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# The Role of Global Standardization Communities in Shaping National Health Information Architectures

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**Abstract.** Health sectors in developing countries are commonly struggling with disarrayed health information architectures, where multiple vertical, disease-specific programmes have implemented their isolated information systems. A consequence is parallel and overlapping systems where information is stored at different locations and in different formats. To address this, multiple global standardization efforts to harmonize health information architectures have been initiated. Still, there is only limited knowledge about the role of these global standardization communities in shaping national health information architectures. This article is based on a case study of the global Open Health Information Exchange (OpenHIE) standardization community. With an Information and Communications Technologies (ICT) ecosystem perspective, we aim to improve our understanding of the relationships between global standardization communities and national ICT ecosystems. Theoretically, we contribute with our conceptualization of national ICT ecosystems.

**Keywords:** Architecture. Health information systems. ICT ecosystem. Standardization.

## 1 Introduction

Health systems in developing countries are commonly struggling with disarrayed health information architectures. Information systems (IS) are often implemented independently and in isolation by different health programmes, ministries of health and donors across different health domains such as health management, logistics, laboratory, and facility registers. As a consequence, information is often disaggregated and stored at different locations and in different formats, making it a difficult task to get access and a pressing need to integrate them [1, 2]. The lack of harmonized national health information systems makes collaboration and sharing of data, information and knowledge among different healthcare personnel and programmes an arduous affair. It is often almost impossible to obtain a clear overview of all the routine health data. At the same time, health systems in developing countries frequently suffer from parallel reporting of routine health indicators. Consequently, there is an urgent need for strengthening the coordination of information collection to support information sharing and strengthen health information architectures [3]. In response to

this need, several global communities work towards standardizing health information architectures, addressing the challenges of fragmentation. In this paper, we try to understand how these global standardization communities influence what we refer to as national ICT ecosystems. National ICT ecosystems encompasses the people, policies, strategies, processes, information and other ICTs that together make up the socio-technical environment surrounding an ICT embedded within a country. Examples of global standardization communities trying to influence national ICT ecosystems are Integrating the Healthcare Enterprise (IHE), the Health Data Collaborative, and the Open Health Information Exchange (OpenHIE). This article is derived from a case study of the latter. OpenHIE intends to address the previously mentioned challenges by facilitating interoperability through the creation of a reusable architectural framework leveraging on standards.

The concept of architecture has been used inconsistently in IS research. It was for example described by Zachman as a logical construct for creating a structured set of descriptive representations of the future state of an undeveloped system [4]. Later, it has been extended to include social as well as the technical aspects [3]. Common to these definitions is a view of architecture as abstract images and blueprints of something to be. They further share a perceptive on architecting as a top down process, implying that there is a single architect in control of the process of implementing the architecture. The IS architecture literature also focus their discussion on interoperability. Arguably, OpenHIE share this view on architecture, as they are abstractly working on a global architectural blueprint. Nielsen and Sæbø [5] focused on another dimension of architecture and conceptualize functional architecting as the process of distributing, allocating or configuring of functional roles of the different components in architectures. As vendors of the different software components seek to retain and strengthen their position, there are strong incentives for extending their software components across (previously) logical boundaries for organizational units, work practices and professions. As a result, functional overlap is not an uncommon phenomenon in health information architectures. The functional architecting perspective can be used to describe what unfolds in terms of implementation and integration of independent software components in health information architectures.

Global standardization is an extremely challenging and complex task, and it is unclear what potential role global standardization communities have on national level information systems architectures. In this paper, we try to understand these communities by asking the following question: *What is the role of global standardization communities working towards harmonizing national health ICT ecosystems in developing countries?* By using a national ICT ecosystems perspective, we make an attempt to address this question by using a case study of the standardization community OpenHIE. Based on the case study, we contribute by improving our understanding of the relationship between global standardization initiatives and national health information architectures. Theoretically, we contribute with our conceptualization of national ICT ecosystems.

The remainder of this paper is organized as follows. In section two, we introduce the concept of the ICT ecosystem. In the third section, we describe our method, followed by a presentation of our empirical case in section four. Then we discuss the

empirical case from a national ICT ecosystem perspective. Finally, we present our conclusions and describe potential future work.

## 2 ICT Ecosystems

In this paper, we argue for taking an ecosystem perspective to understand the role of global standardization communities. The concept of ecosystem is borrowed from biology and is used to describe networks of diverse actors influencing each other's and being mutually dependent within a specific (eco)system [6]. Fransman [7] proposed using ecosystem as a metaphor for understanding the cause of changes in the socio-economy, as *"... the idea of interacting organisms in a constant process of change is more appealing than that of a mechanical system settling into equilibrium, if the aim is to understand living force and movement"* [7].

The ecosystems metaphor has lately been adopted for understanding the ICT sector. The first definition of ICT ecosystems is found in a "Roadmap for Open ICT Ecosystems" from 2005 developed by the Open ePolicy Group [8], where the following definition is provided: *"An ICT ecosystem encompasses the policies, strategies, processes, information, technologies, applications and stakeholders that together make up a technology environment for a country, government or an enterprise. Most importantly, an ICT ecosystem includes people -– diverse individuals who create, buy, sell, regulate, manage and use technology"* [8]. However, the focus in their roadmap is on understanding how ICT ecosystem enable efficiency, innovation and growth, and they do not further elaborate on the concepts of the ICT ecosystem. Fransman [7] has conceptualized ICT ecosystems based on several key concepts. He argued that the term should be used to describe the interaction between four key groups of *players* interacting in a layered and hierarchical fashion: Network element providers; network operators; content and applications providers; and final consumers. These players interact within the same environment. The environment is formed by institutions that define the 'rules of the game' by which the players interact and are influenced by. The principal institutions in an ICT ecosystem include financial institutions, regulators, competition authorities, standardization bodies and universities. These institutions can in turn be changed by organizations which have the powers to do so, such as governments, political parties, cooperate interests and trade unions.

The ICT ecosystem is conceptualized by Fransman [7] as a set of *functionalities*, and the hierarchical nature of the model symbolizes the functional interdependencies required by the system. Each layer is dependent on its bordering layer (or layers). For the ecosystem to function as a whole, each and every layer is required to perform its functional job. The model is an engineering-architectural model and at the same time an economic-institutional model. As an engineering-architectural model, it defines and determines the technical interactions, and as an economic-institutional model, it describes how markets and other institutions shape the evolutions of the system. The purpose of the model is to serve as a tool for analysis of the ICT sector for making informed corporate strategies and government policies [7].

### 2.1 The Process of Change in the ICT Ecosystem

As a part of evolutionary theory, Darwin conceptualized the evolving ecosystem constituting of communities of organisms, or species interacting in a natural environment. Darwin viewed change as an evolutionary process propelled by the interaction between the generation of variety and the selection from that variety. Fransman [7] adopted this evolutionary thinking for analysing change in the ICT ecosystem. To understand the first part of the evolutionary process, generation of variety, Fransman referred to Schumpeter. Schumpeter [9] asserted that change in the capitalist system (in which the ICT sector is a part of) is driven by four different types of innovation: New or improved products or services; new or improved processes or methods of production; new or improved forms of organisation; and new markets.

According to Fransman [7], the generation of variety in the ICT ecosystem is caused by innovation in one or more of these four areas. How does this innovation come about? Fransman [7] argues that the innovations mainly emerge from six symbiotic relationships that transpire within the ICT ecosystem. A symbiotic relationship, or symbiosis, exists when two different species live together in a close and often long-term interaction which may or may not be mutually beneficial. The six symbiotic relationships which take place between the different players at the different layers are [7]:

1. Relationship between network element providers and network operators.
2. Relationship between network operators and content and applications providers.
3. Relationship between content and applications providers and final consumers.
4. Relationship between network element providers and final consumers.
5. Relationship between network element providers and content and applications providers.
6. Relationship between network operators and final consumers.

### 2.2 The Context of the Symbiotic Relationships

Fransman [7] argues that the symbiotic relationships of the players in the ICT ecosystem take place within distinguished context which influences the disposition of the relationships. More specifically, he identified that the context is made up by four different influential factors including competition, financial institutions, regulation and competition law and other institutions. The first influence is *competition*. For example, the relationship between a network element provider and a network operator is affected by the degree of competition which the network element provider faces from competing providers. This in turn influences the types of innovation that the network operator makes. The second influence is *financial institutions*. An illustration of the impact of this influence is the telecoms crash where the unrealistic expectations of the telecom sector caused inexpedient investments which ultimately crashed the stock market in 2001. This event had a significant impact on the function of the entire ICT ecosystem. The third influence is *regulation and competition law*, which are the institutions that define the 'rules of the game' which the symbiotic relationships are governed by. These institutions affect the innovation process and subsequent outcomes of

the symbiotic relationships. The fourth and final influence is *other institutions*, such as legal institutions, standardization bodies and universities. Legal institutions include intellectual property laws and antitrust laws. Standardization has significant influence on the operation of the module producers of the ICT ecosystem and therefore also the interoperability of the system. Universities as institutions conducts research which generates new knowledge which through symbiotic relationships stimulate change in the system [7].

### 2.3 A National ICT Perspective

The ICT ecosystem concept has lately received substantial attention IS research in developing countries, as made evident by a special issue of The Journal of Information Technology for Development named *"The ICT Ecosystem: The Application, Usefulness, and Future of an Evolving Concept"* [10]. Diga and May [10] argue that ICT is to be viewed as embedded in the global, national, and local socio-economic context in which it is utilized. ICTs should not be viewed as technical systems in a vacuum, but rather as a part of a wider network that takes into account non-technical dynamics, being socio-economic, political, spatial, and such. The way in which the technical system is developed and operates is: *"... an aspect of emerging paradigms that consider the interplay between ICT multi-level usage by various players within systems of governance, citizenship, communication, knowledge, and innovation"* [10].

Inspired by Diga and May [10], we have developed a working definition of what we call the national ICT ecosystem based on the definition of ICT ecosystems provided by the Open ePolicy Group [8]:

> *"A national ICT ecosystem encompasses the people, policies, strategies, processes, information and other ICTs that together make up the socio-technical environment surrounding an ICT embedded within a country."*

Applying this perspective, an ICT is not viewed in isolation, but as part of a wider national ICT ecosystem made up by people, policies, strategies, processes, information and other ICTs. Outside the national ICT ecosystems there are several global actors trying to influence them, such as OpenHIE through standardization of national health information architectures. It is this relationship between the global standardization communities and the national ICT ecosystems we are trying to improve our understanding of. In figure 1, the national ICT ecosystem perspective is illustrated.

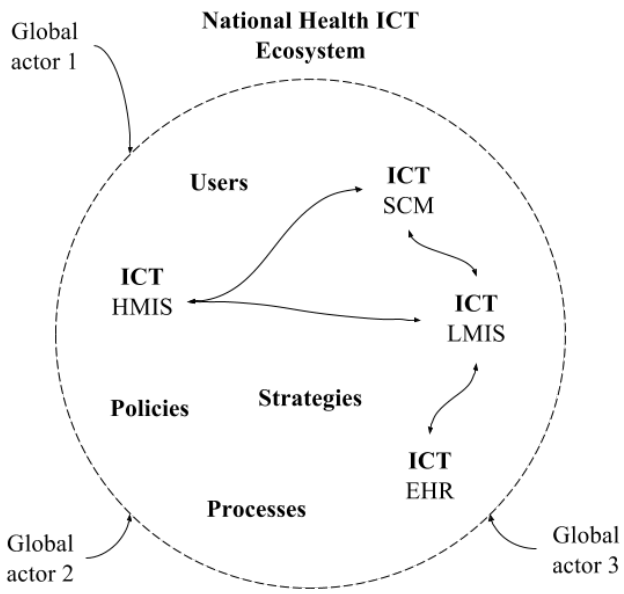


**Fig. 1.** Illustration of the national ICT ecosystem perspective. Here a few common health-related technologies are included: HMIS: Health Information System; SCM: Supply Chain Management System; LMIS: Logistics Management Information System; EHR: Electronic Health Record.

## 3 Method

This article reports from an interpretative case study [11] using an exploratory approach [12], offering the researchers an opportunity to access multiple data sources to study the phenomenon of interest. The empirical setting of this research is the global standardization community OpenHIE. The authors of this article are involved in the Health Information Systems Programme project at the University of Oslo (HISP UiO), a project which for several years has been a part of the OpenHIE community. The primary data collected for the case study is based on interviews conducted with four individuals who have all been a part of the OpenHIE community for several years. Three of them are project members at HISP UiO, and one of them is an independent consultant who has been involved with OpenHIE since its initiation. As HISP UiO is deeply involved in OpenHIE, access to these discussions and their accumulated data is granted. Hence, secondary data used for this case study consist of related documents such as articles from the encyclopedias of the OpenHIE and their partners contributing to the understanding of them.

# 4 Empirical Case: OpenHIE

This research is derived from a case study of OpenHIE, a global standardization community working towards harmonizing national health ICT ecosystems in developing countries. In order to understand the potential role of OpenHIE in doing so, we will in this section present its history and its work.

## 4.1 The History of OpenHIE

In 2010, the President's Emergency Plan for AIDS Relief (PEPFAR) in conjunction with the Innovative Support to Emergencies Diseases and Disasters (InSTEDD) initiative, Regenstrief Institute and Jembi Health Systems formed the Health Informatics Public Private Partnership (HIPPP) in response to the growing problem of fragmented Health Information Systems (HIS). The purpose of the HIPPP was to scale up and advance country ownership and leadership of the implementation of interoperable HIS in low-resource settings with the ultimate goal of improved health access and quality of care and increased productivity.

Over the years, HIPPP has provided different countries with technical support related to health information architecture. The first calls for support came from the Ministries of Health in Rwanda and Cambodia, and during 2011, HIPPP devoted substantial resources on establishing the health information architecture in Rwanda. The Ministry of Health in Rwanda saw an operationalized health information architecture as a crucial means for achieving the Millennium Development Goal of improving maternal health outcomes (MDG 5). They wanted to improve the coordination of care and cut down the number of key indicators by aggregating data from various actors providing care to maternal health patients, including hospitals, health clinics and community health workers. In parallel, the Rwanda Health Enterprise Architecture (RHEA) project was founded by an international project team consisting of the International Development Research Centre (IDRC) and the Rockefeller Foundation. The mission of RHEA was to scale up and advance ownership of an enterprise health architecture at country level. Having common interests, HIPPP partnered up with RHEA to support and deliver a health information exchange in Rwanda, which later became known as the Rwanda Health Information Exchange (RHIE).

According to OpenHIE [13], RHIE demonstrated the potentials of health information architecture, and it was used as a reference example by other actors in the global health community for understanding how to implement interoperability with technical, sociopolitical and capacity development challenges in mind. They further claim that after the launch of RHIE in 2012, there was a need for a more generalized approach as multiple countries requested assistance on health information architecture. In response to this need, the OpenHIE "community of communities" was established in 2013 by HIPPP based on the alleged potentials of RHIE. However, assessments carried out in 2014 of RHIE have quite unambiguously described it as a non-successful initiative [14]. According to the respondents of the assessments, the governance challenges were underestimated, the overall coordination was seen as weak,

and an insufficient amount of time was dedicated to capacity building. In addition, there was a lengthy and challenging process of developing an infrastructure of networks and computers for facilitating RHIE. This was seen as a barrier to system scalability, as it was argued that 3G networks could have been leveraged for the same purpose. Measuring the actual use of RHIE, it was found that about half of the users were satisfied with the system, and most users felt that they had less time to spend with their patients. In terms of scalability, the system was only operational in about half of the initial implantation sites as of 2014. Most interestingly, the assessments found that no significant health impact has emerged from the RHIE initiative.

### 4.2 The Work of OpenHIE

The core activity of OpenHIE, as a global standardization community, is the development of a reusable architectural framework which leverages on health information standards, facilitates flexible implementation on country level, and supports interchangeability of individual components. In terms of standards, they seek to evaluate and implement already existing consensus-based, international interoperability specifications, and to be a driving force in the development of future specifications. They further aim to create an architectural framework where the components are interchangeable by clearly defining standardized interfaces for each component. Each component provides well-described core functionality for core health data management and interoperates with other components making sure that health information from the different components are used to support person-centric and population-based healthcare needs.

The blueprint of OpenHIE's architectural framework contains six open-source software components: terminology service, enterprise master patient index or client registry, shared health record, health management information system (HMIS), health facility registry and health worker registry, and optionally external systems, such as the OpenMRS electronic medical records system. All the systems interoperate via a health interoperability layer, which receives all communications from the different systems and orchestrates message processing among them using a unified person-centric medical record.

OpenHIE describes themselves as a community of communities committed to open collaboration and knowledge sharing. Each community corresponds to one of the components in their proposed architecture framework. In addition, there are three more communities: OpenHIE Implementers Network, a forum dedicated to bringing countries and implementers together for sharing knowledge; Architecture community, an assembly discussing cross-cutting technical issues, and; PEPFAR Data Exchange Implementer Community, a community for DATIM stakeholders. DATIM (Data for Accountability, Transparency, and Impact) is a PEPFAR-specific version of the open source HMIS DHIS2. It was created for PEPFAR's Country Operational Plan and the Site Improvement through Monitoring Systems. All the aforementioned communities are working on implementation processes, standards and at least one reference implementation related to their community.

OpenHIE being organized as a community of communities, was in fact identified as one of its key challenges by an interviewee. He argued that consensus building and community building is a difficult and lengthy process, but that the benefit is a community where competent people are well represented. In terms of competency, he claimed that there is an extensive amount of competency represented in OpenHIE in the form of "on the ground experience" (in relation to country implementations).

One of the main purposes of OpenHIE, an interviewee argued, is to advocate for the underserved regions in other standardization communities, like IHE and HL7, where their voices are not well represented from before. However, based on the interviews, it was evident that the involvement of the underserved regions in OpenHIE community itself is limited. The countries are typically only relating to OpenHIE as an advisory service. However, several of the interview subjects believe that OpenHIE has changed the narrative in the developing countries. It is believed that OpenHIE is giving an approachable way to help articulate interoperability. Therefore, it is also believed that it has changed the way in which countries think about investments that will lead to interoperability at scale.

## 5 Discussion

In this paper, we provide the following working definition of national ICT ecosystems: *"A national ICT ecosystem encompasses the people, policies, strategies, processes, information and other ICTs that together make up the socio-technical environment surrounding an ICT embedded within a country"*. Further, we argue that OpenHIE is a global actor influencing national health ICT ecosystems. In this section, we try to improve our understanding of the relationship between OpenHIE and national health ICT ecosystems by discussing the research question of this paper: *What is the role of global standardization communities working towards harmonizing national health ICT ecosystems in developing countries?*

Arguably, OpenHIE have made an architectural blueprint which would exist in a perfectly harmonized national health ICT ecosystem, where different ICTs have well-defined functional requirements. In reality, the constitution of ICTs within the health sectors of developing countries looks nothing like the architectural blueprint of OpenHIE. The health sector in developing countries is largely a fragmented sector due to the high level of professional specialization it holds, and the fragmentation is also apparent within HIS. In addition, ministries of health, global donors and aid organizations in developing countries are commonly arranged around programmes (such as HIV /ADIS or malaria), for which they have established various segregated IS. While these IS serve the need of their respective health programmes, they also often lead to the presence of overlaps in functionality and data [1, 2]. Therefore, a depiction of the national ICT ecosystem of the health sector in a developing country would most likely contain several redundant and missing actors (or players, put in the terms of Fransman [7]) in terms of the requirements of the OpenHIE architectural blueprint. Implementing the blueprint in real world national health ICT ecosystems will most likely involve extensive introduction and removal of ICTs. National ICT

ecosystems as an analogy to natural ecosystem are extremely complex and sensitive to change. Therefore, it can be very difficult to understand the implications of the changes in the national health ICT ecosystems required by the OpenHIE architectural blueprint. Such changes could cause disturbance and substantial shifts (for better or worse) to the existing national ICT ecosystem. The changes would presumably affect not only the ICTs embedded within a country, but also the people, policies, strategies, processes and information tied to them.

Fransman [7] argued that there are symbiotic relationships between content and applications providers and final consumers in an ICT ecosystem. In the current national health ICT ecosystems in developing countries, some of these symbiotic relationships may be missing, redundant or unnecessarily fragmented**.** Arguably, this is the issue which OpenHIE is trying to address through standardization. Fransman argued that standardization is a part of the context of the symbiotic relationships which *"... crucially affects the way in which the ICT Ecosystem's module producers operate, and in turn the interoperability of the system"* [15]. Smith and Elder [16] asserted that interoperability is the key to establish an open ICT ecosystem. By "open", Smith and Elder (2010) point to universal access, universal participation in informal and formal groups/institutions and collaborative production. In addition, Gasser and Palfrey [17] argued that innovation made possible by interoperability comes with extensive benefits for the people that come to cultivate it. More specifically, they state that the final consumer benefit as *"...interoperability leads to innovation that results in technology systems that work together more easily, with less hassle, and ensures that they have more choice when they are making a decision about what to buy or to use"* [17]. It can be said that OpenHIE is trying to achieve this by bringing harmony to the national health ICT ecosystems through defining both the players and 'the rules of the game', where the rules of the game are the standards which ensures interoperability. Arguably, their main goal is to ensure that the symbiotic relationships between content and applications providers and final consumers cater to the person-centric and population-based healthcare needs. In other words, OpenHIE can be viewed as an organization trying to change the institutions in the national ICT ecosystems of the health sector in developing countries.

Whether or not OpenHIE is actually contributing to the harmonization of national health ICT ecosystems in developing countries is discussable. OpenHIE was formed on basis of RHIE, which they refer to as a successful demonstration of the potentials of a health information architecture. However, according to assessments of RHIE, the project was quite unambiguously described as a non-successful initiative in terms of actual use, scaling and measurable health impact [14]. Hence, using RHIE as an example of harmonization of national health ICT ecosystems is unsubstantiated. Another remarkable observation is that there is little involvement of the developing countries in the OpenHIE community, even though they are the ones who are encouraged to adopt the architectural framework. At the same time, it is important to acknowledge two positive outcomes of OpenHIE: (1) The community is well-represented in terms of competency, and knowledge drawn from this competency is injected into the national heath ICT ecosystems through advisory service; and, (2) it is changing the nar-

rative of the health ICT national ecosystem in terms of what investments that will lead to interoperability at scale.

## 6 Conclusions and Future Work

In this article, we contribute by improving our understanding of the relationship between global standardization communities and national health information architectures. This case study is only the beginning of a longitudinally and multilevel research project studying the phenomena of global standardization communities working towards strengthening HIS in developing countries. Future work therefore includes accumulating more empirical data, including at country level where the implementations are. It will also include studying more than one global standardization community. One candidate is IHE, in which OpenHIE is involved. IHE is working on the issues of interoperability and information sharing between various healthcare systems and medical devices.

This research contributes to the conceptualization of national ICT ecosystems through the development of a working definition and the utilization of this perspective. Hence, future work should continue to strengthen this concept by using it and evaluating its usefulness for understanding the phenomena at hand.

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