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Individualizing Cancer Care with Interoperable Information Systems

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Abstract. There are three levels of interoperable informatics that are co-occurring in the United States to link data to provide more comprehensive care to patients. One is the National Health Information Network (NHIN) that is establishing use case scenarios and standards for interoperability for patients with multiple conditions. The second is the National Cancer Institute's project that supports the enterprise work called the Cancer Bioinformatics Grid (caBIG ®) in linking clinical care with bioinformatics, tissue repositories, and imaging for patients with cancer. The third is in the area of translating the discoveries of biology to bedside care through the National Institutes of Health (NIH) translational research efforts to get these new biomedical and genomic discoveries in practice in multiple healthcare delivery environments. These developments are becoming global networks in the diagnosis and cure of cancer as the primary outcome. This paper describes the national efforts and the global connection to Europe through the caBIG® program. The European program that is beginning to link to cancer research internationally is the National Cancer Research Institute (NCRI) in the United Kingdom. They are developing the NCRI Oncology Information Exchange (ONIX) to provide the cancer research community with the ability to share information.

Keywords: Interoperability, standards harmonization, cancer research and care, translational cancer care, nursing impact

1. Introduction

This paper will review basic concepts of a National Healthcare Information Networks (NHIN), a cancer Biomedical Informatics Grid (caBIG®), and the Translation of cancer information through a national network translated to 4 environments: 1) National Cancer Centers, 2) Health Care Hospital Communities, 3) Primary care Networks, and 4) Community networks. Commonalities for ultimately linking these networks mandate four major transformation areas: interoperability, standards harmonization, privacy/security, and patient centric systems. An international linkage beginning in Europe called the Oncology Information Exchange (ONIX) will be described. The challenges and opportunities for those in nursing informatics summarize this paper.

1.1. The National Healthcare Information Network (NHIN)

Because of the crisis in health care due to Americans living longer, and the volume of persons entering Medicare with chronic diseases, President Bush initially charged and President Obama continues to charge the Department of Health and Human Services (HHS) to develop solutions that will maintain the economic health of the nation. One of the ways to help a growing business such as this is through the use of information technology (IT). That would not only help in the economics of the health delivery but also in quality. Legislation was put forward in 2005 to create a National Healthcare Information Network (NHIN) to facilitate the development and adoption of national standards, and to provide financial incentives for healthcare providers to adopt health information technology.[1] The National Health Information Network (NHIN) is defined as a collection of open, standards-based networking and application services that collectively enable the exchange of Electronic Health Records (EHRs) between any two authorized users securely, quickly, and reliably.

The legislation cited findings from the Institute of Medicine (IOM), the National Committee on Vital and Health Statistics (NCVHS), the General Accounting Office (GAO), and other quality studies conducted through funding at the Agency for Healthcare Research and Quality (AHRQ) concluding that moving toward a NHIN infrastructure will result in improved patient safety, improved health care quality, improved bioterrorism detection, better informed patients, and reduced health care costs.

The purpose of the legislation was to develop and test national standards, and to create incentives to encourage healthcare clinicians to adopt health information technology including electronic health records, electronic prescribing systems, evidence-based clinical support tools, patient registries, and technology to improve patient care.[2] This legislation also authorized the creation and funds for the Office of the National Coordinator for Health Information Technology and Dr. David Brailer was charged as the first; and Dr. Robert Kolodner is the current National Coordinator.

The American Standards Institute (ANSI) Health Information Technology Standards Panel (HITSP) was an established project within ONC to develop the use case scenarios and recommend standards for many areas in healthcare delivery. One of the use cases of importance to cancer care is the personalized healthcare use case.[3] Another important group that was established was the private sector Certification Commission for Healthcare Information Technology (CCHIT) to credential electronic health care informatics products that embodied the standards and concepts of interoperability.

Many of the areas supporting the NHIN and the Office of the National Coordinator remain funded in the new American Recovery and Reinvestment Act of 2009 that proposes $19billion in health IT dollars over the next 10 years. The language maintains the objectives to continue interoperable exchange of health information with information technology and standards. [4]

The functions of the coordination in health IT have recently been extended to a public private partnership called the National eHealth Collaborative (NeHC).[5] This organization is dedicated to the creation of a secure and interoperable NHIN. The NeHC collaborative works in partnership with HITSP, CCHIT, and NHIN. Figure 1 is a depiction of the NHIN presented by the National Coordinator, Dr. Robert Kolodner in June 2008.[6] It demonstrates that the first order of connecting a NHIN is to connect the already linked federal agencies, health IT agencies, state health agencies and public health infrastructures, and public private networks.

1.2. The National Cancer Institute (NCI) cancer Biomedical Informatics Grid (caBIG®)

With the advent of the discoveries in genetics, proteomics, metabolomics, and cancer cell dynamics in the 21st Century, the NCI embarked on the development of the cancer Biomedical Informatics Grid (caBIG®).[7] This is an organized grid platform to connect researchers, cancer centers, and others working in the prevention, diagnosis and cure of cancer to access patient information and monitor research discoveries. The architecture of the caBIG Grid can be found in a recent publication from AMIA.[8] The

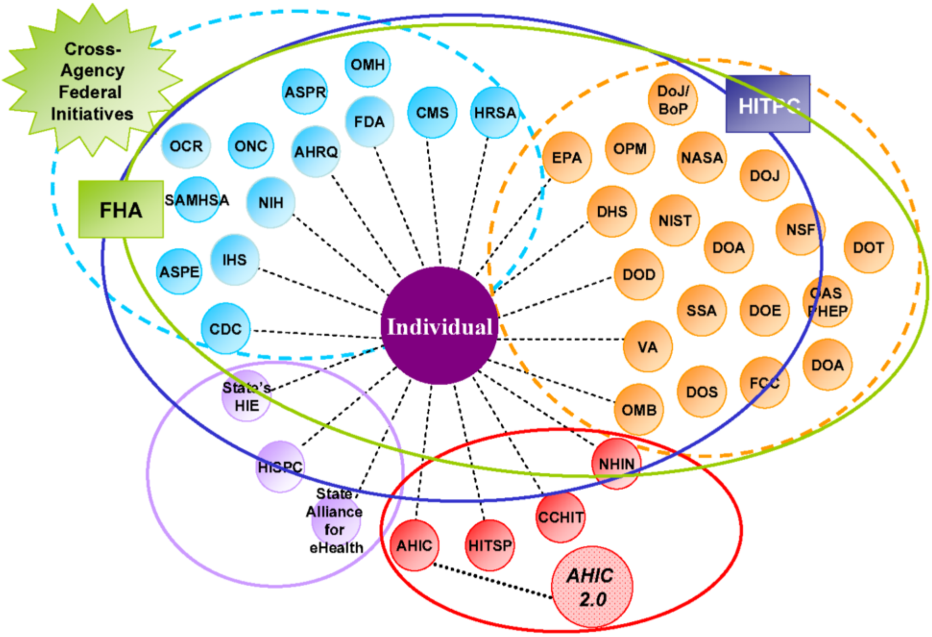

Figure 1. The National Health Information Network (NHIN) (from Kolodner, caBIG Annual Meeting, 2008)[6]

suite of software applications is designed to help those involved in research to identify the policies and rules of data sharing, privacy and security. A central feature of the platform is the common vocabulary so that persons can exchange data and information. The suite of software tools facilitate the biomedical researcher in analyzing complex biomedical data, manage clinical trials, images, and establish tissue banks to share cancer specimens. This network is serving as a model as the electronic health record is advanced with data-driven evidence of the genetics and environmental factors affecting the development, growth, and metastasis of cancer.

The ability to effectively reach the goals of personalized healthcare is embodied in the ability to create interdependencies between different parts of the healthcare system in real time. This requires using interoperable systems and connectivity. The caGRID provides the connectivity and access to integrated tools to collect, analyze, and share data in standardized formats for the platform.[9]

The information from the cancer centers could be set up to flow within the larger national infrastructure, and the larger NHIN could begin connecting to networks already linked through the caGRID. Some of the Regional Health Exchanges also include large hospitals that are already connected to the caGRID, e.g. in states such as North Carolina, and regions such as the northwest, the northeast, the midwest, and the south. Through interoperability, the scientists, clinicians, patients, and other participants can share standardized information. The caGRID platform and caBIG® enterprise provide the most advanced interoperability to advance personalized health in cancer and to translate advances in biomedicine to clinicians in healthcare delivery.[9]

The principles of caBIG® have been 1) open access, 2) open development, 3) open

Figure 2. Essential structural components of caBIG®

source, and 4) federation. This world wide web of cancer is supporting the cancer community network on the caGRID. Figure 2 depicts essential structural components of caBIG®.[10]

1.3. Translating the caBIG® to National Health on the caGRID

There are still not enough healthcare practitioners who use electronic health records (EHRs). This adoption gap has been recently reported by a contract from ONC. The most recent hospital survey was presented in Washington, DC on November 12, 2008. The results demonstrated that 1.7% of private hospitals have fully functional EHRs and up to 78% have demographic data, lab test and radiology. Thirty-six percent (36%) have fully functional nursing assessments, and 20% have nursing assessments on at least one unit. [11] If federal hospitals were included in the analysis that would increase the number of EHRs in the US. Another survey of 2,758 physicians in ambulatory practice demonstrates that only 4% have fully functional EHRs and 13% have a basic record system.[12] A similar survey does not exist for describing the electronic record support for nurse practitioners in primary care throughout the country. Nurses are caring for cancer patients who reside in economically deprived and rural environments and come from diverse backgrounds. Patients with diversities and disparities are on the agenda for the new Health IT implementation plan.

We need healthcare practitioners to be digitized if we are to improve healthcare delivery to cancer patients. Transformation will have to occur. A pathway to achieving these goals is through the establishment of a National Health Information Network (NHIN). Figure 3 is an adaptation from Dr. Kolodner's slide from his presentation at the caBIG Annual Meeting. This figure demonstrates how the caBIG® could fit within the NHIN to translate cancer discoveries to the healthcare community networks (T1,T2,T3, and T4).[6] T1 includes the cancer centers, T2 other Community Clinical Oncology Program facilities participating in clinical trials and Community Cancer Center Programs, T3 are primary care environments, and T4 are state and community networks, faith-based groups, and other areas where cancer patients receive care.

Cancer registries could be included in the model linking NHIN and caBIG® to translate the total information available about cancer in the country. There are several diseases in the United States that require entry into data registries. For example, with

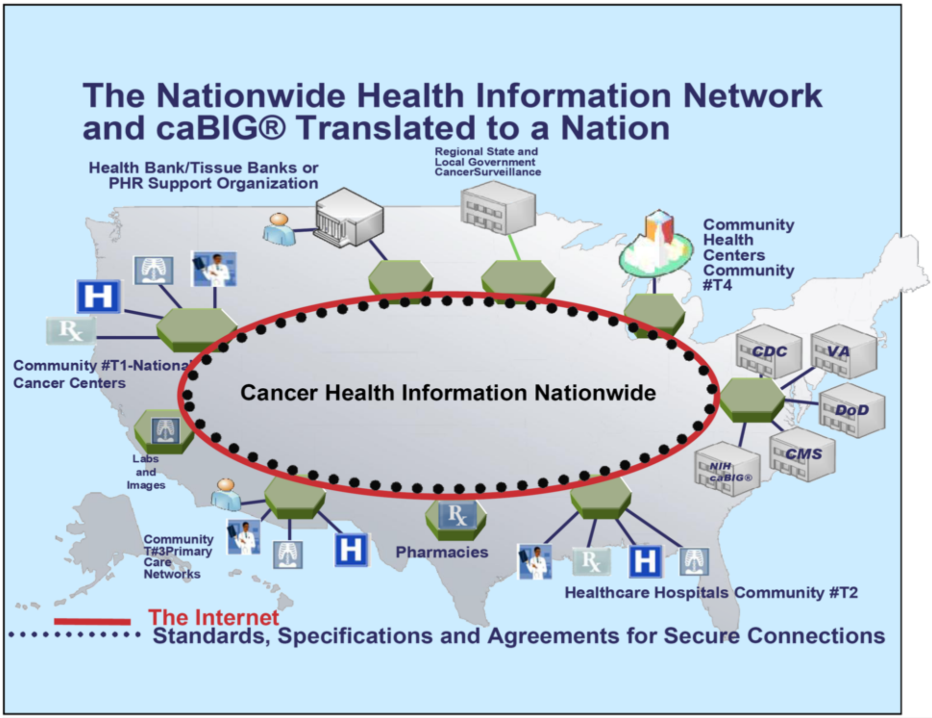

Figure 3. The Cancer Health Information Network, adapted from the National Health Information Network, Kolodner, caBIG® Annual Meeting, June 2008.[6]

cancer, the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI), in collaboration with the North American Association of Central Cancer Registries (NAACCR), collect data and report it on the statistics for cancer cases diagnosed and for cancer deaths that occur. The reports become the official federal government cancer statistics for cases. Cancer incidence data are from the CDC's National Program of Cancer Registries (NPCR) and NCI's Surveillance, Epidemiology, and End Results (SEER) Program. Cancer mortality statistics are from CDC's National Vital Statistics System (NVSS).

2. Concepts of Interoperability and Standards required to link NHIN and caBIG®

The areas requiring transformation in order to make the NHIN for cancer patients a reality are in the areas of interoperability, standards harmonization, protecting privacy and security, and patient centric systems. The concepts of interoperability and standards between the NHIN and caBIG® are presented in Table 1.[9]

In order to improve quality of care, provide clinicians with better decision-making tools, share information between health providers involved in care to persons, track outcomes of care, and coordinate healthcare activities, the information system developed needs to be interoperable. If the care to patients is coordinated, and information is shared between practitioners, redundancies and errors should be reduced. Several models of interoperability precede us in the US. The analogy that the former

Table 1. Concepts of Interoperability in NHIN and caBIG®

NHIN	**caBIG®**
Standards of interoperability	Standards of interoperability
Secure	Secure
Data Sharing	Data Sharing
Privacy	Privacy
Involves human data	Involves human data
Involves use cases	Involves use cases
Defines adverse event reporting	Defines adverse event reporting
	Includes common data elements defined
	Includes enterprise vocabulary
	Billing prototype developed
	Can exchange clinical trials information, images, tissue, and biomedical genomic data separately and ultimately can be integrated

Secretary Leavitt used is the transportation system that was not across America until standards of the width and gauges of tracks were established. Another model is the Post Office that takes packages and envelops going to multiple destinations from one box and distributes them worldwide.

The most important policy solutions have been to guarantee that the privacy and security of patient data is protected, while also permitting the rapid and accurate exchange of information between authorized users. Policies were needed to establish common intercommunication tools such as mobile authentication, web services architecture, and security technologies to support data movement that is inexpensive and secure. The need for privacy and security is fundamental and codified under the Health Insurance Portability and Accountability Act (HIPAA) and other legislation defining protected private information in order to prevent social or financial harm to individuals due to misuse of their medical information. However, the interoperability requirements to freely and quickly get the right information about the right patient to the right provider at the right time require functional interpretations of privacy and security "business rules" into the practical solutions for NHIN architecture and technology at the national, regional and local levels.

The caGRID has been developed with strict protections of patient data and carefully monitored access to biomedical research data. Because NHIN and caBIG® are systems-of-systems, or web-of-webs, the challenge has been to recognize and ensure privacy and security within each system, and that authorization and authentication are handled accurately and efficiently at system interfaces. Encryption policies, which currently protect much national security and commercial information transmitted across the Internet are also defined by NHIN and caBIG®. The movement toward patient centric personalized healthcare focuses on having the genomic data that can define a person's susceptibility to cancer, prevention, diagnosis, and treatment to result in cure. Having personal records then empowers the patient to be an active, informed participant in not only their own medical care but in achieving healthy lifestyles. Healthcare management data on real-time population trends developed using the NHIN and caBIG® can be used to tailor healthcare for the individual patient.

3. International Linkages between caBIG® and the United Kingdom National Cancer Research Institute (NCRI)

While there are many international endeavors linking US national efforts with China, India, and Asia, one that has advanced to incorporating caBIG® into a prototype is the National Cancer Research Institute (NCRI) in the United Kingdom. Similar to the US, the UK espouses that building a platform of interoperability and with common vocabulary is essential to empowering researchers and clinicians to unlock discoveries in cancer cure.[13] By integrating interoperable data, the search for patterns of cancer diseases and the potential prevention and treatments matched to individual patients, aids translational efforts by providing optimal personalized care. The UK model links the researchers with the drug industry and healthcare providers to determine if they can improve safety and efficacy of drug assessment and transfer of results from bench to bedside.[14]

One of the initial products of NCRI is the prototype Oncology Information Exchange (ONIX).[15] This was created to provide the cancer research community with public domain access that is easy to use to discover and share information on the latest developments in genetics and proteomics. Users must register to become participants, but will have access to biomedical data, analytical tools, research publications, and new technology to create information networks that provide resources to those involved in oncology healthcare information technology exchange.

4. Nursing Impact

There are major national and international efforts to link interoperable data for cancer patients. Nurses are engaged in the design, development, and implementation of many of these systems. They remain a prominent healthcare developer of the national and international standards.

Some of the nursing challenges remain focused on providing incentives for billing patients participating in research, scheduling patients with calendar services, supervising workflow and resource consumption, managing ethical concerns in patient recruitment, and administrating policies for shared data from competing environments. Many of the caBIG® tools can facilitate nurses in making decisions and handling these complex issues. Sharing best practices and guidelines for improved patient care, monitoring adverse drug reactions, patient safety practices, best outcomes, and quality can be developed with knowledge management of large knowledge repositories integrated into the electronic health record (EHR) available from the NHIN and caBIG® . Communities of practice are being created to develop social networks of health professionals with similar interests and patients with specific diseases. Many of these communities are being developed and managed by advanced practice nurses. Portals are synthesizing the entry to vast amounts of data and information that was previously inaccessible. Over time, the resources within NCRI and ONIX in the UK may also include tools and services to nurses.

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