems must be maintained and upgrades to those systems could cause interface issues
Promote patient treatment compliance and coordinate patient care.	Federated model with shared repositories	**Advantages:** ♦ Consumer empowerment ♦ Consumers take active participation in healthcare decisions **Disadvantages:** ♦ Increased potential for redundancies and inconsistencies ♦ Standards difficult to enforce ♦ Security can be challenging ♦ Data integrity is more difficult to obtain ♦ Data governance – need to analyze all systems and conduct gap analysis

Mission/Vision /Goals of HIE	Clinical Data Exchange Model	Advantage/Disadvantages
Share data with all providers within a state to improve healthcare outcomes, reduce duplication of services, medical errors, cost, and reduce negative health effects.	Federated model with peer-to-peer + real-time request/delivery of clinical data	**Advantages:** ♦ Real-time request – data available immediately ♦ Quality of care improved ♦ Data providers maintain autonomous systems **Disadvantages:** ♦ Most HIEs lack the knowledge of medical record processes and do not understand the challenge of linking patient records across disparate providers/databases. ♦ Potential for delays in obtaining data due as multiple participating providers return clinical data ♦ Requestor could select incorrect patient and base treatment on incorrect data. ♦ Dependencies on accuracy of data supplying facility – intra-organization duplicates would populate HIE MPI and lack of linking records across participating organizations would cause incomplete results to be returned to requester. Could cause patient care issues.
Provide EMR software to participating small physician office systems	Federated model with peer-to-peer network + clinical data pushed from sending organization	**Advantages:** ♦ If pharmacies, hospitals, physician practices, and other healthcare providers in local area belong to RHIO, quick transmission of data can occur. ♦ Possible way to get EMR technology into physician practices **Disadvantages:** ♦ Requires participating organization to "validate" and "accept" that patient results or reports belong to their patient. ♦ Acceptance of inbound results or reports by a physician practice could cause physician participants to delegate this task. ♦ Results or reports for a patient may end up being stored in an incorrect physician's database. ♦ Potential for unauthorized use of data
Promote the inter-organizational exchange of healthcare data using information technology, standards, and	Federated model with peer-to-peer network – no real time clinical data sharing	**Advantages:** ♦ Relatively easy to implement, although RLS software could be costly ♦ Not dependent upon EHR systems utilized by participating providers

Mission/Vision /Goals of HIE	Clinical Data Exchange Model	Advantage/Disadvantages
administrative simplification, in order to make accurate clinical health information available wherever needed in an efficient, cost-effective, and safe manner		**Disadvantages:** ♦ RLS with a minimum data set increases chance of false positives, especially with more common named patients and multiple birth patients. ♦ Participating providers can identify where a patient has been treated, but has to make a separate request for medical records from participating provider storing the records. ♦ Participating providers may deem little value as access to the clinical data is not provided.
Advances in molecular biology and growing requirements from biomarker validation studies have generated a need for tissue banks to provide quality-controlled tissue samples with standardized clinical annotation.	Non-federated peer-to-peer network (co-op model)	**Advantages:** ♦ The transformation of clinical research, expediting the development of new ways to prevent and treat disease, ♦ Ability to share research efforts that advance disease treatment. ♦ Faster cures through global collaboration to the world's deadliest diseases. **Disadvantages:** ♦ Data standards for genomic and proteomic data still in development. ♦ The value propositions and business cases for each set of stakeholders still undetermined.
Improve the quality, safety and efficiency of healthcare and generate new research topics for the health research community. Link clinical data from all hospitals, clinics, and physician's offices within a geographic area. Provide results viewing and instant communication across various care settings using an integrated access. Allow physician offices, hospitals, public health departments, pharmacies,	Centralized clinical database or data warehouse	**Advantages:** ♦ Redundancies and inconsistencies are reduced. ♦ Standards can be enforced. ♦ Security can be improved. ♦ Data integrity can be improved. ♦ Data requirements can be identified. ♦ Data governance is less difficult to develop. **Disadvantages:** ♦ Potential for record acceptance without identity validation ♦ Possible performance issues due to volume of data, updates and requests ♦ Often data shared is only after participating providers validation, so data may not be most current available. ♦ Requires significant ongoing investment to keep data mapping in sync. ♦ Upgrades to sending contributor systems could cause sent data to not link or map correctly

Mission/Vision /Goals of HIE	Clinical Data Exchange Model	Advantage/Disadvantages
laboratories, and imaging centers to communicate electronically in order to improve patient care and safety and reduce costs. Personalize the healthcare management process for patients with chronic diseases, reduce cost, and improve health		
Collaborative effort by employers, insurers, providers, and consumers to reduce the cost of care	Health claims data bank - centralized database	**Advantages:** ♦ Healthcare is equitable and accessible. ♦ Healthy employees are productive employees. ♦ Employer, employee, and insurer are active participants in healthcare improvement. ♦ Reduce healthcare cost ♦ Increased access to healthcare coverage **Disadvantages:** ♦ Data used for analysis by HIE is only claims data and does not provide a complete clinical view of patient's care. Inappropriate/inaccurate conclusions could be drawn by HIE. ♦ Potential for unauthorized use of data ♦ Potential for employee discrimination based on health history.

Definitions

Federated Identity: In information technology, **federated identity** has two general meanings:

a) The virtual reunion, or *assembled identity*, of a person's user information (or principal), stored across multiple distinct identity management systems. Data is joined together by use of the common token, usually the user name.
b) The process of a user's authentication across multiple IT systems or even organizations.[4]

Centralized identity management solutions were created to help deal with user and data security where the user and the systems they accessed were within the same network – or at least the same "domain of control." Increasingly, however, users are accessing external systems that are fundamentally outside of their domain of control, and external users are accessing internal systems. The increasingly common separation of user from the systems requiring access is an inevitable byproduct of the decentralization brought about by the integration of the Internet into every aspect of both personal and business life. Evolving identity management challenges, and especially the challenges associated with cross-company, cross-domain issues, has given rise to a new approach of identity management, known now as "federated identity management."[5]

Peer-to-Peer Network: A peer-to-peer computer network relies primarily on the computing power and bandwidth of the participants in the network rather than concentrating it in a relatively low number of servers. Peer-to-peer networks are typically used for connecting nodes via largely *ad hoc* connections. Such networks are useful for many purposes. Sharing content files (see file sharing) containing audio, video, data or anything in digital format is very common, and real time data, such as telephony traffic, is also passed using peer-to-peer technology.[6]

A pure peer-to-peer network does not have the notion of clients (the "user's" computer) or servers (where the database resided), but only equal peer nodes that simultaneously function as both clients and servers to the other nodes on the network. This model of network arrangement differs from the client-server model where communication is usually to and from a central server. A typical example for a non peer-to-peer file transfer is an FTP server where the client and server programs are quite distinct, and the clients initiate the download/uploads and the servers react to and satisfy these requests.[7]

Record locator service (RLS): A file of the locations of patient records, able to be queried only by authorized participants.[8] In essence it is a scaled down electronic MPI. The HIE maintains in a central database the RLS data. Typically the record locator service stores a minimum amount of key demographic data (may only be last name, first name, date of birth, gender, and zip code) about a patient and these data points are used to link patient clinical records across the various participating provider organizations. Mathematical, statistical, (probabilistic), or rules-based algorithms are used to link the clinical data/records using the demographic data provided for each patient. Record locator services attempt to minimize false negatives (records that pertain to a patient but are not found) and false positives (matches with records that do not pertain to the subject patient, but are wrongly returned in a search). False positives (matches), in which records associated with one patient are erroneously linked to another patient, can result in "incidental disclosures" of information, which compromise patient privacy and carry a clinical risk as well.

Notes

1. Healthcare Information and Management Systems Society. "HIMSS RHIO/HIE." Available online at www.himss.org/ASP/topics_rhio.asp.
2. Ibid.
3. Berman, Jules J., et al. "The tissue microarray data exchange specification: implementation by the Cooperative Prostate Cancer Tissue Resource", *BMC Bioinformatics* 5:19, 2004. Published online 2004 February 27. Available online at www.pubmedcentral.nih.gov/articlerender.fcgi?artid=373442
4. Wikipedia. "Federated Identity" Available online at http://en.wikipedia.org/wiki/Federated_identity
5. Ibid.
6. Wikipedia. "Peer-to-Peer Network" Available online at http://en.wikipedia.org/wiki/Peer_to_peer_network
7. Ibid.
8. The Connecting for Health. "The Connecting for Health Common Framework." Available online at www.connectingforhealth.org/commonframework.

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