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*Human endeavor is caught in an eternal tension between
the effectiveness of small groups acting independently and
the need to mesh with the wider community.
Berners-Lee, 2001*

American public policy makers have recently established the goal of having electronic health records (EHR) for the majority of Americans by 2014 [Bush, 2004]. This white paper presents aspects of a conceptual and measurement framework that will help us to measure how close we are to reaching that goal. It also touches on another important question, to what extent do EHRs and other innovations in informatics actually improve the performance of the overall health care system and the individuals who serve within it.

It represents a starting point for what will hopefully be a wide-ranging discussion of exactly how we should measure progress toward the achievement of a functional National Healthcare Information Infrastructure (NHII). Such an NHII would allow all patients, healthcare providers, and those interested in population health to have access to comprehensive electronic health records. This discussion will begin at the upcoming NHII meeting to be held in Washington, D.C., July 20-23, 2004.

What is the NHII?

The National Health Information Infrastructure (NHII) is:

- An initiative set forth to improve the effectiveness, efficiency and overall quality of health and health care in the United States
- A comprehensive knowledge-based network of interoperable systems of clinical, public health, and personal health information that would improve decision-making by making health information available when and where it is needed.
- The set of technologies, standards, applications, systems, values, and laws that support all facets of individual health, health care, and public health. [NHII, 2004]

Measuring the progress in creation, deployment and adoption of health information management and communications technology in support of the healthcare delivery process across the nation will be difficult [Ukoununne, 1999]. As we move from the individual patient, to the entire practice of that patient's primary care physician, to the particular inpatient institution at which that physician practices, to the entire health system that encompasses that institution, to the entire community in which that health system exists, to the entire nation, we will be forced to accept less precision in our measurements.

Following an overview of a conceptual model for the NHII, we present a draft measurement framework that would allow us to begin measuring progress towards the successful creation of a fully functional NHII. We will then briefly describe how we might also try to develop a qualitative estimate of the current state of the art regarding various information exchange standards, current and impending legislation, and the "values" of potential users of these systems.

A Conceptual Model of the National Healthcare Information Infrastructure

The NHII can be thought of as a collection of healthcare delivery providers that share patient-level information electronically. More specifically, we conceptualize the NHII as a cluster of nodes. We define a node as a physical healthcare environment with the requisite health information management technology to collect, store, display and transmit patient-identifiable, structured, clinical data in an electronic format. Therefore, a sole practitioner in private practice using a simple, electronic health record (EHR) system and with access to the Internet could function as a node. On the other hand, we would also consider a large, academic medical center's inpatient facility, a single node, as well. We define a cluster as two or more nodes which have an existing written data sharing agreement that allows any node to send (or receive) patient-

identifiable information to (or from) any other node in the cluster through either an intermediary, or directly. A node may belong to one or more clusters (see figure 1 for a diagram showing how nodes and clusters can be related). Those aspects of a cluster that contribute to their persistence also define clusters. For example, a cluster may be created and maintained by one or more of the following attributes: statutory, or legal, agreements, geographic proximity, or financial ownership. Using this definition, several existing Local Health Information Infrastructure (LHII) implementations would be considered clusters (e.g., The Indianapolis Network for Patient Care (INPC), The Santa Barbara County Care Data Exchange (CDE) or Massachusetts SHARE (Simplifying Healthcare Among Regional Entities [NHII, 2004b]).

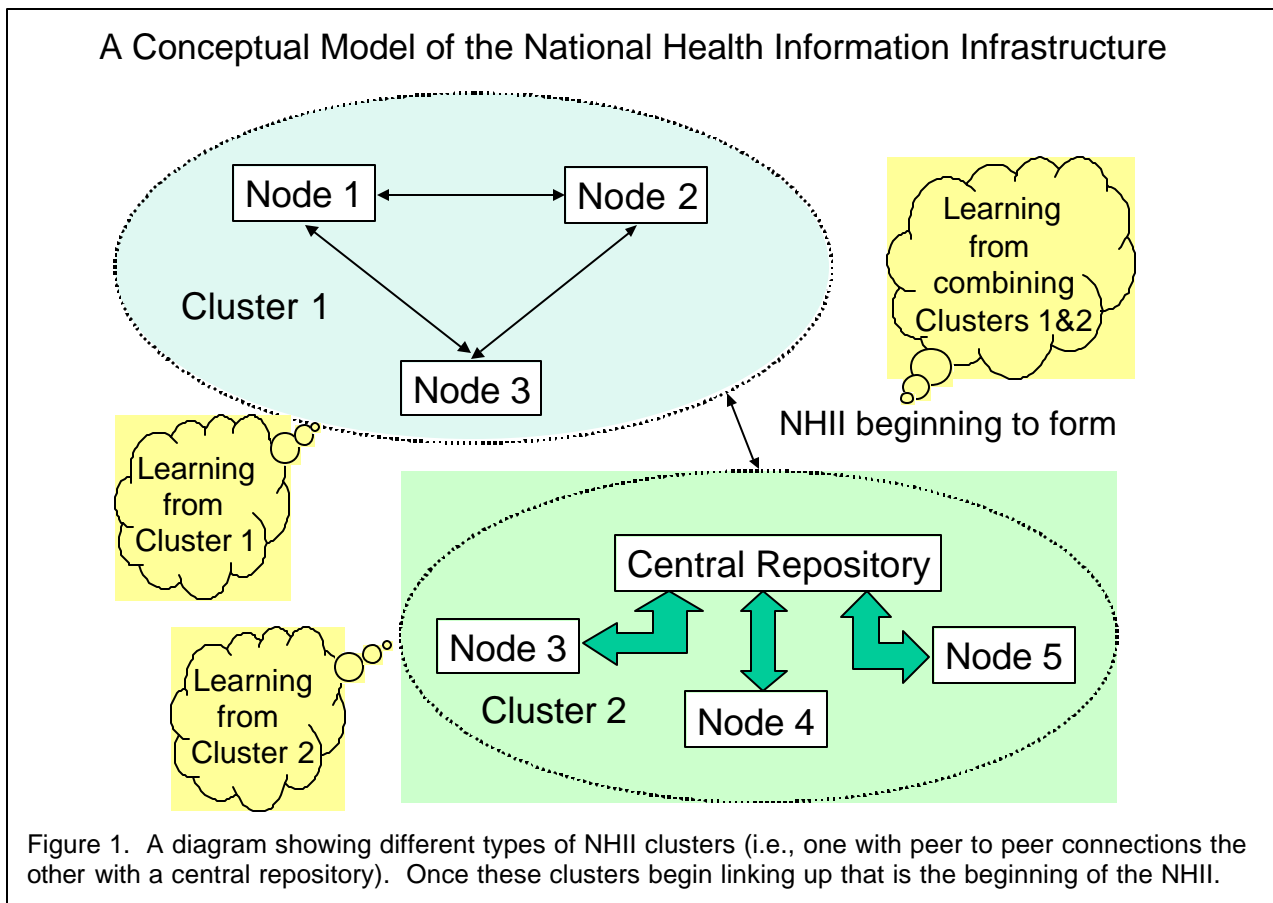
As we go forward, we hope that groups of clusters will form, therefore we add the additional proviso that a cluster can consist of a cluster of clusters. Such a model encapsulates the U.S. Federal government's current articulated plan for achieving a National Health Information Infrastructure (NHII) through the creation of Local Health Information Infrastructures (LHIIs).

Key Users (Stakeholders) of the NHII

The National Committee on Vital and Health Statistics (NCVHS) defined three key dimensions of the NHII functionality "by what they encompass, whom they serve, how they are used, and who has primary responsibility for content and control" [NCVHS, 2001]. These dimensions helped them identify three major groups of users of patient-identifiable health information: patients or consumers, healthcare providers (both individual clinicians and organizations) and communities or population health. Therefore, we believe that we must make measurements with respect to each of these three groups of users.

Using the Conceptual Model to Create a Measurement Framework

Now that we have a conceptual model for the NHII, we can begin developing a measurement framework that will help us evaluate the Nation's progress toward achieving a functional NHII. Borrowing several concepts from conventional quality measurement efforts, we must be able to measure aspects of the structure, process, and outcomes that make up and result from the NHII. These concepts translate into measurements of health information management technology availability, use, and effectiveness at both



the nodal and cluster level. In addition, all of these measurements need to be made from the viewpoints of the key users of the NHII, namely, patients, clinicians, and those involved in population health activities (e.g., public health departments), among other users. The diagram shown in figure 2 helps illustrate this. As in any large-scale measurement and evaluation effort, designing and validating the measures will be one of the most important and difficult challenges to overcome.

Broadening the Conceptual Framework to help us Better Understand the Field

The application of informatics to health care is still in its youth. Little is known about how and when an informatics intervention is most likely to be successful. The scope of harms and benefits has not been well catalogued. Neither have the particular attributes of systems and interventions that do, or do not, work well together. The development of such understanding represents a key aspect of the formative evaluation of the move towards NHII. One further aspect of our measurement framework borrows from both the case study and the quality improvement frameworks. The accumulation of data from LHIIIs and specific initiatives ought to enhance our understanding both of how and when to implement a specific type of intervention in a particular environment, and to improve the nature of the technological innovations themselves. Thus, two axes not indicated on Diagram 2 are the enhancement in processes for assessing readiness and improving implementation, and the enhancement in the nature of the initiatives themselves. A related area is how the development of LHIIIs influences the economic and venture capital markets to stimulate further innovation. These areas can be thought of as the knowledge products of repeated application of the measurement framework of Figure 2 in specific initiatives. As consistent and replicable data are collected and studied, we will be able to develop a more evidence-based understanding of this field, its direction, and its potential.

Phased Approach to Making Measurements

In addition to the conceptual model of the system and identification of the key system users, we believe that we should use an iterative, phased approach, that will allow us to begin making measurements of the NHII, while we continue learning “how best to make these measurements”. This iterative approach will also allow us to move forward at varying rates in different regions of the country. This is based on our firm belief that before one can expect to demonstrate

improvements in any of the outcome measures associated with the NHII, that we must first demonstrate that the key system users are actually using the system. Similarly, we believe that before we can expect to be able to measure any system use, we must be able to demonstrate that the requisite systems are in place and available to our key users. Therefore, we propose a three-phase iterative approach to beginning the measurements in which Phase I will consist of the measurements required to demonstrate “Availability” of the systems. Phase II will consist of the measurements required to demonstrate “Use” of the systems and Phase III will consist of the measurements required to demonstrate the effect of these systems on various outcome measures that are often associated with HIT use.

Phase I – Systems Availability

HIT availability can be defined as the existence of, and access to, the requisite technology to collect, store, display and transmit patient-identifiable, structured, clinical data in electronic formats. Therefore, we must be able to identify whether healthcare institutions and their providers have access to various health information technology components. Potential measurements that we could make in this phase include:

- What is the percent coverage (i.e., patients in a region who have copies of their data available through the LHII) of patient's in a community?
 - Use US census data for a geographic region covered to estimate denominator.
 - Use number of unique patient ID's accessible in the system(s) as the numerator.
 - Say: 5 levels: <20%; 20-39%; 40-59%; 60-79%; 80% or more
- The percentage of clinicians with an LHII login?
 - Use number of unique clinicians with a log-in as numerator.
 - Use ? as an estimate of total clinicians in region eligible for logins.
 - Say: 5 levels: <20%; 20-39%; 40-59%; 60-79%; 80% or more
- The percentage of health care organizations in a geographic region with a signed data exchange agreements with the LHII in place.
 - Use total number of organizations in community (how to measure, what to count?) as denominator.
- Count the numbers of these LHIIIs nationally -- perhaps we could even go back a few years and make estimates of these LHIIIs for 2001 -2003?

Phase II – Systems Use

HIT use can be defined as actual hands-on use of these HIT systems by patients, providers, and those involved in population health, as they care for patients. At the nodal level this equates to actual use of various HIT applications such as clinical results review or provider order entry. At the cluster level, HIT use can be measured by the number of clinicians who routinely use the system to enter and review patient-level data. Example measurements we might be able to make here include:

- The percentage of patients in a region whose data was accessed by someone other than the originator of the data.
- The percentage of clinicians who actually logged-in to the system
- The percentage of healthcare institutions that submitted data to the LHII

Phase III – Effect Measurement

The effects of health-related information technology on health and health care represent a vital metric for the NHII. The value of the infrastructure ultimately must be evaluated perhaps using the six goals from the Crossing the Quality Chasm report [IOM, 2001] (i.e., Safety, Timeliness, Efficiency, Effectiveness, Equitability, Patient-centeredness) as measurement axes. Although benefits and costs of HIT have been measured in limited settings, measurements of effect on the scale envisioned for a national infrastructure have never been made. We believe, however, that measurements of the impact

of NHII on health outcomes are beyond the scope of our current charge and may distract us from the critical measurements of systems availability and use that must be performed first.

Paying for the LHII and the NHII

Clearly all this HIT requires significant financial resources to create and maintain it. Therefore, we must be able to at least estimate how much each node or cluster has spent to create and maintain their systems and services and their source of financing. Using these financial estimates, we can then begin to compare different LHII models based on their return on investment.

When the NHII is up and running

Once we have significant (i.e., > 25%) penetration of the NHII, then we can begin using electronic, randomly determined, sampling methods of various aspects of the NHII systems to generate objective measures of IT availability, use and effectiveness. For example, we could send queries for 1000 specific patients' data (at least one patient in this group should have data from each hospital selected) to 1000 randomly selected hospitals and measure both the number and quality of responses received. The number of responses would tell us "how many hospitals were able to at least respond to queries of this type, which are essential". The quality of the responses, that is the sensitivity and specificity of the patient matches and the amount and nature of the data returned would tell us how effectively, these institutions had implemented the functionality required to implement such a system.

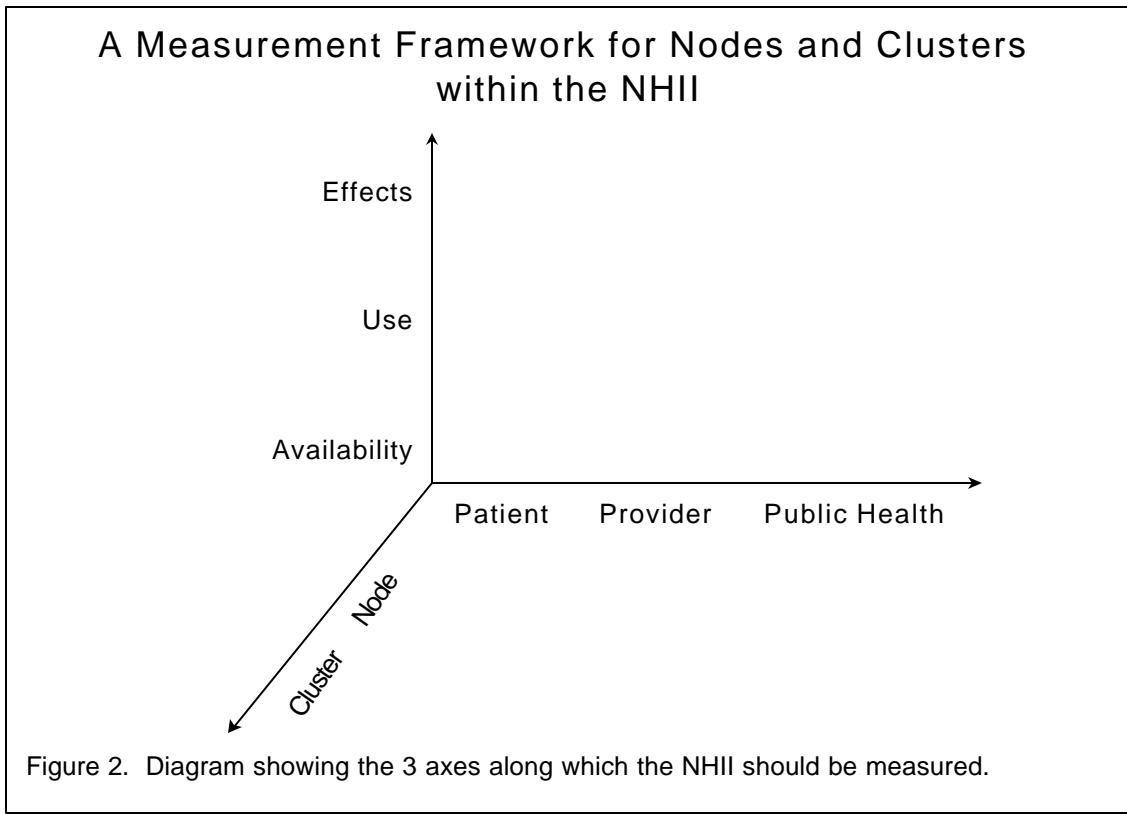


Figure 2. Diagram showing the 3 axes along which the NHII should be measured.

- Random selection of 1000 patients send requests to a randomly selected set of 1000 healthcare institutions, pharmacies, or labs and count the number of replies. This would provide an estimate of the number of institutions that were capable of working in this system.
- Look at NPID database try to estimate number of duplicates as a measure of how well this db is being managed.

Additional Measurement Features

In addition to the measurements associated with elements of the conceptual model described earlier, we also believe that our measurements of NHII progress should include qualitative reviews of the current state of the art with regard to the legislation that is in place or is pending. Likewise, we believe that similar reviews should be conducted on the state of clinical and administrative information exchange standards and on the “values” of potential users of these systems. While these qualitative estimates of progress will not be as easy to interpret, they provide at least a glimpse of the progress that the nation is making in these critical arenas.

Examples of the types of topics these qualitative reviews might address include:

- Qualitative assessment of the legal climate in each state to support NHII
- Patient privacy protections
- Legal restrictions on sending/receiving various data types
- Electronic signatures
- Prescription transmission to pharmacies
- Legal restrictions on sending laboratory results to patients
- Requirements to submit data in electronic format to local, state, federal payers
- Availability of unique provider ID at federal level

Likewise in assessing the values of key system users one might delve into:

- Qualitative assessment of the perceived value of using HIT for patient care
- Incentives to adoption
- Number of insurance companies reimbursing physicians for use of e-visits

Who will make these Measurements?

A public-private partnership could be charged with developing these measurement systems, making the measurements, and reporting the results of these measures on a yearly basis.

For example, a nascent group referred to as the Improve-IT Institute (www.improve-it-institute.org) is forming. Briefly, ImproveIT is a national coalition of institutions and individuals focused on measuring the progress in adoption and utilization of clinical information technology. The ultimate goal of ImproveIT is to help healthcare organizations across the nation make better use of state of the art clinical information technology to improve patient care.

How can or should these measurements be made?

Making measurements of such a multi-faceted, multi-functional set of disparate systems and services will be difficult. Until we have at least 25% penetration in all aspects of these systems (i.e., inpatient, outpatient, data interchange standards, and unique patient ID mechanisms) measurements will need to be estimated from survey or site visit data.

Conclusion

The NHII has the potential to transform health care in America - improving health care quality, reducing health care costs, preventing medical errors, improving administrative efficiencies, reducing paperwork, and increasing access to affordable health care. While the President has set an ambitious goal of assuring that most Americans have electronic health records within the next 10 years”, a significant question remains “How will we know if we are making progress toward that goal?” Using the definitions for “nodes” and “clusters” developed in this white paper along with the resulting measurement framework, we believe that we can begin a discussion that will enable us to define and then begin making the kinds of measurements necessary to answer this important question.

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