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Abstract:

Recently there has been increased focus on the need to modernize the healthcare information infrastructure in the United States[1,2]. The US healthcare industry is by far the largest in the world in both absolute dollars and in percentage of GDP (>$1.5T – 15% of GDP). It is also quite fragmented and complex. This complexity, coupled with an antiquated infrastructure for the collection of and access to medical data, leads to enormous inefficiencies and sources of error. Driven by consumer, regulatory, and governmental pressure, there is a growing consensus that the time has come to modernize the US Healthcare Information Infrastructure (HII). A modern HII will provide care givers with better and timelier access to data. The launch of a National Health Infrastructure Initiative (NHII) in the US in May 2004 – with the goal of providing an electronic health record for every American within the next decade- will eventually transform the healthcare industry in general … just as I/T has transformed other industries in the past. While such transformation may be disruptive in the short term, it will in the future significantly improve the quality, efficiency, and successful delivery of healthcare while decreasing costs to patients and payers and improving the overall experiences of consumers and providers. The key to this successful outcome will be based on the way we apply I/T to healthcare data and to the services delivered through that I/T. This must be accomplished in a way that protects individuals, allows competition, but gives caregivers reliable and efficient access to the data required to treat patients and to improve the practice of medical science.

Introduction:

Improving the state of healthcare I/T has become a bipartisan top-priority issue for the United States. In his State of the Union Address on January 20, 2004, President George W. Bush stated[1]:

> "By computerizing health records, we can avoid dangerous medical mistakes, reduce costs, and improve care."

Also in 2004, Congressman Patrick J. Kennedy (D-RI) officially introduced the "Josie King Act" (also called the "QUEST Act")[3]. This act is named in honor of an 18-month old child who died as a result of preventable medical error. The bill proposes to create an I/T backbone for the American healthcare industry by 2015.

The largest technical challenge we face in realizing a national information infrastructure is to define an implementation model that is simultaneously consumer-centric, cross-institutional and supports the longitudinal healthcare and health record standards emerging around the globe[4-9]. Furthermore the model needs to support the private healthcare provider model of the United States[4]. The system should be scaleable and capable of supporting (in the near term) the Regional Healthcare Information Organizations (RHIOs) and networks that are now emerging at the county and state levels[10,11,12]. As the system grows, RHIOs will become interconnected through a larger NHII network. In a national system, the RHIOs must have access to pointers to Patient data regardless of where the records are located. Through a data federation mechanism, the RHIO will be able to bring together, on the fly, all required patient's

records and present them to a clinician at the point of care.

This new infrastructure would enable providers to cut long-term archiving costs and to provide better care as patient medical histories would always be available. Insurers would benefit, too, as quality of care for their customers improves. Pharmaceutical companies could recruit clinical trial participants more reliably and be able to better demonstrate the efficacy and side effects of medications. Patient safety would be significantly improved and unnecessary testing would be avoided. Privacy would be better protected, as only anonymous global patient identifiers would be needed. Most importantly, a true Electronic Health Record (EHR) with summary and topical parts could be available at the point of care, based on processes that would constantly reconcile and summarize the incoming temporal data received from all providers who have seen a given patient. The combination of the longitudinal EHR along with the ability to leverage this deidentified data for clinical research will allow personalized care for the patient based on best care practices and the patient's individual medical circumstances.

Towards a National Health Information Infrastructure

There are many complex regulatory and policy decisions required to establish an NHII system[5-9]. We must meet critical technical requirements while satisfying a Social Contract for medical care appropriate to the United States. Fortunately the technical challenges are greatly reduced by recent advances in Web Service technologies[13]. The most important of these recent advances is the development of the Enterprise Service Bus (ESB). The Enterprise Service Bus is a scaleable integration architecture that permits incremental integration or addition of new data sources and data services driven by business requirements. Each new integrated component can be wrapped as a web service so the system is not limited by legacy standards or constraints. In IBM Research, we are working with IBM's Healthcare/Life Sciences Division and IBM Software Group to prototype a multipurpose HII test bed based on an ESB architecture.

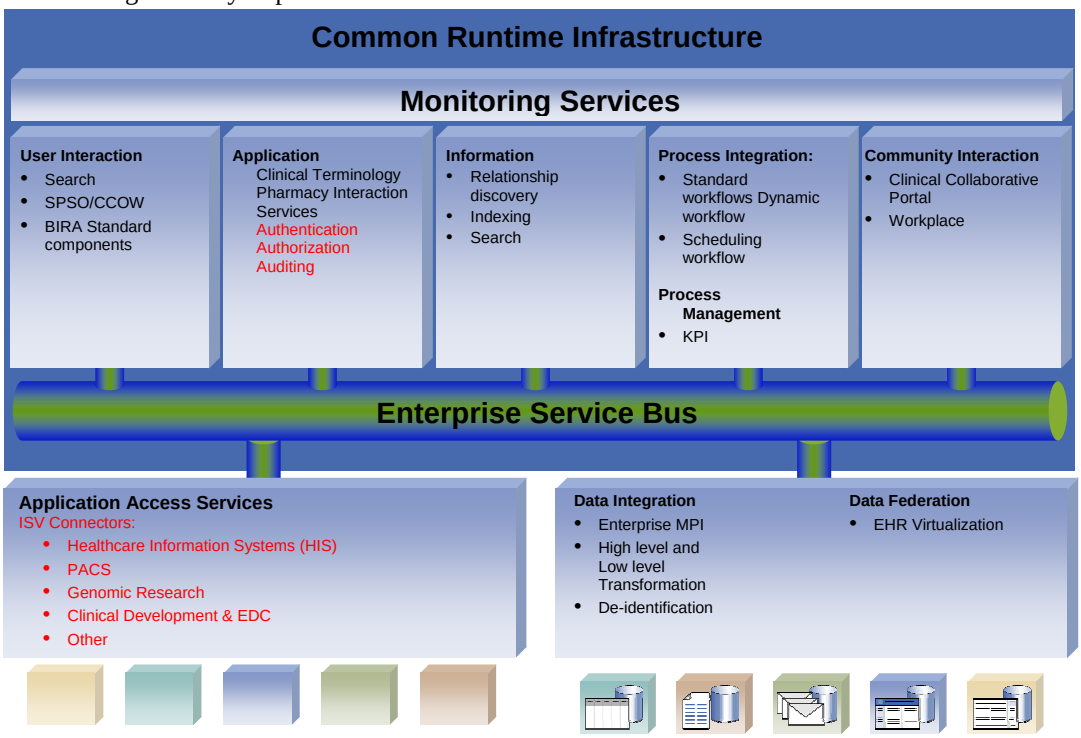

Figure 1: A Services Oriented Architecture for a Model Healthcare Organization

The goal of this test bed is to

- Demonstrate a web service architecture that provides for scaleable integration of

healthcare information across the distributed healthcare enterprise.

- Illustrate a replicable methodology for healthcare data and application integration from the RHIO to the NHII scale

The architecture of the HII test bed will utilize the new Service-Oriented Architecture (SOA) integration model. SOA enables flexible connectivity of applications and resources by representing them as services (JServices), each with a standardized interface. These services exchange standardized data structures (Service Data Objects – SDOs). Utilizing this model, participants in a regional network can make use of JServices that are accessible via a common Enterprise Service Bus. Messaging and pub/sub communication models are also supported. This allows rapid integration of new and existing services and the staged, incremental development of a system on a full national scale.

An important goal of our Research effort is to demonstrate a cross-institutional EHR capability as depicted in Figure 2. In a regional system, organizations including local hospitals and ambulatory networks will continue to rely on local and unique infrastructures of EMR, CIS, PACS, and other clinical data management systems. Such enterprises include providers, medical test laboratories, regulatory agencies (e.g., the CDC), payers, and individuals (personalized healthcare portals). Each of these may have their own enterprise service bus with appropriate services attached, while an additional cross-enterprise service bus will provide access to the cross-enterprise services. Data that moves across enterprises (red dashed line in Figure 2) will need to be de-identified according to HIPAA privacy regulations unless patient consent is secured. To understand the requirements for a NHII system, let us first consider the integration across two regional systems or RHIOs. Each institutional system emulates a community, and as such represents much more than a single hospital or healthcare enterprise. It is the enterprise service bus that takes a heterogeneous institution and transforms it into a single integrated (virtual)

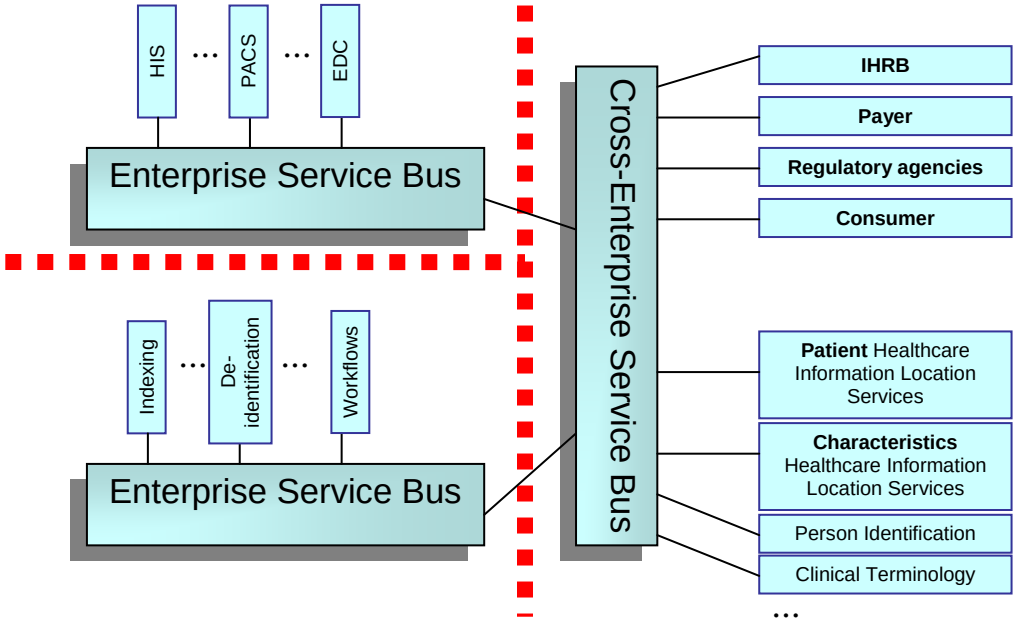

Figure 2: Cross-Institutional EHR Platform

healthcare organization. A fully interconnected national system is represented by a network or hierarchy of RHIOs and satellite institutions (Figure 2).

A key component required to hide the complexity of the diverse and heterogeneous data definitions in use today is an institutional extraction/translation service within each RHIO. The job of this "extractor" is to translate data from individual (ISV) data sources converting proprietary formats into a common standard schema (e.g., HL7 Clinical Document Architecture Release 2). By converting to a standard schema, RHIOs can exchange data nationwide. Data received in the standard schema can in turn be converted to the specific data definition used by particular data stores in the

receiving RHIO. Other services and data adapters will support the most important existing standards including HL7, DICOM, HIPAA, LOINC, SNOMED, CDISC thereby addressing the whole spectrum of biomedical care including healthcare, public health, clinical trials, and the life sciences[14-18].

Extraction, transformation and aggregation services designed to operate on the electronic health records in the Healthcare Information Systems will allow the NHII to offer such innovative functions as:

- Virtualization/federation: the ability to assemble a composite health record from the partial records contained in disparate RHIO's.
- Distribution: the ability to move a record among systems (using standard data exchange format).
- Windowing: the ability to reveal/transmit only relevant portions of a health record for a given purpose and to a given user controlled by record owner policies.
- Delegation: the ability for a record owner to delegate windowing authority to a trusted expert such as a primary care physician.

Data Enabled Services	Other I/T	New Provider Information Services	Web Portal Services (e.g., Enterprise to Web)
Semantic Data Integration Semantic Application Integration ISV Connectors and Adapters Data Integration Services Data Transformation and Extraction Data Mining Service	Application Access Services Clinical Terminology Pharmacy Interaction Services Enterprise Master Person Indentification Enterprise Patient Healthcare Information Location EHR Virtualization	Relationship Discovery: Indexing and Search: Content Management Business Process Integration Standard workflows: Workflows & Scheduling Business Process Management Key Performance Indicators (KPI's) monitoring	Collaboration/Community Decision Support Services Clinical Genomics Outcomes Analysis Community-based Health Portals, User Interaction, Personalized Medicine Enhanced Clinical Trial Recruitment

Table I: Services enabled by a modern NHII

Examples of some possible cross-enterprise services are:

- Patient Healthcare Information Location Service – a service to locate for an identified consumer, the actual location of his data. It includes an index of consumers and references to their data.
- Characteristics Healthcare Information Location Service – a service to locate data by characteristics such as the ability to locate data associated with a specific observation. It includes an index of de-identified consumers data and references to the original data.
- Person Identification Service – a service that correlates the various ids of the same consumer as well as assigns an anonymous global patient id (AGPI) when needed.
- Clinical Terminology Service – a service that enhances the data by adding codes from controlled vocabularies such as LOINC, SNOMED, ICD-9.

The composite of the core components and services will form the infrastructure for a Universal Health Information Integrator.

In the future, individuals will require the ability to control and manage their own healthcare. The ESB architecture supports the creation of various web portal-based applications to support personalized medicine as well as more efficient physician access to patient data. This paradigm change will also enable new service and utility models for the healthcare industry. Once individuals can access and control their own medical data, they can make better informed decisions. The availability of more complete medical data will also lead to the creation of new medical and health services, giving individuals

greater choice and control in planning their own care. Electronic data sources will provide the information necessary to understand the real outcomes of accepted medical treatments, advance medical research, and advance the science of medical care.

With the HII test bed, we can explore many of the advanced services that will be enabled by a nationwide health information infrastructure. Each of these I/T services can be built around reusable technology components per the framework depicted in Figure 1. Some of the many future services are also listed in Table I.

No one single I/T vendor will be able to provide the entire technical infrastructure required for a NHII. IBM is a founding member of an "Interoperability Consortium" (currently consisting of Accenture, Cisco, CSC, Hewlett-Packard, IBM, Intel, Microsoft and Oracle) which formed to produce a joint response to a Request For Information (RFI) that was released during the latter part of 2004 by the US Office of the National Coordinator for Health Information Technology (ONCHIT). The RFI called for business and technical input regarding the establishment of a potential National Health Information Network (NHIN) in the USA. The Consortium's joint response was submitted on January 18 2005 [19]. The IBM Research HII test bed will provide a mechanism for testing out technologies and concepts such as those that are described within the Consortium's response.

Conclusion:

The time is right to begin the work to transform our national healthcare infrastructure through the proper application of IT. However, unlike IT for finance, which evolved over several decades, the escalating cost, demand for, and error rate of our current health care infrastructure dictates that a significant change in healthcare IT must take place this decade as the baby boomers retire. We must achieve this rapid change in a cost effective way that does not violate the social contract between individuals and care givers, and we must get it right the first time. To guarantee success, and to act quickly, we can take advantage of the latest web services technologies and enterprise service bus architecture to create a scaleable system wherein both existing and new data sources and I/T services can be added incrementally as required by an emerging new infrastructure. With proper application of I/T, we have the opportunity to turn a revolution in healthcare into a renaissance of healthcare that provides better, safer, and more efficient care for all.

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