The National Coalition for Health Integration
NCHI

The National Coalition for Health Integration (NCHI) is a public private coalition dedicated to working with our partners to transform healthcare by enhancing the availability, privacy and integration of health information across the country.

NCHI Vision: To create a robust, accessible, integrated health information platform that supports the comprehensive management and exchange of biomedical data on a national scale.

NCHI Objective: To provide an organizational structure through which the secure, national sharing of biomedical information will be feasible. NCHI seeks to develop collaborations through which the technological, financial and institutional resources needed to share data over a comprehensive, low barrier to entry information platform can be leveraged through economies of scale. NCHI will secure and facilitate the distribution of the necessary resources including funding, technology and partnership to create a national health network that is available to the public and private sectors with the goal of improving health for individuals.

INTRODUCTION

The shape of the U.S. health care system and how it should be reformed are widely debated. One of the few areas of broad agreement centers on the need for health information to become more available and accessible. If the health care system is to be transformed the right care needs to be provided to the right patient at the right cost. This will only be possible, however, if the right scientific and personal health information are accessible at the right time.

Health care is a dynamic knowledge enterprise that evolves rapidly over short periods of time. Too often, the knowledge and information generated is not put into practice at the point of care and not made accessible to individuals and their families. In order to change this, what's needed is a comprehensive, national health information technology infrastructure. As researchers argued in a recent New England Journal of Medicine Perspective article, "*No Small Change for the Health Information Economy*" this infrastructure should focus on the development of a general purpose health care computing platform with low barriers to entry rather than on pre-defined end user products. [1] The platform should in turn support a wide variety of health care applications through open architectures. This choice will allow stake holders such as patients, physicians, hospitals, and employers to select the set of applications most appropriate for their local environments.

To address the needs for enhanced access and interoperability of health care information, the National Coalition for Health Integration (NCHI) is assembling a national scale data sharing platform which will support a diverse marketplace of health care applications. This information ecosystem will provide the infrastructure to ensure that health information can be shared across disparate end user systems securely. This health ecosystem will in turn allow for health care services to be provided in innovative new ways.

Just as the World Wide Web allowed people to communicate in new ways, NCHI vision is to develop a comprehensive, national network that will connect the fragmented parts of the U.S. healthcare system. This vision will be achieved through partnership and collaborative efforts.

NCHI's Integrated Health Platform is a systematic approach to developing a comprehensive data exchange infrastructure that will address each domain of the health

system. NCHI's multi-tiered approach of linking technologies, stakeholders, and the delivery of health services across the nation will transform the health system along four fronts:

•   **Transitioning to 21st Century Care**: Creating a model of 21st century care that is data driven, evidence based and integrates research and clinical practice into a continuum that will allow for personalized medicine.

•   **Decreasing costs and enhancing efficiencies:** Facilitating data access that will decrease costs and increase efficiency through the early detection and prevention of disease, increased transparency in costs, administrative streamlining and improved care.

•   **Increasing access to care:** Reducing disparities in care and varying access to health resources by leveraging technologies such as low cost telehealth that increase access in underserved urban and rural areas as well as in primary care specialties such as pediatrics where access to neonatologists and pediatricians is deficient.

•   **Enhancing patient-centered care**. The NCHI network architecture assembles data longitudinally over time with the patient as the starting point. The patient-centered integrated health record is a self-assembly of dynamically changing health information secured and utilized over the lifetime of the patient and their care-givers to maintain health rather than episodic treatment of disease. Information is drawn from the silos where it currently resides and self-assembles around the needs of individuals.
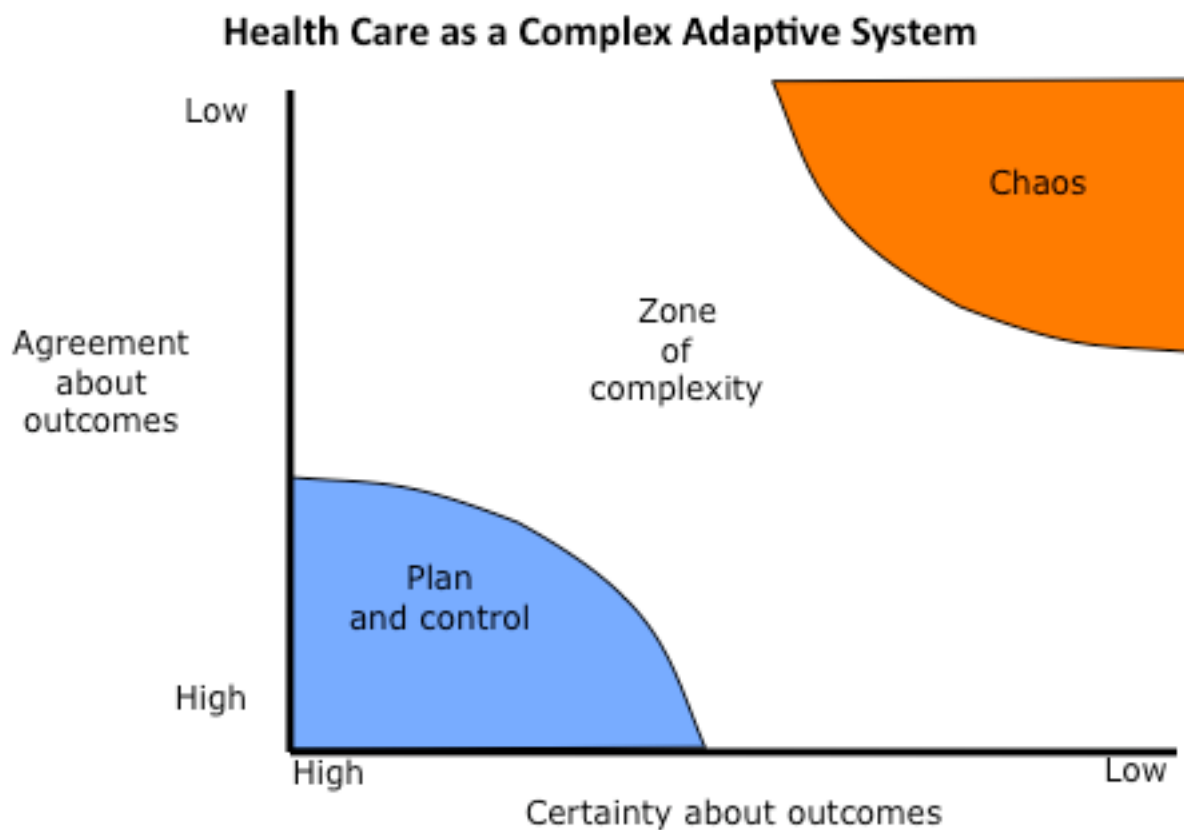

THE NCHI INTEGRATED HEALTH PLATFORM:
An accessible health information technology platform

Health Care and Complexity

Health care is marked by dynamic change and interactions amongst vast arrays of individuals and institutions. In its landmark report, "Crossing the Quality Chasm," the Institute of Medicine argues that health care should be considered a complex adaptive system. A complex adaptive system is a collection of individual agents that have the freedom to act in ways that are not always predictable and whose actions are interconnected such that one agent's actions changes the context for other agents.[2] Complex systems such as health care demonstrate characteristics that include the following [3]:

- Non-linear and dynamic
- Composed of agents are independent and intelligent
- Demonstrate goals and behaviors often in conflict
- Exhibit self-organization through adaptation and learning
- Have no single point(s) of control
- Hierarchical decomposition has limited value

Individuals and institutions in the health care system operate in a space between top down command and control and chaos:

Health Care as a Complex Adaptive System

Low

Agreement about outcomes

High

High   Low

Certainty about outcomes

Chaos

Zone of complexity

Plan and control

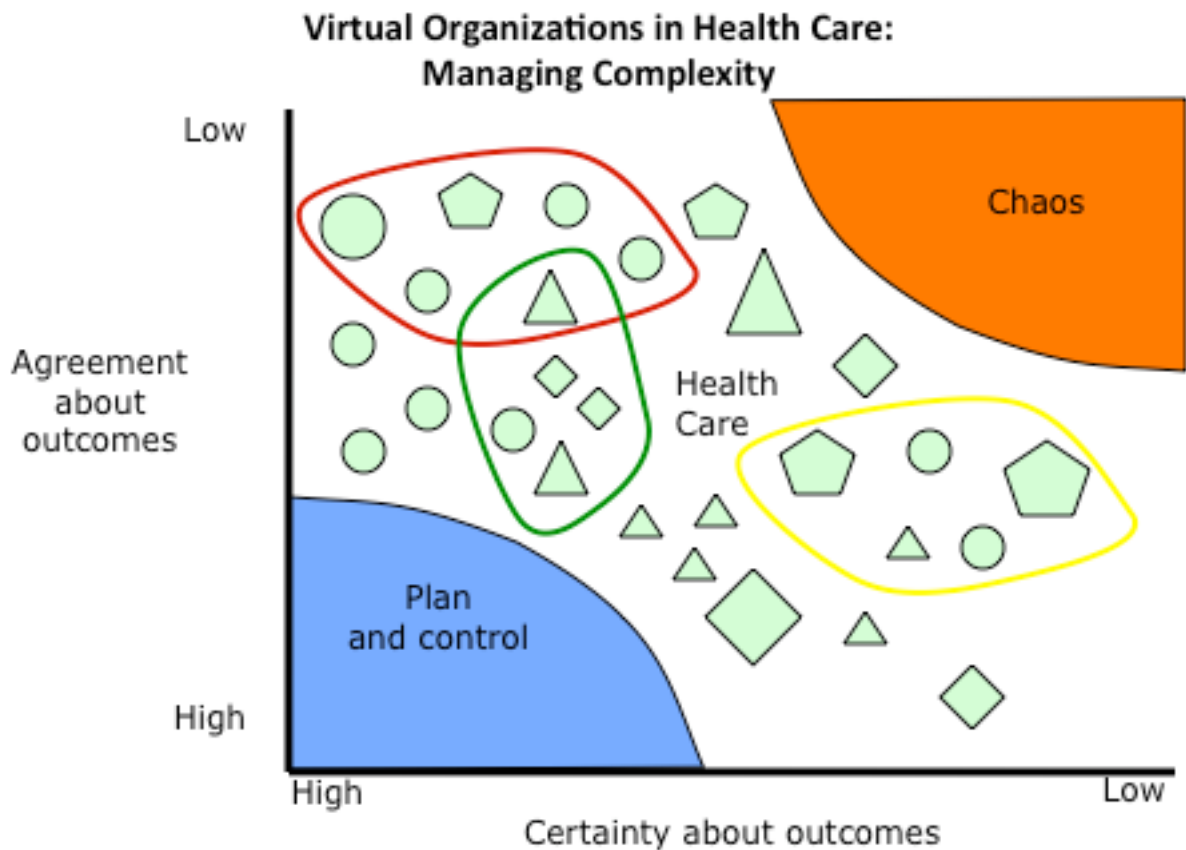Ralph Stacey, *Complexity and Creativity in Organizations,* 1996

The purpose of the NCHI technology platform is to promote the sharing of the information and data individuals and institutions need to navigate through the health care system's zone of complexity.

Health Care and Virtual Organizations

A patient is referred by his primary care physician to a sub-specialist who orders tests that require the patient to get blood drawn at one laboratory facility and an X-ray at an imaging center, with each group sending bills to the patient's insurer. Such complex chains of interactions are the norm in the health care system. A major challenge to providing high-quality cost-effective care is the need for all of the disparate entities involved in the care delivery process to interact efficiently. The primary care physician, sub-specialist, laboratory, radiology center, and insurer may all be completely separate institutions. However, to meet the patient's needs all of these different institutions need to come together dynamically to function as a single "virtual" organization.

A virtual organization is a set of individuals and/or institutions engaged in the controlled sharing of resources in pursuit of a common goal. The health care system is composed of multiple, overlapping virtual organizations. In the highly fragmented U.S. health system, virtual organizations have to form and reform over and over to achieve purposes ranging from providing care to billing to research.

Virtual Organizations in Health Care: Managing Complexity

Adapted: Ralph Stacey, *Complexity and Creativity in Organizations*, 1996

However, currently, even when information is in digital formats, data aren't accessible because they are stuck in different "silos" within and between organizations. In turn, the U.S. health system is hampered by inefficient virtual organizations that lack the mechanisms needed to engage in coordinated action.
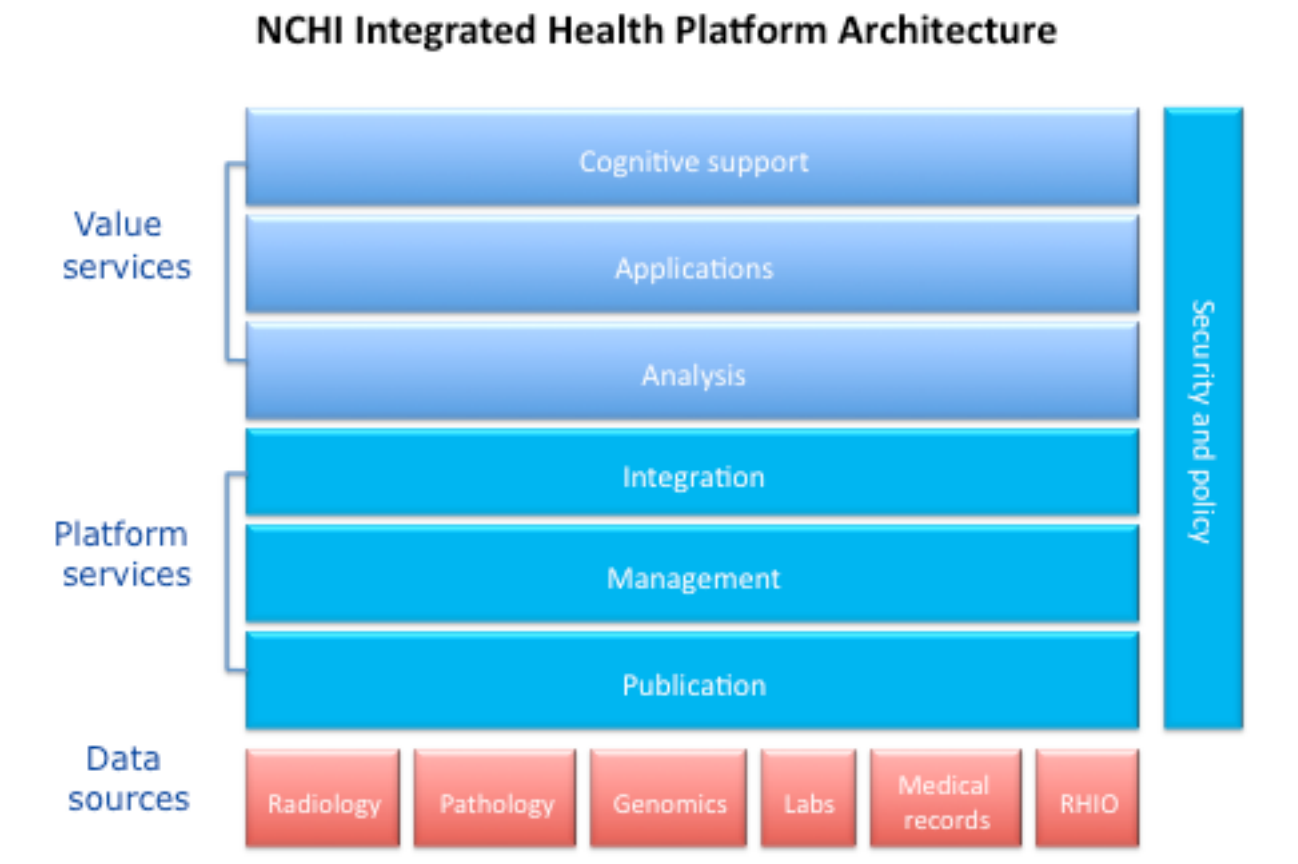

Health Care and Grid Computing

Grid computing is a technology model designed to promote the coordinated sharing of resources in dynamic, multi-institutional virtual organizations. Grid computing focuses on the loose coupling of data and services. This approach allows different institutions to come together to achieve a particular goal while still maintaining local autonomy in issues ranging from information system architecture to institutional policy. This flexibility and focus on controlled sharing makes grid computing particularly well suited to address the complexity of the fragmented health care system.

The NCHI Integrated Health Platform

The NCHI health platform is built on grid computing technologies. Its focus is to create an infrastructure that will allow for the interoperable, secure sharing of healthcare data between institutions that likely have different information systems and policies. The NCHI infrastructure will also be open to end user applications that will form a seamless ecosystem of functionalities that together form a distributed, "virtual" electronic health record platform. Rather than trying to consolidate health data into physical databases, this "virtual" electronic health record will allow data to be stored locally and to be assembled in a dynamic fashion.

The NCHI Integrated Health Platform Architecture

The NCHI platform architecture encapsulates and loosely couples data and services. This structure approach allows for dynamic composition of resources aimed at achieving discrete aims.

NCHI Integrated Health Platform Architecture

Value services — Cognitive support / Applications / Analysis

Platform services — Integration / Management / Publication

Data sources — Radiology / Pathology / Genomics / Labs / Medical records / RHIO

Security and policy

In the NCHI architecture data is held locally and integrated virtually. The publication layer makes data available in a remotely accessible and reusable fashion through secure gateways using technologies such as GridFTP. The data management layer allows for the naming and moving of data. Naming mechanisms allow for the persistent, global naming of digital health objects regardless of their type. The management layer of the architecture also coordinates the movement of data between services. The data integration layer addresses interoperability through data mediation approaches. On top of these platform specific services, the NCHI architecture adds value services that allow for analytics, facilitate the integrate outside applications, and provide for cognative support.

THE NCHI INTEGRATED HEALTH PLATFROM AND INTEROPRABILITY:
Defining terms and establishing a platform to exchange data

Given the complexity and high level of fragmentation in the health care system, the interoperable sharing of data is one of the chief potential benefits of information technology in health care. To date, however, applications such as electronic health records have achieved limited gains with respect to the interoperability. Facilitating the interoperable exchange of health data a primary goal of the NCHI infrastructure.

The NCHI architecture considers interoperability as a three part problem:

- Systems Interoperability: Communicating among system elements in a secure and reliable fashion.
- Data Interoperability: Data interoperability is considered in terms of syntactic and semantic interoperability. Syntactic interoperability is considered the movement of structured data among system elements. Semantic interoperability is considered the use of information across system elements.
- Process Interoperability: Supporting the integration of work across healthcare enterprises.

These three facets of healthcare interoperability are addressed by different layers of the NCHI architecture. Systems interoperability is handled through the publication and management layers. Data interoperability is handled through the integration layer. Process interoperability is primarily handled in the analysis and applications layers.

The NCHI approach towards healthcare interoperability is centered on information integration through mediation methods. Data mediation is based on the construction of frameworks to map between data models. Integration is scoped by targeting it to particular domains of use. These approaches makes it possible to support multiple overlapping integrations as data stays at its source and local data models can be maintained.

Mediation approaches leverage standards when they are available but can still facilitate interoperability in situations where a standards are immature, not agree upon, are implemented in different ways or are absent. In this respect, mediation approaches allow for greater fault tolerance in achieving interoperability.

Currently if standard data models exist, these models will facilitate the sharing of information across participants in the health care system. However, standard data models for desired data don't always exist. In addition, if standards do exist, there are often also alternative standards for the same data. Standards are not static. Generally they will evolve over time. For these reasons, rather than assuming that a standard data model exists, NCHI's approach assumes that there will likely be alternative representations of data in use. NCHI is thus creating an infrastructure that can mediate between these alternatives.

The core component of this approach is the ability to map between data models as a fundamental property. Information is mapped into one or more canonical models when it is published and remapped to local conventions when it is retrieved. When standards exist they can be exploited, however, they are not required for interoperability within the grid framework. This technique has been used successfully in the Grid infrastructure in a number of different data types, most recently in enabling exchange of pathology data in the ECOC 5202 trial.

More specifically, this novel approach is supported in NCHI's technical architecture in several ways:

• Mapping and data translation functions are fundamental components of the solution. These functions provide the ability to map between data representations at point of publication and retrieval. Thus consistency at the source and target are not required. In fact, knowledge of the target is at the time of publication is not required as this approach enables exchange between systems in situations where on does know, in advance, where the data is going.

• Uses extensible sharing frameworks rather than hard coded data formats to create structure for exchange, while factoring out the domain specific details of those information sharing. For example, in NCHI's image sharing pilot, the wide area information exchange knows nothing about the syntax and semantics of DICOM data. This approach is very different then HL7 (or even DICOM), which co-mingle the structure and semantics of the data with the methods used to exchange the data.

• Leverage rich (potentially non-standard) representations in the network level to limit the number of mappings required. In the imaging case, DICOM data model seems to be a pretty good choice. In the case of other types of records, NCHI's technology can identify one or more semantically rich and flexible data models that can be used to exchange information between HL7 implementations, between clinical and research systems, or between HL7 and other data models. In the NCI model, HL7 becomes a lower-level transport mechanism used at the points of publication and retrieval rather than a means for exchanging (and interpreting) clinical information.

• Publish meta-information about the data models to facilitate conversion between them via mapping services that we publish as part of the system. NCHI applies clever technology to semi-automate the creation of mappers, and allow for sharing of information across different mappers. Examples of this type of approach can be found in web scraping technology that infers data structure by looking at the data in question.

• NCHI's model provides general purpose data integration and data mediation services that leverage published meta-data to compose the appropriate mapping services and wrappers to ensure that data is transformed and delivered to an end system in a format that can be interpreted and used by that system.

This bottom up approach towards interoperability allows for the leveraging of standards when they are in place and implemented in a uniform fashion while still allowing interoperability to be facilitated under conditions of heterogeneity, incompleteness and uncertainty.

NCHI'S OPEN INTERFACE MODEL:
Third parties leveraging the NCHI platform

NCHI Platform technologies are based on open architectures with open interfaces. NCHI is actively encouraging third parties to join the network and to utilize the platform to develop innovative ways of delivering services. It is anticipated that this platform will stimulate new industries and economic growth based on both technology and data access.

PROGRAMS AND GRANTS AWARDED BY NCHI AND ITS AFFILIATES:

Grants Awarded To Date (2006-2009):
- Chan Soon-Shiong Center for Life Science, Saint John's Health Center ($35M)
- Chan Soon-Shiong Center for Translational Science, John Wayne Cancer Center ($20M)
- Center for Health Informatics, USC ($20M)
- Center for Health Informatics, UCLA ($1M)
- Center for Health Informatics, University of Chicago, Argonne National Laboratory ($700k)
- California Nanosystems Institute, UCLA ($10M)
- Endowed Professorship for Health Justice, Urban Health Initiative, University of Chicago ($2.5M)
- Dossia Foiundation ($1.5)
- Biomarkers, Clinical Trail and Biorespository, St. Johns, UCLA ($40M)
- Chan Soon-Shiong Scholars at University of Chicago, UCLA and USC ($2.5)
- Coalition for Cancer Cooperative Groups ($7M)

Grants Pending:
- Children's Oncology Group
- California TeleHealth Network

NCHI'S PARTNERSHIP NETWORK:
A comprehensive public-private partnership network to share data securely

NCHI is assembling a diverse set of organizations to develop new technologies, enhance existing technologies and to promote health data exchange on a national scale. Pilot projects to test technologies are also being identified to incubate and scale technologies for use on a state and national level. Partnerships established and under discussion include:

- AltaMed
- CalOptima
- Center for Health Informatics, St. Johns Hospital
- Coalition for Cooperative Cancer Groups
- College of Pharmacy, University of Arizona
- Computation Institute, University of Chicago and Argonne National Laboratory
- Dossia
- Information Science Institute, University of Southern California
- March Vision
- Marshfield Clinic, Wisconsin
- Regenstrief Institute, Indiana
- The Urban Health Initiative, University of Chicago
- The California Telehealth Network
- The California Emerging Technology Fund
- The Children's Oncology Group
- The X Prize Foundation (WellPoint Health X PRIZE)
- Wireless Health Institute, UCLA
- Zirmed, Inc
- Vitality, Inc.
- ITA Partners

SUMMARY:

NCHI is creating a comprehensive technology platform and an association of partners positioned to create radical improvements to the U.S. Healthcare System. NCHI seeks to obtain state and federal funding as a national, public-private collaborative that will accelerate change in this area. Funding will be used to:

- Enhance, advance and accelerate technology development, deployment and maintenance among partner organizations
- Support the existing projects to provide clear evidence of the value of the technology infrastructure in achieving NCHI and the nation's objective of transforming healthcare by enhancing the availability, privacy and integration of health information across the country amongst diverse organizations.
- Establish additional partnerships that will expand the information technology platform and create outcomes that deliver improved healthcare at lower cost.