U.S. National Health Information Network (NHIN) and Open Source Health Information Exchange (HIE) Solutions

Shepherdstown, 17 December 2006 - In the United States, the Office of the National Coordinator for Health Information Technology (ONCHIT) and the National Committee on Vital and Health Statistics (NCVHS) have clearly stated that the long-range strategy for a National Health Information Infrastructure (NHII) requires a national health information network (NHIN) that can provide low-cost, secure data movement. They have stated that an NHIN is needed, along with a public-private oversight or management function to ensure adherence to public policy objectives. Development of this infrastructure is considered a vital national priority. The rapid formation and activities of Regional Health Information Organizations (RHIO) across the country represent major public and private sector collaborative efforts aimed at putting in place key components of the planned NHIN. Several of the health information exchange (HIE) systems proposed by the RHIOs make use of open source or "public domain" solutions.

Background

On July 21, 2004, the U.S. Department of Health and Human Service (HHS) released the Framework for Strategic Action, The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Health Care. It presented four goals and associated strategies to achieve the vision of utilizing information technology (IT) solutions to reduce costs, avoid medical errors, and improve health care in America:

- Inform clinical practice with use of electronic health records (EHR)
- Interconnect clinicians so that they can exchange health information using advanced and secure electronic communication
- Personalize care with consumer-based personal health records (PHR) and better information for consumers
- Improve population health through advanced biosurveillance methods and streamlined collection of data for quality measurement and research

With regards to health information exchange (HIE) systems, ONCHIT believes that a key component of the goal to interconnect clinicians is to promote interoperability, that is, the ability to exchange patient health information among clinicians and other authorized entities in a timely manner and under consistent security, privacy, and other protections.

On November 15, 2004, in an effort to gain broad input regarding the best mechanisms to achieve nationwide interoperability to meet the goal of interconnecting clinicians so that they can exchange health information, ONCHIT released a request for information (RFI). The RFI encouraged the public to explore the role of the federal government in facilitating deployment of a nationwide health information network (NHIN); how it could
be governed, financed, and operated; and how it could be supported by and coordinated with regional health information exchange projects.

The "Summary of Nationwide Health Information Network (NHIN) Request for Information (RFI)" of June 2005 identified the following concepts that emerged from the majority of RFI respondents:

- A NHIN should be a decentralized architecture built using the Internet, linked by uniform communications and a software framework of open standards and policies.
- A NHIN should reflect the interests of all stakeholders and be a joint public/private effort.
- A governance entity composed of public and private stakeholders should oversee the determination of standards and policies.
- A NHIN should be patient-centric with sufficient safeguards to protect the privacy of personal health information.
- Incentives will be needed to accelerate deployment and adoption of a NHIN.
- Existing technologies, federal leadership, prototype regional exchange efforts, and certification of EHRs will be the critical enablers of a NHIN.
- Key challenges will be the need for: additional and better-refined standards; addressing privacy concerns; paying for the development and operation of, and access to, the NHIN; accurately matching patients; and addressing discordant inter- and intra-state laws regarding health information exchange.

The "Summary of Nationwide Health Information Network (NHIN) Request for Information (RFI)" also stated:

"The potential value of the interoperable exchange of health information among disparate entities is substantial. A recent study that estimated a net savings from national implementation of fully standardized interoperability between providers and five other types of organizations could yield $77.8 billion annually, or approximately 5 percent of the projected $1.7 trillion spent on U.S. health care in 2003. Other studies estimate that between 20-30 percent of our healthcare spending, or up to $300 billion each year, is for treatments that do not improve health status, are redundant, or are not appropriate for the patient's condition. Administrative inefficiencies (e.g., paper handling) have been separately estimated to be of similar magnitude. While more work is needed to validate these savings estimates, all-available evidence suggests that implementation of interoperable health information exchange will result in significant savings." (See http://www.hhs.gov/healthit/rfisummaryreport.pdf)

Benefits

The benefits of an interoperable healthcare system are fairly well understood. The availability of information in real-time at the point of care can reduce medical errors,
allow physicians and their patients to make informed decisions about treatment options, and reduce administrative burdens. Some more specific potential benefits include:

- Consumers could consult clinicians more easily without fear of losing their records, repeating tests, or having to recall complex histories for each clinician.

- Payers could benefit from the economic efficiencies, fewer errors, and reduced duplication of effort.

- Clinicians could benefit from having easier access to complete problem lists, procedure histories, allergies, and medication histories at the point of service.

- Interoperability may also lead to meaningful public health reporting, bioterrorism surveillance, quality monitoring, and advances in clinical trials.

According to one of the latest eHealth Initiative (eHI) surveys on RHIOs and the NHIN, interest in improving quality and safety, inefficiencies experienced by providers, and rising healthcare costs are the primary drivers for health information exchange efforts. Ninety-two percent of respondents cited "improving quality" as a significant driver of their HIE efforts, while 82 percent cited "improving safety". Additionally, 70 percent cited "inefficiencies experienced by providers who need information to support patient care" as a significant driver, while 56 percent cited "rising healthcare costs".

Finally, the following chart on estimated annual savings was presented at a Healthcare Information and Management Systems Society (HIMSS) conference on "Building Regional Health Information Networks" and is worth noting.

![Chart showing estimated annual savings](chart.png)

Implementing the National Health Information Network
When discussing operational considerations, many respondents to the RFI recommended that the NHIN follow an evolutionary path, with a gradual rollout. Many respondents stated that an incremental approach that integrates existing networks and builds momentum around early successes is more likely to succeed in the United States.

Most respondents who discussed technical considerations envisioned a NHIN as a decentralized network built around regional exchanges of information run by a Regional Health Information Organization (RHIO). In a decentralized architecture, RHIOs could handle the day-to-day operations of regional health information exchange (HIE) and facilitate integration into a NHIN. Respondents also stated that standards would be needed to facilitate interoperability.

According to Eric G. Brown, vice president of Forrester Research, in his presentation at a Healthcare Information and Management Systems Society (HIMSS) conference on "Building Regional Health Information Networks", public and private sector organizations will need to collaborate and build the trusted Regional Health Information Networks (RHIN). The National Health Information Network (NHIN) will then tie the RHINs together. The challenge is for 100 to 200 regions to build the needed RHINs during the next 5 to 10 years, connecting more than 6,000 hospitals and hundreds of thousands of clinicians.

On December 12, 2005, Health IT World News reported that Accenture, Cisco, IBM, Microsoft, Northrop Grumman, Oracle, and Sun were among the wide range of technology and consulting companies tapped to design an $18.6 million NHIN for the U.S. Department of Health and Human Services (HHS). According to the report, the NHIN will be designed and rolled out through four consortia, each consisting of several IT, consulting, security, and healthcare companies and organizations.

**Current Status**

According to the eHealth Initiative (eHI) Foundation's "Second Annual Survey of State, Regional, and Community-Based Health Information Exchange Initiatives and Organizations" released in 2005, the number of health information exchange (HIE) efforts actively exchanging data has tripled over the past year. There are now more than 100 HIE projects underway in 45 states. A brief sampling of these initiatives includes:

- Delaware Health Information Network
- Florida Health Information Infrastructure
- Indiana Health Information Exchange
- Maine Health Information Network Technology
- Maryland/DC Collaborative for Healthcare IT
- Mesa County Health Information Network (CO)
- Michigan Health Information Infrastructure
• Santa Barbara County Care Data Exchange (CA)
• Taconic Health Information Network and Community (NY)
• The Wisconsin Health Information Exchange Project
• Tri-Cities Care Data Exchange Project (TN)
• Whatcom Health Information Network (WA)

The "Third Annual Survey of Health Information Exchange (HIE) Activities at the State, Regional and Local Levels" was released on September 25, 2006. It reported that there were now 165 HIE initiatives identified, 45 are in the implementation stage and 26 have identified themselves as now being fully operational. See http://toolkits.ehealthinitiative.org/assets/Documents/eHI2006HIESurveyReportFinal09.25.06.pdf

A detailed listing of these and related reports can be obtained by viewing the eHI web site at http://www.ehealthinitiative.org. Also, visit http://aspe.hhs.gov/sp/nhii/statelocal.html.

Use of Standards

Increasingly, health information exchange initiatives are using communications standards for interoperability, according to eHI. For example, 76 percent of respondents to their most recent survey said they expected to use HL7 for messages and 30 percent are expecting to use NCPDP standards within the next six months. Twenty-three percent expect to use DICOM while 30 percent expect to use X12 within six months.

EHI also reports that health information exchange initiatives are increasingly using data standards. For example, 41 percent, 37 percent, 33 percent, and 15 percent are expecting to utilize LOINC, SNOMED, NDC codes, and RxNORM, respectively, within the next six months. Based on this year's survey results, 66 percent of respondents expect to be using ICD-9 while 14 percent expect to be using ICD-10.

Technical Architecture of RHIOs

In a recent eHI survey, when asked about the architectural model they were using, 64 percent of RHIOs stated they were using a federated model and 36 percent stated that they were using a fully integrated repository or database. Of the 42 organizations who were using a federated model, nine cited they were using a federated model with homogeneous data repositories (e.g., using the same software product); 12 said they were using a federated model with heterogeneous software using a standardized data model; and 21 said they were using a federated database with differing data models and standardized middleware.

Health information exchange (HIE) networks being developed by RHIOs include commercial-off-the-shelf (COTS) solutions proposed by vendors in the private sector such as Accenture, Cisco, IBM, Microsoft, Northrop Grumman, Oracle, and others. There are also a number of organizations collaborating on building more low cost, trusted
solutions using "open source" solutions or technology developed by the government which is available in the public domain.

Collaboration, open solutions, and innovation seem to three dominant strategies being employed by all as they strive to design and deploy a trusted HIE architectural solution that will meet the needs of all parties in the public and private sector.

**Selected Case Studies of Open HIE Solutions**

While HIE networks being developed and implemented include both commercial-off-the-shelf (COTS) systems and open source or public domain solutions, in this article the authors have chosen to provide an overview of three particular "open" HIE solutions. They include:

- **Open Source HIE Solution:** Open Health Record Exchange (see [www.openhre.org](http://www.openhre.org))
- **Public Domain HIE Solution:** Federal Health Information Exchange (FHIE)
- **Open Community Solution:** Cancer Biomedical Informatics Grid (caBIG)

**Open Health Record Exchange (OpenHRE)**

OpenHRE.org is a site dedicated to the proposition that in the National Health Information Infrastructure (NHII) Framework, patient records can be linked and exchanged using Free Open Source Software (FOSS).

The OpenHRE.Org is a collaboration between Browsersoft Inc. and the Alliance for Rural Community Health (ARCH). ARCH and Browsersoft believe that the best way to achieve an open and affordable Health Records Exchange throughout the nation is through Free Open Source Software. Their vision is that OpenHRE will enable the secure infrastructure through which both proprietary and open Electronic Health Records systems can exchange information. ARCH and Browsersoft have been developing the Open Source SHARE project to enable the electronic indexing of patients and the exchange of records within and between clinics and hospitals in Mendocino County, California. See [http://www.openhre.org/](http://www.openhre.org/) for more detail.

In 2003 Mendocino SHARE4 was formed as a collaboration among safety net health care sites to demonstrate a health information exchange. In April 2004 Mendocino SHARE hired Browsersoft, Inc., a Kansas City software developer, to build an open source toolkit for the health information exchange. In August 2004 the software was released as OpenHRE ("Open Health Records Exchange"). In 2005 Mendocino SHARE decided to transition the health information exchange to a successor entity.

In 2005 Redwood MedNet7 was formed as a new non profit by local physicians and technologists to develop health information technology solutions for the local health care community. Redwood MedNet proposed Mendocino HRE as a successor to the Mendocino SHARE project. In 2005 Redwood MedNet also began development of a

Federal Health Information Exchange (FHIE)

The U.S. Department of Veterans Affairs (VA) and the Department of Defense (DoD) have developed and put in place a networking solution that allows them to exchange patient information between their two electronic health record (EHR) systems, VistA and CHCS. The VA and DoD, combined, provide healthcare services to approximately 12 million veterans, military personnel, and dependents at an annual cost well in excess of $40 billion. The VHA and the MHS collect and maintain patient health information in separate systems.

Nationwide deployment of the first version of FHIE was completed by the VA on July 17, 2002. This first version enabled the one-way transfer of data from DoD's existing healthcare information system to a separate database that clinicians at VA hospitals could access. In September 2003, enhancements to FHIE were completed and deployed that added to the base of health information made available to VA clinicians from DoD. It included discharge summaries, allergy information, consultation results, and other selected patient data. The FHIE system transitioned into "steady state" and ongoing operational support in FY 2005.

FHIE provides up-to-date, near-real-time data feeds electronically from the Military Health System databases to the FHIE repository node for active duty, retired, and separated service members. Current data are being sent in Health Level Seven (HL7)-like messages. The following categories of DoD medical data currently being transferred to FHIE are:

- Patient demographics
- Pharmacy data
- Radiology reports
- Laboratory results
- Allergen information
- Discharge summaries
- Consultation reports
- Standard Ambulatory Data Record (SADR) information
- Inpatient Admission/Discharge/-Transfer (A/D/T) information

FHIE has provided clinicians at the VA with the capability of having almost instantaneous display of DoD patient data in the same format as other local patient data on veterans is displayed in CPRS. In 2005, program management officials stated that the repository contained data on well over 2 million patients.
VA and DoD have since moved forward with a new project called the Bi-directional Health Information Exchange (BHIE) that builds on the accomplishments of the highly successful FHIE solution.

**FHIE Benefits**
The one-way transfer of healthcare data from DoD to VA using FHIE has already allowed clinicians in VA medical centers to make faster, more informed decisions through ready access to information on almost 2 million patients, thereby improving their level of healthcare delivery. In testimony to Congress on December 15, 2003, FHIE program officials and physicians cited various clinical and other benefits from using information provided via FHIE.

- **Enhanced standardization and continuity of health care**
- **Improved clinician**
- **Improved patient satisfaction**

VA and DoD are also proceeding with development of interoperable data repositories that will support the bi-directional exchange of computable data between the DoD Clinical Data Repository (CDR) and the VA Health Data Repository (HDR), known as Clinical Data Repository/Health Data Repository (C/HDR).

For more detailed information, there is an excellent article published in the Journal of AHIMA in August 2006 entitled "Architecture of the FHIE", written by Mr. Donham, the FHIE Project Manager. Also visit Federal Health Information Exchange (FHIE): [http://www.va.gov/vadodhealthitsharing/](http://www.va.gov/vadodhealthitsharing/)

**Cancer Biomedical Informatics Grids (caBIG)**

While not specifically a health information exchange (HIE) solution that allows for patient records to be shared, the Cancer Biomedical Informatics Grid (caBIG) is an example of a voluntary biomedical informatics network or grid that virtually connects individuals and institutions that should be mentioned. It enables both individuals and institutions to effectively share data and research tools in an open environment with common standards. There is a need to invest in the development and deployment of these type of specialized HIE networks alongside the RHINs.

caBIG provides a true world-wide-web of cancer research and development providing a common unification that accelerates understanding of the disease and delivers new approaches for the prevention, early detection, and treatment of cancer. Its goal is to create more global opportunities to make important new cancer-related findings, quickly and efficiently. Over 600 individuals have contributed to the caBIG initiative and more than 24 new products are expected to be available to the caBIG and cancer research communities through the grid during 2005. caBIG is being developed under the leadership of the National Cancer Institute's Center for Bioinformatics (NCICB).
The caBIG Web site reports that during its first year, they launched more than 75 projects, including the first iteration of the caBIG Compatibility Guidelines and end-to-end solutions like caARRAY and genePattern that provide micro array tools at both ends of the process, or cytoscape and caWorkbench that provide analysis capabilities for molecular pathways.

cabIG is built on the principles of open source, open access, and open development. By definition, this means that this shared environment is readily available to anyone in biomedical research. Rather than operating in a vacuum, NCI believes that cabIG will not only re-define how cancer research is conducted, but it will change how all future health-related research is conducted.

The three major components of the caCORE infrastructure are caBIO, caDSR, and EVS, which are available under an Open Source licensing agreement. caCORE components are powered by open source software represented by a series of Apache projects.

- **Cancer Bioinformatics Infrastructure Objects (caBIO)** creates models of biomedical objects to facilitate the communication and integration of information from the various initiatives supported by the NCICB.

- **Cancer Data Standards Repository (caDSR)** stores the Common Data Elements developed by NCI-sponsored organizations.

- **NCI Enterprise Vocabulary Services (EVS)** contains standard vocabularies for a variety of settings in the life sciences. The EVS project produced the NCI Thesaurus (provided under an open content license) and the NCI Metathesaurus (based on NLM's Unified Medical Language System Metathesaurus supplemented with additional cancer-centric vocabulary).

cabIG participants include approximately 500 people from 50 NCI-designated cancer centers and hospitals, universities, and other organizations. For a complete listing, visit the caBIG Web site at [https://cabig.nci.nih.gov/](https://cabig.nci.nih.gov/).

Regional Health Information Organizations (RHIOs) can learn valuable lessons from NCI's work on cabIG. Currently there are between 200 and 300 RHIOs being developed in the United States, with approximately 20 of them already exchanging information. However, there are still a large number of patient records dispersed throughout the healthcare community in hospitals, physician offices, labs, and so on. The cabIG offers important solutions to exchanging clinical data among organizations and improving health care through information sharing and collaboration. cabIG also successfully demonstrates how open solutions can facilitate communication between organizations and allow for free flow of information in a secure and private environment.

**Recommendations and Next Steps**

- Identify the RHIOs and HIE initiatives in your geographic area.

- Consider getting involved with a selected state or local RHIO and its HIE activities.
• Conduct a Cost-Benefit Analysis and Return on Investment for this type of initiative for your organization.

• Obtain lessons learned from others participating in existing RHIO and HIE projects.

• Investigate changes in clinical practices and business processes that your organization may need to make in anticipation of participating in a RHIO and its HIE project.

• Help the RHIO determine whether to acquire and implement a commercial or open source HIE solution.

• Begin to plan and budget for your participation in the RHIO and eventual implementation and use of an HIE solution.

A couple of closing comments. In order to exchange electronic patient data, your organization will have to acquire and implement an electronic health record (EHR) system. Again, you will be faced with acquiring a commercial-off-the-shelf (COTS) system or an open source solution. Consider looking at the VistA public domain system (www.worldvista.org) or one of several other open source EHR systems, e.g. OpenEMR, OSCAR, AMPATH, FreeMED. Second, within the next 3-5 years, once you are able to exchange information between your own facilities, your healthcare organization will most likely be participating in a RHIO or HIE network out of necessity.

The authors delve deeper into this area in their recent book "Medical Informatics 2020: Quality and Electronic Health Records through Collaboration, Open Solutions and Innovation" from Jones and Bartlett Publishers. See http://www.jbpub.com/catalog/0763739251

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