

## National and Regional Health Information Infrastructures: Making Use of Information Technology to Promote Access to Evidence

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### Abstract

*The vision for national and regional health information infrastructures (HII) includes provision of a framework that is supportive of access and integration of health information with the goal of improving the health and safety of individuals, public health systems, and nations. Internationally, prominent examples of national and regional HIIs exist that provide a means for achievement of this goal. Using the United States' National Health Information Infrastructure (NHII) as an example, the authors describe expansion of the conceptual framework to explicitly acknowledge the role of access to evidence at the overlap between the three dimensions of the NHII to create an "evidence-based" link between interrelated components. The role of national measures in setting e-communication goals and evaluating the evolving infrastructure in meeting informational needs of users is discussed. Additionally, automated knowledge management tools such as practice guidelines are presented as a means by which access to critical information is delivered to users, in a format that is appropriate for their health literacy level and that provides adequate support for informed decision making.*

### Keywords:

National and regional health information infrastructures, Healthy People 2010, evidence-based practice guidelines.

### The Role of National and Regional Health Information Infrastructures in Promoting Access to Evidence

International advances in informatics systems over the past decade have crafted a vision of seamless data integration and communication that has driven work to define and implement national and regional health information infrastructures (HIIs). The shared vision for HIIs includes provision of a framework that is supportive of access and integration of data, information and knowledge with the goal of improving the health and safety of individuals, public health systems, and nations. The purpose of this paper is to offer a brief description of universal components of HIIs and the significance of access to evidence for all users in realization of their vision. Internationally, prominent examples of HIIs exist that provide a means for achievement of this goal. The United States' National Health Information Infrastructure (NHII) is employed as an example of an evolving conceptual framework that supports universal access to evidence to drive informed decision making.

As the international healthcare community faces information challenges due to increasing amounts of available data and infor-

mation from disparate sources, there is a drive towards using evolving technologies to ensure the quality, reliability and timeliness of information used for planning and managing healthcare delivery and public safety. In many developed countries, a coordinated effort is underway to build national and regional health information infrastructures (HIIs) to provide a means of linking disparate sources of data in a way that greatly enhances healthcare decision making. Examples include the "National Health Information Agreement (NHIA) (Australia), "Infoway" (Canada), "Information for Health" (United Kingdom), "National Health Information Infrastructure" (NHII) (United States) and Working to Add Value to E-information (WAVE) (New Zealand). Although national differences exist, there is widespread international recognition that HIIs should strive to meet the information needs of providers, consumers and communities on local, regional and national levels [2-5]. A summary of the role of these interlocking dimensions in improving access to information and driving informed decision making is described below.

- **Providers:** There is widespread agreement that a provider component to national and regional HIIs will make patient information and evidence available at the time when critical decisions are made. Access to essential information at the point of care is expected to have an immense impact on the ability of clinicians to routinely provide health care that is safe, cost effective and of high quality[2-5]. Electronic access to patient information assures that all clinicians have access to the information that is needed to treat patients, regardless of where they are hospitalized. Accurate patient data prevents unnecessary tests that may put patients at risk and drive up the cost of health care. Electronic evidence in the form of practice guidelines, decision support and telehealth applications will improve access for disparate populations to the same quality care offered in national centers of excellence.
- **Consumers (includes patients):** A shared goal of the consumer/patient component of HIIs is to guide decisions to seek care and to promote active participation in wellness management, disease prevention and shared decision making in management of acute and chronic conditions[2, 4]. The consumer component may include a personal health record that is owned and maintained by the consumer and provides a means by which health record keeping and health related tracking is documented [2, 4]. A consumer

component to HIIIs would also facilitate the use of e-health technology for monitoring patients. This holds potential for improving access for underserved populations.

- Communities (includes public health departments and local, regional and national governments): There is wide agreement that a primary function of a HIIIs is to serve the information needs of community users at local, regional and national levels[2-5]. A coordinated national public health database facilitates continuous surveillance of the health and safety of citizens and those factors that influence health and safety[2, 4, 5]. The community component may also provide a means to continuously assess for threats of bioterrorism and prompt delivery of alerts and information to drive a rapid, coordinated, response and to prevent mass casualties [2, 6]. In addition, it is recognized that a community component facilitates targeting at-risk populations with public education programs designed to reduce risk and conduct continuous evaluation of efforts.

Table 1: Evaluating the utility of MHII Using HP2010 Communication Objectives.

| HP2010<br>Communication<br>Context [1]                                  | NHII Dimensions                     |                                 |                                   |
|---|-------------------------------------|---------------------------------|-----------------------------------|
|   | Healthcare<br>Provider<br>Dimension | Personal<br>Health<br>Dimension | Population<br>Health<br>Dimension |
| Provider-patient<br>relations   | X                                   | X                               |                                   |
| Exposure to, search<br>for and use of health<br>information             | X                                   | X                               |                                   |
| Adherence to clinical<br>recommendations and<br>regimens                | X                                   | X                               | X                                 |
| Construction of<br>public health<br>messages and<br>campaigns           |                                     | X                               | X                                 |
| Dissemination of<br>individual and<br>population risk<br>information    | X                                   | X                               | X                                 |
| Images of health in<br>mass media and<br>public at large                |                                     |                                 | X                                 |
| Education of<br>consumers regarding<br>access to health care<br>systems |                                     | X                               | X                                 |
| Development of<br>telehealth applications                               | X                                   | X                               | X                                 |

The National Health Information Infrastructure (NHII) in the United States (US) consists of three interactive and interdependent “virtual” dimensions that are conceptualized by the content, function, scope, services and individuals who maintain responsibility and control of the content area. The NHII includes Personal Health, Provider Health, and Population Health Dimensions and was modeled using many of the international HIIIs principles described above[7]. The NHII is defined as a “set of technologies, standards, and applications that support

communication and information to improve clinical care, monitor public health, and educate consumers and patients”[2].

## Evaluating the Impact of NHII on Health Communication and Bridging the Digital Divide

Identifying a means with which to measure effectiveness remains a key challenge of the NHII and other HIIIs. Healthy People 2010 (HP2010) is a national health promotion and disease prevention program in the United States that has begun to define measures of health communication including the use of e-resources for improving the nation’s health status. In this context, health communication is defined as “the study and use of communication strategies to inform and influence individual and community decisions that enhance health.”[1]. An overarching goal of HP2010 is to eliminate health disparities. The HP2010 health communication goal aims to use communication to strategically improve health. The program has gathered baseline data and set target goals related to the following objectives that may be useful for evaluating the evolving NHII in meeting informational needs of users:

1. Increase the proportion of households with access to the Internet at home.
2. Improve the health literacy of persons with inadequate or marginal literacy skills.
3. Increase the proportion of health communication activities that include research and evaluation.
4. Increase the proportion of health-related World Wide Web sites that disclose information that can be used to assess the quality of the site.
5. Increase the number of centers of excellence that seek to advance the research and practice of health communication.
6. Increase the proportion of persons who report that their health care providers have satisfactory communication skills.

By clearly defining objectives, targets, baseline measures and data sources, the HP2010 Health Communication goal offers a practical step towards setting national e-communication goals and an approach to evaluating the success of the evolving NHII infrastructure in meeting the informational needs of primary recipients. The NHII will facilitate a coordinated and systematic data collection effort from data sources within the three dimensions. Ongoing data aggregation and analysis facilitates systematic exploration of the factors that contribute to health. Strategies can then be implemented, based on these data to influence national, regional and local factors. In addition, the HP2010 Health Communication goal offers the following set of attributes of effective health communication: accuracy, availability, balance, consistency, cultural competence, evidence base, reach, reliability, repetition, timeliness, and understandability[1]. Each attribute is clearly defined and provides an additional means from which the effectiveness of health communication strategies are measured within the three dimensions of the NHII.

In its capacity to create linkages between disparate data sources, NHII can facilitate health communication and contribute to all aspects of disease prevention and promotion. The three dimensions of the NHII are tabled below within the appropriate context of the HP2010 Health Communication Goal. As noted in Table 1, there is an inherent linkage between the HP2010 Health Communication goal and the three dimensions of the NHII. Health

communication in the form of data input, information flow and knowledge generation exists across the three dimensions and provides a means for systematically evaluating the utility of the NHII to primary recipients within the three dimensions and the overall impact of the NHII on bridging the digital divide.

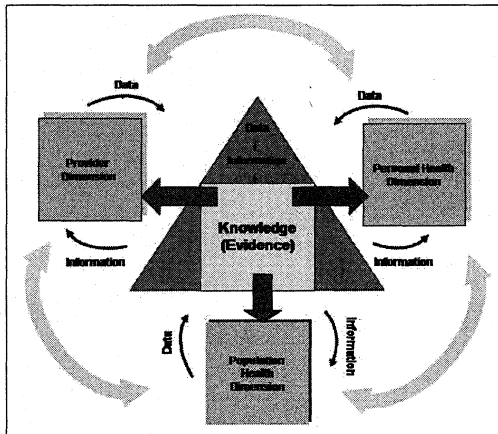


Figure 1 - The NHII Data-Information-Knowledge Cycle

## The NHII Data-Information-Knowledge Cycle

The overlap of the virtual dimensions of the NHII link health care services across the continuum of care and over wide geographic areas. With essential privacy safeguards in place, the NHII facilitates the movement of data among and between content areas. The aggregation, analysis and experience afforded by free flow between interacting dimensions of the NHII facilitates the movement of data to information and the ultimate transformation of information into knowledge [2]. Therefore, making knowledge widely available in the form of evidence becomes a worthy goal of the NHII.

The addition of a content area that acknowledges the role of “access to evidence” by consumers, providers and communities to the existing NHII conceptual model at the overlap between the three dimensions, is necessary for creating an “evidence-based” link between interrelated components. The concept of shared access to evidence is consistent with the UK’s conceptual model employed in “*Information for Health*” which explicitly recognizes how information derived within sub-dimensions as a result of the fundamental purpose of the NHS is subsequently analyzed for the benefit of all, and employed to continuously improve treatment and care in the future[4]. Although the use of evidence is tailored to meet the needs of primary recipients within a virtual dimension, there are universal uses of evidence as well. As noted in the UK model, linkages between the three dimensions assure that new data is continuously fed into the system improving the information available to primary recipients and continuously strengthening the knowledge base[4].

It has been noted that realizing the full potential of the NHII requires that it is viewed as both a tool for managing existing information and knowledge and as a driver in the generation of new knowledge and improved system performance [8]. Figure 1 illustrates the role of individual NHII dimensions in providing

data that is transformed into information and then fed back into the system. New information is combined with data and information generated by other dimensions, leading to transformation of information into knowledge or evidence. Evidence is then available in real time to inform decisions made by primary recipients within the virtual dimensions. In this model, research is an essential component of the NHII; intertwined within the three dimensions and knowledge generated through the research process is available globally. In the sections below, the data output and role of each dimension in knowledge generation and translation of knowledge to meet the needs of primary recipients is described.

## Healthcare Provider Dimension

Individualization of care based on research evidence, patient needs and preferences is a cornerstone of evidence-based practice [9]. Improved access to evidence in the healthcare provider dimension implies that providers have the information necessary for provision of safe, effective and quality care to all patients. The NHII provides the supporting framework from which knowledge management tools such as practice guidelines and clinical pathways emerge. Decision support tools such as prompts and reminders, automated standard orders, automated access to evidence (such as Infobuttons[10]) provide a means of translation of evidence into a format that is useful to busy clinicians at the point of care.

Automated pathways that employ local evidence along with patient specific data available in a computerized documentation system (CDS) are supported by the NHII infrastructure and determine the foci and tools of the patient education and self-management training process. Availability of data from the population and personal health dimensions assures that materials given to patients are of high quality, audience appropriate and are designed to meet the specific needs of patients from all segments of the population, including the underserved.

With the aid of decision support tools and practice guidelines, evidence regarding the use of interventions with effectiveness on specific types of patients or unique risk levels within subsets of the population can be accessed and made available to drive informed decision-making at the point of care. Input from the provider dimension in conjunction with that generated from the Personal Health and Population Health dimensions facilitates tailoring of guidelines to include recommendations for specific segments of the population who may benefit from interventions with known efficacy and facilitates exclusion of those who will not benefit. Continuous input of data from primary recipients of each of the three dimensions will produce new information and update what is known about the efficacy of interventions in subsets of the population. Data input across the three dimensions of the NHII will assure that sufficient data are available relative to all segments of the population, including minority groups who have been traditionally underrepresented in health promotion and disease prevention efforts. Aggregation and analysis of data and input related to the experience of recipients in each of the primary dimensions serve as building blocks of new knowledge. Conceptually, current knowledge or evidence is available for providers at the content overlap of the three dimensions under

“access to evidence”. With a fully functioning NHII, quality of care is less dependent on where a patient presents for treatment and more dependent on the informatics competency level of clinicians and the general ability of the provider dimension to routinely translate and present data, information and knowledge in a format that is accessible, easy to use, and appropriate to a patient’s current clinical status [9, 11].

### **Personal Health Dimension**

Access to evidence in the personal health dimension means that consumers will have the same quality information available for decision-making, (including the risks and benefits of treatment), that are available to providers recommending treatment. Comparable evidence is employed by primary recipients in the population health dimension in a more global format to inform interdisciplinary guidelines and health policy. Consumer access to evidence has potential for creating a means of bridging the digital divide in a way that is quantifiable using the Healthy People 2010 communication objectives as described above. Of particular interest to primary recipients in the personal health dimension include improving provider-patient relations; exposure to, search for and use of health information; and education of consumers regarding access to health care systems.

A recent study by the Pew Internet and American Life Project suggests that finding health information is a key incentive to Internet use. In 2003, 80% of adult Internet users, or about 93 million Americans went online to seek health information [12]. According to this same study, those with poor health status use the Internet most frequently for this purpose. The Internet provides a means from which evidence can be disseminated to consumers and tailored to individual determinants of health and the health literacy level with the use of web-based forms and algorithms. In a fully functional NHII, evidence is applied to practice when consumer-oriented views of practice guidelines are individualized based on patient data in the clinical information system and accessible through the personal health record. The NHII would provide a means for channeling safe, accurate and complete health information at the time of need and eliminate the range of quality currently encountered by consumers seeking health information on the Internet.

It is well documented that the health literacy level of many adults presents a barrier to understanding their conditions and managing their treatment plans [13-15]. In providing access to sound quality health information, the NHII may improve consumer health literacy level. Knowledge management tools such as patient pathways may be employed during periods of acute illness to assist patients with day to day management or to assist with developing and refining a self-management plan to prevent exacerbation in chronic illness. Patient response to treatment entered through the personal health dimension adds an additional source of data and facilitates building evidence from practice.

### **Population Health Dimension**

The Population Health dimension provides a means through which standardized data are collected to continuously support and drive health services research and improved public health systems. Data, information and knowledge generated from this

dimension are expected to have a substantial impact on mass health communication activities, public safety initiatives, and the building of a scientific foundation for population-based recommendations [2].

The Population Health dimension may contribute to availability of information and knowledge generation to support community, regional and national health programs and public health improvements. The NHII will facilitate the aggregation of disparate de-identified patient data so it can be used for public health and research purposes and to support health promotion [9]. Potential e-health applications facilitated by a functional NHII are numerous and include video conferencing among public health officials during emergent situations, incident reporting, disease surveillance, and real time access to local, regional and national epidemiologic data [7]. Data generated from these sources would inform public health and safety campaigns by effectively targeting segments of the population and tailoring interventions based on known behavioral determinants of health within sub-populations.

### **Discussion**

It has been noted that to improve health in the United States, the following cornerstones of the health system must be integrated and strengthened: personal health management, health care delivery, public health and research[8]. Personal health management, health care delivery and public health directly correspond with the three dimensions of the NHII. Research is inherent in all dimensions and a byproduct of the interaction among and between the three dimensions. A system that supports continuous input and aggregation of data and information promotes research and becomes a vehicle from which knowledge is generated. The addition of “access to evidence” to the content overlay between the three dimensions of the NHII supports the framework as one in which research is continuously supported and generates new knowledge that is immediately available for primary recipients in all dimensions.

Generation of up-to-date practice guidelines integrated into decision support functions in a format useful for informed point of need decision-making are recognized internationally as an important means for dissemination of research evidence to primary recipients within multiple dimensions of an HII[3, 4]. As currently envisioned, the NHII will facilitate continuous provider access to guidelines along with notes, orders and a host of decision support tools. Practice guidelines that have been individualized and translated into a format that is appropriate for individual patient factors, including health literacy level, will be used by consumers to inform decision-making regarding treatment. In addition, practice guidelines may be useful in the population health dimension for directing organization of care to drive optimal disease management nationally.

Methods for evaluation of the ability of the HIIs to meet the information needs of primary recipients will need to be addressed as an essential component of the evolving infrastructures. In the US, Healthy People 2010 Health Communication goal represents an initial effort at devising a framework for ongoing evaluation of the NHII with regard to health communication and dissemination. Health communication in the form of data input,

information flow and knowledge generation exists across the three dimensions and provides a means for systematically evaluating the utility of the NHII to primary recipients within the three dimensions and the overall impact of the NHII on bridging the digital divide.

Although much international effort has been directed towards laying the groundwork for HIIs, it is clear that several key challenges remain related to privacy, standards, and funding [3-5, 8]. Free-flow of data collected from disparate sources during clinical and non-clinical encounters is dependent on public confidence in routine policies, procedures and practices related to de-identification of personal health information. In addition, standards are necessary for combining data from disparate sources. In the US, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) has introduced important safeguards to protect consumer privacy and confidentiality of health information. In addition, this legislation has established standards to facilitate electronic data exchange and has driven consensus on messaging standards for communicating administrative, clinical, and financial transactions. The NLM negotiated contracts with SNOMED CT and LOINC provide additional access to standard clinical and laboratory terminologies. In addition, long-term funding from public and private sources is needed to foster a sense of collaboration and commitment to a system that will meet the needs of providers, consumers, communities and a robust health research agenda [8].

## Conclusion

The interlocking components of HIIs provide a supporting framework for improving consumer, patient, provider and community access to health information. Currently, a mechanism is needed for linking HIIs with existing knowledge, automated processes and evaluation of the ability of these infrastructures to meet the information needs of primary recipients. Openness to continued evolution and expansion of the conceptual frameworks on which HIIs are based is necessary for supporting knowledge generation and real time access to research evidence. In addition, further methods are needed to evaluate the ability of HIIs to meet national health information needs. In the US, the Healthy People 2010 Health Communication goal and objectives offer a practical step towards setting national e-communication goals and evaluating the evolving NHII infrastructure in meeting the informational needs of primary recipients. Additionally, automated knowledge management tools such as practice guidelines may provide a means by which access to critical information is delivered to consumers, providers and communities, in a format that is appropriate for their health information needs, health literacy level and that provides adequate support for informed decision making.

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