Developing a General Framework for National Health Information Network for Developing Countries

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Abstract

The National Health Information Network (NHIN) is one of the key issues in the field of health information systems in any country. On the other hand, the development of this network should be based on an appropriate framework. Unfortunately the conducted projects of health information systems in the Ministry of Health of Iran do not have full compliance with the concept of NHIN. The present study aimed to develop a general framework for NHIN of Iran. In this study, in the first stage the required information about the concept of the NHIN framework and related NHIN documents in the USA and the UK was collected based on literature review. Then, according to results of first stage and with regard to the structure of Irans health system, a general framework for NHIN of Iran was proposed. The Delphi technique was conducted to verify the framework. Data related to experts opinions were analyzed using SPSS 13 software. The proposed framework for NHIN of Iran includes three dimensions, including: components, principles and architecture. Over 80 percent of experts have evaluated all three aspects of the framework on an acceptable scale. In total, the proposed framework has been evaluated by 83.85 percent of the experts on an acceptable scale.

Keywords:

National Health Information Network, Health Information Exchange, National Health Information System, Health Information Systems

1. Introduction

Nowadays despite the fact that Ministry of Health (MoH) is the protector of public health and is responsible for collecting, processing and using health data nation-wide, there are also some other departments involved in health domain and information[1-3]. Actually there is significant relationship between the health information systems of MoH and information systems of other departments and organizations including Atomic Energy Organization, Ministry of Interior, Ministry of Defense, Ministry of Industry, Ministry of Agriculture, etc.[3-4]. Considering these relationships the notion of *National Health Information Network* (NHIN) is emerged [5-6]. NHIN is a network that relates all health service providers, health plans and projects, health information providers, governmental organizations and health related organizations in order to exchange health information [6]. NHIN is expected to collect health data of different systems and share them among the stakeholders. By using these data the health activists especially from MoH can meticulously monitor health problems of the whole nation [1, 6-7].

Developed countries have paid too much attention to the importance of NHIN for many years. In order to develop NHIN, the US (United States) and the UK (United Kingdom) have taken great steps since early 2000s. Their projects were entitled Nation-wide Health Information Network (NHIN) and National Programme for Information Technology (NPfIT) in the NHS (National Health Service) [6, 8-9]; whereas the studies in developing countries show that lack of policies and comprehensive plans on national health information is a serious deficiency in these countries [10-11].

In Iran review of the documents related to projects on health information systems of MoH including Electronic Health Record (SEPAS), National Health Network (SHAMS) and Integrated System of Iran's Health Statistics and Information System (SINASA) [12-15], and their assessment based on NHIN's definitions in valid texts [6] demonstrate that the above mentioned projects do not have full compliance with the concept of NHIN. Generally, in these projects internal standpoint is governing because SEPAS acts as the connector between hospital information systems and SHAMS is considered as the communication infrastructure of medical and diagnostic centers [13-14]; while SINASA is integrated database of statistics and information of MoH [15].

Review of National Scientific Health Plan [2007), Health System Reform Plan (2011) and other documents

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including the Fifth National Development Plan in health domain represent that NHIN in Iran is not taken seriously as it should be [16-18]. National studies also indicate some deficiencies of National Health Information System including lack of standards, laws and regulations and inappropriate infrastructure [3]. Besides, in evaluation of Iran's National Health System the World Bank pointed out strengths and weaknesses of Iran's health information systems and also suggested some advices to improve National Health Information System among which the need for designing NHIN was notable[19].

In general, insufficient attention to developing NHIN in Iran is a remarkable deficiency [12-16]. On the other hand, it is evident that in order to achieve the ultimate goal of health improvement and other advantages of developing NHIN it is essential to design it based on an appropriate framework [4, 20]. In this framework, Stead (2005) mentioned some issues such as governance, policy and architecture of the network [4]; Moreover, the Office of National Coordinator for Health Information Technology (ONC) in the US emphasized on the architecture of NHIN [21-22]. Moreover, Health Metrics Network (HMN) and its stakeholders suggested a framework to developing National Health Information System (NHIS) [20]. From HMN standpoint NHIS framework entails components, principles and processes that form NHIS [20].

However, the structure of health system is unique for each country and a common framework cannot be proposed to all country's NHIN. *On the other hand, unfortunately the conducted projects of health information systems in the Ministry of Health of Iran do not have full compliance with the concept of NHIN; therefore it* is a remarkable deficiency in the field of health information systems of Iran. *So,* the present study aimed to develop a general framework for the NHIN of Iran.

2. Methods

In the first phase of this applied study based on the literature review, the concept of NHIN framework was defined in three dimensions of components, principles and architecture. Secondly, the documents related to the NHIN project of the US and the UK were obtained through the review of the scientific databases and MoH website of these countries. Then the documents were analyzed regarding the dimensions in NHIN framework. In the second phase of study by using the information of NHIN framework of the mentioned countries, valid scientific literature and considering the structure of Iran's health system [23-25], a framework was suggested for Iran's NHIN and then the Delphi method [26] was conducted to verify the framework. In conducting the technique, we used some experts. The experts consisted of ten specialists in the field of medical informatics and health information management. They were all faculty member of Iran's universities with the rank of assistant professor and above and they had more than ten years of job experiences. Besides, some other experts included previous and present officials of Information Technology and Statistics Office of Iran's MoH. In the second phase of the study, a semi-structured questionnaire was used for data gathering. Its validity was assessed through specification of content validity and the reliability was interpreted by Cronbach's Alpha method (α=0.88). The questionnaire was divided into three sections, including Framework Components, Principles and Architecture with nineteen, five and three close-ended questions, respectively. Furthermore, at the end of each closed-ended question there was an open-ended question for the experts' comments. Each closed-ended question was designed with multiple choices of "acceptable", "relatively acceptable" and "unacceptable" respectively with numerical value of 3, 2 and 1. Thus regarding ten participants in Delphi technique the maximum and minimum scores for each question could be respectively 30 and 10. Hence, according to these maximum and minimum scores, the acceptance, rejection and revision of each item were as following: each item score $\geq$25 = acceptance; 20 $\leq$ each item score < 25 = revision; each item score < 20 = rejection. Distributing and collecting the questionnaires were done both in person and through e-mail. Finally, data were analyzed by using SPSS-13 software.

3. Results

Results of the study are presented in two sections: 1) review and comparison of NHIN framework in the mentioned countries and proposal for Iran's NHIN; 2) verifying and developing a general framework for Iran's NHIN.

3.1 Review and Comparison of NHIN framework of the US and the UK and suggestion for Iran's NHIN

Tables 1 and 2 respectively depict the comparison of the principles and the components aspects of NHIN framework

in the mentioned countries. The architecture of NHIN in these countries and the suggested architecture for Iran's NHIN are elaborated anon.

Table1. Comparison of the principles dimension of NHIN framework in the US and the UK and suggestion for Iran's NHIN

Country / Principles	United States (NHIN)	United Kingdom (NPfIT)	Iran (NHIN)
Country leadership and ownership	ONC(office of national coordinator for HIT)	HSCIC(health and social care information center)	Center for IT and Statistics
Responding to country needs and demands	NHIN Coordination Committee + compiling national strategic plan for HIT + Published RFI, RFP	Partially focused on needs + compiling strategy for HSCIC	NHIN Coordination Committee + national strategic plan for HIT+ Various committees and teams
Building upon existing initiatives and systems	(NHIN as a network of networks, without replacing other systems)	Because of the centralized view in NPfIT, this principle has not been observed.	NHIN as a network of networks
Building consensus and stakeholder involvement	NHIN Coordination Committee	In NPfIT this principle is not observed.	NHIN Coordination Committee
Gradual process with a long-term vision	Compiling national strategic plan for HIT	(Substantial changes during the programme)	Compiling national strategic plan for HIT

Table2. Comparison of the components dimension of NHIN framework in the US and the UK and suggestion for Iran's NHIN

Country / Components		United States (NHIN)	United Kingdom (NPfIT)	Iran (NHIN)
Leadership and coordination		ONC + Coordination Committee + federal advisory committees + HIT strategic plan	HSCIC + managerial Board of the Ministry of Health + strategy of HSCIC	Center for IT and Statistics + Coordinating Committee+ Various committees and teams+ HIT strategic plan
Information policies		DURSA + federal and state laws related to Information security and privacy	the Information Governance Statement of Compliance (IGSoC)	• formulation of laws and policies for : data use , privacy, security and local accountability • legal agreement
Financial Resources		Decentralized	Centralized	**National** and **provincial** basis
Human Resources		Training human resources by universities + certified exam by ONC	Training human resources by HSCIC and universities	human resources at the **national** and **provincial** levels through academic centers
IICT	**hardware**	Computers+ network equipment	Computers + network equipment	Computers + network equipment
	software	NHIN gateway+ Federal Information Systems + member's Information Systems	N3 gateways + National Systems	enterprise systems, **provincial** data centers, Interfaces, **National** health data repository
	infrastructure	Internet	private WAN + Internet	**National** Intranet
Health Indicators		National Health Indicators	National Health Indicators Portal	National Health Indicators' Portal

Health Data Sources	As members of NHIN	As members of N3	Public and private organizations involved in health
Data management	Locally + National Health indicators Portal + definition of minimum data set (MDS)	Nationally + National Health indicators Portal + definition of MDS	Provincial basis : data centers, coding systems, defined MDS and community health indicators National basis : national integrated data repository, defined MDS and national health indicators
Information Dissemination and use	by DURSA agreement, used for different purposes (NHIN and member organizations)	by the Information Governance Statement of Compliance (IGSoC) and used for different purposes	By legal agreement At regional, national and international levels For the purposes of the network and member organizations

4. Comparison of the architecture dimension of NHIN framework in the mentioned countries and suggestion for Iran's NHIN

In this study the NHIN's architecture contains three dimensions of 1) network members; 2) interfaces (interactions between members); 3) communication with environment (security and confidentiality) [21, 27-28]. According to this definition, the assessment of NHIN's architectures showed that both countries have done almost similarly in developing interfaces and adjusting the security and confidentiality of NHIN. They both defined the gateways for the connections of members [21, 29-30] and communication with environment was set by autonomy and local responsibility, technical strategies and setting up legal agreement for exchanging and using health data [31-33]. Besides, about the members of the network it can be said that NHIN in the US is formed by the connection of Health Information Exchange centers, Regional Health Information Organizations, integrated delivery networks, state-wide health information exchange programs, federal agencies (including 33 agencies and national organizations), state and local governments, hospitals, clinics, drug stores, laboratories, imaging centers, Insurance and Reimbursement System, local health centers and health care organizations[21-22]. In the UK members of the N3 include Community of Interest Networks (CoINs), gateways to other networks (including gateways of internet, phone and mobile network, pharmaceutical network, academic network, gateways to the National Health System (NHS) in Wales and Northern Ireland, gateway to government network including governmental departments and local authorities and agencies) and direct members (including acute ambulance and care trusts, dentists, foundation trusts, general practitioners, health system and software providers, hospice centers, independent health care sector, local authorities, mental health trusts, national blood service, systems of Health and Social Care Information Center (HSCIC), Insurance and Reimbursement Systems, primary care trusts, special health authorities[30, 32].Figure 2 illustrates the suggested architecture for Iran's NHIN.

5. Developing and verifying a general framework for Iran's NHIN

The findings related to the suggested framework and the architecture of Iran's NHIN are depicted in figures 1 and 2 and experts' opinions on this framework are demonstrated in table 3, 4 and 5.

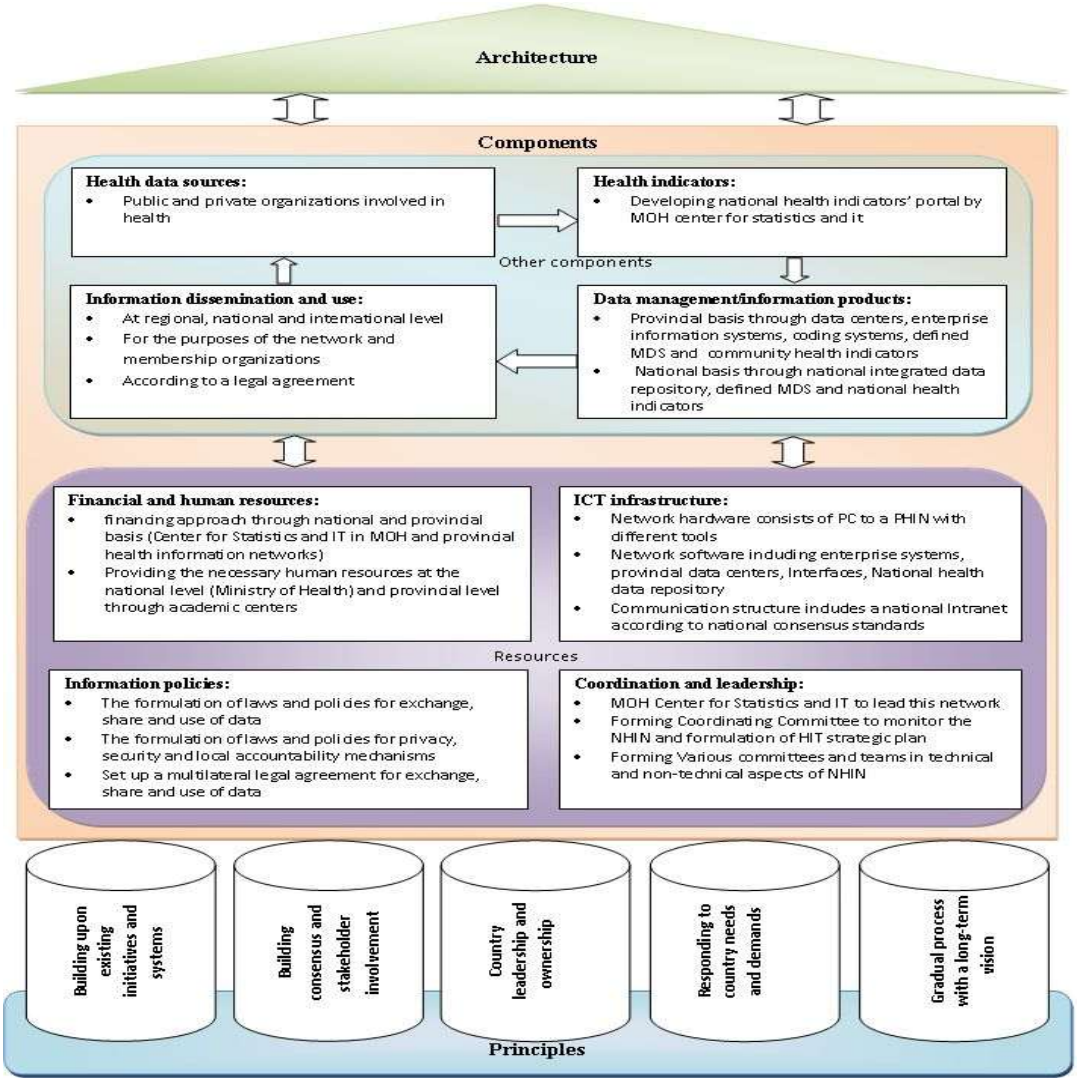

Figure 1. Suggested framework for Iran's NHIN

According to figure 1 the suggested framework for Iran's NHIN has three dimensions that are: components, principles and architecture. The components constitute of eight key elements. The principles consist of five essential principles that work as the infrastructure of two other dimensions (the components and the architecture). The architecture comprises of network members/nodes, interfaces and communication with environment. Figure 2 demonstrates the suggested architecture of Iran's NHIN.

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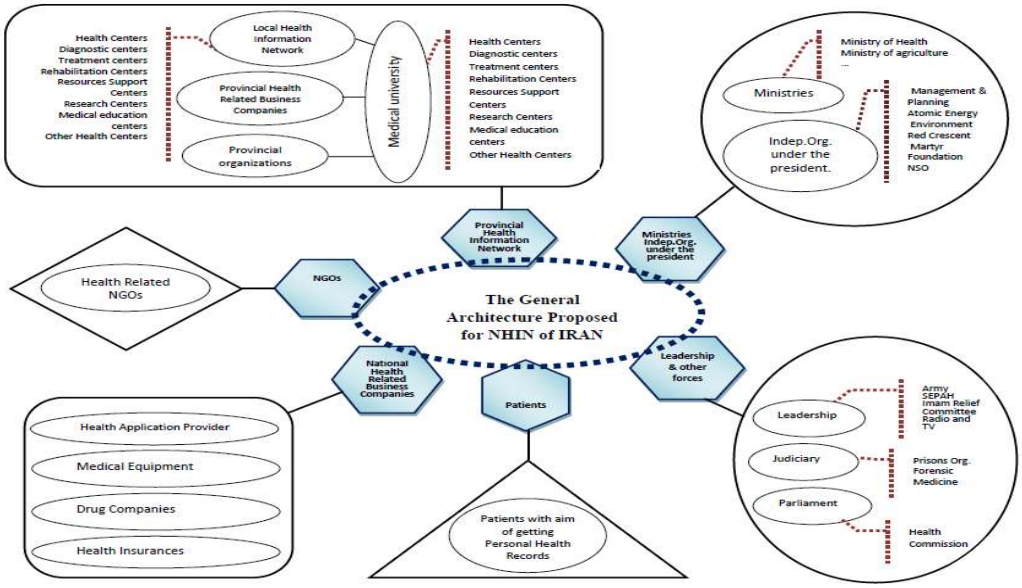

Figure 2. Suggested architecture for Iran's NHIN

According to figure 2 foundation of the suggested architecture for Iran's NHIN entails provincial health information networks. The Interfaces contain gateways that will be developed by private and public sector organizations based on their needs, standards and technical requirements. Communication of NHIN with environment will be set based on technical requirements, multilateral agreement of exchanging, sharing and using health data and information, and local authority. Tables 3 and 4 show the frequency distribution of experts' opinions and scores of items in each dimension of the proposed framework. Table 5 also reflects the view of experts on the proposed framework.

Table 3. Frequency distribution of experts' opinions in the components dimension of the suggested framework

Choices & Frequency / The Components	Acceptable		Relatively Acceptable		Unacceptable		Score of each item out of 30
	Frequency	percent	frequency	percent	frequency	percent	
Leadership & coordination							
Network leadership(Center for IT and Statistics)	7	70	3	30	0	0	27
Establishing the coordination committee from the key stakeholders	6	60	4	40	0	0	26
Establishing related committees and teams	10	100	0	0	0	0	30
Total	23	76.67	7	23.33	0	0	
Information policies							
Compiling legal agreement for using data	9	90	1	10	0	0	29
Compiling rules for confidentiality	10	100	0	0	0	0	30
Compiling rules & policies for security	10	100	0	0	0	0	30
Compiling rules for local responsibility	10	100	0	0	0	0	30
Total	39	97.50	1	2.50	0	0	
Supplying financial & human resources							
National & provincial supply of financial resources	6	60	3	30	1	10	25

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Supplying human resources	9	90	1	10	0	0	29
Total	15	75.00	4	20.00	1	5.00	
Resources & infrastructure of ICT							
Network hardware	10	100	0	0	0	0	30
Network software	8	80	2	20	0	0	28
Communicational structure of network	6	60	4	40	0	0	26
Total	24	80.00	6	20.00	0	0	
Health indicators							
developing a portal for national health indicators	8	80	2	20	0	0	28
Total	8	80.00	2	20.00	0	0	
Health Data Sources							
Specifying health data sources (health related org.)	8	80	2	20	0	0	28
Total	8	80.00	2	20.00	0	0	
Data management							
Provincially via provincial networks of health information	9	90	1	10	0	0	29
Nationally via integrated national health data repository	7	70	3	30	0	0	27
Total	16	80.00	4	20.00	0	0	
Information Dissemination and use							
Information Dissemination and use at various levels	9	90	1	10	0	0	29
Using data and Information for different objectives	8	80	2	20	0	0	28
Management of data exchange, share & use	8	80	2	20	0	0	28
Total	25	83.33	5	16.67	0	0	
Sum total for the component dimension	158	81.57	31	17.81	1	00.62	537

Table 4. Frequency distribution of experts' opinions in dimensions of the principles and the architecture of the suggested framework

Choices & Frequency / principles and architecture	Acceptable		Relatively Acceptable		Unacceptable		Score of each item out of 30
	frequency	percent	frequency	percent	frequency	percent	
principles							
Country leadership and ownership	9	90	1	10	0	0	29
Responding to country needs and demands	9	90	1	10	0	0	29
Building upon existing initiatives and systems	6	60	4	40	0	0	26
Building consensus and stakeholder involvement	8	80	2	20	0	0	28
Gradual process with a long-term vision	8	80	2	20	0	0	28
Total for the principles dimension	40	80.00	10	20.00	0	0	140
architecture							
Members/Nodes	9	90	1	10	0	0	29
Interfaces	9	90	1	10	0	0	29
Relationship with the environment	9	90	1	10	0	0	29
Total for the architecture dimension	27	90.00	3	10.00	0	0	87

Table 5. Frequency distribution of expert's opinions on the proposed framework

Choices & Frequency / Dimensions of the proposed framework	Acceptable		Relatively Acceptable		Unacceptable		total	
	frequency	percent	frequency	percent	frequency	percent	frequency	percent
the components dimension	158	81.57	31	17.81	1	00.62	190	100
the principles dimension	40	80.00	10	20.00	0	0	50	100
the architecture dimension	27	90.00	3	10.00	0	0	30	100
total	**225**	**83.85**	**44**	**15.95**	**1**	**00.20**	**270**	**100**

Overall, according to the findings of Table 5, the proposed framework was assessed by 83.85, 15.95 and 00.20 percent of the experts on an acceptable, relatively acceptable and unacceptable scale, respectively.

6. Discussion

The main objective of the present study was to develop a general framework for the NHIN of Iran. In order to achieve this goal, we tried to consider valid scientific literature, the framework developed by the Health Metrics Network [20] and the approaches related to NHIN architecture [34-35]. In addition, the experiences of the two leading countries in the development of NHIN, namely, the US and the UK, and the structure of the health system of Iran were also considered.

Based on the analysis of the findings related to comparison of NHIN framework in the studied countries, it can be said that generally, developing NHIN in the US is adjusted with the decentralized approach while it is adjusted with centralized approach in the UK [21, 9]. In NPfIT project in the UK, sovereignty, launching the systems and specifying the members of N3 network were entirely defined centralized [9, 32]. However, in NHIN project of the US most of the issues in dimensions of the components, the architecture and the principles of NHIN framework were decentralized [21, 36]. Among the weaknesses of the centralized approach of the NPfIT program are the following: low attention to local needs and end-users, and lack of flexibility versus technological changes; in return Examples including high data quality, better data use and management, and ultimately better control on the budget spending are the strengths of this approach [8, 34-35]. In the approach used by the US in the NHIN program, poor data quality and minimal use of data at national level are among the weaknesses. There are also strengths in this approach, including focusing on local needs and end-users, and flexibility versus technological changes [34-35].

In any case, the development of Iran's NHIN has been done in a way that minimizes the weaknesses in the two approaches mentioned. In order to achieve this goal, many items related to the components and the architecture dimensions in the suggested framework are proposed as a combination of national and provincial levels. On the other hand, the Middle Out approach [34] has also been at the forefront. Considering that the main basis of the geographical divisions of the country is the province, and on the other hand, the responsibility for the health of each province is related to the medical university, and at the national level this role is played by the Ministry of Health [23-25] Therefore, components such as financial resources, software applications and data management are proposed as a combination of both national and provincial levels to address local and national needs, and also there will be a kind of competition among PHINs . In some cases, including the communication structure in the ICT resource element, due to the state of the country's communications infrastructure, including Internet service problems, the National Intranet has been proposed to be in the best position to respond to the network in the long run. This is somewhat similar to the situation in the UK. The findings of the study conducted by Damanabi (2014) are also consistent with the proposed components in this framework. She introduced the inputs of the Iranian National Health Information System into eight dimensions: data sources, coordination and leadership, information policies, human resources, financial resources, facilities, information and communication infrastructure, and, finally, the cultural and institutional aspects [37].

In general, based on the literature review, there are three approaches for NHIN architecture [34-35]. The NHIN architecture in the US, which involves connecting regional health information networks and other health-related organizations and centers, is known as the bottom-up approach [34-35]. This approach is unlike the type of the architecture used on the N3 network from the UK's NPfIT program. The members of the N3 network and its information systems are centrally defined, which is known as a top-down approach[8, 34-35].Studies in the design and architecture of NHIN, in addition to these approaches, have also referred to a third approach called "Middle -Out" [34]. In this approach, the needs of healthcare providers, the IT industry and government are considered, and then common goals are defined for technical and non-technical issues of NHIN. The government takes the lead in developing the network and plays a facilitating role. Then, by defining the interoperability standards, the NHIN is formed by connecting PHINs and other stakeholders[34].Based on the findings of the Coiera (2009), given the large scale of the NPfIT project, the NHS top-down approach does not have the ability to adapt quickly to the challenges associated with providing health services. In contrast, the bottom-up approach is robust against severe changes, including new technologies or re-engineering of systems [34]. It should be recalled that in the NHIN projects of the countries under consideration some changes were also made in the direction of the Middle-Out approach. In the US, due to the inability

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to finance RHIOs and the lack of attention to the needs of some states, the State Health Information Exchange Programs was eventually introduced in 2010[36] and in UK, in the middle of the NPfIT program, the Community of Interest Networks (CoINs) and local ownership was also introduced [9, 29].

However, selection of any of these approaches depends on the structure and the nature of the health system of a country. The health system is quite centralized in some countries, and in others it is completely decentralized. Certainly, the type of NHIN architecture in these types of systems will be somewhat different [34]. Given the above mentioned points and considering that the main structural blocks of Iran's health system are medical universities in each province, and this structure is more compatible with Middle-out approach, this approach was used in the NHIN architecture of Iran. The main foundation of this architecture is provincial health information networks led by the medical universities of each province. The findings of the Targowski (2011) are consistent with the findings of the proposed architecture of the present study. He has developed the NHIN architecture in the United States at four levels, including local, regional, national and international levels. The local level refers to service providers at the local level; the regional level includes state governments, health centers and regional organizations. The federal government, federal agencies, centers and national organizations are also at the third level, nationally. The fourth level also refers to service providers who provide health services to citizens of other countries [38].

About the principles of the proposed framework, since these principles are presented within the framework of the HMN, and On the other hand, it was approved by more than 100 ministers and responsible officials for international agencies [20], therefore, suggested as the guiding principles for developing of the NHIN of Iran, and put forward by experts. According to the findings of Table 4, 80 percent of experts have evaluated these principles on an acceptable scale, indicating acceptance of these principles at a high level.

Overall, Conclusion and analysis of expert's opinions about the acceptability of each aspect of the proposed framework (80%, 81.57% and 90% on an acceptable scale, the principles, components and architecture, respectively), and finally, the acceptable rate of the proposed framework (83.85% on an acceptable scale)) suggests confirmation of the proposed framework by an overwhelming majority of experts and demonstrates the strength of the proposed framework. It is expected that the proposed framework will lead to greater coordination among stakeholders of information and health services across the country; and serves as the basis for all projects of the Ministry of Health in order to manage the health information of the country. In other words, the framework can serve as a starting point for moving towards the design and creation of NHIN in Iran. In this regard, suggestions are made for the development of NHIN in Iran, Including :All ministries and also stakeholders of health realm must confirm IT and Statistic Center of MoH as the leader of all activities related to national health information and statistics, Compiling the national plan of health IT to design and develop NHIN with the presence of stakeholders of health domain, Specifying the role and responsibilities of stakeholders of the network and training how to use data and information according to the legal agreement, Specifying vital resources for developing NHIN, Specifying the members as producers and users of health data considering the suggested architecture, Specifying how to manage the data, Assessing the suggested architecture and modifying SEPAS and SHAMS projects based on it; besides, it is needed to consider the proposed principles as the red lines in designing and developing the network. On the other hand, considering the steps to develop this framework, especially considering different approaches to the design of NHIN, it seems that countries with government and health system structure like Iran can use this framework as a road map to develop NHIN.

7. Conclusion

Finally, it can be said that developing NHIN do not only mean to launch national system or systems, or to connect local systems, but also it is needed to have a framework in which most related issues to the formation of the NHIN would be noted. The experience of two leading countries in developing NHIN, approaches in designing NHIN, and the structure of Iran's health system were considered in the suggested framework. The framework is expected to serve as the starting point for moving towards the design and creation of Iran's NHIN. At any rate, the suggested framework could be criticized and it could be only used for the countries with the structure of health system almost similar to Iran's.

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