

National Health Information Network: Lessons Learned from the USA and the UK

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ABSTRACT

National Health Information Network (NHIN) is a network in which all healthcare organizations, government agencies and other health-related organizations are connected to each other in order to exchange information about health. Due to the necessity of a framework for NHIN development, in this paper, according to the literature review, a definition for NHIN framework was provided, and then the NHIN-related projects were reviewed in the United States of America (USA) and the United Kingdom (UK), NHIN and National Program for Information Technology in the NHS (NPfIT), respectively. The Review of NHIN framework in the countries studied show some similarities and differences in each dimension that are discussed in this framework. NHIN guiding principles in the NHS NPfIT were not regarded or were considered incomplete, compared to the US. NHIN architecture in the US is decentralized while it is centralized in the UK. Based on the review of NHIN framework, these two countries represent important points that can be used in many other countries. However, it can be said that the development of NHIN not only means the implementation of national system or systems, or the binding of local health information systems, but it also needs to build on a framework in which many of the issues related to the formation of NHIN would be considered, including the cooperation between government, private sector and stakeholders with regard to local, national and international needs.

Keywords: National Health Information Network; National Health Information system; Health Information systems

INTRODUCTION

National Health Information Network (NHIN) is a network in which all healthcare organizations, government agencies, other health-related organizations and health plans are connected to each other in order to exchange information regarding health [1-5]. In fact, NHIN is a network of networks created by the connection of public and private sectors involved in the field of health. Using this network, patients' information can be detected anywhere in the healthcare delivery system. In addition, information will be available for the purposes of healthcare system decision-making process, treatment process and public health [6]. Creation of Electronic Health Record (EHR) also depends on complete implementation of the network [7]. By creating databases of patient data, this network can accelerate medical studies and researches [8]. In total, it is expected that NHIN collects health data from multiple

systems, sharing them among all stakeholders so that different audiences in the health sector can be able to use them logically. Ultimately it leads to the promotion of public health [9-10]. It is clear that achieving the ultimate goal of health promotion and benefits of launching NHIN requires support for the design of the network [11]. In other words, it is essential that its design and development be based on an appropriate framework. Stead (2005) in this framework has referred to issues including governance, policies and network architecture [12]. Office of National Coordinator for Health Information Technology in the US (ONC) has also discussed the architecture of the network through NHIN documentations [13-14]. On international level, Health Metrics Network (HMN) and its partners have introduced a framework for National Health Information System (NHIS) development [15] The framework consists of three parts: (1)

components, (2) principles and (3) the process of NHIS development and improvement. The components include: resources of NHIS, health indicators, health data sources, data management, production and use of healthcare information. The principles also refer to five principles in the development of NHIS and the process refers to the components implementation chart [15-19]. Since in the framework introduced by HMN, the process dimension is different in every country considering the health system of that country, and on the other hand, the health data sources refer to the overall architecture of NHIN, in this study, with regard to HMN and World Health Organization(WHO) documentations,[9,15-18] documentations of NHIN architecture in the US[13-14] and related articles[12], NHIN framework is introduced in three dimensions, including: components, principles and overall architecture of the network. In this paper, according to the dimensions outlined in the NHIN framework, the NHIN-related projects including NHIN (Nation-Wide Health Information Network) and NPfIT (National Programme for Information Technology in the NHS (National Health Service)) were reviewed in the US and the UK, respectively. The results of this study are expected to be of use for other countries, especially the developing countries.

BACKGROUND

The US and the UK are among the leading countries that have established projects in order to deal with the challenges of fragmentation of health information systems [20]. The most notable project has been the NHIN [21-23]. A background of these projects in the two countries is provided as follows.

National Health Information Network in the US

The history of the development of the NHIN in the US dates back to 1986, when the national biomedical computer network was developed by the National Library of Medicine [24]. Later, the concept of the National Health Information Infrastructure (NHII) was introduced, and in 2004, President George W. Bush issued the widespread use of Electronic Health Record, creating the Office of National Coordinator for Health Information Technology (ONC) in the Department of Health and Human Service (HHS) to

manage the system [25-29]. In November 2004, ONC introduced the NHIN and released the Request for Information (RFI); and in June 2005, with the publication of the Request For Proposal (RFP) for NHIN architecture, signed contracts with Accenture, CSC (Computer Science Corporation), IBM (International Business Machine) and Northrop Grumman companies[13-14,28-33]. After collecting architectural prototypes, NHIN generally constituted of the following: Health Information Exchange Centers (HIEs), Regional Health Information Organizations (RHIOs), Health Information Service Providers (HSPs), participants and members with specific goals such as public health, quality assessment and health studies [13]. Finally, the overall architecture of NHIN was introduced as a network of nodes that were various types of health information organizations participating in information exchange through the NHIN gateway [14]. NHIN gateway launches NHIN technical specifications to each node so that it can support secure health information exchange on the NHIN level. The CONNECT application developed by the Federal Health Architecture (FHA) is a sample of NHIN gateway. Implementation of NHIN gateway in each node maintains their autonomy and enables them to communicate with each other while receiving NHIN specifications [14, 34-36]. In September 2007, the Department of Health and Human Services signed a contract with nine health information exchange centers and a number of federal agencies in order to implement a pilot NHIN. The NHIN was scheduled to come into operation in 2010, so in early 2009, the federal and non-federal entities that had participated in NHIN experimental phase began to exchange information [27, 29, 32, 37]. By 2010, integration of local systems, RHIOs, HIEs, federal agencies, and other large health care systems such as Kaiser Permanente into a comprehensive system with prevalent standards, became the national health information architecture model for the United States. Based on this design, RHIOs were the main building blocks of the US government's efforts to exchange health information. Due to financial issues and problems related to the maintenance of these organizations, the benefits reached were not significant; consequently, according to the HITECH act (The Health Information Technology for Economic and Clinical Health), during Obama's term, ONC did

not finance regional health information organizations directly. Instead, through the regulation, ONC financed the States to develop comprehensive state-wide health information exchange programs. In some states, including Indiana and Delaware, RHIOs were continued, but in some, including California, state-wide health information exchange programs were introduced instead of RHIOs. Due to these changes, ONC in its 2011-2015 Strategic Plan confirms the use of a web-based model in which there are different types of networks in a region for sharing health information. Some of these networks are hospital networks, group practice, companies providing EHR systems, local area networks such as RHIOs, companies providing medical, laboratory and drug equipment, and services [38-43]. It should be noted that joining NHIN, sharing and using data and information in this network requires the signing and verification of Data Use and Reciprocal Support Agreement (DURSA). DURSA is a comprehensive and reliable multilateral legal agreement that is based on a number of policy assumptions which can connect a variety of state and federal laws and policies to each other while supporting multilateral exchange of information through NHIN. This agreement plays an important role in security of information exchange, determining the levels of security, sending and monitoring of transactions as well as identifying and responding to invasive softwares (malwares). On the other hand, organizations that are involved in NHIN are responsible for the privacy and security of patients' personal information. Signing DURSA further specifies the responsibilities of participating members in NHIN for data providing [14, 44]. ONC is the only federal entity that is responsible for coordinating national efforts in NHIN. This entity operates to achieve its mission using defined programs and structures, including: state-based cooperation plan for the electronic exchange of health information, development and training plans for human resources, coordination, policy and standards committees [27, 39-43]. NHIN Planning, monitoring NHIN policies and procedures are examples of responsibilities of the coordination committee. The technical committee (standard committee) is involved in NHIN specifications and testing approaches. Policy committee is also involved in providing suggestions to NHIN policies

[45-46]. It should be noted that the National Committee on Vital and Health Statistics(NCVHS), has the role of the general advisory committee to HHS, the committee provides advice to the Minister of Health on national health information policies[47].

National Health Information Network in the UK

In 1998, the British government announced the national health information strategy for the NHS (National Health Service) titled "Information for Health". The plan was aimed to develop and operate EHR by 2005[48-51]. In June 2002, the Department of Health published a document titled "Providing the 21st century IT support for the NHS: National Strategic Plan". This document confirmed the importance of the objectives in the strategy of 1998, pointing out that for reasons such as financial issues, central government interference and poor network facilities, there is no possibility of developing EHR. The NHS authorities stressed that a fully centralized approach to the NHS information technology program is the only strategy to deal with these problems and obstacles. Therefore, in 2002, NPfIT was replaced with the Strategy of 1998 [49, 51-52]. Due to these changes, the agency NHS- CfH (NHS-Connecting for Health) was founded in April 2005 as part of the Department of Health in the UK. This agency replaced the previous administration entitled "NHS Information Authority". Until 2009, the NPfIT had been managed by CfH and 10 strategic health authorities. On March 31, 2013 CfH was diminished and its projects and responsibilities were assigned to the new center entitled: "Health and Social Care Information Centre" (HSCIC) [51, 53-60]. Review of NPfIT documentations show that from January 2009, while some systems of this program were created, other key components were delayed for about 4 years. By 2011, the majority of the program's elements had been fully operational. The Summary Care Records (SCR) system was the only element with noticeable delay in a way that only about 10% of NHS organizations were ready to be used. Until March 31, 2011, only 8.5 million summary care records were created while 54 million SCR were expected to be created [61-66]. NPfIT is a program of the Department of Health, which aims to propel NHS towards the creation of centralized

Electronic Health Record for patients as well as linking health care providers [49, 51-53]. In general, the structure and scope of this program is divided into three main sectors including the clusters and local service providers (LSPs), national systems and national service providers, and the N3 network. NPfIT divided The UK into five regions as clusters. For each cluster, it assigned LSPs to provide the systems needed on the local level. In addition to LSPs, National Application Service Providers (NASPs) were assigned responsibility for national systems [51, 61-64]. National applications are known as "The Spine" [51]. The Spine is a set of eight applications that support National Care Record System (NCRS). Three of the applications keep Care Record data, four applications had security purposes, and the other is an instant messaging service that interface between the Spine and other systems, including choose and book, and electronic prescription [51,61,67]. The third sector of the NPfIT is the N3 network. The N3 is a private wide area network of NHS that connects all NHS sites, including hospitals and other non-NHS sites that provide healthcare services [51, 61, 68-70]. Members of the N3 generally include Community of Interest Networks (CoINs), gateways to other networks, and direct Members. CoINs have been developed for local NHS community. In 2013, more than 70 CoINs were connected to the N3 [69-74]. The N3 has a number of gateways to other networks. The important ones are Internet, pharmacy, JANET (joint academic network), NHS in Wales and Northern Ireland, and Government network gateways. There is a completely secure connection between the N3 and a series of other networks entitled "Government Secure intranet" (GSI). The government departments and local authorities are located in this intranet. These communications can improve information sharing between sectors that provide social and health care services [75-78]. Apart from CoINs and gateways connected to the N3, other users of the

network include: acute, ambulance and care trusts, dentists, general practitioners, health system providers, hospice care centers, independent health care sector, local authorities, mental health trusts, national blood service, pharmacies, data centers, and health application providers [70-71, 73, 79]. The N3 contract was valid until March 2014, until the new network HSCN (Health and Social Care Network) replaced it [73-74, 80]. The department of health is supporting NPfIT. On a higher level, board of managerial departments in the Ministry of Health has the duty of managing this program, [56-60] while on lower levels, the leadership and ownership of the N3 network in England and Scotland belong to HSCIC and National Service Scotland (NSS), respectively [68-71]. The N3 security is also supported through security protocols and local responsibility (data senders and receivers) [69, 71]. On the other hand, in order to use the systems and services of the HSCIC including the N3, all users and member organizations of the network must accept and sign the Information Governance Statement of Compliance (IGSoC) [81]. In other words, in data exchange and use, this statement plays a legal framework role [81].

RESULTS AND DISCUSSION

NHIN Framework in the US and the UK

A comparison of NHIN framework in countries under study is presented using tables and lists, in accordance with the framework dimensions.

NHIN Components

NHIN components include leadership and coordination, information policies, financial and human resources, ICT (Information and Communication Technology), health indicators, health data sources, data management/information production, and ultimately the distribution and use of information [15-18]. Table 1 presents a comparison between these components in the NHIN projects of the studied countries.

Table 1. Component dimension of framework in the US and the UK

Country components		United States (NHIN)	United Kingdom (NPfIT and the N3)
Leadership and coordination		ONC + Coordination Committee + federal advisory committees + National Committee on vital and health statistics + HIT strategic plan	HSCIC + managerial Board of the Ministry of Health + strategy of HSCIC
Information policies		DURSA + federal and state laws related to Information security and privacy	the Information Governance Statement of Compliance (IGSoC)
Financial Resources		decentralized by: ONC, State-wide health information exchanges and RHIOs,	Centralized by the Ministry of Health and HSCIC
Human Resources		Training human resources by university centers (with the guidance and financing of ONC) + certified exam by ONC	Training human resources by: HSCIC and universities
ICT Resources	hardware	Computers+ network equipments	Computers + phone + mobile network equipments
	software	NHIN gateway+ federal information systems + member's Information Systems + Verified software	N3 gateways + the national systems that have been launched at local level
	Communication infrastructure	Internet	private WAN + Internet
Health Indicators		National Health Indicators in National Center for Health Statistics [82]	national health Indicators portal in HSCIC [83]
Health Data Sources		As members of NHIN	As members of N3
Data management/information production		Locally + National Health indicators Portal + definition of minimum data set (MDS)	Nationally and limited locally + National Health indicators Portal + definition of minimum data set (MDS)
Information Dissemination and use		Multilaterally by DURSA agreement, used for different purposes (NHIN and member organizations)	Multilaterally by the Information Governance Statement of Compliance (IGSoC) and used for different purposes

The Principles for Developing NHIN

NHIN design and development should be based on a set of basic principles including leadership and ownership, focusing on the needs, developing and building existing and already-in-use structures, broad consensus and employment of a gradual approach. These are principles that

are confirmed by more than a hundred ministers and senior officials of international agencies and organizations in the Paris Declaration on March 2nd, 2005. The Comparison of these principles in the NHIN plan of the studied countries has been shown in Table 2.

Table 2. The guiding Principles for NHIN development in the US and the UK projects

Country Principles	United States (NHIN)	United Kingdom (NPfIT and the N3)
Determining Country leadership and ownership	ONC	HSCIC
Responding to country needs and demands	Published requests for information, request for proposal for NHIN + NHIN Coordination Committee + compiling national strategic plan for HIT	In NPfIT and its network (N3) partially has been focused to needs + compiling strategy for HSCIC
Building upon existing initiatives and systems	This principle has been fully respected (NHIN development as a network of networks, without replacing other systems)	Because of the centralized view in NPfIT, this principle has not been observed.
	Publication of Request for	In NPfIT this principle is not visible.

Building consensus and stakeholder involvement	information + NHIN Coordination Committee	
Gradual process with a long-term vision	This principle has been respected	This principle has been partially met.(Substantial changes during the program)

National Health Information Network Architecture

Due to the different views on the so-called architecture and network architecture [14, 84-86], in this article, the NHIN architecture encompasses three dimensions including: (1) network members/nodes (2) interfaces (interactions between members), and (3) relationship with the environment (security and privacy). According to this definition, in network architecture, the constituents include sub-systems, interfaces and their relationship with the environment [14, 84-

86]. The NHIN sub-systems, in fact, will be the information systems of stakeholders. These systems, at any given point, will be at different stages of their life cycle. Therefore, for NHIN development and operation, we focus on the interfaces between different systems while they interact with each other, so that the participation in the NHIN would not be required to remove and replace the current systems [14]. Lists 1 and 2 show architectural dimensions of the NHIN in the US and the UK, respectively.

List1. architectural dimensions of the NHIN in the US

Network members/nodes

Federal agencies (the most recent list includes 33 ministries, agencies and national organizations with their sub-centers)

Health Information Exchanges(HIEs)

Regional Health Information Organizations (RHIOs)

Integrated Delivery Networks(IDN)

Personal Health Record(PHR)

Registries & Repositories

Pharmacies

Clinics

Hospitals

Imaging centers

Laboratories

Community health centers

Insurance and Reimbursement System (s)

State and local government

State-wide Health Information Exchange Programs

Interfaces

NHIN gateway

Relationship with the environment

(Security and confidentiality)

Autonomy and local responsibility

Technical solutions

Legal agreement (DURSA: Data Use and Reciprocal Support Agreement)

List 2. architectural dimensions of NHIN (the N3) in the UK

Network members/nodes

- Community of Interest Networks (CoINs))
- Direct network members
 - Acute Trusts
 - Ambulance Trusts
 - Care Trust
 - Dentists

- Basic Trust
- Family Physicians
- Providers, Health Systems and Software
- Hospice healthcare Centers
- Independent Healthcare Sector
- Officials and Local Authorities
- Mental Health Trusts
- National Blood System
- Systems of HSCIC
- Insurance and Reimbursement System (S)
- Primary Care Trusts
- Special Health Authorizes
- gateway to other networks
 - Internet Gateway
 - Mobile and phone network
 - pharmacy (pharmaceutical network)
 - Joint Academic Network(JANET)
 - Gateways to the NHS in Wales and Northern Ireland
 - Gateway to the government network, including government departments, local authorities and agencies

Interfaces

- Aggregators
- Gateways

Relationship with the environment (Security and confidentiality)

- Local responsibility
- Security protocols
- Legal agreement (Information Governance Statement of Compliance (IGSoC))

The review and comparison of the NHIN framework in the US and the UK reveals some similarities and differences in different aspects of the framework. According to table 1, significant differences in the component aspect of the NHIN framework include some issues in leadership and coordination, software, and data management employed. In NPfIT, a coordination committee has not been established to take the comments of stakeholders [55]. However, in order to achieve success in Information Technology (IT) projects, the involvement of stakeholders is inevitable, especially in national-scale projects. Many studies have noted the role of stakeholders in the design and development of NHIN [87-90].

In the Information and Communication Technology (ICT) component, review of projects in studied countries shows significant difference

in the software section. Design and installation of single national systems has not been taken into account in the approach employed by ONC. The aim has been to use the existing infrastructure and systems instead, [14] but in the HSCIC approach, the national systems have been defined which should have also been launched on local levels [51]. Given the perspective of HMN, building upon existing initiatives and systems is one of the most important principles in the NHIN development; therefore it seems that the NHS approach has not been correct in the design and implementation of national systems, nonetheless. Conducted studies also rule out the launching of a single national system. In this case, Stead (2005) states that given the challenges facing the NHIN including complex health care processes, variety of patients' health data, biomedical knowledge

and important aspects of NHIN, developing a single, massive and national system is not justified and cannot support the network's goals [12]. Data management is also affected by the use of national systems. Since national systems are used in the NPfIT, data management is centralized [51], while in America's NHIN project, this one is completely decentralized [14]. Considering the fact that the main purpose of data management is archiving data in a way that long-term analysis and using them would be possible for different purposes- including analysis of disease patterns, quality evaluation of services, health policy making and finally promoting the health of the community and public [15]- health data are collected from various sources while each member of the network and local networks have special needs. Therefore, as it is best to manage data on the local level, and on the national level, designing Integrated Data Repository (IDR) is recommended. This approach will meet the local needs and on the national level will ensure data quality and their proper use. HMN also suggests integrated data repository for data processing at national level [15]. The communication infrastructures of the NHIN in the surveyed countries are somewhat different. In this case, compared with the US that uses internet as the main infrastructure of the NHIN project, [14] the UK uses the private Wide Area Network (WAN) using internet connection [69-71]. Several factors are involved in the communication infrastructure, from which at least two important things should be noted: a) continuity of network connection and preventing its interruption, and b) security and privacy. Therefore, according to these vital factors, the use of private network in national intranet basis appears to be a good choice. This choice is very important, particularly in countries with permanent internet connection problem. According to Table 2, the comparison of the NHIN guiding principles in the NHIN projects of the studied countries suggests that almost all of these principles are considered in the US NHIN project. In the NHS NPfIT, with the exception of the first principle, determining country leadership and ownership, other principles were not respected or were considered incomplete. As discussed previously, due to the centralized view in NPfIT, in developing national systems with

more focus on technology rather than the needs of the users, these four principles are disregarded. Similarly, Coiera (2009) indicated the weakness of NPfIT in his studies [91]. These guiding principles are also approved and accepted by more than one hundred health ministers, chiefs of international agencies and organizations [47, 92]. Because of the importance of these guiding principles, it is clear that the national health authorities of each country should consider them in the design and development of NHIN. The review of the NHIN Architecture (the third dimension of the framework) in the US and the UK indicates that the two countries have been performing similarly in the interface development and setting the security and confidentiality issue of NHIN. The only major difference lies in the architectural arrangement of the NHIN members or nodes. In other words, NHIN architecture in the US is formed by the connection of local networks including Health Information Exchanges (HIEs), Regional Health Information Organizations (RHIOs), integrated delivery networks, state-wide health information exchange programs, federal agencies and other health-related organizations [14]. This type of architecture in the literature is called the bottom-up approach [91,93], while in the UK, the architecture of the N3 network (related to NPfIT) is centralized, which means that the governance, systems development and network members or nodes have been defined centrally [51,71]. This approach is known as top-down approach [91, 93]. The technological changes and the need for updating systems, compatibility of the systems with user and local needs, training of personnel and related costs are examples that are easier to carry out in the bottom-up approach. However, in the top-down approach, only in the case of technological changes, it is necessary to replace or update the entire systems with high costs. The cost of training personnel will be added as well. In contrast, the difficulty to align the local networks with the national goals is an example of the disadvantages of the bottom-up approach [21, 91]. However, either of the approaches used in the NHIN architecture has both advantages and disadvantages. However, the important point is that choosing each approach depends on the structure and nature of the health system of a

country [93]. While the health system is highly centralized in some countries, it is completely decentralized in the others. Certainly, the NHIN architecture will be somewhat different in these systems. Therefore, some studies propose Middle-Out approach for NHIN architecture [88, 91, 93]. In this approach, the needs of health care providers, IT industry and the government are to be considered first, and then the shared goals are defined in the technical and non-technical aspects of the NHIN. Government takes over the leadership of the network and plays the role of a facilitator and the NHIN is formed by defining interoperability standards and connection of provincial (state) health information networks and other stakeholders' networks [88,91,93]. The review of the NHIN framework in these two countries, however, collectively represents some important points that can be applied in many countries. There are several important lessons pointed out based on the results of this study, among which are the following of the NHIN guiding principles, determining a center at the national level (usually in the Ministry of Health) to lead efforts of the NHIN design and development and to cooperate with stakeholders and advisory bodies, compiling national health information technology strategic plan by considering NHIN, information policy making as the legal and organizational framework of the network, taking into account the human and financial resources, using ICT resources based on existing infrastructure, considering the needs of users and interested organizations, identifying the data sources and the combined health data management approach (local and national levels), and designing NHIN architecture by taking into account existing structures and local, national and international needs.

CONCLUSION

Ultimately, it could be stated that the development of the NHIN does not only mean the implementation of national system or systems, or the binding of local health information systems, but it also needs to build on a framework in which many of the issues related to the formation of the NHIN would be considered. The experiences of the countries, the US and the UK indicate that the

design and development of this network should be done jointly through the cooperation among government, private sector and stakeholders with regard to local, national and international needs.

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