United States Department of Health & Human Services

HL7 NLM Interoperability Survey

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EXECUTIVE SUMMARY

Health Level Seven (HL7) commissioned this report under its Electronic Health Record (EHR) contract with the National Library of Medicine (NLM) (henceforth, 'the Project'). The Project is tasked with accelerating the efforts of nascent health information exchange networks in the United States (U.S.). This survey's objective was to assist HL7 in defining and scoping the Project's Phase II work by drawing lessons in standards and tool development from existing interoperability efforts. The survey process consisted of a brief literature review and a combination of interviews and self-reported data via a structured data-collection tool; reference materials are included in the Appendices.

Methodology

During April 2005, over 100 known sites were contacted, to ascertain: Is the network live? Are users (clinicians or administrators) viewing or using the data exchanged? Are data and messaging standards being used? If so, which ones? How are end users viewing the data? Are the end systems heterogeneous?

Four sites, Finland, Greece, the Netherlands, and Inland Health (Spokane, Washington), were selected for broad review, with research spanning the breadth of the sites' implementations. These were the anchor points of this analysis. An additional four sites were selected for more focused review, narrowing in on one particular dimension of their implementation: Germany (focus: small office connectivity); Bangor, Maine (focus: Master-Patient-Index, Master-Person-Identification (MPI)); Mendocino County, California (focus: use of open source); Seattle, Washington (focus: laboratory or pharmacy data shared between heterogeneous participants).

The survey included a brief literature review, interviews, and the completion of a survey instrument. Site visits were not performed, and data provided was not independently validated. While every effort was made to faithfully represent these sites and to handle the information provided in a responsible manner, an unintended and undetected error in interpretation could easily distort the overall picture.

Analysis and Recommendations

The sites exhibited striking similarities, including shared services (those available through the network), content exchanged, and business issues faced (surprising, in light of the disparities in the funding and provision of healthcare internationally).

Shared Services

Patient Cross-Referencing: The Master Patient (or Person) Index (or Identifier) (MPI) appears to be the most consistently mature technology implemented at the sites studied. The most likely reason is because the data generally comes from administrative systems – patient accounting, admissions-discharge-transfer (ADT), or practice management, which are more widely implemented and mature in both hospitals and physician offices. In addition, just as a local MPI is a pre-requisite to local integration of disparate clinical systems, a shared, cross-enterprise patient matching function is a pre-requisite to many forms of networked record sharing.

Recommendations

1. Develop or adapt an open-source, web service-based MPI. Consider converting the Person Identification Service (PIDS), as used in Crete, to a web service.
2. Write an implementation guide for HL7 Version 2 (V2) or HL7 Version 3 (V3) messaging with the open source MPI referenced in Recommendation #1.

Search and Distribution: Significant variation was found in the terminology used to describe search capabilities with significantly less variation in end-user functionality. Spokane and Mendocino have combined patient cross-referencing with the search function so that in a single interface users work with both applications. The rest of the 'broad' sites (Finland, Greece and the Netherlands) have a clearly delineated search-and-retrieval service.

Although most of the sites employ a query-response model, several of them publish at least a subset of network data. Universally, the sites search by 'patient' using a variety of data elements (most often, the same elements found in the MPI: name, date of birth, etc.). Once data has been retrieved, data typically remains with the originating system, rather than being imported into the local application.

Recommendations

3. Study Clinical Observations Access Service (COAS), Integrated EHR Indexing Service (I-EHR IS), and Integrated EHR Update Broker (I-EHR UB)[1] as implemented in Crete, and compare with the freely-available tools under consideration by U.S. network efforts, specifically: Integrating the Healthcare Enterprise (IHE) Cross-Enterprise Document Sharing[2] (XDS, based on ebXML open source tools) and the Markle Foundation Record Locator Service (RLS)[3]. Summarize the analysis and prepare implementation guide(s) for one or more of these tools.
4. Implement the HL7 NLM Phase I point-to-point search tool as a web service[4].
5. Develop or adopt registries that track 'identity' and 'roles' for applications, providers and organizations, similar to what was implemented in Crete, or the 'dictionaries' used in Spokane.

Data Display: All sites give access to imported data through a web browser interface, a sort of 'poor man's electronic medical record (EMR)' that is provided for end-users who do not have a local application, EMR or clinical information system (CIS) for viewing data. While many have EMRs implemented locally, most do not provide an EMR as a network service and none have made EMR implementation a pre-requisite for interoperability.

Recommendations

6. Develop or adapt a lightweight, open source 'viewer' (e.g., browsers and data managers) that can be used to display clinical data, possibly including an export from a local EMR application, as in Crete.
7. Pilot the integration of imported data into a local EMR.
8. Introduce context management (HL7s Clinical Context Object Workgroup or CCOW) for single sign-on and ease of use.

Security: Securing federated systems is notoriously difficult because combining multiple systems expands the system 'perimeter'. The security models in place at the survey sites are less evolved than the other shared services and appear to have their roots in some of the trust relationships inherent in intra-organizational security models. This suggests that security is not a barrier to network formation, but may provide a 'gotcha' in more mature implementations. Without exception, security services were provided both locally and as a shared service on the network. All sites described authentication, authorization and audit services; none of the sites described incremental integrity or attribution services (beyond what might be contained in the data or document itself).

Recommendations

9. Pilot authentication, integrity and/or attribution services as implemented in other industries (e.g., financial services). One possibility: Liberty Alliance[5], an alliance of more than 150 companies committed to developing an open standard for federated network identity, participated in the 'Common Framework' ONCHIT RFI response spear-headed by the Markle Foundation[6]
10. Develop or adapt a service for assigning roles and access privileges, possibly using Health Resource Service (HRS)[7] in Crete as a model.

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[1] D.G. Katehakis, S.G. Sfakianakis, D. Anthoulakis, G. Kavlentakis, T. Z. Tzelepis, S. C. Orphanoudakis and M. Tsiknakis, "A Holistic Approach for the Delivery of the Integrated Electronic Health Record within a Regional Health Information Network", Foundation for Research and Technology - Hellas, Institute of Computer Science, Technical Report 350 (FORTH-ICS/ TR-350), Heraklion, Crete, Greece, February 2005.

[2] IHE IT Infrastructure Technical Framework, Supplement 2004-2005, Cross-Enterprise Document Sharing (XDS) http://healthcare.xml.org/resources/IHE_ITI_Cross-enterprise_Doc_Sharing_2004_08-15.pdf IHE (15 August 2004)

[3] Markle Foundation, The Collaborative Response http://www.connectingforhealth.org/resources/collaborative_response/hie_model/chapter.php The Markle Foundation et al (18 Jan 2005)

[4] HL7/NLM Phase I search tools deliverables: http://www.hl7.org/nlmcontract/ehrPhaseI.cfm

[5] The Liberty Alliance Project: http://www.projectliberty.org/about/index.php

[6] Markle Foundation, The Collaborative Response

[7] Katehakis: http://www.ics.forth.gr/eHealth/technology_HII_1.html

11. Develop data standards for audit logs, to enable velocity checks (alerts generated by a rules engine that is configured to recognize potential fraud and abuse scenarios) and cross-log queries in healthcare.

Vocabulary: A vocabulary service is defined as a technology component that allows corresponding, communicating applications to use terminology in a consistent way. One of the strong findings is that all the implementations studied employ some degree of shared vocabularies and vocabulary services. Where a standard, controlled vocabulary was not available, local terminology was developed. This reinforces the key role of common terminology in semantic interoperability, and the strong need to make common terminology services understood and available.

Recommendations

12. Develop or adapt terminology services applications for network deployment in conjunction with the NLM HL7 vocabulary project.
13. Develop OID (globally-unique object identifiers as specified by ISO) source and registry as shared service (similar to the OID registry on HL7.org).

Content

Clinical Domains: "Clinical domains" are defined as the area of specific types of data exchanges seen from a functional, clinical perspective. The types of data exchanged fall into these categories: medications, laboratory, medical images and reports, patient summaries and clinical notes. Most of the survey sites started with a focus on one domain area and then expanded, with the choice of area depending on the immediate value derived based on the local business of healthcare. Of those surveyed, patient summaries are the most common first domain implemented and, in most cases, were already in place.

Recommendations

14. Create standards-based implementation guides for different types of clinical information. High-return areas may include pathology and medical imaging reports, if they are not already covered by other standards or professional organizations.
15. Pioneer direct device monitoring for U.S. networks, possibly starting with emergency room/ambulance connectivity as in Crete.

Standards and Source Code: The secondary selection criteria for inclusion in this survey was the use of standards, therefore, all sites, by design, are heavy users of some type of standard specification. There is a great deal of heterogeneity in the choice and application of standards. Generally, HL7 V2 is used when there is an installed base and precedence for its use in an intra-enterprise setting with HL7 V3 being used exclusively only in the Netherlands. Two of the sites embraced open source development: Crete and Mendocino.

Recommendations

16. Ensure that all source code developed in the NLM HL7 EHR Phase II Project is 'open source,' meaning that both the source and compiled code can be freely and widely distributed, and that the code resides in an open source repository (e.g., SourceForge.net) for ongoing management and derivation by the open source development community.
17. Support the use and implementation of HL7 V2 where these standards are well established (e.g., patient accounting systems, laboratory systems). Support the use and implementation of HL7 V3 messaging standards in areas where HL7 V2 is less entrenched (e.g., clinical documents, medical imaging studies, medications).
18. Develop clinical document architecture (CDA) implementation guides.
19. Create profiles for web services, including a strong recommendation on which approach(es) can be used, for example, to create packages of documents with images (i.e., binary content), etc. and wrap them in a signed envelop (which may or may not be encrypted).

Patient Participation

Every site surveyed is patient-centric in that the organization of data and system functionality revolves around capturing, sharing and viewing patient-specific information. Still, consumers today are not central players in these networks. This raises potentially significant adoption issues down the road, particularly in the area of patient consent.

Recommendations

20. Select a Phase II pilot site focused on consumer-engagement as a key implementation objective. The minimum selection criteria would be that the project intends to allow patients to query and input their clinical data. Possible sites include Whatcom County, Washington and Spokane.
21. Develop or adapt an open source, web-based patient health record that reads and displays standardized messages and documents.
22. Develop or adapt an open source patient consent framework, which allows patients to specify consent with more granularity than on/off (e.g., by diagnosis, date, provider, etc.) Possible examples of consent models include shared-calendar functions (e.g., .Mac) and social networking applications like Tribe and Linked-In.
23. Develop a patient-level security standard that moves beyond a simple login and password. Examples could include the card verification value (CVV) consumers use to verify that they are legitimately using a credit card when they purchase online, the use of tokens or other physical media, or biometric authentication.

Business Issues

Unrealized Business Value: The survey identified four healthcare data domains: administrative, patient care, research and public health. The sites rarely work cross-domain. The strongest value proposition for standards-based networks is the potential for information reuse - what HL7 defines as semantic interoperability. This is an area that warrants significant, future exploration.

Recommendations

24. Clinical documents (e.g., laboratory reports, medical imaging reports) commonly exchanged in RHIOs can also be reused in administrative processes. Select a pilot site such as Empire Medicare Services[8], which has a claims attachment pilot underway, and demonstrate that in addition to the documents, the services (patient cross-referencing, distribution and search, security, vocabulary) necessary to facilitate the movement of clinical data can be reused for other purposes.

Value Proposition: All efforts defined a value proposition as a starting point with the proposition defining and impacting how the effort rolled out. Internationally, the value was frequently defined for the population as a whole, with quality and safety as forefront. Significant funding was generally required to move the effort ahead. In the US, efforts tended to develop regionally with leadership originating through efforts of a small number of executives. In this scenario, the funding followed and reflected the magnitude of the effort.

Cost Benefit Analysis: Until there are ‘standard’ metrics for this analysis, it will be very difficult to make apples-to-apples comparisons across projects and to really understand what constitutes a tangible success. Thus, the costs associated with these projects varied dramatically, producing little in the way of convergent observations. However, the smaller and more contained the project, the clearer the benefit profile became. Part of the challenge in undertaking a Regional Health Information Organizations (RHIOs) is to understand what truly drives cost (and benefit).

Conclusions

The primary mission of this work was to provide a set of actionable recommendations to the NLM HL7 EHR Project; and thus the Recommendations form its Conclusions. Given the timeframe, goals and sample size, many observations and recommendations contained in this report require more investigation. It is also possible that the selection of different sites would have cast a different light on the understanding of RHIOs. Irrespective, Crete and Finland (and possibly Denmark) are some of the most extensive standards-based interoperability networks for healthcare information in the world. The iteration and growth of these projects could provide a wealth of experience and technology assets, and is still poorly-understood by decision makers planning similar efforts in the US.

The purpose of the HL7 NLM EHR Project is to provide tangible assistance to RHIO developers and implementers. While acknowledging that the Project is neither a public relations nor marketing campaign for either HL7 or NLM, the survey underscores the need for a shift in attitude toward standards in the US. The HL7 NLM EHR Project is uniquely positioned to send the message that standards are an enabling factor for interoperability, not an impediment. A landscape of projects using a small set of competing standards is vastly preferable to a landscape of projects populated mostly by

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[8] Empire Medicare Services Claims Attachment Pilot Project Overview <http://www. wedi.org/cmsUploads/pdfUpload/WEDIBulletin/pub/ClaimsAttachmentsPilotOverviewFINAL_111004.pdf> WEDI Claim Attachment Pilot Advisory Committee (10 November 2004).

competing, proprietary solutions. Similarly, the Project can reinforce that source code is a reusable asset, but is not equally sustainable for all types of applications. The PICNIC Project, a 5-year EU-funded project ending in 2002 that elicited voluntary participation from over a dozen countries, provided a wealth of open source components still in use today; the HL7 NLM EHR Project is a natural inheritor of the PICNIC legacy, and every effort should be made to continue work in this direction.

INTRODUCTION

Health Level Seven (HL7) commissioned this report under its Electronic Health Record (EHR) contract with the National Library of Medicine (NLM) (henceforth, 'the Project'. The Project is tasked with accelerating the efforts of nascent health information exchange networks in the United States (US). This survey's objective was to assist in defining and scoping the Project's Phase II work by identifying areas for leadership in standards development and tool development. The survey process consisted of a brief literature review and a combination of interviews and self-reported data via a structured data-collection tool; reference materials are included in the Appendices.

The survey conformed to the timetable and requirements of the Project. Of the hundred-plus sites inventoried, the scope was necessarily limited to eight sites for review: four to be studied broadly and four to be studied with a focus on a specific area of interest. The primary selection criterion was evidence of existing day-to-day clinical interoperability. The secondary criterion was use of standards. The third criterion was that heterogeneous systems were being used to both populate and view data on the network. Of the sites selected, four were in Europe, four in the US The US sites selected are less well known than, for example, Indiana or Santa Barbara; this choice was a conscious attempt to illuminate new lessons and opportunities from around the country. The sites selected for broad, review included: the regional and national networks of Finland and The Netherlands and the regional networks in and around Crete (Greece) and Spokane, Washington. The sites selected for investigation of a focused area of interest included: regional networks in Germany (Small Office Penetration); Bangor, Maine (Master Person Index); Seattle (Clinical Domains); and Mendocino County, California (Open Source).

The survey offers a view of current exchange networks that provide value beyond the immediate Project-Phase II planning requirements. Results indicate a high degree of commonality in certain network services, including patient cross-referencing, use of Internet protocols and web services, and common terminology services. The choice of what gets sent across the network is consistent with local requirements and, in most cases, leads to the exchange of patient summary information as a first implementation, or, where standards support more highly structured information, diagnostics such as radiology or laboratory results, and medication lists. Consistently, sites report a high value on patient participation; without exception, they have deferred implementation of the services and applications that would facilitate direct patient participation toward later in their implementation schedules.

The recommendations are segregated into two categories: those for consideration for the HL7 NLM EHR Phase II project (numbered 1-24) and those that fall outside of the scope of the HL7 NLM work (ten bulleted recommendations following the latter). The numbered, Phase II recommendations focus on the tools and technologies that form the core, required infrastructure for interoperability – the places in such an infrastructure where the survey identified local strengths, or gaps that could be addressed within the framework of this project. In general, these recommendations are technical in nature, and are organized by topic: shared services, shared content and patient participation. Finally, the conclusion includes some thoughts on the place of standards in regional health information organization (RHIO) development and the important role the Project can play in their development and promotion. The remaining recommendations (bulleted in the report) are included for completeness, as they fall within the scope of similar non-profit or public projects, and are unlikely to be addressed through commercial ventures. In general, they are focused on organizational and business issues.

Note: Throughout this paper, a variety of common healthcare and technology acronyms are used. They are defined throughout the report, and more comprehensively in Appendix D.

METHODOLOGY

Selection Criteria

The breadth of possible selection criteria was as diverse as the interoperability efforts themselves. In the end, the Project concluded that three basic criteria were most likely to result in observations (and recommendations) that would be helpful in scoping Phase II efforts:

- Is the effort real? Are users (clinicians or administrators) viewing or using the data exchanged?
- Are data and messaging standards being used? If so, which ones?
- How are end users viewing the data? Are the end systems heterogeneous?

In addition to these criteria, four others helped further describe the diversity of the possible survey sites:

- How many participants (patients, providers, users, organizations) does the effort cover?
- What type of data (administrative, patient care, clinical trial, public health) is being exchanged?
- What makes the initiative interesting or unique? (Note: the assumption is that *every* project offers innovations; this criterion wasn't designed to rank or quantify how innovative a project is, but rather to illuminate the elements that made a particular project unique.)
- How familiar is the project within the US? (to see where new lessons might be learned)

Prioritization and Process

During late March - early April 2005, contact was initiated with 100-plus interoperability efforts worldwide (see Appendix A). The Initial Information Request included seven questions; these are included in Appendix B. In total, almost thirty active networks (where data is being exchanged) were identified. From this list, eight sites were selected for study: four for broad review, and four for focused review. Respondents were asked to complete the entire survey in both types of review; however, in the broad review, the interviews spanned the breadth of the survey instrument, and in the focused reviews, the discussion was limited to items relevant to the focus (e.g., security). In simple alphabetical order, Table 1 lists the broad-review initiatives, and Table 2 the focus review initiatives. Table 3 lists the other projects identified as 'active' (exchanging data on a network), including the rationale for its consideration in the Project.

Table 1: Sites Identified for Broad Analysis

Initiative / Scope	Rationale
Finland National EHR	Largest extant project; largest-scope project, utilizing HL7 version 2 (V2); compelling cost-benefit
Greece – Crete Regional, becoming national	Mix of standards, healthcare domains; geographically distributed; great mix of input devices; creative use of modest resources; using HL7 V2
The Netherlands National EHR	Largest extant data-centered effort; data-focused record-locator service (RLS) contrasts with other RLS efforts; using HL7 V3
US – Spokane, Washington (Inland Health) Local and regional	Broad scope, with mixed local and regional effort; interesting 'viewing' devices; cost-benefit; using HL7 V2

Table 2: Sites Identified for Focused Analysis

Initiative	Rationale	Proposed Focus Area
Germany	Scale; clinical scope; maturity; integration of	Small office connectivity

Regional	HL7 V2; distribution doesn't use RLS	
US – Bangor, Maine Regional	Movement of images in a rural area, both within and across enterprises;	Master-Patient-Index, Master-Person-Identification (MPI)
US – Mendocino County, California Local	Bootstrap project using (and promulgating) open source solutions via openhre.org	Use of open source
US – Seattle, Washington Local	Relationships established with key ancillary content vendors (e.g., LabCorp); technology built with scale in mind	Laboratory or pharmacy data shared between heterogeneous participants

Table 3: Sites Actively Exchanging Data

Initiative	Rationale
Canada – Alberta POSP (Physician Office Systems Program) National / Provincial	One of the InfoWay initiatives
Canada – BCE Emergis (part of Bell Canada Enterprises) / Claims National / Provincial	Claims driven cost-benefit
Canada –Electronic Medical Summary (eMS) National / Provincial	Document exchange; using Clinical Document Architecture (CDA) HL7 V3
England National / Provincial	Enormous scale and scope; may constrain bottom-up learning
New Zealand National	Messaging program; mostly single-vendor interface
US – Anchorage, Alaska Local	Solution maturity ; homogeneity constrains broad applicability
US –Bio-Informatics Research Network (BIRN) at the University of California, San Diego (UCSD) National	Represents a different definition of community (business-focused rather than geographically-focused); mediator allows for complex querying despite the use of different standards
US – East Lansing, Michigan Local	Focus on disadvantaged populations; need better understanding about architecture
US –Massachusetts - Simplifying Healthcare Among Regional Entities (MA-SHARE) Local / Regional	Medication list and e-prescribing; early work focused on development in a single domain (with possible cost-benefit implications)
US – (North Carolina Healthcare Information and Communications Alliance (NCHICA) Statewide	Several disparate efforts under one umbrella; could provide insights on how to start small(er) and add functionality
US – Portland, Oregon Statewide	'Dataveillance' (data surveillance) project focuses on identifying public health risks; could suggest business

	model for a 'first start'
US – Santa Barbara, California or Indiana	Could provide contrast to other efforts; relatively better understood than other initiatives
US – Santa Cruz, California Local	Proprietary solution (Axolotl Corporation); maturity; also in Cincinnati, Ohio through HealthBridge
US – Utah Health Information Network (UHIN) Statewide	Parity of entity regardless of size; simple, cost-effective solutions; strong focus on value to participants
US – Veterans Administration / VistA (Veterans Health Information Systems and Technology Architecture) National	Open system; homogeneous input and viewing

Survey Process

The purpose of the study was to review many different health information exchange networks from around the world and gain insight about lessons learned and opportunities. The final analysis seeks to identify methods and tools to be considered for the Project's Phase II demonstration, which seeks to advance efforts for health data interoperability in the US

During April and May 2005, secondary source material was reviewed and contacts were interviewed at each of the selected sites (see Case Studies). In most cases, multiple contacts (often representing business and technical interests) participated in the interview. The first interview was usually 1-1.5 hrs; most of the reviews required more than one conversation, as well as follow-up emails. Because of the time constraints on this project, sites visits were not conducted and applications were not reviewed. In addition to the interview, contacts were asked to complete a survey form (see Appendix B). The form was designed to be broad – there was no expectation that a single respondent could answer every question. Instead, it was assumed that each project's strengths would emerge through the responses.

Limitations

The limitations of this analysis are clear. The size of the sample used in this study was small and not randomized. It is entirely possible that the selection of different sites would cast a different light on the understanding of Regional Health Information Organizations (RHIOs) development. While every effort was made to faithfully represent these sites and to handle the information provided in a responsible manner, an unintended and undetected error in interpretation could easily distort the overall picture. It is worth noting that the entire survey was conducted remotely, and thus governed by the usual constraints of language when discussing complex topics (words mean one thing to the speaker, another to the listener, and neither may recognize this at the time).

ANALYSIS AND RECOMMENDATIONS

The Analysis section is divided into five sub-sections: shared services, content, patient participation, business issues and general observations. The structure of each section consists of observations of the commonalities and differences across the sites; recommendations to NLM and HL7 to support the nascent RHIOs (numbered items are relevant to Phase II; bulleted items are general recommendations); and a brief site-by-site summary for the topic being discussed (e.g., security)

Recommendations were culled from observations across all of the available data from each survey site, and do not relate specifically to any one site. That is not to say that there aren't specific features worthy of follow-up research at each site; these are highlighted in the observation and innovations sections of the Case Studies. The four broad-analysis sites are the anchor points of this analysis. The sites selected for focused analysis are referenced when they are relevant to the topic being discussed.

Shared Services

Shared services are those services available through the network, in contrast to services or applications available behind the firewalls of participant organizations. There was strong symmetry in the following shared services provided by the sites surveyed:

- Patient Cross-Referencing
- Search and Distribution
- Data Display
- Security
- Vocabulary

Patient Cross-Referencing

The MPI appears to be the most consistently mature technology implemented at the sites studied. The most likely reason is because the data generally comes from administrative systems – patient accounting, admissions-discharge-transfer (ADT), or practice management, which are more widely implemented and mature in both hospitals and physician offices. In addition, just as a local MPI is a pre-requisite to local integration of disparate clinical systems, a shared, cross-enterprise patient matching function is a pre-requisite to many forms of networked record sharing.

All of the sites use a probabilistic model with significant consistency in the data elements used for matching (see Table 4). Finland uses their national identifier as a match indicator. In the rare case where a Finnish ID is not available, they issue one unique ID within the healthcare system. The Netherlands passed a law recently that will require all patients to provide their new, national identifier as a condition of receiving health services starting in 2006. With all of the debate about national identifiers in the US, it is interesting to note that the Finns still perform cross-referencing, even with a national identifier.

Table 4: Data Used in Patient Cross-Referencing

Data Element	NL	Finland	Crete	Spokane	Bangor
Medical Record # (network, participant organizations)	X (until Jan 2006)		X	X	X
National Identifier	Jan 2006	X			
Non-Network Identifier (e.g., SSN)			X		X
Name (partial, full)	X	X	X	X	X
Age / Date of Birth	X	X	X	X	X

Gender	X	X	X	X	X
Address		X		X	
Encounters, Providers (associated with the patient)				X	

The sites use different methodologies for documenting and indexing matches, including:

- Mapping each participating organization's 'medical record number' to a single (invisible) 'network medical record number'; and
- Combining each participating organization's medical record number, to form a unique string that functions as the 'network' medical record number.

Of the sites surveyed, half are using commercial applications. Crete and Mendocino have developed open source utilities based on the Person Identification Service (PIDS) developed by CORBAmed, an OMG domain task force for healthcare active in the late 1990s. Currently, the CORBA-based implementations are being re-worked as web services.

The sites had vastly different experiences with the patient cross-referencing process. In Seattle, only a small number of records from the initial load had to be reviewed manually; in Bangor, they monitor the manual effort required to cross-reference patient data, and use the lessons learned for training purposes. All sites balance automated patient cross-referencing with manual intervention in the process. Spokane uses patient cross-referencing, but relies on human review as needed. In the Netherlands, they manually review 100 percent of patient cross-references, and will continue to do so until the national identifier is implemented on January 1, 2006.

Recommendations:

1. Develop or adapt an open-source, web service-based MPI. Consider converting the Person Identification Service (PIDS), as used in Crete, to a web service.

   Rationale: Every interoperability effort surveyed required an MPI. While there are numerous commercial solutions available, evaluating and selecting ***one*** *creates an early (and unnecessary) implementation hurdle. The availability of an open source alternative would a) promote re-use of this key architectural component, and b) allow communities to focus their initial implementation effort(s) on components that universally require significant development or customization.*

2. Write an implementation guide for HL7 Version 2 (V2) or HL7 Version 3 (V3) messaging with the open source MPI referenced in Recommendation #1.

   Rationale: While an open-source MPI is valuable without an implementation guide, the addition of one further reduces early implementation hurdles. See 'Standards and Source Code' for a discussion of HL7 V2 v. V3.

Supporting Observations:

- Finland: patient cross-referencing, even with national identifier
- Crete: open source MPI (PIDS), migrating from ODBC to web services
- The Netherlands: MPI; 100 percent manual check of matches in the period pre-national identifier
- Spokane: commercial MPI (MEDITECH)
- Bangor: commercial MPI (Cerner) for cross-entity patient identity; append all MR numbers to create an 'invisible' network identifier
- Mendocino: open source MPI (PIDS-based); may experiment with using Markle RLS as MPI
- Seattle: commercial MPI (SeeBeyond)

Search and Distribution

Significant variation was found in the terminology used to describe search capabilities, with significantly less variation in actual functionality. For clarity site-specific terms are generalized as follows: 'search' refers to the process of finding data on the network; ‘registry’ refers to all permutations of network-based, centralized search and retrieval tools, including record locator services, indices, pointers and services; ‘repository’ refers to the data store or database, whether network-based or local; ‘distribution’ refers to the act of moving data from the repository in which is resides to where it is viewed by the end-user; ‘query-response’ refers to a search method in which a requestor initiates an action to get data; ‘publish’ reflects a search methodology where a shared service pushes data based on negotiated business partner agreements; and ‘subscribe’ reflects a search methodology where the receiver tells the shared service what data they would like pushed.

Both the architecture and the search models vary from site to site. Spokane and Mendocino have combined patient cross-referencing with the search function so that in a single interface users work with both applications. The rest of the ‘broad’ sites (Finland, Greece and the Netherlands) have a clearly delineated search-and-retrieval service. In addition to the networked search capabilities possessed by most of the survey sites, many sites had implemented at least some point-to-point search capabilities, built upon trusted business or organizational relationships.

Crete’s search architecture is as follows:

- COAS (Clinical Observation Access Service, an OMG specification) retrieves data from the primary data sources;
- EHR Indexing Service (I-EHR IS) manages indices to the sources of primary information; and
- EHR Update Broker (I-EHR UB) keeps the indices (I-EHR IS) in sync with the data available in COAS.[9]

Universally, the sites search by ‘patient’ using a variety of data elements (most often, the same elements found in the MPI: name, date of birth, etc.). Most of the sites use simple patient-centric queries such as when all of the imaging studies for a particular patient are identified. The final responsibility remains with the end-user for selecting the correct imaging study. In general, no tightly specified search capabilities were identified at any site (e.g., “show me the ER visit that occurred in June”).

Although most of the sites employ a query-response model, several of them publish at least a subset of network data. For example, Crete publishes patient demographic data when that data changes and the Netherlands publishes specialists’ reports to the referring primary care physician. In Spokane, the network conducts a sweep of the data repositories every hour and pushes new data to connected physician-office EMRs. Crete is the only site surveyed that reported using subscriptions to help the end-user manage the data they received.

Once data has been retrieved, data generally remains with the originating system, rather than being imported into a local system. The exceptions to this are usually driven by concern about network performance rather than record compilation. Both Seattle and Crete have local caches available to requestors, in large part, to insure against network downtime or slow response times. One of the Finnish regions has developed alternative search methods for this same reason.

Recommendations:

3. Study Clinical Observations Access Service (COAS), Integrated EHR Indexing Service (I-EHR IS), and Integrated EHR Update Broker (I-EHR UB)[10] as implemented in Crete, and compare with the freely-available tools under consideration by U.S. network efforts, specifically: Integrating the Healthcare Enterprise (IHE) Cross-Enterprise Document Sharing[11] (XDS, based on ebXML open source tools) and the Markle Foundation Record Locator Service (RLS)[12]. Summarize the analysis and prepare implementation guide(s) for one or more of these tools.

   Rationale: All of these tools facilitate distribution and search. RHIOs would benefit from an analysis of these tools (similarities, differences), as well as guidance on how to implement one or more of them in conjunction with the open source MPI described above.

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[9] Katehakis

[10] D.G. Katehakis, S.G. Sfakianakis, D. Anthoulakis, G. Kavlentakis, T. Z. Tzelepis, S. C. Orphanoudakis and M. Tsiknakis, "A Holistic Approach for the Delivery of the Integrated Electronic Health Record within a Regional Health Information Network", Foundation for Research and Technology - Hellas, Institute of Computer Science, Technical Report 350 (FORTH-ICS/ TR-350), Heraklion, Crete, Greece, February 2005.

[11] IHE IT Infrastructure Technical Framework, Supplement 2004-2005, Cross-Enterprise Document Sharing (XDS) http://healthcare.xml.org/resources/IHE_ITI_Cross-enterprise_Doc_Sharing_2004_08-15.pdf IHE (15 August 2004)

[12] Markle Foundation, The Collaborative Response http://www.connectingforhealth.org/resources/collaborative_response/hie_model/chapter.php The Markle Foundation et al (18 Jan 2005)

4. Implement the HL7 NLM Phase I point-to-point search tool as a web service[13].

   Rationale: Most of the sites surveyed utilized at least some point-to-point search tools, in instances where relationships already existed between network participants. The reason: this represents a low-cost, low-overhead starting point and supplement to distributed record locator services. The phase I prototype becomes more usable (as a model or a tool) if it is a web-service.

5. Develop or adopt registries that track 'identity' and 'roles' for applications, providers and organizations, similar to what was implemented in Crete, or the 'dictionaries' used in Spokane.

   Rationale: Identification, whether of a patient or a location or a physician, is necessary both to find data ('show me all of the data on patient John Smith,' 'how many ERs connected to the network have local EMR systems registered?'). Much attention is focused on identifying the patient; less on identifying the other stakeholders in the equation.

Supporting Observations:

- Finland: primarily using RLS, but one rogue region uses point-to-point for query, much like the NLM Phase I project; national deployment will use more extensive caching, possibly some centralized repositories.
- Crete: uses OMG COAS and related components, migrating to web services; other than query-side caches (for performance), the data remains with the originating system; metadata resides at the network level, indexing all encounters.
- The Netherlands: national registry accepts a query routing it to the proper place(s).
- Spokane: network cache, persistent stores are local; point-to-point, commercial search engine.
- Germany: point-to-point using web services.
- Mendocino: Markle RLS[14] pilot implementation site; currently using shared repository and index services; share some open source code base with Crete.
- Seattle: local cache for all patient safety information.

Data Display

The end-users at the projects studied have very different experiences, and do not universally have EMRs (either locally or as a network-based service). Having said that, the sites consistently give access to retrieved data through a network-based web browser, for users who do not have access to an EMR. In Bangor, physicians use web access to view medical images and reports. In Spokane, a commercial viewer fulfills the same function for physicians not using a local EMR. Extensive use of open source, networked software was found to be used in place of an EMR or as a "poor man's EMR" in Crete, where it is having a profound impact on network adoption.

It is noted that one of the compelling reasons for the re-thinking of the Finnish RLS is to allow tighter integration of imported data into local EMRs, because the physicians will no longer tolerate the use of two applications (a browser-style viewer and their own EMR). It may be discovered upon further review in the US that when practitioners become dependent and accustomed to the sharing of information, tolerance for separate application interfaces for local and imported data will decrease.

Recommendations:

6. Develop or adapt a lightweight, open source 'viewer' (e.g., browsers and data managers) that can be used to display clinical data, possibly including an export from a local EMR application, as in Crete.

   Rationale: Survey data suggest that interoperability will spur the adoption of EMRs, while simultaneously suggesting that EMR adoption is not a pre-requisite for health data exchange. Most of the sites surveyed provided an 'EMR-Lite' for participants that did not have an EMR implemented. The simplest version of this could be a web page that can display both documents and messages; more sophisticated versions could group like-elements (e.g.,

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[13] HL7/NLM Phase I search tools deliverables: http://www.hl7.org/nlmcontract/ehrPhaseI.cfm

[14] "Prototype for a Nationwide Health Information Exchange Launched by Connecting for Health" http://www.connectingforhealth.org/news/pressrelease_060105.html The Markle Foundation (1 June 2005).

all lab reports), and parse structured data elements, as well as 'receive' data from EMR applications. Crete's version is somewhere in between these two extremes, and might provide a good model for the Phase II Project.

7. Pilot the integration of imported data into a local EMR.

   Rationale: Once EMRs have been implemented, the more mature survey sites found that clinicians had little tolerance for the use of multiple applications to view clinical data. Thus, a pilot that supports the integration of data in-situ could be valuable. Of necessity, this requires cooperation and participation from the EMR vendor community.

8. Introduce context management (HL7s Clinical Context Object Workgroup or CCOW) for single sign-on and ease of use.

   Rationale: Adding separate network applications or services decreases ease-of-use for the end user, unless coordinated through a context manager. Today, each site must address this individually. This project can encourage a standards-based approach by developing CCOW-compliant solutions.

Supporting Observations:

- Finland: physicians recently began requesting integration with existing EMRs in lieu of network-based browser.
- Crete: researchers populated initial, primitive EMR: constructed user interface (UI) for viewing integrated data.
- The Netherlands: 50-75 percent of the GPs use a full EMR.
- Spokane: integrated with EMRs for 30 percent of physicians; providing MEDITECH 'viewer' component to those without EMRs.
- Bangor: participants may use the local radiology information system (RIS) (Agfa), their local clinical information system (CIS), or a web-browser to access radiology images and reports.

Security

Securing federated systems is notoriously difficult because combining multiple systems expands the system 'perimeter'. One participant's undocumented assumptions relied upon when designing a security model, can easily violate or be violated by other participant's systems not sharing the same assumptions. All participants will trust all other participants to 'tell the truth.' However, if Hospital B has looser security standards than Hospital A, Hospital B's trust in its own security process is not sufficient for Hospital A to feel confident that security has been maintained.

For clarity security includes: identity and authentication, authorization and access control, integrity, attribution, and audit services. Identification services enable a system to 'recognize' a user, generally through unique, machine-readable names, while authentication services ensure that an entity is who that entity purports to be. Authorization services ensure that people and computer systems can use only those resources they are authorized to access and for only the purposes for which they are authorized. Integrity services verify that the data is intact and has not been modified by unauthorized resources (human or automated). Attribution services confirm that actions performed on a system are attributable to the person who performed them and that the actions cannot be repudiated. Audit services provide a record of all attempts to access or modify data, and include both logging and retrieval services.

The security models in place at the survey sites are less evolved than the other shared services and appear to have their roots in some of the trust relationships inherent in intra-organizational security models. This suggests that security is not a barrier to network formation, but may provide a 'gotcha' in more mature implementations. Without exception, security services were provided both locally and as a shared service on the network. All sites described authentication, authorization and audit services; none of the sites described incremental integrity or attribution services (beyond what might be contained in the data or document itself).

Authentication

Non-technologists often assume that end-point applications are secure, and that risk exists primarily within the Internet, which they consider insecure and easy to 'wire-tap.' In reality, the situation is the reverse. Because of the way packets are routed on the Internet, it is extraordinarily difficult to 'steal' data en-route, or to meaningfully interpret it even if it is accessed. With simple data encryption, the Internet is, for all practical purposes, a secure network. In contrast, people routinely share passwords or use insecure passwords (e.g., their child's name) to access legacy applications. This makes it extremely difficult to reliably tell who did what on the system. For this reason, the identification and authentication of individuals – patients, and the providers who care for them – is one of the more important elements of the security model.

Finland is just beginning to design their authentication service and is exploring alternative tokens (e.g., smart cards) and mechanisms (e.g., online bank accounts, which, in Finland, offer authentication services; mobile phones, where a digital certificate is stored on the phone's SIM (memory) card) for authenticating users. Although small pilots are beginning to test these approaches, most of the infrastructure for the Finn's authentication service will be drawn from well-established technologies in other industries.

Greece described robust authentication services, which were implemented at the middleware layer of the Healthcare Information Infrastructure and include an Authentication Server and a User Profile Server supporting smart card authentication and digital signatures (for caregivers). The Authentication Server registers and verifies the identity of health care professionals including possible roles or attributes; issues certificates of names and public keys; issues digitized cards with private keys and certificates of authentication; provides a service for revocation of certificates; and provides a directory service containing the public key certificates and revocation lists. In return, the application or technology must be able to generate a random challenge for the authentication protocol; verify the response from the smart card component; validate the certificate contained in the response; verify that the certificate is not revoked through communication with the Authentication Service; and extract the authenticated user identity and other attributes from the certificate.

In addition to person entities, there are other entities that must be authenticated. For example, information systems also use public key-based authentication when communicating. In Finland, the regional information systems implemented have mutual authentication over Secure Socket Layer (SSL), which is part of the SSL specification, although something not typically implemented in general web applications.

Authorization

Authorization is generally handled locally and usually depends on the system being accessed. In Finland, some systems have role-based access controls, most of which are established locally. In Crete, the I-EHR maintains and manages roles and role-based permissions. Users are assigned roles or capabilities based on their organization and other criteria. Roles are granted access based on 'allow' or 'deny' statements. All statements include the rule, the source system, and the data type to which the rule applies (and the person to whom the rule applied). At present, access is controlled at the source system, data type, and user levels. Other levels of granularity are possible (e.g., diagnosis), but haven't been needed. Seattle allows policy to be set at three levels: patient, physician and facility.

Audit

While most respondents have some audit capabilities, Finland seems to represent the norm: detailed logs of network activity are available, sometimes real-time, sometimes in batch mode. However, at the local application level, each participant and system keeps its own log(s) although the different log facilities are not unified preventing cross-application log queries and reporting. The Netherlands described the closest thing to a 'velocity check' – the alerts used in financial services to identify unusual behaviors and patterns: blanket queries against a patient name are prohibited and, if overridden, must be accounted for.

Future Issues

Security – both technologies and policy – pose possibly the least understood risks of health data exchange. Spoof e-mails claiming cancelled accounts or hacked data are routinely targeted at users of well-known sites such as Citibank, Yahoo!, and eBay, creating confusion and anxiety. Similar attacks on healthcare users are only imagined at this point, but the imagery of phony drug recalls, alarmist warnings or alerts around treatment options, threatened exposure of sensitive medical conditions or fraudulent low-cost drugs speaks to the importance of education and source verification for both consumers and providers.

As more data becomes shared electronically, data will be diverted for different agendas. New policy, new legislation, and new methods of enforcement will need to be developed. Earlier this year, the Attorney General of Kansas requested the names, medical history, sex life details, birth control practices and psychological profiles of 90 women who'd had abortions[15]. The clinics were prevented from even disclosing to patients that their records were being sought. Whatever your stance on this particular issue, the example highlights just one of the policy decisions faced by participants in health data exchange efforts.

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Recommendations:

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[15] Slevin, Peter. 2005. "Criminal Inquiries Trump Issues of Privacy, State Says." *Washington Post*, March 15, p. A03.

9. Pilot authentication, integrity and/or attribution services as implemented in other industries (e.g., financial services). One possibility: Liberty Alliance[16], an alliance of more than 150 companies committed to developing an open standard for federated network identity, participated in the 'Common Framework' ONCHIT RFI response spear-headed by the Markle Foundation[17]

   Rationale: The requirements for these services are consistent across architectural models, and there's no need for healthcare to build something from scratch.

10. Develop or adapt a service for assigning roles and access privileges, possibly using Health Resource Service (HRS)[18] in Crete as a model.

    Rationale: This has not been widely implemented in a standards-based, open implementation. Developing such a service would encourage the use of HL7 messages to support it.

11. Develop data standards for audit logs, to enable velocity checks (alerts generated by a rules engine that is configured to recognize potential fraud and abuse scenarios) and cross-log queries in healthcare.

    Rationale: Other sectors have invested significantly in audit logs and statistical analysis of audit log data. In finance, velocity checks flag possible fraud or abuse (e.g., banks/ATMs limit how much can be withdrawn in a day). In healthcare, velocity checks might include requesting all information on a patient, requesting only sensitive information, multiple requests made from disparate geographic locations, multiple requests for the same patient within the same day, etc. Work with Visa or MasterCard to develop velocity checks, or with one of the system-security vendors (e.g., VeriSign) or professional associations (e.g., Information Systems Audit and Control Association (ISACA)) to develop robust audit capabilities.

- Catalyze or endorse security policy designed to protect patients and providers from the misappropriation of clinical data.
- Educate consumers and providers on the new risks associated with electronic health data, and ways to safeguard it.

Supporting Observations:

- Authorization (nearly) universally handled locally; authentication universally handled centrally
- Finland: implementing authentication, probably using tokens and mechanisms as developed in other industries; role-based authorization
- Crete: mix of centralized and decentralized policy and technologies; authentication utilizes private keys and challenge / response

Vocabulary

A vocabulary service is defined as a technology component that allows corresponding, communicating applications to use terminology in a consistent way. One of the strong findings is that all the implementations studied employ some degree of shared vocabularies and vocabulary services. Where a standard, controlled vocabulary was not available, local terminology was developed. This reinforces the key role of common terminology in semantic interoperability, and the strong need to make common terminology services understood and available.

Each of the sites had shared (albeit often specialized) vocabularies. The actual vocabularies being used differ and depend on licensing and availability. Wide deployment of vocabulary can influence the selection of the clinical data to be shared and the semantic interoperability of that data, such as in the Netherlands where the Dutch pharmaceutical terminology supports highly structured exchange of current medications between providers. Interestingly noted, the Dutch conducted a detailed study of the Systematized Nomenclature of Medicine (SNOMED), and concluded that it was the best candidate although not sufficiently mature or well understood (in the Netherlands) for immediate use.

Also observed was the central role of network identifier servers. Finland initiated widespread use of OIDs (globally-unique object identifiers as specified by ISO) as part of their CDA deployment. The service was so well used that is has been adapted for use outside of healthcare in other Finnish industries.

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[16] The Liberty Alliance Project: http://www.projectliberty.org/about/index.php

[17] Markle Foundation, The Collaborative Response

[18] Katehakis: http://www.ics.forth.gr/eHealth/technology_HII_1.html

Recommendations:

12. Develop or adapt terminology services applications for network deployment in conjunction with the NLM HL7 vocabulary project.

    Rationale: One of the surprises of the survey data was that sites adopted vocabulary relatively early in the implementation timeline; any progress that accelerates this will add value.

13. Develop OID (globally-unique object identifiers as specified by ISO) source and registry as shared service (similar to the OID registry on HL7.org).

    Rationale: HL7 already offers this service through its web site. Extending it as a RHIO network service would support implementers who need to manage OIDs if they are working with CDA or any of the HL7 V3 specifications.

Supporting Observations:

- Finland: national vocabulary server updates each new code set; national OID server manages identifiers.
- Crete: Lexicon Query Language (LQS from OMG); migrating to web services.
- The Netherlands: have national (Dutch) medication vocabulary; studying SNOMED, but want more expertise, knowledge, and vocabulary maturity.
- Spokane: local clinical vocabulary (necessary for external communication, despite consistent implementation of MEDITECH).

Content

Clinical Domains

"Clinical domains" are defined as the area of specific types of data exchanges seen from a functional, clinical perspective. The types of data exchanged fall into these categories:

- Medications
- Laboratory
- Medical imaging reports
- Patient summaries
- Clinical notes

Most of the survey sites started with a focus on one domain area and then expanded, with the choice of area depending on the immediate value derived based on the local business of healthcare. Of those surveyed, summaries are the most common first domain implemented and, in most cases, were already in place (see Table 5). The only study site with coded medications as the first area of application was the Netherlands where there is an established national drug vocabulary. The other sites that are complete or nearly complete in topical coverage are Finland, Crete and Seattle; the former two rely heavily on document-centric exchange.

Table 5: Clinical Domains

Domain	NL	Finland	Crete	Spokane	Germany	Bangor	Seattle
Medications	X	X	X		X		
Laboratory		X	X	X			X
Medical Imaging		X	X	X		X	
Patient Summaries (conditions, allergies, etc.)	X	X	X		X		X
Clinical Notes (e.g., discharge summaries)		X	X	X			

Device Data (e.g., EKG)			X				

When cache is used for primary access, the sites differ in the length of time over which access to historical data is maintained. In the Netherlands, for example, medication history is kept between 4 and 6 months. Seattle based their decisions on 'safety' factors, and determined that the following would be retained: meds (2 years), allergies (all / always), problems (all / always), diagnoses (all / always), immunizations (all / always), laboratory results (6 months).

The regional networks in Crete have networked multimedia devices, blurring the lines between RHIO and telemedicine in this rural environment. In contrast to all other sites, Crete connects diagnostic devices directly to the network for immediate distribution. Apart from, or in addition to, the impact on quality of care, this service is an excellent method of invoking support from patients who can see the immediate results of the network.

Recommendations:

14. Create standards-based implementation guides for different types of clinical information. High-return areas may include pathology and medical imaging reports, if they are not already covered by other standards or professional organizations.

    Rationale: The most commonly implemented data sets included patient care summaries, lab, radiology and pharmacy. The Care Record Summary already addresses basic patient summary document. Professional bodies in lab, radiology and pharmacy are working to standardize content within their domains, and there may be an opportunity to coordinate their efforts with HL7 messages (V2, V3)

15. Pioneer direct device monitoring for U.S. networks, possibly starting with emergency room/ambulance connectivity as in Crete.

    Rationale: Devices are just another source of information on a health data exchange network. While a number of devices produce a steady stream of data (which requires relatively sophisticated filtering to separate signal from noise, particularly for presentation to a clinician), a number of them (e.g., EKG machines) produce a point-in-time reading that can be readily incorporated into an EMR. At this level, the device is producing data that needs to be 'messaged' to the receiving application in the same way that a laboratory system produces a lab report that is incorporated into a patient record. This direction leverages existing investments in telemedicine.

- Develop tools and metrics for assessing and asserting the value proposition of different types of information exchange for RHIOs making determinations about domains.

Supporting Observations:

- Finland: all domains; extract from legacy EMR into HL7 CDA for distribution, local viewing by web browser.
- Crete: lightweight, open source EMR that creates HL7 CDA documents; monitoring device input direct to network; full-spectrum documentation and extensive use of multimedia.
- The Netherlands: implementing medications first, then patient summaries; the rest to follow
- Spokane: laboratory, medical imaging (pictures and reports).
- Germany: summaries, prescriptions.
- Bangor: medical imaging (pictures and reports).
- Seattle: laboratory orders and results, patient summary (includes health conditions, medications, allergies, etc.).

Standards and Source Code

There is a great deal of heterogeneity in the choice and application of standards. Crete, which is extremely heterogeneous in its use of standards, and the Netherlands, which uses HL7 V3 almost exclusively, are the two extremes. There is also a sharp contrast between the top-down planning in the Netherlands, based on a single set of standards and a single information model, and the relatively bottom-up, heterogeneity of the work initiated through the FORTH research institute in Crete. The Dutch effort is only three years old, where the work in Crete dates back to 1992. This report does not speculate as to the cause of this disparity in either approach or process (or its impact on cost-effective interoperability), but observes that both projects expect to have completed most national coverage within another two years.

In terms of content, both clinical and administrative, HL7 V2 is used when there is an installed base and precedence for its use in an intra-enterprise setting. In Crete, the national planners decided they were “not ready” for HL7 V3, although one site with many GPs and no installed base using V2 may go direct to HL7 V3. Finland, Germany and Crete are heavy users of HL7 CDA implementation guides. These three document-based sites have invested in standards-based structured information with the design and implementation of the documents persisting across changes in messaging strategy. Finland has been implementing CDA in Release 2 (R2) since the HL7 early drafts were available and is migrating its implementation guides to the newest release. The higher degree of semantic interoperability provided in R2 is already being used in a pilot to drive decision support as a shared network service. Elsewhere there is fairly consistent reliance on the development of local web services profiles. In Crete, a user of ODBC, they are migrating to web services.

Based on the study’s data, there is a correlation between EMR penetration and the extent of subject matter coverage and no correlation between the extent of EMR penetration and the use of messages or documents for exchange. Finland, the implementation with the greatest coverage as an absolute number and as a percentage of national population and clinical domain, has very high EMR usage (over 90 percent among GPs). It uses standard documents created as the output of legacy EMR systems for exchange. The second-strongest national effort studied, Crete, relies on documents also with a mixed record of EMR adoption. All sectors seem to be higher than the US, and are increasing. While interfaces, services, data and communication protocols are standardized in the European implementations, none of the networked sites, in the US or overseas, require standardized EMRs for interoperability or offer proposed standards for local EMRs. In terms of certification of applications, only the Netherlands is proposing this possibility.

All of the sites, without exception, see the essential role of standards. One observation was a fundamentally different set of expectations between the European and US initiatives: the Europeans *expect* to experiment, extend, and combine standards, and to generally tailor them to their requirements, all within the defined parameters of the standard’s specification, sometimes working within their national standards bodies and sometimes with HL7 or other multi-national organizations. In the US, organizations appeared to use standards much more passively, generally adopting them ‘through a vendor,’ and sometimes extending them with proprietary solutions to fit local needs. However, there appears to be little interest in connecting back to the broader standards-development effort.

The connection to a larger development community was notably different in Mendocino, where the commitment to open source technology is deep with the push of development back into the open source community a core tenet. The other site to significantly embrace open-source development is Crete. Both of these projects owe much to the PICNIC Project, a 5-year EU-funded project ending in 2002 that explored, developed and promoted standards-based solutions and developed many open source components being leveraged today (see Appendix D). It will be interesting to observe over time the efficacy of different types of open source tools. Source code is a reusable asset, but is not equally sustainable for all types of applications. In the Netherlands, the government has discouraged open source development as a potential threat to the commercial viability of their small market. Market size is not a concern in the US, although other factors should be considered before encouraging either commercial or open source development. For example, it would appear that certain shared services, such as patient cross-referencing, could be supplied by a shared code base while other applications with higher potential investment and return are more productively left to commercial development (e.g., decision support tools).

Recommendations:

16. Ensure that all source code developed in the NLM HL7 EHR Phase II Project is ‘open source,’ meaning that both the source and compiled code can be freely and widely distributed, and that the code resides in an open source repository (e.g., SourceForge.net) for ongoing management and derivation by the open source development community.

    Rationale: Millions of dollars have been spent on the development of network services and applications for the exchange of health information. While there is clearly a market for proprietary, commercial services and applications, part of the value NLM and HL7 can bring is promoting re-use in the instances where a service doesn’t have to be ‘invented’ for each RHIO. In addition, this conforms to HL7’s stated policy on code development.

17. Support the use and implementation of HL7 V2 where these standards are well established (e.g., patient accounting systems, laboratory systems). Support the use and implementation of HL7 V3 messaging standards in areas where HL7 V2 is less entrenched (e.g., clinical documents, medical imaging studies, medications).

    Rationale: Based on survey data, the rival for the use of HL7 standards is NOT other standards, but is instead the use of proprietary solutions when a standard isn’t a ‘perfect’ fit. Thus, the emphasis of the Phase II Project should *be on promulgating standards widely, and little effort should be spent on (for example) developing a tool that is BOTH HL7 V2 and V3 compatible.*

18. Develop clinical document architecture (CDA) implementation guides.

    Rationale: CDA documents are independent of the distribution, storage and management technology applied to them, so efforts invested in CDA data definition apply across all the architectures surveyed. Most sites exchange some form of documents, but in a proprietary format, which severely limits interoperability and reuse.

19. Create profiles for web services, including a strong recommendation on which approach(es) can be used, for example, to create packages of documents with images (i.e., binary content), etc. and wrap them in a signed envelop (which may or may not be encrypted).

    Rationale: There is a plethora of web service standards emerging. A profile is a narrowing-down of a messaging communication standard (healthcare or web messages), and can be used, for instance, to demonstrate how to use HL7 V2 (or V3) in conjunction with web services.

- Establish the value proposition for standards-based interoperability versus interoperability based on proprietary solutions; create a "call to action" for broad use and experimentation with multiple standards in the RHIO efforts.

Supporting Observations:

- Finland: HL7 V2, CDA
- Crete: HL7 V2, HL7 CDA, OMG, CEN, DICOM and web services
- The Netherlands: HL7 V3, by government mandate
- Spokane: Hl7 V2
- Germany: HL7 CDA
- Bangor: HL7 V2, DICOM
- Mendocino: Hl7 V2, OMG
- Seattle: HL7 V2

Patient Participation

Every site surveyed is patient-centric in that the organization of data and system functionality revolves around capturing, sharing and viewing patient-specific information. Everyone says patient participation is important, but it has not been widely implemented.

Consumers today are not central players in these networks, but they have significant rights to the data. Medical data has moved from a provider work product to something that a consumer owns as well. As consumers exercise their right to their data, the current processes, business models, and stakeholder mix will be transformed, and control of the network will shift. While this is recognized, there is little available to the nascent networks in the way of support.

While deferring direct patient participation may make sense in terms of the current business model and the early value proposition, it ignores lessons that can be drawn from the evolution of ecommerce in other industries, particularly financial services: when information is available online, consumers clamor for it. Seattle involved patients early on through their advisory process. However, Crete is the only survey site that made a concerted effort early in their implementation to take the case directly to consumers. Their telemedicine clinics for asthmatic children had a profound, immediate and positive impact on consumer acceptance. Showing consumers tangible benefits from the network builds support for the effort, which also motivates and involves participating providers.

The second element of this issue pertains to patient consent. While all but one of the sites had some kind of a patient consent model, all but Finland reported 'on' or 'off' switches. Seattle does allow providers of services related to sensitive services (mental health, AIDS) to invoke an exception to Seattle's general rule that anyone who uses the network data must also supply network data. At this time, there are few patient consent tools available in the survey sites or the broader marketplace. Even with the tools, there is a wealth of policy issues that need to be understood with choices made (e.g., if a patient elects not to share their data regarding a medication, what is the liability associated with an adverse drug reaction), as well as likely technical gaps in the standardization of consent documents and vocabulary.

Recommendations:

20. Select a Phase II pilot site focused on consumer-engagement as a key implementation objective. The minimum selection criteria would be that the project intends to allow patients to query and input their clinical data. Possible sites include Whatcom County, Washington and Spokane.

    Rationale: Even if the services (patient matching, distribution and search, security, vocabulary) selected for the Phase II Pilot are not patient-specific, testing them in an environment where the patient is an active participant is likely to illuminate issues and opportunities that might otherwise be missed.

21. Develop or adapt an open source, web-based patient health record that reads and displays standardized messages and documents.

    Rationale: Our hypothesis is that consumers will seek to aggregate and integrate their healthcare information in much the same way they have their financial and personal information (e.g., contacts, calendars). Consumers will not long be satisfied with multiple providers having multiple (and different) views of their data. NLM and HL7 could add significant value by developing a patient-centric 'viewer' that integrates documents and messages from different physicians and providers.

22. Develop or adapt an open source patient consent framework, which allows patients to specify consent with more granularity than on/off (e.g., by diagnosis, date, provider, etc.) Possible examples of consent models include shared-calendar functions (e.g., .Mac) and social networking applications like Tribe and Linked-In.

    Rationale: This is a specific break-through opportunity for NLM and HL7. Prior efforts by PICNIC and CORBA created many network tools being used today. The Markle Foundation and IHE have developed search and distribution tools. Security tools have been developed in other industries by groups like the Liberty Alliance, and are likely re-usable in healthcare. Patient consent is one of the areas unique to healthcare and, to the best of our knowledge, few are thinking through the issues with much specificity. In conjunction with an access framework like COAS, patient consent applications would create a significant opportunity to contribute groundbreaking work.

23. Develop a patient-level security standard that moves beyond a simple login and password. Examples could include the card verification value (CVV) consumers use to verify that they are legitimately using a credit card when they purchase online, the use of tokens or other physical media, or biometric authentication.

    Rationale: According to a recent Gartner study[19]*, 60 percent of consumers are concerned or very concerned about online security. A similar study by security vendor RSA Security*[20] *found that consumers were curtailing their online purchasing because of security concerns. Both studies report that consumers do not believe that login-password is sufficient to protect their data. This same belief seems likely to challenge or compromise the growth of health information exchange networks, particularly where consumers are active participants on the network.*

Supporting Observations:

- Generally accepted binary model for patient consent (yes/no).
- Little or no direct patient participation, particularly in early phases (other than in advisory capacity).

Business Issues

Although each initiative surveyed has its own approach to the business of health information exchange, some common themes appeared.

Unrealized Business Value

The survey identified four healthcare data domains: administrative, patient care, research and public health. Observed was that the sites rarely work cross-domain. Only Finland noted using data collected in their clinical data applications to feed public health reporting. Crete combined research and outreach under the direction of a medical center and network of community practitioners to launch their first project. The Netherlands intends to use their problem list and disease management messaging for quality monitoring. This same observation appears to hold true for the other sites identified and inventoried but not surveyed: if the network developed to serve a public health purpose, it did not expand into

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[19] Gartner: Consumers Dissatisfied with Online Security <http://www.computerworld.com/securitytopics/security/story/0,10801,98083,00.html> Paul Roberts (6 December 2004)

[20] RSA Security Consumer Study Reveals Major Concerns Over Online Security and Identity Protection <http://www.rsasecurity.com/press_release.asp?doc_id=5522&id=1034> RSA Security (14 February 2005).

patient care; clinical trial and research networks exist in a parallel universe and generally have not leveraged electronic medical records. No one is using network resources for real-time monitoring of drug safety across a wide patient population.

It makes sense that when initiating a network, stakeholders will generally come together (with funding) for a single purpose, although there is a potential problem that must be factored into design. The strongest value proposition for standards-based networks is the potential for information reuse - what HL7 defines as semantic interoperability.

Data for Research or Quality: Networks that collect and share data for research and quality exist today in various degrees of sophistication. Although these networks were not conceptualized as RHIOs, the potential to use the existing trust relationships, business models, user adoption, while building on the existing technology has the potential to fast track the development of direct patient-centric networks.

Administrative Networks: Much like research or quality networks, administrative networks exist today passing data primarily between payers and providers, and are imbedded in the workflow of provider offices. To date, there has been little focus on leveraging existing administrative networks and solutions as the foundation for clinical RHIOs. Given the maturity of many of these solutions, and the number of motivated vendors and EDI providers, exploration of leverage potential could yield rich rewards.

Recommendations:

24. Clinical documents (e.g., laboratory reports, medical imaging reports) commonly exchanged in RHIOs can also be reused in administrative processes. Select a pilot site such as Empire Medicare Services[21], which has a claims attachment pilot underway, and demonstrate that in addition to the documents, the services (patient cross-referencing, distribution and search, security, vocabulary) necessary to facilitate the movement of clinical data can be reused for other purposes.

    Rationale: One of the most compelling barriers to health data exchange is the business model. There are significant benefits to plans and providers of automating the claims process[22]. Under the Health Insurance Portability and Accountability Act (HIPAA) Notice of Proposed Rule-Making (NPRM) on Claims Attachment Transactions,[23] the claims attachment process is likely to become automated over time. Claims processing and clinical services converge at the claims attachment, a clinical document used first to document care provided, second to explain (justify) a request for payment. By tangibly demonstrating that these documents can be created once and used in multiple ways, NLM and HL7 would demonstrate significant progress on the business case for health data exchange.

- Examine existing projects in rural health, telemedicine, and clinical trials for leverage in fast tracking further RHIO development.

Supporting Observations:

- Crete: Coordinated research project involving network of community physicians, medical students and research institute helped launch network, build local support.
- Little reuse of core clinical data, but when demonstrated, provides substantial support for network.

Value Proposition

All efforts defined a value proposition as a starting point with the proposition defining and impacting how the effort rolled out. Internationally, the value was frequently defined for the population as a whole, with quality and safety as forefront. With the exception of Crete, governance and leadership tended to be top–down model, developing over extended periods of time with funding following the model. Significant funding was generally required to move the

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[21] Empire Medicare Services Claims Attachment Pilot Project Overview <http://www.wedi.org/cmsUploads/pdfUpload/WEDIBulletin/pub/ClaimsAttachmentsPilotOverviewFINAL_111004.pdf> WEDI Claim Attachment Pilot Advisory Committee (10 November 2004).

[22] Case Study: How We Finished HIPAA in New England <http://www.ehcca.com/presentations/HIPAAColl2/halamka.pdf> John D. Halamka MD (2001).

[23] Administrative Simplification in the Healthcare Industry <http://aspe.hhs.gov/admnsimp/index.shtml> US Department of Health and Human Services (23 January 2004).

effort ahead. In the US, efforts tended to develop regionally with leadership originating through efforts of a small number of executives. In this scenario, the funding followed and reflected the magnitude of the effort.

When local organizations were committed to the value, they funded projects internally or extended a pre-existing foundation or process (e.g., rural health in Mendocino, and shared rehabilitation services in Spokane) and adoption spread organically throughout the community. There was an interesting convergence in Crete, which acted as a conglomerate; the vision was national but the implementation was small arising from the efforts of a research organization on Crete. Funding was essentially local, driven by the value perceived by the participating local health systems and clinics, leveraging open source and shared development.

The rural aspect was powerful with clear demonstrable value at the individual level apparent and early on, as seen in Bangor, Mendocino, Crete, and parts of Spokane.

Recommendations:

- Articulate the value propositions that will drive regional participation, recognizing that organic growth will evolve the network and that governance will evolve naturally, either bottom up or top down, as defined by the early participants.
- Further characterize the hypothesis that implementation costs can be kept low by building on existing networks, solutions, and natural constituencies like telemedicine projects and other efforts to reach into rural areas.

Supporting Observations:

- The Netherlands: only example of top-down national planning as early stage of deployment.
- Crete, Finland, Germany: local and regional exchange networks driven by local requirements being assessed and redesigned in context of national deployment.
- Seattle and Mendocino: conceptualized locally, but with an architecture designed to scale.
- Spokane and Bangor: conceptualized and executed regionally.

Cost Benefit Analysis

Limitations of Analysis

There are a number of constraints to the cost benefit analysis. The first was the inability for respondents to fully articulate the costs associated with their projects or to go to original sources to derive the data. In many cases, the projects have been evolving over many years, and it is difficult to say which of the current, historical and projected costs components are part of the interoperability project(s) and which are related to health technology, but not part of the network.

The section is present to give readers a gross estimate of cost magnitude in the hope that it will help put the projects studied into perspective highlighting the urgent need for consistent cost and benefit accounting metrics. Part of the challenge in undertaking a RHIO is to understand what truly drives cost (and benefit). Until there are ‘standard’ metrics for this analysis, it will be very difficult to make apples-to-apples comparisons across projects and to really understand what constitutes a tangible success.

Operating Costs

In the instances where operating costs could be collected, the range was astoundingly broad – from $400,000 US to 40,000,000 euros annually, depending on the scope of the project. This broad range illuminates one of the most difficult challenges in estimating the costs and benefits associated with health data exchange efforts: there is no common framework, no agreed-upon rules for what is included in the analysis. Depending on the project, operating costs included:

- Network hardware, software and maintenance costs.
- Applications that run on the network, even if they are owned by a participant organization.
- Education, training and/or help desk support for the network and/or associated applications.
- Bandwidth, connectivity and/or communication charges.
- On-going development costs for the network (e.g., upgrades, new functionality, etc.).
- Management e.g., people, systems, etc.).

As an example of allocation, Crete estimated their operating expenses in the following buckets:

- Management (of new funding opportunities): 10 percent.
- Network Maintenance (includes system maintenance and security monitoring for about 1,000 PCs): 30 percent.
- New Development (new services, new technologies): 40 percent.
- Training (for new doctors, new users): 5 percent
- Other: 15 percent.

Implementation Costs

Estimating operating costs is almost an easy exercise when compared to estimating implementation costs. The challenges with this part of an analysis:

- All of the projects surveyed were implemented in phases, often spanning many years.
- Most of the projects are implementing a network, but they are also looking at projects with complex business choreography like e-prescribing. It is difficult to isolate which costs are associated with health data exchange between providers and which are associated with business partner agreements made possible with interoperable data.

Crete estimates that 10 million euros has been spent in the last 10 years on just the projects directly in their control. They could not estimate the cost (or the benefit to them) of other projects sponsored by the Greek government or by the European Commission (e.g., EuriPACS, OpenECG). For the national rollout (16 other regions), the Greek Ministry of Health has budgeted 150 million euros over four years (2002-2006) or approximately 10 million euros per region over four years. Another perspective to consider is a per capita basis: approximately 16 euros cost for each of the estimated 10 million Greeks. Finland has estimated the total implementation costs for its multi-year project at 80 million euros, but those close to the project believe this is a low estimate. Note the population of Finland is half that of Crete as are their projected implementation costs.

Again, Crete provided the following estimate of implementation expenses by category:

- Network Hardware (local area infrastructure): 10 percent.
- Local (Organizational) Development / Licenses (3rd party systems): 10 percent.
- Integration of Local Services with Network (salaries for research, technologists): 40 percent.
- Training: 10 percent
- Network costs (operating a 2MB backbone, 256 KB to each primary care center): 20 percent.

Benefit Models

The most consistent observation made about benefits at the survey sites: the smaller and more contained the project, the clearer the benefit profile. Bangor can provide specific insights as to how the medical imaging network has reduced unnecessary referrals, enabling patients to receive quality care in their home locale while reducing the cost of their care (no duplication of service; remote, expert consultation). Spokane can clearly point to savings with the cited savings attached to concrete operating costs (e.g., the savings from shared rehabilitation or IT resources).

Trends

Every implementation site required that participants provide some of the implementation funding. Whether stated or not, the belief was the need for having ‘skin in the game’ is valuable. In Finland, this equated to 25-75 percent of the entire implementation cost; in bootstrap efforts like Crete, the self-funded percentage was even higher. When money is made available by the government, it is often the local decision makers who make the spending decisions, as long as national interoperability is advanced.

Another trend observed: the innovative application of resources. Despite the increasing sums of money spent on healthcare interoperability over the last 5-10 years, many initiatives described being under-funded and creative ways to close the funding gap:

- Spokane’s hospitals implemented non-technology projects (e.g., a shared helicopter rescue program), and used some of the cost savings associated with these programs to help fund the technology development and implementation costs necessary to build-out the network infrastructure.
- In Crete, the human network formed the critical mass out of which the technical network was built. During the bootstrap phase, medical and health students at University Hospital went to local primary care centers, to help construct a primitive EMR. In return, GPs provided clinical data for research purposes at the university.

- Bangor has financed expensive medical imaging equipment for some participants. Network participants are charged a cost-based, per-service charge for imaging studies; an incremental fee is added to this transaction cost when the participant is using financed equipment.
- Crete developed a program to educate consumers about their project: they had university-based infant asthma specialists see 150 patients in one of the pilot programs. Within the context of a normal care process, they were able to demonstrate to consumers the benefits of having a specialist be able to read and review case information during the consult process.

Recommendations:

- Develop a common framework for estimating costs and benefits where value is clearly defined.
- Study the impact and viability of various types of open source solutions and tools.
- Study the impact of standardization on the different constituent pieces of the network to best understand and predict the rationale for standardization.

General Observations

Implementation approaches varied significantly primarily driven by whether the project was rolled out with a top-down perspective or with a local control perspective, but evolutionary movement was consistent: steady movement to include more data, engage more participants, and implement more end-user technology, like EMRs, and include more population.

Failure was as an aide, not an impediment to development in the European efforts and was recognized as such, which prompted revision in direction. On the contrary as observed among the full spectrum of US-based efforts, there is a greater reluctance to describe course changes, perhaps due to the greater reliance on profit-driven commercial development.

Education and support is a critical component for success. Finland has a fully-staffed help desk for implementers. The Netherlands reports that education is the critical factor in speed of deployment. Crete is budgeting up to 10 percent of funds for these purposes. Bangor invests in training on the creation of the medical record number.

Recommendations:

- Develop self-paced, interactive training tools to support the specifications, implementation guides and tools developed under the HL7 NLM Project.
- Develop a clearinghouse for technology assets and project reports, so that RHIOs can find the information they need to make informed technology decisions.
- Develop and maintain a Help Desk for the RHIOs, staffed by experts knowledgeable in healthcare data and messaging standards, and who understand the implications of their use in community data exchange.
- Look for and illuminate failure and lessons learned to improve efficiency of the rollout of networks.

CASE STUDIES

Broad Analysis

Finland

The population of Finland is about 5 million. Health care responsibilities lie largely with the municipalities (~450), which are organized into 20 provinces or regions. The Primary Health Care Act 1972 introduced primary care centers, public organizations responsible for integrating prevention and illness activities, and increased the focus on primary and preventive care. The hospitals are also public. Most physicians are salaried; the municipalities pay both the physicians and the hospitals. There is little private insurance.[24]

The Finnish Health Information Infrastructure is in its third generation of development and deployment and expects to be implemented nationally within approximately two years. The first generation, started in 2001-2002 and called the Satakunta Macropilot, was implemented in a single region. Today, most of the twenty regions have implemented some services. According to some European informaticists, Finland has the most advanced health information infrastructure in Europe. The Finns are more modest stating that the only other country with their level of coverage may be Denmark, which uses EDIFACT messaging (Electronic Data Interchange for Administration, Commerce and Transport), an international standard developed in 1986 providing data syntax, data interchange, and standard messages for multi-country or multi-industry data exchange. All generations of health information infrastructure planning and deployment have shown maturation, incremental development and refinement. Major innovations slated for the next stage include:

- National PKI (public key identification – see Security) management with strong authentication;
- Refinement of the record locator service (RLS) with more central caching;
- Integration of records into local electronic medical records (EMRs), possibly with desktop context management; and
- Upgrading the level of coding (structure) to CDA Level 2, allowing for more robust usage.

In primary care, over 90 percent of General Practitioners (GPs) have an EMR with about 90 percent of the GPs using them. In specialized care (e.g., hospital settings), 60 percent have an EMR and usage varies widely, from 10-90 percent. In the private sector, about 80 percent have an EMR. Thus, EMR availability is high, but not always used. The market consists of many different vendors, and the systems are thoroughly standards-based and cover all types of clinical information (structured and unstructured).

Patient Cross-Referencing: Finland issues a national identifier (ID) to every citizen for use in healthcare and other business areas. When the identifier is unknown or unavailable, a system-wide unique ID is generated. The International Organization of Standardization unique object identifiers (ISO OIDs) are used for healthcare providers and facilities and are managed nationally through an identity server. Local Master Person Indexes (MPIs) are updated from the national service with provider index systems supporting healthcare provider credential validation.

Distribution: The primary means of information distribution include four autonomous, regional record locator services (RLSs), which cover about half the country, including the capitol city of Helsinki. In addition, one region is using a joint EMR across all hospitals and health centers. Of the four regions with RLSs, one has developed a competing system for direct query and retrieval between facilities, largely in response to concerns about central network availability. In all cases, communication is by web services with ebXML-like information added to the header (transparent information preceding the transmission). ebXML is within the family of eXtensive Markup Language-based standards focused on electronic business.

The Finnish RLS is a registry that can be queried for pointers to the location of patient health information. Upon request, the patient information is extracted from a legacy EMR and converted into an exchange format, which is HL7s Clinical Document Architecture (CDA). The CDA is then transmitted as XML and rendered locally on a web browser. In all but one region, the data is not stored locally once it has been displayed.

The final wave of connectivity may centralize some critical health summary documents, in large part to avoid possibly expensive (time, resources) on-demand extraction from legacy systems. In addition to lessening these demands on

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[24] European Observatory on Health Care Systems – Finland http://www.euro.who.int/observatory/Hits/20020525_2 (2002)

legacy applications, the next generation system will look at how to import viewed data (documents, messages) into the local EMR applications.

Security: Access is controlled locally including management of patients' consent for access. Patients are allowed to place some restrictions on access. One project connecting an academic medical center with other local facilities has established a central certificate authority and is using public key infrastructure (PKI) with the exchange of health records. Nationally managed certificates are planned within the next stage of expansion.

Vocabulary: A vocabulary service support nation-wide coordination of codes and controlled vocabulary within healthcare records.

Clinical Applications: There is wide penetration of EMRs alongside continued use of voice interface (dictation). Device data (e.g., EKG) is entered into the EMRs and exchanged within standard documents; devices are not connected directly to the infrastructure. There are some web applications for provider order entry and there is heavy use of a web interface for information retrieval (a second application, used in addition to their EMR).

Data Standards: Finland relies primarily on CDA Release 1(R1) for exchange of EMR records. One region has been implementing CDA Release 2 (R2), which is currently in draft form. They have a series of CDA implementation guides, the key ones consisting of a unified CDA structure for EMR data and electronic forms and a patient care summary used for provider referrals. All implementation guides for R1 are being updated for R2 with the expectation that all regions will migrate to R2.

Currently, some systems continue to rely on an XML implementation of EDIFACT, which was in place before the current system but will be replaced by the end of 2007. HL7 V2 is used for laboratory reports, but, interestingly, these are translated to CDA for archival storage and for decision support. The rationale is that CDA is a persistent data format and putting laboratory reports into CDA means a common data format for the decision support application(s). One reason given for the ease of introducing CDA was that there was already a high degree of consistency in the format of the paper medical records used nation-wide. Consistent paper formats are easier to migrate to consistent electronic formats (in the form of the CDA). Digital Imaging and Communications in Medicine (DICOM) is used for exchange of images e.g., Computerized Tomography (CT) and Magnetic Resonance Imaging (MRI).

Business Model: There is a mix of public and private healthcare in Finland, but the burden of the private sector, paid directly by patients, is much lower than in the US (about 10 percent). The next and final stage of establishing a national health information infrastructure is funded and managed as part of the "National project to secure the future of health care," a program to ensure universal access to care. They estimate that the national EHR, by the end of 2007, will save 200 million euros per year for the system as a whole.

Summary Observations: The Finnish RLS has been the model for much activity in the US, hence its evolution and refinement should be studied carefully. While it is clearly successful in the primary objective of providing cross-enterprise access to information, in doing so, it has raised expectations that must be met by the next iteration. Specific demands for system improvement focus on the reliance of on-demand record generation and the desire for improved integration between retrieved records and the local EMR system (currently a second desktop interface is used for externally-retrieved records requiring providers to use both their EMR and a second application / machine).

Innovations: The Finns continue to push the boundaries of the system with a series of pilot projects. Currently, one region uses CDA R2 notes to drive a shared decision support service that supplies real-time prompts and alerts to the physician desktop. Another innovative use of CDA, possibly unique, is for queue adjudication and monitoring for their 3-days, 3-weeks, 3-months quality of care initiative. This program uses CDA to monitor the timeliness of care provision according to nationally mandated guidelines, and could be adopted for other types of quality monitoring. An additional program collects all records generated across the country during two days out of every month and archives them for a retrospective cross section of the state of Finnish health and healthcare, for public health and research purposes. In addition to the availability of implementation guides, a national help desk and robust education for vendors and implementers have been key factors in the successful expansion of this program.

Interviews: Jari Porrasmaa; Project Team Member, Association of Finnish Local and Regional Authorities; HL7 Finland TC; jari.porrasmaa@uku.fi; Vesa Pakarinen: VTT Information Technology; Coordinator for HL7 portion of National Project; HL7 PR; vesa.pakarinen@vtt.fi; Timo Tarhonen: CEO, Tietotarha Corp; Chair, HL7 Finland TC; timo.tarhonen@tto.fi

Resources (in English):

Decision in Principle by the Council of State on securing the future of health care, MINISTRY OF SOCIAL AFFAIRS AND HEALTH, Helsinki, 2002: http://pre20031103.stm.fi/english/eho/publicat/bro02_6/bro02_6.pdf

HL7 Presentations: http://www.hl7.de/cda2002/progoverz.html, http://www.hl7.de/iamcda2004/fprogram.html,

Greece – Crete

The population of Greece is about 10.5 million people. Until 1983, their health care was financed mainly through social insurance. Reforms enacted in 1983 were to change this, by creating what was supposed to be a tax-financed National Health Service (NHS). However, the financial relationship between the insurance funds and the NHS was never defined, so the social insurance funds continue in existence, but with increased public subsidies. However, the health reform of 1983 did make significant changes to how care was delivered: primary care was to be provided by health centers and their provincial clinics in both rural and urban areas. While this did materialize in the rural areas, both public and private provider settings continue to deliver primary care in the urban areas. Physicians in rural areas are generally government employees; those in urban areas (private practice) can be contracted with one or more insurance funds, and funded by a combination of patients and insurance.[25]

Greece is in its third wave of shared care applications and networking. The first wave started on the island of Crete at the Foundation for Research and Technology-Hellas (FORTH) Institute of Computer Science (ICS) and has spread to ten other regions, most thoroughly to the Santorini region of the Southern Aegean. Today, the technology and approach initiated over ten years ago by FORTH is the basis for development of full national health information interoperability slated for completion in another two and a half years. This study focuses primarily on the home base of Crete and discusses how this work has been adopted by other regions and adapted for national implementation.

FORTH has been a constant source of innovation both technically and logistically, a pathfinder optimizing the use of technology for better care delivery. Major innovations coming from the Institute include:

- Extensive deployment and utilization of open source components;
- Development of a light-weight virtual EHR supporting small practices; and
- Integration of real-time diagnostic imaging devices (telemedicine) within the information exchange network.

The degree of EMR adoption varies widely over the 250 small practices, 16 small, primary care hospitals and the seven district hospitals. At least three of the primary care hospitals are fully electronic and a program for remote access called Twister is reaching remote practices with access through a virtual EHR. There is on-going training and adoption rates are slowly climbing. No single vendor dominates the implementation and open source components are widely used.

Patient Cross-Referencing: Patient identifier cross-referencing and management is provided via a shared service called Person Identification Service (PIDS) designed by Object Management Group (OMG, an international standards organization) and implemented using various technologies (see Appendix C on the use of open source components).

Search and Distribution: Crete uses middleware services for access to data through repository caching and through registry pointers. The service layer contains registries of feeder systems, patient demographics and pointers to locally held data. Access methods and choreography are diverse, using Common Object Request Broker Architecture (CORBA) object references (an OMG-sponsored standard for software components), HTTP, X.500/LDAP for directory infrastructure, and dedicated gateways. Most access is through query and response using Clinical Observation Access Service (COAS, an OMG specification) with patient demographics updated through a publish-subscribe-notification sequence. Taking advantage of OMG service specifications, the original design heavily used Open DataBase Connectivity (ODBC, a standard for data exchange). The regional infrastructures are moving to loosely coupled, messaging-based methods. When HL7 V2 is used locally, it is being adapted for regional use. An indexing server, another open source component, records all encounters. Data is stored locally, but cached at the query site for performance reasons.

Security: The Health Resource Service (HRS) issues identifiers for healthcare staff and facilities and tracks their associations (user IDs, roles, and role-based permissions). Thus there is central administration of IDs, usernames, passwords and certificates, while authorization is de-centralized. Each region defines its own rules, which encompass source and information type as well as user. An application is provided to local administrators for assigning roles and access privileges.

Vocabulary: There is a separate Lexicon Query Language service (LQS) that is used in conjunction with the query service (COAS)

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[25] Health Care Systems in Transition – Greece <…> World Health Organization - Regional Office for Europe (1996)

Clinical Applications: The distributed, virtual EHR created by FORTH is specialized for primary care, emergency care, inpatient, cardiology, pediatrics, pathology and so on. There is a sequential (encounter-based) view and a problem-oriented view. Effort has been made to structure as much of the data as possible, but free text remains in widespread use. There are healthcare discipline-specific problem lists covering cardiology, radiology and respiratory problems. Information is extracted from legacy systems and imported into CDA-compliant forms for distribution and print. There are viewers for ECG (EKG) and imaging data in standard formats.

Various commercial laboratory information systems (LISs) and hospital information systems (HISs) are integrated into the network using HL7 V2. Through Picture Archiving and Communication Systems (PACS, databases for medical images) the data is integrated to include both the images and their reports.

Ambulance-acquired ECG, spirometer and vital signs are transmitted via Global System for Mobile Communications (GSM, an international wireless communications standard) and are available at the receiving emergency department.

A laboratory information infrastructure is already in place nationally and will become part of the greater framework. Each of the regions is starting with a different base, but eventually the national system will cover patient administration, transfer of care notes (referrals, discharges), and laboratory results. In addition, the system will cover 20-30 key performance indicators that measure utilization and efficiency.

Data Standards: The FORTH projects have been voracious consumers of healthcare specifications, starting with the CEN TC 251 HISA (European Committee for Standardization, Technical Committee, Healthcare Information System Architecture) and greatly influenced by the work of the CORBAmed (the division devoted specifically to healthcare) within OMG. The CEN 13606 specification shaped the record folder concept used for another FORTH project, Integrated Electronic Health Record (I-EHR).The OMG specifications have been implemented in patient identification, record location and retrieval and access control both in the original CORBA implementation and the more recent Java and web services-based applications. The virtual EHR manages clinical documents using CDA R1. Laboratory data is imported as HL7 V2 and medical images are exchanged in DICOM.

Overall, the ODBC connections used in the initial work on Crete are being replaced and are not part of the national plan. Most implementations will start with HL7 V2. One site is considering HL7 V3, but when the original analysis was done in 2002, HL7 V3 was considered an unknown risk due to lack of broad implementation.

Business Model: FORTH, funded mostly through research grants with some provider funding, has acted as an incubator with Crete as the beta site for an extensive array of applications. A key factor in early development was collaboration between the research institute and a university hospital working in conjunction with a network of community physicians.

Other regions have chosen projects for local implementation according to their own business requirements. The Southern Aegean region of Santorini appears to have gone the furthest with many other regions, including a pilot in a Muslim community, adopting projects more selectively.

In 2003, the national government announced request for proposals (RFPs) for implementing the infrastructure across the 17 regional authorities. FORTH is one of the bidders. Implementation under these contracts will start the end of 2005 through 2008. Three of the 17 regions declined to participate in the national program, choosing to work with private consultants to implement systems based on the national standards.

The national health authority created an Information Society to support the regional information technology (IT) authorities. Funds are distributed centrally. The regional authorities work with the healthcare professional societies (i.e., the equivalent of county medical societies or regional associations of lab professionals) on implementation and deployment.

Summary Observations: The design is evolving from tightly-coupled, fine-grained interfaces to a loosely-coupled coarse-grained architecture is instructive:

"Message queues and relevant technologies fit perfectly into these scenarios, where documents are exchanged using a well-defined and general interface (the send/receive message methods or equivalent) and *the importance shifts from the definition of interface contracts to the design of the documents' schemas*."[26]

In other words we generically change the way we communicate more often, and with less difficulty, than we change what we say. This indicates that an investment in standards-based, structured information can outlive changes in distribution and communication systems.

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[26] Katehakis p 14 (emphasis added)

Innovations: Crete is the only instance identified with open source components not only supporting interoperability, but also having a key role as end-user applications. The full catalog of the applications is too extensive to present in this report. Two examples include desktop conferencing for real-time, multi-party consultation and a collaborative environment built around the virtual EMR that includes personal web pages, information channels, bulletin boards, discussion lists, e-mail and shared workspaces. The Crete site is one of the most extensive deployments of media-rich services and the only site known with direct connectivity for diagnostic equipment like spirometers and ECGs.

It is the only site identified with a regional information network launched by community-based physicians, in part, and with bidirectional support through academic research.

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Resources (in English):

HygeiaNet, the Integrated Health Telematics Network of Crete: http://www.hygeianet.gr/

HL7 Presentations: http://www.hl7.de/cda2002/progoverz.html, http://www.hl7.de/iamcda2004/finalmat/day3/2004-10-20-cda2004_v3.pdf

Whitepaper:
http://www.ics.forth.gr/eHealth/publications/papers/2005/2005.TR350_Holistic_Approach_Delivery_Integrated_Electronic_Health_Record.pdf

The Netherlands

The population of the Netherlands is about 16 million. The majority of health insurance and healthcare providers are private. The Dutch are eligible for public health insurance based on annual income; about two-thirds of the population qualify. State health insurance, provided by about 20 different companies, covers doctor's visits, hospitalization, and prescription drugs. All physicians must contract with the public health insurance providers. Patients must see their GP before being referred to a specialist. The insurers are paid PMPM, with adjustments based on specific medical conditions. Private health insurance covers the same services as public insurance, but may include extras (e.g., dental). Private insurers must contract with all hospitals, but can selectively contract with physicians. Physicians, pharmacies and hospitals are reimbursed on a fee-for-service basis.[27]

This project is the youngest of the national-scale projects studied and is distinct in several respects. Although the Netherlands launched a series of regional pilots in 2004, the Nationaal ICT Instituut in de Zorg, (NICTIZ) project is centrally-planned and specified in a manner that could be described as a "top-down" approach. This is in contrast to the other national-scaled projects reviewed, which developed from local initiatives ("bottom-up" approach). Another distinction is that unlike the other European projects identified, NICTIZ will target exchange of clinical data with a clear return on investment. The project will start with an exchange of current medication lists and summaries moving to health condition-oriented data for treatment of diabetes, cardiology and cardio-pulmonary disease with others to follow. The future vision is a fully functional virtual electronic health record without a central repository.

The distinguishing features of the NICTIZ plan are:

- Centrally-planned, top-down, nation-wide design; and
- HL7 V3, model-based messaging tailored to the Dutch national project.

In 2004 the project pilot connected over a dozen provider systems using the five types of EMRs common in the Netherlands. Of the five EMR types, three met the requirements for system testing.

In Holland, there are approximately 8,500 GPs organized into 6,500 practices; 100 hospitals; 125 posts (walk-in clinics) serving a population of about 16,000,000 Dutch people. Between half and three quarters of the GPs use a full EMR. Acute care is publicly funded with about six major, private insurers covering primary care needs.

Patient Cross-Referencing: Currently there are several types of patient identifiers issued by regions, hospitals, GPs, midwives and others. On January 1, 2006, the Netherlands will switch to using their social security number as a single identifier. Two regions currently have cross-enterprise indices that will be merged into one national index. The current

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[27] Overview: The Dutch Medical and Dental Market <http://www.infomedics.nl/en/overview.html>

work, in absence of a national ID, uses several parameters for cross-matching patients ***and*** utilizes 100 percent manual verification when sending information between systems. When the national ID is operative, local lookup by patient name will return the identifier, which will then be the sole patient query parameter.

Distribution: GP data must be available 24/7 to the system, so some GPs will connect directly and others will connect to a regional system with a daily batch upload. A national search registry is the switching point. It will receive queries and route them to the appropriate local system where data is extracted on demand. The system is primarily query-response based, although after a medical consultation, the resulting report will be pushed to whoever referred the patient (most often, their GP)

The medication summary describes prescriptions filled, rather than prescriptions ordered (but possibly not filled). Electronic prescribing has been easier to implement in outpatient settings than in hospitals. Almost all pharmacies are automated – they track prescriptions ordered and filled – but drug dispensing by GPs may not be captured. The actual workflow for capturing fulfillment data is derived from CEN 13607 (a European standard used for electronic transfer of prescriptions focusing on a standard business view).

Security: With perhaps the strongest security features being those enforced by law, blanket queries against a patient name are prohibited and, if overridden, must be accounted for. Access control will be based on rules adjudicated by a shared service with central administration of PKI certificates. It is unclear as to how fully this access control method is now implemented.

Vocabulary: The vocabulary for medications is the central code system of the Dutch Pharmacists Association, which has nine million identifiers for retail pharmaceutical products and additional identifiers for laboratory results (reports) and inpatient pharmacy. The vocabulary includes a drug's commercial or brand name, pharmaceutical name and component ingredients.

Clinical Applications: Summary messages covering basic patient safety data (such as medications, allergies, and health conditions) will be created from legacy EMRs and translated to HL7 V3 summary messages supporting the transfer of care (referrals, discharges). By the end of 2006, all physicians will be required to check orders for new medications against a full list of current medications for possible interactions. Those who are not yet participating in the full electronic system will have web access to medication lists against which they can do a manual check. This group is expected to include some GPs as well as midwives, dentists and others. The current pilot among 20 GP offices includes an electronic medical journal covering the past four months, which includes notes on major diagnoses, allergies, medications and contraindications.

Data Standards: It is instructive to examine the approach to HL7 V3 taken in the Netherlands:

"It is generally accepted that HL7 version 3 (HL7 V3) will become the standard for messaging in the healthcare sector. NICTIZ has therefore chosen to align as much as possible with the developments within HL7 V3. However, in the short term it is not expected that the standardization for HL7 V3 will lead to a stable definition of the message structure, given that this is not where priority is placed in the standardization process. Moreover, a specific (often national) description of the message content ("payload") must be defined per domain. In order to achieve the desired results within the time frame of the NICTIZ Master Plan, NICTIZ will partly have to decide for itself when it comes to message structure and message design."[28]

Thus the Netherlands approaches HL7 V3 as a development environment that can be tailored to national requirements rather than a set of pre-determined message structures. System design calls for local translation between current EDIFACT or V2 messages and the national V3 messages; the actual transport layer will be HTTP or SMTP.

Business Model: While dedicated to the improvement of healthcare nationwide, the NICTIZ project is also targeting areas with significant savings accruing to the system as a whole through the elimination of duplicate orders and better management of resource-intensive health conditions. A major change in retail pharmacy operations will follow the advent of electronic prescribing when government-insured patients gain the right to transfer prescriptions between pharmacies. The pharmacies have opposed this practice, along with making their databases of fulfillment data available.

NICTIZ supports open standards that encourage a robust commercial market, but is concerned that government funding of open source software could threaten market forces. With no prohibition to introducing open source applications the

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[28] "Design Of The Architecture Basic Infrastructure For Healthcare, Version 2.0", National IT Institute for Healthcare in the Netherlands (NICTIZ), December, 2002, Section C, p 53.

prevailing opinion is that the size of the Dutch market is small enough not to inhibit commercial investment and development.

Summary Observations: This project is in its early days, so it is difficult to compare effectively to the third-generation projects in Finland and Greece. At the same time, it is larger and bolder in scope than the local and regional efforts studied. Several aspects of the implementation are hallmarks of the NICTIZ work: the effective engagement in the standards process through a national body that coordinates with HL7; the high incidence of EMR use; and the availability of Dutch Pharmacists Association's drug vocabulary.

Innovations: Holland has taken a strong stance on standards-based interoperability, tailoring a suite of messages for national use, much like the Canadian InfoWay project, but with a centrally planned, executed, and rapidly deployed schedule.

Interviews: Jos Baptist: ;baptist@nictiz.nl; Dick Donker: ; donker@nictiz.nl; William Goossen: ;Williamtfgoossen@cs.com; Robert Stegwee: ;robert.stegwee@capgemini.com

Resources (in English):

Nationaal ICT Instituut in de Zorg website: http://www.nictiz.nl/kr_nictiz/default.asp?datoom=2129

"Design Of The Architecture Basic Infrastructure For Healthcare, Version 2.0", National IT Institute for Healthcare in the Netherlands (NICTIZ), December, 2002.

US – Spokane, Washington

Spokane developed as a result of market pressures on community health systems in Eastern Washington. This specific area is characterized by strong local communities with a history of sound communication even while separated by significant distances and faced with major competition from large, national hospital chains. The program grew from the effort of a single health system, Inland Health, wanting to integrate its own systems across multiple facilities and to gain economies of scale through shared services and centralization of resources. In collaboration with other local community hospitals, they consolidated non-technical hospital services valued to the community, but that had traditionally lost money (e.g., rehabilitation services). Inland Health then moved to shared technology and shared data services. Today, about 75% of the patients covered by the network live in Spokane and 25% live in outlying rural (referral) areas.

Patient Cross-Referencing: A single MPI is created the first time a patient presents to any participating hospital or laboratory. This unique identifier is provided to all the interconnected MEDITECH systems so that each patient's unique identifier is registered in all participating facilities. An algorithm of demographic data is used to ensure accurate matching when patient encounter data are logged, creating an index of all encounters. Metadata captures data type and location. Laboratory and radiology vendors on the network can also access this MPI and encounter data.

Distribution: Data is viewed in the MEDITECH patient viewer called Patient Care Inquiry (PCI), which is a network component that can view enterprise-level data. When specific patient data is requested, PCI queries the MPI for all encounters and locations, then retrieves data from each organization's MEDITECH implementation (if relevant). Over time, external partners and laboratories have been added. The partners may query the MPI and add data into the network.

Security: Access is controlled locally including management of patient consent for access. Physicians can access all available data for their patients through any system within the network.

Vocabulary: A locally developed vocabulary was developed as a shared service.

Clinical Applications: Initially multiple MEDITECH implementations were hosted in a central data center within Inland Health. Data from each system was stored separately, and not merged, maintaining the integrity of the data for each MEDITECH implementation. A consolidated view of data at the patient level was accessible to approved physicians through the MEDITECH patient viewer (PCI). External data sources such as laboratory and radiology were integrated into the system with the external data cached centrally and made available to the PCI as well. Over time, additional hospitals outside the Inland Health system moved to MEDITECH and outsourced their information systems to the Inland Data center sharing data at the point of care. As a result, all local hospitals are able to share data with one another and local physicians have a single point-of-access for inpatient information and outpatient laboratory and radiology results.

There is relatively wide penetration of EMRs with over 30 percent of providers within the region having the applications. As physicians adopted the system within the hospital, they pushed for similar functionality in their offices. Non-MEDITECH EMR vendors including IDX, GE, and NextGen were connected to the network. Physicians without EMRs use the PCI to view data. A new pilot will provide consumers with direct access to their data through a service on the network.

Data Standards: Clinical data is imported into the EMRs using HL7 V2.

Business Model: The system is entirely private funded by provider users with the exception of interfaces into the EMRs, which the vendors funded and developed. From its original, community hospital roots, the network is expanding to new levels of sophistication. The network is being extended to tertiary academic centers in other areas of the state, into neighboring states and out to consumers, which will require a federated, decentralized system. HL7 standards and locally developed vocabulary have enabled the network to continue evolving.

Summary Observations: This project is significant in the US as it grew solely from efforts of local hospitals to share patient information across an expanding area of the Northwest. Initial leadership was strong, and governance remains simple with two key principles being set by Inland Health: no central data store and access controlled locally. Growth is driven by the financial value received by the participants. Although the initial architecture was MEDITECH to MEDITECH, basic services of patient matching and record locator were added on top of the single-vendor implementations. As it gained scale, the architectural complexity has grown, so that a heterogeneous array of applications types and vendors are supported.

Innovations: The system has acted as a magnet, drawing in more and more users. Physicians have accelerated the adoption of EMRs as they discovered the value of shared data in the hospital setting, resulting in adoption rates significantly higher than other parts of the US Experimentation has become significant with pilots to share data with consumers and a distant academic research center being rolled out currently.

Interviews: Fred Galusha: CIO, Inland Northwest Health Services; fgalusha@prodigy.net

Focused Analysis

Germany

Germany has several interoperability proposals pending with no single national strategy for sharing clinical information. This case study reports on one of the proposals, which uses point-to-point communication and a document-based strategy for referrals and reimbursement, much like the draft proposed HIPAA-compliant attachments, referrals and authorization in the US Work on the **S**tandardized **C**ommunication of **I**nformation **S**ystems in **P**hysician **O**ffices and **HO**spitals (SCIPHOX**)** began in early 2000. The features of the project include:

- Support for transfer of care (referrals) using simple clinical notes, independent of transport mechanism; and
- Reuse of standardized clinical notes supporting reimbursement and disease management.

Through SCIPHOX several implementation guides for standard clinical documents were designed. The project's focus was communication between general practitioners using a proprietary (commercial) data format, and between hospitals using a standard HL7 V2. The business driver was the collection of information with sufficient structure to drive reimbursement and the insurance company's disease management database.

SCIPHOX differs from the other network projects reviewed in that it stressed persistent, standards-based information design with no transport mechanism specified in the implementation guides. In practice, organizations in the pilot region for disease management use existing point-to-point messaging to transport the documents; other sites used XML, Simple Object Access Protocol (SOAP), or alternate web services.

SCIPHOX encompasses administration data (insurance), laboratory results, diagnoses, medications, procedures and patient referral data. The rationale for using CDA was the prevalence of an XML-like markup specification in GP offices in conjunction with widespread use of HL7 V2 in hospitals. In addition, the document format was familiar to providers, so user-compliance was improved.

The first phase of the project looked at the use of structured data in clinical documents to drive business processes with the first application for clinical note sharing in the transfer of care situations. The second phase, e-prescribing, produced Implementation Guides, but has not been piloted as robustly (i.e., it may be used for provider orders, although will not be adopted by pharmacies for reimbursement).

Partners for this first phase came from the Physicians Statutory Organization and associated institutes, POS and HIS vendors, various vendors associations, the HL7 user group Germany (the German international affiliate of the HL7 US organization) and some universities.

Interviews:

US – Bangor, Maine

In 2004, the Eastern Maine Health System (EMHS) brought its Regional Picture Archiving System online in Northern Maine. It currently covers four hospitals, one imaging center and two mobile imaging units. By the end of the summer, it will cover an additional 10 hospitals. The project is unique in that it covers relatively small patient (300,000) and provider (1,000) populations spread over a large (300 mile radius) geographic region.

The impetus for the project was twofold: cost management (similar to Spokane) and improved quality care and the patient experience. Because most of the hospitals in the area are small, resources to develop robust imaging capabilities (professionals or technology) at each facility were limited. As the regional referral center, the EMHS facility in Bangor routinely cared for patients who required more specialized imaging services. However, they often found they lacked the original imaging studies and duplicated them or they found the patients could have been managed medically without transferring them to Bangor for additional study. Since bringing the project online, EMHS has seen a significant drop in the number of duplicative studies and unnecessary referrals, which improves the patient experience since they remain in their local area for treatment.

The crux of the system consists of a WAN that covers the entire geographic area. The participants fall into the following categories, each of which has different access privileges and uses for the systems.

		Organization Type	
		Affiliated (EMHS)	Non-Affiliated (EMHS)
User Type	Radiology / Emergency Department (ED)	EMHS Agfa Radiology Information System (RIS)	Local RIS gateway or EMHS RIS (at provider preference)
	Primary Care / Other Specialties	Cerner Clinical Information System (CIS)	Browser-based display, Cerner CIS (if providers have a local install)

Interview: Deb Sanford: Patient Care Administrator (Imaging), Eastern Maine Medical Center; dsanford@emhs.org

US – Mendocino County, California

The Mendocino Securing Health Access and Records Exchange (SHARE) project started through a partnership with the Alliance for Rural Community Health (ARCH). ARCH is an association of rural health clinics in Mendocino and Lake Counties in California. The SHARE network has three shared services: the Records Locator Service (RLS), the Clinical Data Exchange Service (CDE), and the Authorization and Access Decision Service (AAD).

The RLS can be used to provide a cross-system enterprise-wide MPI. It can also be used to provide a controlled-access record locator service across several enterprises or RHIOs. The RLS is based on the OpenEMed implementation of the OMG PIDS standard, and it is a J2EE-based CORBA service, which can be deployed in configurations ranging from stand-alone to distributed and hierarchical. The matching services of the OpenEMed PIDS are being enhanced to include "fuzzy" matching algorithms, such as NYSIIS (New York State Identification and Intelligence Algorithm) and Metaphone. Ultimately the RLS will be able to store many "medical record folder" identifiers, or even identifiers for individual records along with other identifying information for each patient.

The CDE is supplied with a set of "record folder" identifiers and responds to requests by retrieving the related records from organization's EMR systems or their proxies using federated queries, followed by caching, optional de-identification, and formatting of the data for presentation sequentially and/or longitudinally. The CDE uses the University of California, Los Angeles (UCLA) data server code, which in turn is based on the Cocoon J2EE platform with configuration, rather than coding, as the key feature. Heavy use of XSL transformations are used for the presentation of the clinical data in any desired format on a multitude of potential devices.

The AAD implements Kerberos and LDAP-based user authorization, encryption, and password management, and policy-driven fine-grained access control. The open-source MIT Kerberos and OpenLDAP codes are used. The access decision code is based on Sun's OpenXACML. Although ultimately the XACML standard is used for storing the access policies, OpenHRE provides a web-based Security Administration tool that provides an easy to use graphical user interface (GUI) for user and policy management. Organizations can assign uniform resource identifiers (URIs), a W3C identification system used to allow one party to share information with another party globally, to any level of data, including individual records or even data fields within those records. , and the AAD will pass or fail the URIs that are presented to it, based on the policies encapsulated in the XACML.

Interviews: Greg Wenneson, Project Manager, SHARE of the Alliance for Rural Community Health; gregw@ruralcommunityhealth.org; Don Grodecki: don@browsersoft.com; Joe Panther: joe@browersoft.com

US – Seattle, Washington

Seattle developed as a partnership between one pilot community and several vendors. The group identified common interests in creating interoperability between systems within a community in order to move clinical data in response to patient care needs while simultaneously improving patient safety, quality of care, and reducing costs. The project went live in January 2003. The initial pilot sites included Swedish Hospital and Providence Health systems. Today there are 19 sites that feed data through the system including LabCorp and Dynacor laboratory.

The development of the technology was funded by the early participants with the goal of bringing a product to market. Initially, the goal was to move clinical data between institutions across the state, but this quickly devolved to moving data within a single, distributed health system in Seattle as the value of integrating care across multiple facilities within the system was powerful. The technology was developed according to robust business and technology requirements, designed to scale, and envisioned to be a commercial product.

The system was initially developed as a federated model, without a central data store. Because many of the initial hospitals did not have existing systems that were available 24X7, a distributed set of data caches was developed, so that basic safety data would always be accessible. This data was stored “as is” so laboratory data that came in as Logical Observation and Identifier Names and Codes (LOINC) was stored as such without any normalization. Efforts to support normalization are currently underway.

Within the center, three shared services were developed and deployed: the patient matching function, the record locater service, and the policy server. The patient matching service resolves duplicate entries and incomplete matches through an algorithm that uses up to 8 data elements. Matching is very robust. Currently the system holds information for 650,000 people in Seattle, with 48,000 duplicates found. Less than 0.1 percent needed to be resolved manually. The RLS works through a hub, which contains a “pointer” system that knows where a patient’s data is and can direct retrieval. The third function supports access control through a policy server. Access is defined for each participating enterprise and can be controlled at three levels: patient, physician and facility.

In order to make the system useful from the beginning, basic safety data was explicitly defined and agreed, upon, including medications, allergies, health problems, diagnoses, immunizations, laboratory results, and transcribed notes. Having past data available immediately was valuable to the initial users. The second installation did not preload data due to budget and scope decisions, resulting in users having access to data only as it was found and cached. Any data stored in legacy systems not accessible in real-time was not available. Although this approach allowed the phase II systems to go-live sooner, users decided to load legacy data within the first year after implementation.

The technology has since been implemented for University Hospitals Health System (UHHS) in Ohio, as well as in Waterbury Connecticut.

Interviews: Joe Kasper, First Consulting Group, technical architect

CONCLUSIONS

The primary mission of this work was to provide a set of recommendations to the NLM HL7 EHR Project that would be actionable under the terms of the current contract, and thus the Recommendations form its Conclusions. Given the timeframe, narrow goals and small sample, the weight of the observations and recommendations contained in this report require more investigation. In the authors' opinion, Crete and Finland are the most extensive standards-based interoperability networks for healthcare information in the world (with the possible addition of Denmark) fully covering patient data for millions of lives on a daily basis. The iteration and growth of these projects could provide a wealth of experience and technology assets still largely outside the understanding of those decision makers planning similar efforts in the US.

This report describes the critical role that can be played by non-commercial, open source software. An important point to similarly emphasize is the enabling effect that the judicious application of open standards and open source software can have in expanding the market for commercial development. In a standards-based system, the same data that sustains interoperability can support value-added processes like research, quality monitoring, practice management and public health. The same is not necessarily true of networks built on proprietary data formats. Standards can act as either a brake or a spur to innovation and market growth. For the most part, poor standards simply will not be implemented, although they still have a net drag on the market through wasted time and effort and lost opportunity cost. Well-designed standards open up a market, increasing the value to all players. In a system as complex as healthcare information networks, not every constituent part is an equal candidate for standardization. What is needed is an understanding as to when and how to require conformity such that the conformity grows the market and does not distract or inhibit it.

The purpose of the HL7 NLM EHR Project is to provide tangible assistance to RHIO developers and implementers. While acknowledging that the Project is neither a public relations nor marketing campaign for either HL7 or NLM, the survey underscores the need for a shift in attitude toward standards in the US. The HL7 NLM EHR Project is uniquely positioned to help send the message that standards are an enabling factor for interoperability, not an impediment to be imposed or mandated. While the primary client for this report is a particular standards body, it is suggested that adoption of any set of standards is preferable to none. While the other client for this report is a government agency it is suggested that the apparent need for strong direction toward a single cohesive and comprehensive set of standards is less pressing than it might appear. A landscape of projects using a small set of competing standards is vastly preferable to a landscape of projects populated mostly by competing, proprietary solutions. NLM and DHHS play an important role in supporting this Project, and all efforts should be made to continue in this direction.

A final acknowledgement is to the lasting legacy of the PICNIC Project, a 5-year EU-funded project ending in 2002 that elicited voluntary participation from over a dozen countries and contributed to the foundation of many of the strong international projects seen today. Under the PICNIC umbrella, a multiplicity of standards-based solutions were explored, developed and promoted in an atmosphere of collaboration and cooperation. The EU project funded initial development of some of the open source components still in use today; the HL7 NLM EHR Project is a natural inheritor of the PICNIC legacy.

APPENDICES

Appendix A: Inventory of Initiatives

	Country	Initiative Name (if known)
1	Finland	Aluetietojärjestelmä
2	Germany	SCIPHO
3	Netherlands	(EHR)
4	Greece	Twister
5	England	NPfIT
6	New Zealand	(Messaging program)
7	Australia - Brisbane	Brisbane Southside HealthConnect Trial
8	Japan - Shizuoka Prefecture	Shizuoka Prefecture EMR project
9	Singapore	
10	Hong Kong	
11	Canada - Alberta	Physician Office System Program
12	Canada - BC	e-MS
13	Canada	Claims Processing (BCE Emergis)
14	Canada	InfoWay
15	US - Nationwide	DoD, VA, TriCare
16	US - Birmingham, AL	Dynamic Online Event Reporting System
17	US - Montgomery , AL	Montgomery Area Information Network
18	US - Anchorage, AK	Multi Facility Integration (MFI)
19	US - Juneau, AK	Alaska Health Passport
20	US - Fayetteville, AR	Washington Regional HealthMedx HIE
21	US - Phoenix, AZ	AHCCCS Health Information Exchange
22	US - Tucson, AZ	Health-e-Arizona
23	US - Fairfield, CA	Virtual Clinical Network Expansion
24	US - Fontana, CA	Healthy Fontana Online
25	US - Grass Valley, CA	Sierra Nevada Health Care Data Exchange
26	US - Long Beach, CA	Long Beach Networking for Health & Surveillance
27	US – Los Angeles, CA	Provider-Payor Network clinical data exchange
28	US – Los Angeles, CA	Virtual Information Highway (VIH) model
29	US – Los Angeles, CA	Health-e-LA
30	US - Santa Barbara, CA	Santa Barbara Care Data Exchange
31	US - San Diego, CA (nationwide)	BIRN - Bio-Informatics Research Network

32	US – San Diego, CA	Circle of Care
33	US – San Diego, CA	Clinical Information Exchange Improvement Through Direct Patient Data Entry
34	US - Santa Cruz, CA	Santa Cruz County Health Information Exchange
35	US - Tulare, CA	Tulare District Hospital Patient Care Collaborative
36	US - Woodland, CA	Collaborative Health Information Project (CHIP)
37	US – CA	Partnership Health Plan
38	US – CA	California County Clinic Lab Exchange (CHCF)
39	US - Carbondale, CO	Roaring Fork Valley Community Health Plan
40	US - Denver, CO	CoHIE
41	US - Denver, CO	Colorado Access Project to Enhance Provider-Member-Plan Communications
42	US - Grand Junction, CO	Mesa County Health Information Network
43	US - Derby, CT	C-VAMS
44	US – New Haven, CT	Wellness Information Network
45	US - Dover, DE	Delaware Health Information Network
46	US - Longwood, FL	Improving Health and Communication with the Patient Centric Record
47	US - Orlando, FL	Healthcare Access Demonstration
48	US - Atlanta, GA	Georgia EMR
49	US - Augusta, GA	OrderComm
50	US - Augusta, GA	Tri-County Plus Rural Health Network (TCPRHN)
51	US - Carrollton, GA	West Georgia Health Information Exchange
52	US - Honolulu, HI	Hawaii Health Information Exchange
53	US - Honolulu, HI	Quality Healthcare Alliance Health Information Exchange
54	US - Sandpoint, ID	North Idaho Community Connections (NICC)
55	US - Chicago, IL	Advancing an HIE for Cardiovascular Care
56	US - Chicago , IL	ePrescribing HIE
57	US - Northfield, IL	Electronic Cancer Reporting
58	US - Bloomington, IN	South-Central Indiana E-prescribing Network
59	US – Fort Wayne, IN	Allen County Connections for Care Network
60	US - Indianapolis, IN	IHIE / Regenstrief
61	US - Logansport, IN	Connecting Cass County for Better Health
62	US - South Bend, IN	South Bend Community HealthLinks

63	US - Davenport, IA	Telehealth
64	US - Iowa City, IA	Using Physician-Patient Online Messaging to Improve Outcomes
65	US - Pratt, KS	Jayhawk P.O.C.
66	US - Lexington, KY	Connecting Healthcare in Central Appalachia
67	US – Jena, LA	Catahoula Consortium on Health Information Exchange
68	US - Metairie, LA	Project Overcoming Isolation
69	US - Bangor, ME	Regional Picture Archiving Communication System for Northern Maine
70	US - Lexington, KY	Community Based Intervention System (CBIS)
71	US - Baltimore, MD / Washington DC	MD/DC Collaborative for HIT
72	US - Reisterstown, MD	Smart E-Records across Continuum of Health (SERCH)
73	US - Silver Spring, MD	HHCC Practice Patterns and Outcomes
74	US - Boston, MA	The Boston Community Health Information for Improvement (CHII) Project
75	US - Boston, MA	MaeHC
76	US - Boston, MA	Connecting Consumer Communities to Healthcare Providers
77	US - Worcester, MA	SAFE Health - Central Massachusetts
78	US - Worcester, MA	Medication Administration Program
79	US – MA	MA-SHARE
80	US – Ann Arbor, MI	Inter-Plan Guideline Adherence
81	US - Detroit, MI	Voices of Detroit Initiative
82	US – East Lansing, MI	Implementing Interorganizational EMR to Improve Care for Disadvantaged Populations
83	US - Grand Rapids, MI	Use of Smart Card Technology to Promote Community-Wide Diabetic Quality Improvement
84	US - Grand Rapids, MI	CLEAN: Communities Leveraging e-Health for Asthma Needs
85	US - Lansing, MI	Picture Archiving and Communications Systems
86	US - Lansing, MI	The Health Care Interchange of Michigan Care Data Exchange
87	US - Marquette, MI	Upper Peninsula Health Data Repository

88	US - Duluth, MN	Patient Management System for Emergency Health Preparedness
89	US - Minneapolis, MN	Minnesota Health Data Institute
90	US - Rochester, MN	MN Collaborative Health Information Exchange System
91	US - Waite Park, MN	Central Minnesota Health Information Network
92	US - Billings, MT	Using Health Information Exchange to Reduce Medication Errors in the Rural Healthcare Setting
93	US - Billings, MT	Community Health Access Partnership
94	US - Kimball NE	Nebraska Panhandle Regional Health Record Planning
95	US - Lincoln, NE	Behavioral Health MIS Integration Project
96	US - Bedford, NH	Furthering User-Friendly Systems for Informatics and Patient Online. (FUSION)
97	US - Holmdel, NJ	Medication Information Network Exchange, (MINE)
98	US - Princeton Junction, NJ	New Jersey Primary Care Association EMR Project
99	US – Las Cruces, NM	eMS Health
100	US - Lovelace, NM	
101	US - Brooklyn, NY	Implementing the EMR into the Pediatric Subspecialty areas of the Ambulatory Health Network.
102	US - Buffalo, NY	Western New York Emergency Department Triage Surveillance Project (WNYEDTSP)
103	US - Fishkill, NY	Taconic Health Information Network
104	US - Glens Falls, NY	AMI Online Network (AMION)
105	US – New York, NY	Continuum Health Partners - MedMined Virtual Surveillance Project
106	US – New York, NY	NYC Syndromic Surveillance
107	US – New York , NY	Anti-Coagulation Lab results through Open standards Technology (ACLOT)
108	US – New York, NY	Advancing Therapeutics in Parkinson's (APT)
109	US – New York, NY	Community Health Center HIE Consortium
110	US - Rochester, NY	Rochester HealthNet
111	US - Rochester, NY	Health-e-Access
112	US - Research Triangle Park, NC	NC Community Medication Management Project
113	US - Raleigh, NC	North Carolina Health Information Exchange Consortium (NCHIEC)
114	US - Gastonia, NC	Patient Safety Net for Heart Failure Disease Management
115	US - Chapel Hill, NC	Perinatal EMR
116	US - Asheville, NC	WNC Health Network

117	US - Cincinnati, OH	HealthBridge
118	US - Circleville, OH	Berger Health System CPOE
119	US - Cleveland, OH	Pathways to Medication Safety
120	US - Dayton, OH	HealthLink Miami Valley
121	US - Dennison, OH	Connecting Rural North East Ohio For Better Health
122	US - Elyria, OH	Women & Children Data Exchange
123	US - Marietta, OH	Rural Health Exchange
124	US - Sylvania, OH	Coordinated Patient Record System
125	US - Wilmington, OH	Laboratory Information System
126	US - Wilmington, OH	Radiology Information System
127	US - Tulsa, OK	Saint Francis Heart Hospital HIE
128	US - Portland, OR	OHSU / State of Oregon Department of Health
129	US - Jersey Shore, PA	SVRHP Regional Remote Pharmacy System
130	US - Narberth, PA	HIE to Prevent Blindness
131	US - Philadelphia, PA	Mercy Circle of Care Exchange Model
132	US - Philadelphia, PA	Service Point
133	US - Pittsburgh, PA	The Pittsburgh Health Information Network (PHIN)
134	US - Pittsburgh, PA	Patient/Physician Information Exchange (P2P)
135	US - Scranton, PA	Scranton Temple HIE (STHIE)
136	US – RI	Rhode Island Quality Institute
137	US - Sioux Falls, SD	Sioux Valley Clinical Information System
138	US - Kingsport, TN	Tri-Cities TN-VA
139	US - Memphis, TN	Memphis Metro Area Technology Collaborative for Health (MATCH)
140	US - Nashville, TN	Volunteer eHealth Initiative
141	US - Nashville, TN	Williamson-Wired Health Exchange for Kids
142	US - Houston, TX	Integrated Clinical Information System
143	US – San Antonio, TX	UHS HIE
144	US – UT	UHIN
145	US - Barre, VT	Community Electronic Health Record

146	US - Richmond, VA	CenVaNet
147	US - Charleston, WV	West Virginia Patient Safety Project
148	US - Bellingham, WA	Whatcom County ePrescribing
149	US - Seattle, WA	(Patient Safety Institute)
150	US - Seattle, WA	CHITA
151	US - Spokane, WA	Community-Based Diabetes Health Information Exchange Project
152	US - Spokane, WA	Inland Health
153	US - Washington, DC	Connecting Visiting Nurses, Patients and Physicians
154	US - Washington, DC	Evidence-Based Medicine (EBM) Online
155	US - Milwaukee, WI	Wisconsin HIE

Appendix B: Blank Survey Form

Initial Information Request

These are the questions that were emailed to all candidate initiatives when developing the short-list of initiatives.

1. What is the stage of implementation?

a. Planned

b. Pilot or prototype

c. In production

2. How are end users viewing the data? Do they use paper, browsers or applications? If they are using browsers or applications, do the end users have local electronic medical records? If so, do they come from a single vendor or multiple vendors?

3. How many participants are using the system now? How many when fully implemented?

4. What type of data is covered by electronic data exchange?

a. Administrative data – claims, reimbursement, eligibility

b. Patient care - all, lab, pharmacy

c. Clinical trials

d. Public health

5. What data standards are used?

a. HL7 version 2

b. HL7 version 3 messages

c. HL7 CDA

d. ASTM CCR

e. DICOM

f. NCPDP

g. X12

h. CEN 13606

i. openEHR

j. Other (please specify)

6. Can you provide a short characterization of the architecture? (central vs. distributed, record locator vs. notification, etc.).

7. What areas do you feel are unique to your project?

Survey

PROJECT DETAILS

Name

Location

Contact

Title / Role

Email

TECHNOLOGY

1. Please provide an overview of the architecture. At a high level, describe the network *(e.g., federated, stand-alone),* the services it offers *(e.g., search, patient matching)* and the applications that connect to it *(e.g., EMRs, decision support tools)*.

Note: Text boxes have no character limit

2. Describe choreography / workflow on the network *(e.g., query-response, publish-subscribe)* and how policy is negotiated *(e.g., contractually, manually, automatically)*

Note: Text boxes have no character limit

NETWORK SERVICES

Patient Identity and Matching

3. Do you use a master-patient index? Is it inter- or intra-organizational? What patient identifiers are stored at the network level? Which are stored locally? How were these decisions made?

Note: Text boxes have no character limit

4. What data do you use to confirm patient identity (check as many as apply)?

Data Element		Description / Standards Used
☐	(Scoped) Patient Identifier *(e.g., whose patient identifier is it?)*	
☐	(Scoped) Patient Identifier *(if more than one)*	
☐	Gender	
☐	Name	
☐	Address	
☐	Date of birth	

☐ Age	

User and Organizational Identity

5. How are user and organizational identities managed? Which functions are performed locally? Which are performed on the network? How are users and organizations added or deleted?

Note: Text boxes have no character limit

Security

6. How does the network ensure that an entity is who that entity purports to be (authentication)?

For example: describe data sources; incremental authentication for updates (e.g., new documents); session length, extent; local / remote authentication practices *Note: Text boxes have no character limit*

7. How does the network ensure that people and computer systems can use only those resources for which they are authorized access, and for their authorized purposes (authorization)?

For example: describe users types (update, create, read); whether practices apply to groups or individuals; the use of proxies *Note: Text boxes have no character limit*

8. How does the network know who can access what capabilities (access control)?

For example: based on user role / profile; based on context (e.g., time of day, location); based on usage pattern (e.g., connect time, number of patients queried); based on patient consent; based on originator (physician) consent; based on content (e.g., sensitivity of the data) *Note: Text boxes have no character limit*

9. What audit features exist on the network?

For example: what data is captured; how does logging work; what query capabilities are supported; what monitoring processes are in place. *Note: Text boxes have no character limit*

Search

10. Describe the general search architecture. Is search distributed or point-to-point? Are registries used? How?

Note: Text boxes have no character limit

11. For what information is search supported? Using what parameters and tools? Describe as many as apply.

Search for …	**Search Parameters**	**What query language is used?**
☐ Patients	*(e.g., last name, patient identifier, address)*	SQL Other (describe)
☐ Physicians	*(e.g., last name, facility, physician ID)*	SQL Other (describe)
☐ Locations	*(e.g., EDs, within a specialty / dept, facilities)*	SQL Other (describe)
☐ Diagnoses	*(e.g., CHF, diabetes, pregnancy)*	SQL Other (describe)
☐ Document Type	*(e.g., discharge summaries, referrals)*	SQL Other (describe)

APPLICATIONS

12. List applications and devices that are used in conjunction with the network. Are they used for data input, viewing data, or both? Please describe all applications that any user can connect to (to send or receive data) from the network, even if they are local applications (rather than network services).

Application	**Number of Different Vendors / Versions**	**Data Entry**	**Data Viewing**
☐ Electronic Medical Record *an application that provides a patient-centric record of a patient's care*		Is this a way data is entered on the network? Yes Please describe What % of the data entered is structured? Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)	Is this a way data is viewed on the network? Yes Please describe Is data viewed in this application integrated with non-network data? How? Yes Please describe Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)

☐ Electronic Medical Record – Patient Viewable *an application that provides a patient-viewable, patient-centric record of a patient's care*		Is this a way data is entered on the network? Yes Please describe What % of the data entered is structured? Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)	Is this a way data is viewed on the network? Yes Please describe Is data viewed in this application integrated with non-network data? How? Yes Please describe Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)
☐ Clinical Information System *an application used in an acute or long-term care environment to track orders and results*		Is this a way data is entered on the network? Yes Please describe What % of the data entered is structured? Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)	Is this a way data is viewed on the network? Yes Please describe Is data viewed in this application integrated with non-network data? How? Yes Please describe Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)
☐ Ancillary Clinical Systems *applications used to manage workflow for ancillary services (pharmacy, lab, radiology, etc.) in either a regional or inpatient facility*		Is this a way data is entered on the network? Yes Please describe What % of the data entered is structured? Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)	Is this a way data is viewed on the network? Yes Please describe Is data viewed in this application integrated with non-network data? How? Yes Please describe Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper

			☐ Tablet ☐ PDA Other (describe)
☐ Decision Support Application *applications used to compare care delivered against accepted protocols, and to provide notifications when there are deviations from best practice*		Is this a way data is entered on the network? Yes Please describe What % of the data entered is structured? Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)	Is this a way data is viewed on the network? Yes Please describe Is data viewed in this application integrated with non-network data? How? Yes Please describe Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)
☐ Registries – Immunizations, Disease *applications that inventory all patients with a certain immunization or condition*		Is this a way data is entered on the network? Yes Please describe What % of the data entered is structured? Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)	Is this a way data is viewed on the network? Yes Please describe Is data viewed in this application integrated with non-network data? How? Yes Please describe Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)
☐ Voice interface / Dictation *applications that provide a voice-to-text interface for providers*		Is this a way data is entered on the network? Yes Please describe What % of the data entered is structured? Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper	Is this a way data is viewed on the network? Yes Please describe Is data viewed in this application integrated with non-network data? How? Yes Please describe Devices used:

		☐ Tablet ☐ PDA Other (describe)	☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)
☐ “Smart” Devices *medical devices that produce data that can be incorporated into the network (e.g., a sensor)*		Is this a way data is entered on the network? Yes Please describe What % of the data entered is structured? Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)	Is this a way data is viewed on the network? Yes Please describe Is data viewed in this application integrated with non-network data? How? Yes Please describe Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)
☐ Browser based viewers *Internet-based ‘portals’ that allow patients or physicians to view health data* ☐ HTML ☐ XML (server side transform) ☐ XML (client side transform)		Is this a way data is entered on the network? Yes Please describe What % of the data entered is structured? Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)	Is this a way data is viewed on the network? Yes Please describe Is data viewed in this application integrated with non-network data? How? Yes Please describe Devices used: ☐ Desktop ☐ Telephone ☐ Laptop ☐ Paper ☐ Tablet ☐ PDA Other (describe)

Data Management

13. Where is data stored, locally or on the network? What kind of data is stored in each location?

Locally

Other (describe)

Note: Text boxes have no character limit

14. How is data managed once it has been displayed? Does the architecture include data caching? Printing? Import? Why were these decisions made (e.g., performance, local control, etc.)?

Note: Text boxes have no character limit

15. If local data is updated from shared data, how are source and access handled? Are any data integrity checks performed at the point of update? If so, what kind? Why were these decisions made?

Note: Text boxes have no character limit

DATA & INFORMATION

16. What type(s) of information are being exchanged? Please describe the forms the data takes

Data Type ***(****See outline, below, in Table 1)*	**Form** *(e.g., messages, images, documents)*	**Standards** *(e.g., HL7 vX, IHE profiles, X12, etc. – see drop down)*	**Degree of Semantic Interoperability** *(see options, below, in Table 1****)***
☐ Patient history (family, patient) Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Patient summary (conditions, meds, allergies) Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Discharge summaries Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Orders – lab Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Orders – imaging Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Orders – pharmacy Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Orders – other Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Results – lab Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Results – imaging reports Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Results – images Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)

☐ Referrals and authorizations Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Claims / reimbursement Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Managing payments Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Provider credentialing Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Public Health: surveillance / outbreak detection Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Public health: trending Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Public health: adverse event Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Public health: health protection actions Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Public health integrated with patient care (reports derived automatically or data available for query) Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Clinical trial: inclusion / exclusion Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Clinical trial: Post-release (guideline, drug) approval Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)
☐ Clinical trails integrated with patient care (reports derived automatically or data available for query) Describe (if necessary)	Messages	HL7 v2 Other (describe)	Level 0 Other (describe)

Table 1 - Degrees of Semantic Interoperability

Level	Description	Example
Level 0	Readable, but little or no potential for	document images (fax, bitmaps)

	reuse	
Level 0.5	Tractable to full text search.	word processing, PDF, ASCII
Level 1	Industry standard meta-data.	CDA header, non-XML body
Level 1.3	As above, conforming to Implementation Guide	As above, conforming to Implementation Guide
Level 1.5	Industry standard meta-data and XML body	CDA w/XML body
Level 1.8	As above, conforming to Implementation Guide	As above, conforming to Implementation Guide
Level 2	Industry standard meta-data and coding to section, title, sub-section level.	CDA with coded sections
Level 2.3	As above, conforming to Implementation Guide.	CCR
Level 3	Industry standard meta-data and coding of clinical statements.	CDA Level 3
Level 3.3	As above, conforming to Implementation Guide.	As above, conforming to Implementation Guide.
Level 3.5	Fully coded data.	HL7 V3 result message
Level 3.8	As above, conforming to Implementation Guide	As above, conforming to Implementation Guide

PARTICIPATION

17. Which stakeholders use the network? How many are there? How do they input data? How do they view data? For these latter two questions, we ask that you answer the question both for those with medical record technologies, and for those without (since the answers may differ)

Users	Describe	Current Quantity	Planned Growth	Permissions
Patients				None
Physicians		Small (<5) Med (5-20) Lge (>20)	Small (<5) Med (5-20) Lge (>20)	None
Hospitals				None
Standalone Labs				None
Standalone Imaging				None
Payers				None
Standalone Pharmacy				None
Pharma				None

Public Health				None

18. In the question above, we asked you to describe the network participants. Are there any sponsors – advocates for, funders of – the network that don't actually services on the network? If so, please describe them in the table (below).

Stakeholder	Describe	Current Quantity	Planned Growth
☐ Professional Societies			
☐ Vendors			
☐ Universities			
☐ Employers			
☐ Foundations			

19. Do patients choose to participate in the network? Is consent required? If so, what data is captured around their consent? Where is that data stored? Please provide your answers in the table (below)

Type of Consent	Explanation	Description / Data Storage
☐ No Consent Required	All patients are included in the network	
☐ Global	If a patient opts-in, all information is shared with all authorized caregivers	
☐ Selective: Diagnosis-specific	Patient can choose to include or exclude a particular diagnosis in the information shared	
☐ Selective: Time-based	Patient can choose to include or exclude information about a particular time period	
☐ Renew-ability	Patient consent 'expires' at some point, and must be renewed	

BUSINESS

ORGANIZATION

20. What organization is responsible for the network? Please describe how it was chartered and how it is structured.

Note: Text boxes have no character limit

IMPLEMENTATION

21. How long has the network been operational?

Note: Text boxes have no character limit

22. In the following table, we've described common design and implementation milestones. Please list the resources required to achieve each milestone.

Milestone	**Date Work Began** *(planned or actual)*	**Date Milestone Achieved** *(planned or actual)*	**Person Effort** *(in months)*	**Estimated Cost**
Concept				
Coalition Built *(if relevant)*				
Architectural Consensus				
Pilot				
First Implementation Live				
Full Implementation				

23. Did you utilize any consultants or vendors – organizations focused specifically on healthcare interoperability – in the implementation? Which vendors did you use? What role(s) did they play?

Note: Text boxes have no character limit

24. What were the bigger implementation barriers faced? Please give particular emphasis to challenges around data and interoperability. You do not need to complete the entire table – leave blank any areas where there were no SIGNIFICANT challenges.

Stakeholder	**Barrier**	**Resolution**
☐ Patients		
☐ Hospitals		
☐ Plans		
☐ Large MD Practices (>20)		
☐ Medium MD Practices (5-20)		
☐ Small MD Practices (<5)		
☐ Pharmacies		

☐ Ancillary		
☐ Professional Societies		
☐ Vendors		
☐ Universities		

FUNDING AND BUSINESS MODEL

25. How was the network funded initially?

Funding Type	**Description (if needed)**	**Approximate Contribution / % of Total**
	Total Cost	/ 100%
☐ Foundation / Grant		/
☐ Donation		/
☐ Participant Funded		/
☐ Government Funded		/

26. What were the bigger implementation-related expense items?

Expense	**Description (if needed)** Total Cost	**Approximate Cost / % of Total** / 100%
☐ Management		/
☐ Consulting Services		/
☐ Network Hardware		/
☐ Network Service(s) Development / Licenses		/
☐ Local (Organizational) Development / Licenses		/
☐ Integration of Local Services with Network		/
☐ Training		/

27. What are the bigger on-going operational costs?

Expense	**Description (if needed)** Total Cost	**Approximate Cost / % of Total** / 100%

☐ Management		/
☐ Network Maintenance		/
☐ New Development		/
☐ Training		/

28. How are expenses shared with network participants?

Stakeholder	**Fee Structure**					
	Per trans-action	**Per seat**	**Per organ-ization (flat)**	**Per organ-ization (scaled)**	**None**	**Other**
Patients	☐	☐	☐	☐	☐	Other (describe)
Hospitals	☐	☐	☐	☐	☐	Other (describe)
Plans	☐	☐	☐	☐	☐	Other (describe)
Large MD Practices (>20)	☐	☐	☐	☐	☐	Other (describe)
Medium MD Practices (5-20)	☐	☐	☐	☐	☐	Other (describe)
Small MD Practices (<5)	☐	☐	☐	☐	☐	Other (describe)
Pharmacies	☐	☐	☐	☐	☐	Other (describe)
Ancillary	☐	☐	☐	☐	☐	Other (describe)
Professional Societies	☐	☐	☐	☐	☐	Other (describe)
Vendors	☐	☐	☐	☐	☐	Other (describe)
Universities	☐	☐	☐	☐	☐	Other (describe)

29. Are there any (other) sources of revenue? What are they? How are they generated?

Note: Text boxes have no character limit

CONCLUSION

30. Do you have any other comments for us? Things that you think we should have asked about, but didn't? Questions about this project and what happens next? If so, please let us know!

Note: Text boxes have no character limit

Appendix C: Guide to PICNIC Open Source Applications & Implementations

Acronym	**Component Name**	**Function**	**Standards Used**
PIDS	Person Identification Service	Assignment of IDs in a domain Correlation of IDs across domains	CORBA 2.0 HL7 v2.3 vCard v2.1(electronic business card)
COAS	Clinical Observations Access Service	Interfaces and data structures which a server can supply clinical observations	HL7 V2.3 lab messages DICOM MIME (RFC2048) LOINC ICD-9 NCPDP Timestamp (ISO8601) SCP-ECG CEN/TC 251/N98-116 PIDS LQS
SRIS	Shared Resource Indexing Server	IT Service which retrieves information pointers (no data) from patient records	-
SRUB	Shared Records Update Broker	IT Service which inserts, updates and deletes information pointers	-
LQS or TQS	Lexicon Query Service or Terminology Query Service	Lexical Query	ICD-9 ICPC
COLS	Collaboration Server	platform to share patient information in a teleconsultation session	PIDS HL7 v2.3 ENV 13606 SCP-ECG vCard v2.1(electronic business card) DICOM H.320, H.323, H.324 videoconferencing
RESS	Resource Server	actor information and accessing methods	-

PICNIC Projects

Project	Country	Project Objective	Standards / Components
SEBT	UK	View patient data off hours	ICD-10 PIDS SRIS SRUB RESS COLS
GMS	Ireland	Pharmacy eligibility and reimbursement	EDIFACT/MEDRUC PIDS
NWHB	Ireland	Nurse EHR	PIDS
FORTH1	Greece	Patient data viewer Integrated access to patient data at the hospital level.	SCP-ECG DICOM ICD-9 ICPC PIDS SRIS SRUB LQS COAS
FORTH2	Greece	Collaboration	DICOM SCP-ECG RESS COLS
FUNEN	Denmark	Telehealth by electronic messaging	DICOM RESS LQS COLS
SAS	Spain	Integrated electronic health record services	ICD-9 ICPC SRIS
OpenEMED (formerly Telemed)	US	Network environment to facilitate distributed applications	PIDS LQS COAS

Appendix D: Commonly Used Acronyms and References

Term	Translation	Meaning
ANSI	American National Standards Institute	A private, non-profit organization that administers and coordinates the US voluntary standardization and conformity assessment system http://www.ansi.org
CCOW	Clinical Context Object Workgroup	Using a technique called "context management", CCOW provides the clinician with a unified view on the information held in separate and disparate healthcare applications referring to the same patient, encounter or user. Can be used for single sign-on. http://www.hl7.org/special/Committees/ccow_sigvi.htm
CDA	Clinical Document Architecture	“The HL7 Clinical Document Architecture (CDA) is a document markup standard that specifies the structure and semantics of "clinical documents" for the purpose of exchange.” A clinical document has the following characteristics: Persistence, stewardship, potential for authentication, context, wholeness and human readability. (ANSI/HL7, CDA R2, 2005)
CEN TC 251	European Committee for Standardization, Technical Committee 251	CEN TC 251 is the body within Europe mandated to develop standards for Health Informatics.
CEN TC 251 HISA	European Committee for Standardization, Technical Committee 251, Healthcare Information System Architecture	Architectural specifications defining the scope of middleware services. A common middleware allows for the storing and retrieval of common data through services independent from specific technical environments. HISA must be complemented with specifications details of interfaces for each service to guarantee physical connection to software applications.
COAS	Clinical Observations Access Service	A set of OMG interfaces and data structures with which a server can supply clinical observations http://www.omg.org/technology/documents/domain_spec_catalog.htm
CORBA	Common Object Request Broker Architecture	A standard for software componentry. The CORBA standard is created and controlled by the Object Management Group (OMG). It defines APIs, communication protocol, and object/service information models to enable heterogeneous applications written in various languages running on various platforms to interoperate http://www.corba.org/
EbXML	Electronic Business using eXtensible Markup Language	A family of XML based standards sponsored by OASIS and UN/CEFACT whose mission is to provide an open, XML-based infrastructure that enables the global use of electronic business information in an interoperable, secure and consistent manner by all trading partners. http://www.oasis-open.org/home/index.php
EDI	Electronic Data Interchange	A general term for string-based messaging.
EDIFACT	Electronic Data Interchange for Administration, Commerce and	An international standard provided by ISO 9735 (created in 1986) that: provides a set of syntax rules to structure data; provides an interactive exchange protocol (I-EDI); and provides standard messages (allows multi-country and multi-industry exchange)

	Transport	http://www.iso.org
EHR	Electronic Health Record	A general term for longitudinal clinical records for a shared patient population.
EMR	Electronic Medical	A general term for practice-based longitudinal clinical records for a patient population.
GP	General Practitioner	A general term for an MD, usually a primary care physician
IETF	Internet Engineering Task Force	A completely open community of engineers, vendors, and researchers concerned with the development and evolution of the Internet architecture http://www.ietf.org/overview.html
IHE	Integrating the Healthcare Enterprise	A joint project sponsored originally by HIMSS and RSNA to create implementation profiles for interoperability between healthcare applications. http://www.himss.org/ihe
ISEG	Internet Engineering Steering Group	The IETF Area Directors, who each lead a collection of topic-specific working groups (e.g., Security)
ISO	International Organization for Standardization	ISO is a network of the national standards institutes of 151 countries, on the basis of one member per country, with a Central Secretariat in Geneva, Switzerland, that coordinates the system. http://www.iso.org/iso/en/ISOOnline.frontpage
Kerberos		A protocol that uses ‘symmetric cryptography’ to authenticate network users http://www.tech-faq.com/kerberos.shtml
LDAP	Light-weight Directory Access Protocol	A security protocol defined by IETF RFCs 2251-2256 and 2829-2831 http://www.ietf.org/html.charters/ldapbis-charter.html
OASIS	Organization for the Advancement of Structured Information Standards	Not-for-profit global consortium that drives the development, convergence and adoption of e-business standards. http://www.oasis-open.org/home/index.php
ODBC	Open DataBase Connectivity	A general term for a standard database access method developed by the SQL Access group in 1992. The goal of ODBC is to make it possible to access any data from any application, regardless of which database management system (DBMS) is handling the data. ODBC manages this by inserting a middle layer, called a database driver, between an application and the DBMS.
OID	Object Identifier	Defined by ISO.
OMG	Object Management Group	A standards body. Open membership, not-for-profit consortium that produces and maintains computer industry specifications for interoperable enterprise applications. http://www.omg.org
openEHR	Open Electronic Health Record	An international foundation whose goal is to promote interoperable, life-long electronic health records, proven in practice,’ and addressing the technical and social issues associated with these records http://www.openehr.org/
Open	Open Source Health Records	An open source community committed to advancing the National Health Information Network (NHIN) by developing, distributing and supporting Master Patient Index

HRE	Exchange	and Health Record Exchange systems and components http://www.openhre.org/
PICNIC	Professionals and Citizens Network for Integrated Care	Project of the European Union to standardize approach to health information exchange. A public-private partnership with industry and telecom providers. to prepare the regional health care providers to implement the next generation, secure, user-friendly health care networks. http://www.medcom.dk/picnic/projects/default.htm
PIDS	Person Identification Service	An OMG software specification used to identify a person. Open source implementations in use by regional exchanges. http://www.omg.org/technology/documents/formal/person_identification_service.htm
PKI	Public Key Infrastructure	A general term referring to a system of digital certificates, Certificate Authorities, and other registration authorities that verify and authenticate the validity of each party involved in an Internet transaction; also referred to as a 'trust hierarchy'
RLS	Record Locater Service	A general term referring to an index to patient records for a shared patient population. The index may contain metadata on the records and must contain locating information.
SDO	Standards Development Organization	
SOAP	Simple Object Access Protocol	A communication protocol for communicating over the Internet between applications
UN/ CEFACT	United Nations Centre for Trade Facilitation and Electronic Business	A United Nations body dedicated to economic development in the European community. Their mission: 'Simple, transparent, and effective processes for global business.' http://www.unece.org/cefact/
URI	Uniform Resource Identifier	On the Web, a W3C identification system used to allow one party to share information with another party globally http://www.w3.org/Addressing/
W3C	World Wide Web Consortium	SDO that develops interoperable technologies (specifications, guidelines, software, and tools) for the Web. http://www.w3c.org
XACML	Extensible Access Control Mark-Up Language	An OASIS standard designed to track role-based access hierarchies http://www.oasis-open.org/specs/index.php#xacmlv1.0
XDS	Cross Enterprise Document Exchange	An IHE profile for locating and transferring documents within a regional exchange network. http://www.himss.org/ASP/topics_ihe.asp
XSL	Extensible Stylesheet Language Family	A set of W3C recommendations for defining XML document transformation and presentation. http://www.w3.org/Style/XSL/

Appendix E: Inventory of Recommendations

For HL7-NLM EHR Project Phase II:

Shared Services

Patient Cross-Referencing

1. Develop or adapt an open-source, web service-based MPI. Consider converting the Person Identification Service (PIDS), as used in Crete, to a web service.

   Rationale: Every interoperability effort surveyed required an MPI. While there are numerous commercial solutions available, evaluating and selecting ***one*** *creates an early (and unnecessary) implementation hurdle. The availability of an open source alternative would a) promote re-use of this key architectural component, and b) allow communities to focus their initial implementation effort(s) on components that universally require significant development or customization.*

2. Write an implementation guide for HL7 Version 2 (V2) or HL7 Version 3 (V3) messaging with the open source MPI referenced in Recommendation #1.

   Rationale: While an open-source MPI is valuable without an implementation guide, the addition of one further reduces early implementation hurdles. See 'Standards and Source Code' for a discussion of HL7 V2 v. V3.

Search and Distribution

3. Study Clinical Observations Access Service (COAS), Integrated EHR Indexing Service (I-EHR IS), and Integrated EHR Update Broker (I-EHR UB)[29] as implemented in Crete, and compare with the freely-available tools under consideration by U.S. network efforts, specifically: Integrating the Healthcare Enterprise (IHE) Cross-Enterprise Document Sharing[30] (XDS, based on ebXML open source tools) and the Markle Foundation Record Locator Service (RLS)[31]. Summarize the analysis and prepare implementation guide(s) for one or more of these tools.

   Rationale: All of these tools facilitate distribution and search. RHIOs would benefit from an analysis of these tools (similarities, differences), as well as guidance on how to implement one or more of them in conjunction with the open source MPI described above.

4. Implement the HL7 NLM Phase I point-to-point search tool as a web service[32].

   Rationale: Most of the sites surveyed utilized at least some point-to-point search tools, in instances where relationships already existed between network participants. The reason: this represents a low-cost, low-overhead starting point and supplement to distributed record locator services. The phase I prototype becomes more usable (as a model or a tool) if it is a web-service.

5. Develop or adopt registries that track 'identity' and 'roles' for applications, providers and organizations, similar to what was implemented in Crete, or the 'dictionaries' used in Spokane.

   Rationale: Identification, whether of a patient or a location or a physician, is necessary both to find data ('show me all of the data on patient John Smith,' 'how many ERs connected to the network have local EMR systems registered?'). Much attention is focused on identifying the patient; less on identifying the other stakeholders in the equation.

Data Display

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[29] D.G. Katehakis, S.G. Sfakianakis, D. Anthoulakis, G. Kavlentakis, T. Z. Tzelepis, S. C. Orphanoudakis and M. Tsiknakis, "A Holistic Approach for the Delivery of the Integrated Electronic Health Record within a Regional Health Information Network", Foundation for Research and Technology - Hellas, Institute of Computer Science, Technical Report 350 (FORTH-ICS/ TR-350), Heraklion, Crete, Greece, February 2005.

[30] IHE IT Infrastructure Technical Framework, Supplement 2004-2005, Cross-Enterprise Document Sharing (XDS) http://healthcare.xml.org/resources/IHE_ITI_Cross-enterprise_Doc_Sharing_2004_08-15.pdf IHE (15 August 2004)

[31] Markle Foundation, The Collaborative Response http://www.connectingforhealth.org/resources/collaborative_response/hie_model/chapter.php The Markle Foundation et al (18 Jan 2005)

[32] HL7/NLM Phase I search tools deliverables: http://www.hl7.org/nlmcontract/ehrPhaseI.cfm

6. Develop or adapt a lightweight, open source 'viewer' (e.g., browsers and data managers) that can be used to display clinical data, possibly including an export from a local EMR application, as in Crete.

   Rationale: Survey data suggest that interoperability will spur the adoption of EMRs, while simultaneously suggesting that EMR adoption is not a pre-requisite for health data exchange. Most of the sites surveyed provided an 'EMR-Lite' for participants that did not have an EMR implemented. The simplest version of this could be a web page that can display both documents and messages; more sophisticated versions could group like-elements (e.g., all lab reports), and parse structured data elements, as well as 'receive' data from EMR applications. Crete's version is somewhere in between these two extremes, and might provide a good model for the Phase II Project.

7. Pilot the integration of imported data into a local EMR.

   Rationale: Once EMRs have been implemented, the more mature survey sites found that clinicians had little tolerance for the use of multiple applications to view clinical data. Thus, a pilot that supports the integration of data in-situ could be valuable. Of necessity, this requires cooperation and participation from the EMR vendor community.

8. Introduce context management (HL7s Clinical Context Object Workgroup or CCOW) for single sign-on and ease of use.

   Rationale: Adding separate network applications or services decreases ease-of-use for the end user, unless coordinated through a context manager. Today, each site must address this individually. This project can encourage a standards-based approach by developing CCOW-compliant solutions.

Security

9. Pilot authentication, integrity and/or attribution services as implemented in other industries (e.g., financial services). One possibility: Liberty Alliance[33], an alliance of more than 150 companies committed to developing an open standard for federated network identity, participated in the 'Common Framework' ONCHIT RFI response spear-headed by the Markle Foundation[34]

   Rationale: The requirements for these services are consistent across architectural models, and there's no need for healthcare to build something from scratch.

10. Develop or adapt a service for assigning roles and access privileges, possibly using Health Resource Service (HRS)[35] in Crete as a model.

    Rationale: This has not been widely implemented in a standards-based, open implementation. Developing such a service would encourage the use of HL7 messages to support it.

11. Develop data standards for audit logs, to enable velocity checks (alerts generated by a rules engine that is configured to recognize potential fraud and abuse scenarios) and cross-log queries in healthcare.

    Rationale: Other sectors have invested significantly in audit logs and statistical analysis of audit log data. In finance, velocity checks flag possible fraud or abuse (e.g., banks/ATMs limit how much can be withdrawn in a day). In healthcare, velocity checks might include requesting all information on a patient, requesting only sensitive information, multiple requests made from disparate geographic locations, multiple requests for the same patient within the same day, etc. Work with Visa or MasterCard to develop velocity checks, or with one of the system-security vendors (e.g., VeriSign) or professional associations (e.g., Information Systems Audit and Control Association (ISACA)) to develop robust audit capabilities.

Vocabulary

12. Develop or adapt terminology services applications for network deployment in conjunction with the NLM HL7 vocabulary project.

    Rationale: One of the surprises of the survey data was that sites adopted vocabulary relatively early in the implementation timeline; any progress that accelerates this will add value.

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[33] The Liberty Alliance Project: http://www.projectliberty.org/about/index.php

[34] Markle Foundation, The Collaborative Response

[35] Katehakis: http://www.ics.forth.gr/eHealth/technology_HII_1.html

13. Develop OID (globally-unique object identifiers as specified by ISO) source and registry as shared service (similar to the OID registry on HL7.org).

    Rationale: HL7 already offers this service through its web site. Extending it as a RHIO network service would support implementers who need to manage OIDs if they are working with CDA or any of the HL7 V3 specifications.

Content

Clinical Domains

14. Create standards-based implementation guides for different types of clinical information. High-return areas may include pathology and medical imaging reports, if they are not already covered by other standards or professional organizations.

    Rationale: The most commonly implemented data sets included patient care summaries, lab, radiology and pharmacy. The Care Record Summary already addresses basic patient summary document. Professional bodies in lab, radiology and pharmacy are working to standardize content within their domains, and there may be an opportunity to coordinate their efforts with HL7 messages (V2, V3)

15. Pioneer direct device monitoring for U.S. networks, possibly starting with emergency room/ambulance connectivity as in Crete.

    Rationale: Devices are just another source of information on a health data exchange network. While a number of devices produce a steady stream of data (which requires relatively sophisticated filtering to separate signal from noise, particularly for presentation to a clinician), a number of them (e.g., EKG machines) produce a point-in-time reading that can be readily incorporated into an EMR. At this level, the device is producing data that needs to be 'messaged' to the receiving application in the same way that a laboratory system produces a lab report that is incorporated into a patient record. This direction leverages existing investments in telemedicine.

Standards and Source Code

16. Ensure that all source code developed in the NLM HL7 EHR Phase II Project is 'open source,' meaning that both the source and compiled code can be freely and widely distributed, and that the code resides in an open source repository (e.g., SourceForge.net) for ongoing management and derivation by the open source development community.

    Rationale: Millions of dollars have been spent on the development of network services and applications for the exchange of health information. While there is clearly a market for proprietary, commercial services and applications, part of the value NLM and HL7 can bring is promoting re-use in the instances where a service doesn't have to be 'invented' for each RHIO. In addition, this conforms to HL7's stated policy on code development.

17. Support the use and implementation of HL7 V2 where these standards are well established (e.g., patient accounting systems, laboratory systems). Support the use and implementation of HL7 V3 messaging standards in areas where HL7 V2 is less entrenched (e.g., clinical documents, medical imaging studies, medications).

    Rationale: Based on survey data, the rival for the use of HL7 standards is NOT other standards, but is instead the use of proprietary solutions when a standard isn't a 'perfect' fit. Thus, the emphasis of the Phase II Project should be on promulgating standards widely, and little effort should be spent on (for example) developing a tool that is BOTH HL7 V2 and V3 compatible.

18. Develop clinical document architecture (CDA) implementation guides.

    Rationale: CDA documents are independent of the distribution, storage and management technology applied to them, so efforts invested in CDA data definition apply across all the architectures surveyed. Most sites exchange some form of documents, but in a proprietary format, which severely limits interoperability and reuse.

19. Create profiles for web services, including a strong recommendation on which approach(es) can be used, for example, to create packages of documents with images (i.e., binary content), etc. and wrap them in a signed envelop (which may or may not be encrypted).

    Rationale: There is a plethora of web service standards emerging. A profile is a narrowing-down of a messaging communication standard (healthcare or web messages), and can be used, for instance, to demonstrate how to use HL7 V2 (or V3) in conjunction with web services.

Patient Participation

20. Select a Phase II pilot site focused on consumer-engagement as a key implementation objective. The minimum selection criteria would be that the project intends to allow patients to query and input their clinical data. Possible sites include Whatcom County, Washington and Spokane.

    Rationale: Even if the services (patient matching, distribution and search, security, vocabulary) selected for the Phase II Pilot are not patient-specific, testing them in an environment where the patient is an active participant is likely to illuminate issues and opportunities that might otherwise be missed.

21. Develop or adapt an open source, web-based patient health record that reads and displays standardized messages and documents.

    Rationale: Our hypothesis is that consumers will seek to aggregate and integrate their healthcare information in much the same way they have their financial and personal information (e.g., contacts, calendars). Consumers will not long be satisfied with multiple providers having multiple (and different) views of their data. NLM and HL7 could add significant value by developing a patient-centric 'viewer' that integrates documents and messages from different physicians and providers.

22. Develop or adapt an open source patient consent framework, which allows patients to specify consent with more granularity than on/off (e.g., by diagnosis, date, provider, etc.) Possible examples of consent models include shared-calendar functions (e.g., .Mac) and social networking applications like Tribe and Linked-In.

    Rationale: This is a specific break-through opportunity for NLM and HL7. Prior efforts by PICNIC and CORBA created many network tools being used today. The Markle Foundation and IHE have developed search and distribution tools. Security tools have been developed in other industries by groups like the Liberty Alliance, and are likely re-usable in healthcare. Patient consent is one of the areas unique to healthcare and, to the best of our knowledge, few are thinking through the issues with much specificity. In conjunction with an access framework like COAS, patient consent applications would create a significant opportunity to contribute ground-breaking work.

23. Develop a patient-level security standard that moves beyond a simple login and password. Examples could include the card verification value (CVV) consumers use to verify that they are legitimately using a credit card when they purchase online, the use of tokens or other physical media, or biometric authentication.

    Rationale: According to a recent Gartner study[36], 60 percent of consumers are concerned or very concerned about online security. A similar study by security vendor RSA Security[37] found that consumers were curtailing their online purchasing because of security concerns. Both studies report that consumers do not believe that login-password is sufficient to protect their data. This same belief seems likely to challenge or compromise the growth of health information exchange networks, particularly where consumers are active participants on the network.

Business Issues

Unrealized Business Value

24. Clinical documents (e.g., laboratory reports, medical imaging reports) commonly exchanged in RHIOs can also be reused in administrative processes. Select a pilot site such as Empire Medicare Services[38], which has a claims attachment pilot underway, and demonstrate that in addition to the documents, the services (patient cross-referencing, distribution and search, security, vocabulary) necessary to facilitate the movement of clinical data can be reused for other purposes.

    Rationale: One of the most compelling barriers to health data exchange is the business model. There are significant benefits to plans and providers of automating the claims process[39]. Under the Health Insurance Portability and Accountability Act (HIPAA) Notice of Proposed Rule-Making (NPRM) on Claims Attachment Transactions,[40] the claims attachment process is likely to become automated over time. Claims processing and clinical services converge at the claims attachment, a clinical document used first to document care provided, second to explain

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[36] Roberts

[37] RSA Security

[38] Empire Medicare Services Claims Attachment Pilot Project Overview <http://www.wedi.org/cmsUploads/pdfUpload/WEDIBulletin/pub/ClaimsAttachmentsPilotOverviewFINAL_111004.pdf> WEDI Claim Attachment Pilot Advisory Committee (10 November 2004).

[39] Halamka

[40] HHS: Administrative Simplification

(justify) a request for payment. By tangibly demonstrating that these documents can be created once and used in multiple ways, NLM and HL7 would demonstrate significant progress on the business case for health data exchange.

For Other Non-Profit or Public Projects:

Shared Services

Security

- Catalyze or endorse security policy designed to protect patients and providers from the misappropriation of clinical data.
- Educate consumers and providers on the new risks associated with electronic health data, and ways to safeguard it.

Content

Clinical Domains

- Develop tools and/or metrics for assessing and asserting the value proposition of different types of information exchange for RHIOs making determinations about domains.

Standards and Source Code

- Establish the value proposition for standards-based interoperability versus interoperability based on proprietary solutions and create a “call to action” for broad use and experimentation with multiple standards in the RHIO efforts.

Business Issues

Unrealized Business Value

- Examine existing projects in rural health, telemedicine, and clinical trials for leverage in fast tracking further RHIO development.

Value Proposition

- Articulate the value propositions that will drive regional participation, recognizing that organic growth will evolve the network and that governance will evolve naturally, either bottom up or top down, as defined by the early participants.
- Further characterize the hypothesis that implementation costs can be kept low by building on existing networks, solutions, and natural constituencies like tele-health projects and other efforts to reach into rural areas.

Cost Benefit Analysis

- Develop a common framework for estimating costs and benefits where value is clearly defined.
- Study the impact and viability of various types of open source solutions and tools.
- Study the impact of standardization on the different constituent pieces of the network to best understand and predict the rationale for standardization.

General Observations

- Develop self-paced, interactive training tools to support the specifications, implementation guides and tools developed under the HL7 NLM Project.
- Develop a clearinghouse for technology assets and project reports (similar to the Health Information Technology Resource Center envisioned by AHRQ, but not limited to funded or US-based projects), so that RHIOs can find the information they need to make informed technology decisions.
- Develop and maintain a Help Desk for the RHIOs, staffed by experts knowledgeable in healthcare data and messaging standards, and who understand the implications of their use in community data exchange.
- Look for and illuminate failure and lessons-learned to improve efficiency of the rollout of networks.