Needs for information sharing in healthcare:
Case study of maternity care pathway in Pudong, Shanghai

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Abstract

Many benefits could be gained from regional health information sharing. It is important to identify the needs for it from different viewpoints; health managers, health providers, citizens, etc. Finnish and Chinese partners are studying health information sharing in a pilot project in Pudong, Shanghai, using maternity care pathway as a case. This paper describes the pathway using an activity-driven process modeling framework, describes the information currently shared, and identifies needs for better information sharing. The main challenge for Information Systems researchers is to combine bottom-up process modeling with top-down data set standardization.

Keywords: Information sharing, Dataset standards, Process modeling, Healthcare, Maternity

1. Introduction and Background

The information to improve health status and quality of life is derived from independently designed data systems that range from population-based health surveys to health records used in managing individual patient care (Erickson, 2004). Information sharing would bring many benefits for different users, e.g. citizen/patients, health providers, health managers, health administrators, policy makers, etc. The development of regional data sharing between healthcare organizations is viewed as an important step in the development of health information management (Korst, 2008). Sharing of information should be abided by national regulations regarding medical data confidentiality (Ferranti et al., 2006). Regional information sharing is not only a technical problem, but also relies on the government policy and local health reform.

Several standards are also required to produce the functional and semantic interoperability necessary to support the exchange of data: a common reference information model, common set of data elements, common terminology, common data structures, and common transport standard (Ferranti et al., 2006). The purpose of the core data set is to develop a longitudinal patient health record and medical history using a common set of standard data elements. Chinese government noticed the importance of data standards in public health, and has developed the core dataset for instance for maternal and child healthcare. It has totally 8 basic datasets and 368 data elements (Jin et al., 2007). However, much effort is needed to carry standards into practical use.

ICT in healthcare is developing very fast in China at present, electronic health record (EHR) systems and regional health information sharing being the hot topics (Fan et al., 2002). However, the large number of systems designed by different software companies and the lack of standards lead to information isolation. Now many projects in China are starting to study regional information sharing. For example, the main target of the Pudong New Area district government in Shanghai is to establish a regional health platform to fulfill information sharing between all the healthcare organizations based on the existing systems.

A joint China-Finland e-health research project has been approved to the bilateral governmental China-Finland Science and Technology Programme. This project is organized into four main research themes: 1) Needs and requirements, 2) Architectures, interoperability and standards, 3) Data set definition for electronic health records, and 4) Evaluation. This paper focuses on the data theme. Within each theme, the Finnish counterparts’ previous research results are applied to benefit the project. The research project contributes to the Pudong pilot project and aims at generalizing the experience for being applied more generally.
Maternity care pathway was selected as the case for detailed study, since the pathway always contains more than one healthcare organization and information sharing between them is a recognized need. Two healthcare organizations in Pudong New Area, i.e. Weifang Community Health Center (CHC) and East Hospital, were selected as target organizations.

This paper describes how the information flows in the case setting were studied and what needs for information sharing were identified. Generalized conclusions from the results are discussed.

2. Research Question

When we study regional health information sharing, the most frequent question is: What information shall we share with each other? This paper is to identify what are the core data for healthcare information sharing mainly from the viewpoint of health care providers (clinicians), but also from the viewpoints of the patients/citizens and health care authorities/managers.

Theoretically the question is about combining data standardization with process modeling; i.e., do the standard data sets match the real-life information sharing needs in healthcare processes?

3. Research Methodology

The main idea was to identify the current situation in community health centers and hospitals, and their needs for health information from others. The data for needs analysis was collected by interviews and group discussions, in field studies at the pilot hospitals and by brainstorming in shared workshops. Both Finnish and Chinese partners jointly worked on that.

General needs for information sharing were first identified by group discussions. The maternity care pathway was then studied in detail. We first described how the organizations, activities and actors are involved during pregnancy and newborn care. Then we identified what core information is currently used within and between these organizations, and where there are needs for improvements. The process modeling framework applied was the Activity-Driven Information Systems Development Model (Luukkonen et al., 2007; Mursu et al., 2007). The basic idea of the model is that the starting point in information systems development is to study the work activity as a whole, in interaction with the actors using participatory methods.

4. General Needs for Information Sharing

In order to find out the needs for regional healthcare information sharing, different health providers and health managers from pilot hospitals were invited to participate in group discussions and shared workshops for brainstorming. This section describes the main needs as identified by the participants, according to different stakeholders’ viewpoints.

From the government’s viewpoint it is important to have the unified identification number for patient; integrate the public health system with the clinical EHR system; and set up a regional platform for information sharing among hospitals.

From health providers’ viewpoint it is important to integrate the doctor workstation and EHR with other different systems; to have integrated data of patient’s health status, e.g. patient history, basic information, test results, drug usage, treatments, diagnosis, discharge summary, etc; and to have an effective communication system between health providers.

From citizens’ viewpoint it is important to be able to check on-line one’s health status and have effective communication with health providers for homecare.
Common needs identified by participants included: Information sharing and seamless patient care between healthcare organizations based on the EPR/EHR system; Tele-consultation and two-way referral system between health organizations; Ability to print out test reports by any organization and to send test results by SMS; Availability of patient registration and reservation information to any health organization; Standard workflow and information flow between health organizations; Standards for data exchange based on the Health Level 7 (HL7) standards.

5. The Detailed Case Study: Maternity Care Pathway

In this section the basic flow of maternity care pathway is described, and the stakeholders, actors and information flows are also identified. It is followed by the description of shared information used currently in Weifang CHC and East Hospital.

5.1. Maternity Care Pathway Overview

Figure 1 presents an overview of the maternity care pathway. Organizations are depicted with rectangles, activities with ovals, and actors involved are named inside the ovals. The timeline depicts the duration of the pregnancy.

Figure 1: Activities related to maternity care in Weifang CHC and East Hospital

Maternity care services are given in community health centers (1st level of care) and hospitals (2nd and 3rd levels). Women are advised to visit a CHC according to the community they live in, but they can choose what hospital they will visit. Women mostly visit a hospital to confirm if they are pregnant. Floating people are advised to register pregnancy at the Birth Control Office. CHC establishes the paper-based Maternity Card kept by the mother. The mother visits CHC during the first 16 weeks of pregnancy and a hospital after that. High risk pregnancies are recommended to a special hospital. Birth giving takes place in hospitals. CHC takes care of follow-ups for the mother and newborn after the childbirth by two home visits. When the baby is one
month old, the mother shall bring s/he to the Maternal and Child Care Hospital for an examination. 42 days after delivery the mother should go to the delivery hospital for body check.

5.2. Shared Information in the Maternity Case

After we had a clear picture of the maternity pathway, we also studied the information flow and information sharing needs in three main phases (early pregnancy, late pregnancy and after delivery). This section describes what information is used and shared in the case setting.

The paper-based Maternity Card booklet with orange cover and the patient record are the most important information tools, collecting cumulative data of an individual mother’s whole maternity pathway of pregnancy, delivery and follow-up. The data on the booklet is heavily shared between different health facilities. The booklet records the personal data, childbirth history, husband and family history, hereditary diseases, basic pregnancy information, delivery information, important examinations, laboratory test results, expected date of childbirth, etc.

The clinical data are copied on paper-based maternity health records, too, kept at CHC and hospitals, where doctors share the historical data, like the prescription, medication, laboratory results, diagnosis and treatment, etc. Finally part of the collected data is typed into a computer-based maternity health management information system.

In the early pregnancy phase, information of pregnancy confirmation and registration is documented on a paper-based note. The pregnant woman herself will transfer it from one organization to another. The same happens with referral letters from CHC to higher-level hospitals. Laboratory test orders applied by CHC and results analyzed in a higher-level hospital are transferred by post. In Weifang CHC, a paper-based form is used to record information about regular examinations and testing. This information stays at the Weifang CHC.

In the late pregnancy phase, the first page of the medical record, a paper form recording regular examinations and tests, is kept at the East Hospital. Discharge summaries, delivery information, and information on the infant are paper-based and they are given to the mother. Referral letters and test orders to higher-level hospitals are on paper and transferred by post.

After delivery, follow-up and home service information on paper is kept at the CHC.

Several areas for improvement were identified. Health providers were not satisfied with lack of information in their daily work, duplicated work and manual data collection from different sources. The shared data are all paper based, and electronic data for sharing are strongly required. Standardization of data is a key enabler for data exchanging and information flow, while data security and patient privacy should be given more emphasis when information sharing increases.

6. Conclusion

In this paper we presented the methodology and results of a study on regional health information sharing needs. Maternity care pathway in Pudong was used as a case. The core data needed in care activities in different organizations were identified and areas for improvement discussed.

The study is part of a larger project aiming at achieving regional health information sharing at Pudong and generating general guidelines and recommendations. The results described in this paper are a basis for the other parts of the project. Regarding the data theme, the next task is to compare the core data sets identified in practice with the data standards developed in a top-down way, to show where existing standards should be applied in new computer-based systems, and where there is still need for standards development.
More generally, the results show that the activity-driven approach is highly useful in identifying needs for information sharing in healthcare processes. The main challenge for Information Systems researchers is how to combine bottom-up process modeling with the top-down logical approaches of data modeling currently used in data set standardization.

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