

Factors Affecting Views On Electronic Health Data Sharing – A Survey of Chinese Residents

Ying He (✉ 51228486@qq.com)

Hunan Normal University

Lun Li

Dalian University of Technology

Weihong Wang

Hunan Normal University

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Abstract

Background: China has been promoting electronic health data sharing for years. However, few studies have focused on Chinese residents' views on sharing personal health data or analyzed factors that affect them. This study targets this gap and investigates China's public attitude toward sharing EHRs and the influential factors, including awareness of privacy and security and potential benefits of sharing EHRs.

Methods: The survey adopted multi-stage stratified sampling to select residents in Hunan province randomly and received 932 responses. The primary outcome measures were the responses to the 29-item questionnaire evaluating different views on privacy and safety of Electronic Health Record Data Sharing, using a five-point answering scale with the extremes labeled as "poor" and "excellent".

Results: Most Chinese residents hold reservations about sharing them. 297 (32.18%) were willing to share their healthcare data between institutions; 438 (47.45%) supported sharing only for a better healthcare service. The Logistic Regression ($\alpha_{in}=0.05, \alpha_{out}=0.10$) was used to find out the factors affecting willingness. The results demonstrated that people who hold the following characteristics would be more likely to consent to share EHRs: (1) have EHRs, (2) value potential benefits of sharing EHRs, (3) believe sharing EHRs would improve quality of care, (4) disagree that sharing EHRs would increase the risks of privacy breach, (5) prefer benefits of sharing EHRs than protecting privacy, and (6) work in a healthcare-related position. (likelihood-ratio chi-squared test 274.058, $P<0.05$).

Conclusions: The attitude of the Chinese public towards data sharing in electronic health records is influenced by several factors. Our study provides new and solid references for Chinese public opinion on EHRs. Those results may assist related research or benefit public health administration, like formulating policies to improve public acceptance of EHRs and promoting EHRs-based public health services.

Introduction

Advances in healthcare digitalization have proliferated Electronic Medical Records (EMRs) and Electronic Health Records (EHRs), generating mountains of clinical and health information data. Sharing those data through secure networks has been believed to benefit multi-stakeholders, like improving patient care, facilitating the allocation of medical resources, retaining control of medical costs, or upgrading healthcare management. Over the past few years, EHRs/EMRs have been even transmitted from medical fields to a larger area covering social security systems and civil administrations, exhibiting the potential to assist public health authorities.

However, consumers' willingness to share electronic health data varies in different situations. A survey conducted by Weitzman et al. indicated that people's willingness or reticence to share personal data changed with different ages, diseases, service providers, or data usages [1]. Other factors that could influence willingness may include personal health conditions, social-economic status, and education levels. Ancker et al. found that people who have been highly educated were more likely to hold firmer confidence in the expectation that sharing health data could improve public health and quality of care [2].

However, as Page et revealed, they were also more reluctant to share their personal EHRs[3]. Some researchers suggested other factors, like nationalities and races [4–5] and personal experiences on computers and health services [6–8]. However, consumers' main concern is a breach of privacy [9–10]. These concerns would potentially lead to refusal or limited consent to share personal health data.

China also faces accumulating EHRs/EMRs, but public view toward sharing them has seldom been explored. A better understanding of Chinese residents' views on sharing health data may facilitate healthcare management and enhance public trust in healthcare services. This study addresses this issue and analyzes factors, like demographic features, expectations on health data privacy, and benefits of sharing, that could affect the willingness.

Method

Sampling design

We adopted a method of multi-stage stratified sampling to randomly select residents in Hunan Province, China. The questionnaire we designed was distributed to those selected residents from April 2019 to June 2019. The survey was approved by the Ethics Committee at The Third Xiangya Hospital of Central South University.

First, we divided cities and counties in Hunan Province into three categories based on their economic development levels that were released by Hunan Statistic Year Book 2012[11]: (1) The developed region where the GDP per capita is greater than 85,000 RMB, including the Chang-Zhu-Tan region; (2) The developing region where the GDP per capita is between 50,000 and 85,000 RMB, including six cities and their counties as Hengyang, Chenzhou, Yueyang, Loudi, Yiyang, and Changde; (3) The underdeveloped region where the GDP per capita is lower than 50,000 RMB, including five cities and their counties as Shaoyang, Yongzhou, Huaihua, Zhangjiajie, and Xiangxi Autonomous Prefecture.

Second, we randomly selected one city from each of the three categories and further randomly selected a resident committee that belongs to an urban area and a village that belongs to a county from each of the three selected cities. Thus we got six basic strata from both geographically and economically different regions.

Third, we randomly selected 148 residents from 148 families of each of the six strata and sent them the questionnaire. We received 932 responses at last and obtained the subject's informed consent.

Survey Domains and Instrument

The survey was designed from themes from reviews on extensive literature and focus group discussions of the views and influence factors that other researchers conducted[12]. The core of the questionnaire is a set of 29 questions evaluating Influential Factors of Views on Electronic Health Data Sharing, using a five-point answering scale with the extremes labeled as "poor" and "excellent". The items are organized into four domains: (1) General willingness to share EHRs; (2) Experiences on EHRs; (2) Public

acknowledgment of the benefits of sharing EHRs; and (4) Public awareness of potential risks of sharing EHRs. General and demographic data were also collected from the participants. We handed out the questionnaire to 30 people with different ages, genders, education levels, health conditions, and healthcare experiences for the preliminary test and revised the questionnaire based on their responses.

We deployed our questionnaire on an online survey platform called WJX and send it through E-mail, WeChat(a chat APP).

Data analysis

Statistical analysis was conducted using SPSS22.0 software. The questionnaire items were summarized by general descriptive analysis, chi-square test, and multinomial logistic regression. The bilateral inspection level was 0.05.

Results

Sample characteristics

Of the 932 respondents, 649(71%) were aged between 18–45; 393(42.58%) were male, and 530(57.42%) were female. Nearly half of the participants(414, 44.85%) had completed college education, and also nearly half of them (414, 44.85%) were from families with a household income between 2,000 to 5,000 RMB per month. As the survey reported, 199 (21.56%) respondents worked at public institutions, and 193(20.7%) were freelancers.

General Willingness to Share EHRs

Among the survey respondents, 663(71.83%) of them consented to have their EHRs established; 297(32.18%)were willing to share their healthcare data between different institutions; 282 (30.55%) would allow their data used in a more enormous scope beyond healthcare purposes; 439(47.56%) accepted the use of their EHRs for medical research if anonymously; 438(47.45%)supported sharing only for a better healthcare service.

Features Related to Willingness

Some demographic characteristics, including age($X^2=48.63$, $P < 0.05$), education level($X^2=44.079$, $P < 0.05$), living in urban or suburban regions($X^2=10.703$ $P < 0.05$), and job-related to healthcare($X^2=7.814$ $P < 0.05$), exhibited relations to respondents' willingness to share.

Of the factors within the scope of experiences on EHRs, those may relate to willingness included knowing about EHRs($X^2=48.63$, $P < 0.05$), having established EHRs($X^2=32.577$ $P < 0.05$), knowing about what kinds of personal healthcare data would be collected($X^2=33.175$ $P < 0.05$), and knowing about the purposes of EHRs($X^2=51.134$ $P < 0.05$).

We also enumerated several factors related to the benefits and risks of sharing EHRs in the questionnaire. The results revealed eight of them might affect the participants' willingness: general acknowledgment of benefits and risks ($X^2=46.83, P < 0.01$), awareness of unsecured management of personal healthcare data ($X^2=47.412, P < 0.01$), awareness of the risk of privacy leakage ($X^2=47.876, P < 0.01$), awareness of risks of breach of privacy ($X^2=60.741, P < 0.01$), awareness of risks of abuses of personal data ($X^2=52.056, P < 0.01$), awareness of the benefit of improving quality of care ($X^2=79.824, P < 0.01$), awareness of the benefit of reducing the cost of healthcare service ($X^2=95.616, P < 0.01$), and personal inclination between benefiting healthcare service and protecting privacy ($X^2=221.098, P < 0.01$).

Factors Affecting Willingness

We defined the willingness to share as the dependent variable, and the 16 related features described in the previous sections as the independent variables. The Logistic Regression ($\alpha_{in} = 0.05, \alpha_{out} = 0.10$) was used to find out the factors affecting willingness.

The resulted value of the likelihood-ratio chi-square test was 274.058 with $P < 0.05$, validating the Logistic regression model. The efficacious factors the model found out are listed in Table 1. The results demonstrated that people who hold the following characteristics would be more likely to consent to share EHRs: (1) have EHRs, (2) value potential benefits of sharing EHRs, (3) believe sharing EHRs would improve quality of care, (4) disagree that sharing EHRs would increase the risk of privacy breach, (5) prefer benefits of sharing EHRs than protecting privacy, and (6) work in a healthcare-related position.

Table 1
Factors affecting willingness to share EHRs

Factor	Regression coefficient	Standard error	Z value	P value	OR value
Establishment of EHRs	0.495	0.209	2.376	0.018	1.641
General acknowledgement of benefits and risks of sharing EHRs	-0.429	0.198	-2.169	0.03	0.651
Awareness of risks of privacy breach	-0.313	0.157	-1.996	0.046	0.731
Awareness of benefit of improving quality of care	0.246	0.124	1.991	0.046	1.279
Personal inclination between benefiting healthcare service and protecting privacy	1.185	0.16	7.415	0.000	3.27
Job related to healthcare	0.512	0.216	2.37	0.018	1.669

Discussion

General Willingness to Share EHRs

Most respondents in our survey were in favor of establishing electronic health records. However, the percentage of respondents in our survey who would agree to share personal healthcare data between different institutions dropped to less than a half, implying a concern about risks that data transmitting would trigger. The result is similar to studies in other countries. For example, a previous study in Greece revealed the same public doubt: 48.8% of their participants worried that an unauthorized third party would access their personal information[13]. These privacy concerns may arise from the sensitive personal characteristics that EHRs describe, like reproductive conditions or psychological and mind states[14].

The main result of our work was to show that most Chinese residents hold reservations about sharing them, which differs from the results of previous studies. In the Chinese traditional culture, privacy was initially equated with stigma, which can be construed as illegal secrets, selfishness, and conspiracy. The usual moral standards are pursued by the ancients, such as "gentleman magnanimous," suppressed the development of personal privacy. Many scholars think that Chinese cultural history is a culture of shame. This kind of incentive mechanism for face, shame, and cultural ideals of saint personality leads to insufficient resources for the legitimacy of privacy. The right to privacy is too challenging to be universally recognized by members of society. With the popularization of the Internet, the influence of traditional Chinese culture on the concept of privacy had declined. For example, a survey conducted by the China Youth Social Center showed that most respondents (88.8%) realized that they had experienced improper processing of their data[15]. Therefore, in contemporary China, where the economy, culture, and social structure are undergoing drastic changes, the awareness of information privacy protection is increasing, and further efforts are needed to promote the sharing of electronic health records.

Factors Affecting Willingness

Demographic characteristics

Although we listed four demographic characteristics in our questionnaire, only one of them was proved to be an efficacious factor that would influence willingness: whether the participant's job is related to healthcare. A study in Macao may help to understand our results: 78% of physicians interviewed believed that EHRs facilitated smooth communication between physicians and patients[16]. Healthcare-related practitioners' support may account for the advantages they tasted during daily practice. However, some previous surveys provided more. They suggested that age or education also could affect willingness. For example, research in the UK declared that the younger participants (25–34 years old) would be more likely to support EHRs than the older ones (35–64 years old)[17]. Given that most demographic characteristics relate to local cultures, beliefs, and conditions of sharing EHRs, variations by country are reasonable. Nevertheless, it is worth further investigating public views and preferences based on demographic distribution, especially in China, where healthcare-related administrative decisions and public education would be more effective if demographic differences were considered.

Experiences on EHRs

Our study suggested that participants who have had EHRs established tended to prefer sharing EHRs. Their experiences may have helped them better understand EHRs and gain direct impressions of perceived benefits and risks. Surveys conducted in 2011 and 2013 in the USA also demonstrated that consumers who had used EHRs were more likely to trust EHRs benefits on care quality and less likely to worry about potential privacy threats[18]. This result indicates that expanding EHRs users would assist the promotion of EHRs and further propel sharing of them.

The balance between benefits and risks of sharing EHRs

Respondents of our survey, who agreed that sharing EHRs would benefit healthcare services and related research, were more likely to consent to share their personal data. This result echoed a study from Ireland that found that 89.5% of participants would consent to share their anonymous personal data[19]. They believed that sharing EHRs would help physicians elevate the diagnosis process and specific care. Another factor we found out is worries about potential security threats. Previous studies presented the same observations. Roughly two-thirds of American adults assumed that privacy of personal health data would be undermined during electronic transmission[20]. A survey conducted on 1,000 Americans demonstrated that 41.2% believed EHRs would cripple patients' privacy[21]. Canadian people worried the same. In 2007, nearly two-thirds of interviewees expressed concerns about perceived threats that EHRs would bring to privacy[22], and this trend remained still in 2012[23]. Similar studies had been conducted in China, the results show that the public has a relatively poor understanding of EHR. 84.69% of the respondents worry that health information might disclose their privacy unintentionally, and 63.55% of the respondents have experienced or heard about data breaches of health information[24].

Public willingness to share EHRs seems to fluctuate with different situations. Preference for sharing depends on the balance between privacy protection and benefits for society[25–26]. While supporting a certain level of sharing in consideration of the benefits of EHR sharing, there are concerns about the privacy and security of individual health information. Culnan and Armstrong's computational theory of privacy suggests that users who disclose personal information in exchange for some economic or social benefit are assessed to ensure that their private information is not used illegally and that the individual is not adversely affected[27]. In short, users will reveal personal information in a transactional environment if the benefits outweigh the risks. When the privacy risk was little likelihood, or when the risks typically have a significant impact on specific individuals rather than the majority of the general population, people were likely to expect some form of social gain from sharing their health information. For example, when potential security threats were small or only targeted specific persons instead of the majority, the public focus would pivot to expected benefits or social gains of sharing EHRs. As most people acknowledge that sharing EHRs would favor healthcare services, extra strategies to shield privacy will ameliorate public concerns and raise the probability of willingness to share.

In the specific context of China, the Chinese public is very concerned about the privacy of electronic health records, which has become an essential consideration for the public in deciding whether to share health information. At the same time, the public has shown a positive attitude toward the use of health information in the modern trend of network and big data technology, which is also related to the

traditional Chinese culture that attaches more importance to collective and public interests. This empirical survey further established that the privacy issue of electronic health records is a factor of great concern in the data utilization of electronic health records. We should strengthen the research and propaganda of electronic health records sharing and utilization policies in the future, increase the protection of personal privacy, and reduce the public's concern about the privacy leakage of personal electronic health records.

Limitations

The study is a single-site study limited within Hunan Province, China. Findings related to demographic characteristics may not be generalized to other populations. The multi-stage stratified sampling we used had eliminated bias as much as possible, but the resulted samples roughly shared a typical profile: young, highly educated, and sensitive to privacy. We intend to diversify samples in future work further.

The questionnaire focused on general attitudes toward EHRs, instead of explaining specific scenarios. Thus interpretations of those questions, especially those related to privacy and security, would vary among participants and subsequently impact the answers. Descriptions of practical projects or real-life situations could be added to the future investigation.

Conclusion

Although most residents in Hunan Province, China report supporting EHRs, they are cautious about sharing them, and the reticence level is exceptionally high around topics of EHRs shared between different institutions or used beyond healthcare scope. Factors affecting willingness include jobs related to healthcare, having EHRs established, awareness of benefits and risks of sharing EHRs.

Critical factors that our study reveals would facilitate healthcare services in multi-aspects. Responses to the questionnaire indicate why people hesitate to share EHRs. Those reasons would inspire administrators to develop specific strategies targeting public acceptance of EHRs, public confidence in sharing EHRs, and research on medical big data. Our study also initiates disclosure of public perspectives on privacy and security. Further investigation on related issues is worth proceeding, including scope and types of personal health data that would be shared, forms of informed consent to share, and de-identifying personal health characteristics, and measures for privacy protection.

Abbreviations

EHRs

Electronic Health Records

EMRs

Electronic Medical Records

Declarations

Ethics approval and consent to participate

The experimental protocol was approved by the Human Ethics Committee of Hunan Normal University(the committee's reference number is 2019-204). Written informed consent was obtained from individual or guardian participants.

Consent for publication

Not Applicable

Availability of data and materials section

The datasets used or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

There are no known conflicts of interest associated with this publication, and there has been no significant financial support for this work that could have influenced its outcome.

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Authors contribution

We confirm that the manuscript has been read and approved by all named authors and that there are no other persons who satisfied the criteria for authorship but are not listed. We further confirm that the four authors have contributed to this research, and all authors have approved the order of authors listed in the manuscript. The roles are as follows:

Ying He conceptualized and designed the study, collected and analyzed raw data, drafted the manuscript version, and completed the final version of the paper.

Lun Li helped in developing the research model.

Weihong Wang revised the draft version and final version of the paper

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