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Patients' perceptions of a health information exchange: A pilot program in South Korea

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ABSTRACT

Objectives: We examined patients' perceived need for a Health Information Exchange (HIE), their preferences regarding information exchange operations, endorsement of the technology, and expected and perceived benefits and concerns about the technology. Through an HIE pilot program in South Korea, we also explored the influence of demographic characteristics and HIE experience on patients' perceptions.

Material and methods: We collected data from patient surveys administered through a structured questionnaire pre- and post-implementation of an HIE in South Korea. The study database contained 730 records collected by survey before program rollout, 306 records from patients who had experienced the HIE, and 180 records in the comparison group A who experienced an offline-based exchange through procedures such as bringing copies of medical records and imaging results from the clinic to the hospital and 208 records in the comparison group B who brought only a referral letter. We computed descriptive statistics based on survey responses and performed multiple analyses of variance and chi-square tests to examine whether patient characteristics and HIE experience influenced responses.

Results: Despite their concerns about information safety and security, respondents in all 4 (1 pre-implementation and 3 post-implementation) surveyed groups indicated an acceptance of and willingness to endorse HIE technology. Eighty percent of respondents with the HIE experience chose HIE as their preferred operation of information exchange whereas the figure was 55% and 59% in the comparison groups A and B, respectively. The proportion of respondents who indicated improved quality as the reason for their willingness to recommend or to participate was higher than the proportion who cited reduced healthcare bills in all 3 groups – 8% in the HIE group and 13% and 23% in the comparison groups A and B, respectively, cited improved quality as the reason and .4% in the HIE group and 4% and 8% in the comparison groups A and B, respectively, cited reduced healthcare bills as the reason.

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Conclusions: The public sentiment is favorable for HIE technology in South Korea, but study findings indicate a gap among perceptions of different patient groups. Education and other efforts to give the public accurate information on benefits and adverse effects of the technology are needed. Also, additional objective studies with empirical data should be conducted to obtain quantitative evidence of benefits and adverse effects of the technology.

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1. Introduction

The health information exchange (HIE) is an integral component of the health information technology (HIT) infrastructure that is designed to move health-related information among organizations electronically [1,2]. The technology enables care providers to access patients' health-related information scattered across different organizations during the care process. The HIE has been hailed for its potential to improve the quality and efficiency of healthcare delivery by providing care providers with patients' clinical information at the point of care [3-8]. Seamless and promptly available patient information from organizations where the patient previously had care would reduce delays in care process, expedite the physician's decision about the care process, reduce redundant tests, prevent adverse drug-drug interactions, improve communication between care providers, and improve workflows of care providers.

However, previous studies have reported numerous challenges to the successful implementation of the sustainable infrastructure capable of accruing the expected benefits of the system, and patients' acceptance of the technology is one of challenges that is not fully understood [6,9–16]. Obtaining coordination and collaboration among stakeholders such as patient groups and healthcare providers who are producers and users of health information, and health insurers, regulators, and policy makers who are usually users of information requires tremendous efforts. Issues concerning patient information safety and security pose technical, legal, and operational challenges to providers. The cost of building and implementing an HIE system which assures interoperability, information security, and information safety is substantial.

The need for infrastructure is particularly great in countries with a high degree of healthcare delivery fragmentation, such as South Korea. Hospitals in South Korea usually employ their own medical staff and do not allow physicians practicing in community clinics to practice medicine at their hospitals. Therefore, patient care at a clinic is disconnected once the patient is referred to a hospital by a community physician for further care at the hospital and vice versa when the patient is referred back to the clinic after the completion of care at the hospital, unless the patient makes a copy of medical records and brings it to the care provider offline. Patients' acceptance and support for the technology is particularly critical in South Korea where provider rivalry and the fee-for-service third-party payment system pose additional obstacles to HIE implementation.

Previous studies indicated that patients were positive about HIEs because of the potential benefits the system offers, but they were also deeply concerned about potential privacy and

security breaches related to the technology [17-20]. Through focus group interviews of patients recruited from a Massachusetts community in the United States, Simon et al. found that patients without experience in HIE technology eagerly anticipated its use because of the quality and safety benefits it promises for healthcare delivery, but they were worried about privacy and security breaches and wanted more information about the system, especially during the consent process [19]. Whiddett et al. also found that surveyed patients who visited primary care clinics in New Zealand were more likely to accept dissemination of their health information when it is shared between health professionals, non-identifiable, and of a less personal nature [20]. However, little detail is known of patients' attitude regarding the type of information they would like to have exchanged, which domain of expected benefits led them to endorse the technology, and whether experience with the technology affects their attitudes about it. Such information is needed to design a successful adoption policy that fosters further HIE efforts.

The objectives of this study are to assess patients' perception of an HIE which includes patients' preferences regarding information exchange operations, endorsement of the technology, and expected and perceived benefits and concerns about the technology, and to examine the influence of demographic characteristics and HIE experience on patients' perceptions. To assess patients' information-exchange needs as well as the expected benefits and perceived risks of an HIE, we surveyed patients before the rollout of an HIE pilot program in South Korea. After the implementation of the HIE system, we surveyed program participants and nonparticipants to see whether experience with the HIE and other patient characteristics affected patient perceptions of the technology. We also used the data to assess participant satisfaction with the system and the willingness of nonparticipants to be engaged in an HIE effort. We studied three types of information exchange operations: paper-based offline, CD- or memory stick-based electronic offline, and online electronic exchanges. Following the definition by the National Alliance for Health Information Technology of the United States, in this paper, we restricted the term health information exchange to an online electronic exchange of health information even though South Korea does not yet have nationally recognized standards for an HIE [1].

2. Methods

2.1. Setting

The Korean government funded a 3-year HIE pilot program in November 2007 to gain broad knowledge needed in its efforts to introduce HIE systems in South Korea. The Seoul National University Bundang Hospital (SNUBH), a medical

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