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Patient Empowerment and Electronic Health Record Systems Sharing: A Design Perspective

Completed Research

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Abstract

Patient empowerment through health information technology is a relevant area in healthcare transformation; however, research has not adequately addressed how electronic health record (EHR) systems design can enhance this phenomenon in the care process. This study proposes a design artifact (EHR sharing) that focuses on empowering patients and EHR use to achieve patient centered care. Using a sample of 154 in a real-world scenario (diabetes) and a design science approach, we tested and evaluated the effectiveness of our proposed artifact for both the traditional and the current design approaches. The t-test statistics results show that using the current approach, patients are more empowered when they have access to their health information, interact with the physicians, have choice options to make decisions, and when the physician blends with patient in a more natural way. Some design principles, contributions and implications to research and practice and avenues for future research are discussed.

Keywords

Patient empowerment, EHR sharing, access, choice, interaction, naturalness, patient centered care.

1. Introduction

The concept of empowerment is increasingly being studied in different academic fields. For instance, one study looked at economic empowerment as having control over resources to make decisions (Golla et al., 2011). In the healthcare setting, physicians sometimes exercise control during the care process by focusing more on delivering care and less on empowering the patients. One possible explanation to this is due to the physician's workload and time constraints to meet their daily work demands, which could affect their full attention on empowering the patients and giving them control during the care process. Recent literature have emphasized the need to focus on patient-centered care by empowering patients to be involved in the care process (Holmström & Röing, 2010). Another study revealed that due to the traditional approach (paper chart record systems) to care, making a paradigm shift is often difficult regarding embracing patient empowerment (Anderson & Funnell, 2010). The paper-based system has various disadvantages such as, lack of access and availability of patients' health information and loss or misunderstanding of health information by patients (van Deursen et al., 2008), which has led to lower patient care outcomes. As such, patients do not seem to enjoy a good patient-physician interaction. As a result of the difficulty instigated by the paper-based approach, patients feel that they do not get enough attention from physicians during the care process. Physicians on their part, do not enjoy a good work-life balance as they pile up backlogs of documentation work, which they either complete at home or carry over into their new work week. Additionally, despite the advantages of electronic health record (EHR) systems, physicians think they spend so much time on the EHR systems through clicking, typing, and trying to figure out where information is located in the EHR systems. The documentation workload and the difficulty of navigating the EHR system have given rise to the problem of information overload—a phenomenon that is widely experienced by medical practitioners as a consequence of the rapid advances in information and communication technologies like EHR systems (Edmunds & Morris, 2000).

Besides showing less focus on patient empowerment, research has not adequately addressed how EHR sharing can both enhance patient empowerment and the effective use of EHR systems by physicians (Kwon & Johnson, 2018). Prior literature have looked at patient empowerment or physician use of EHR systems separately. We seek to bridge this split in literature by studying patient empowerment and EHR use from a design science perspective. The scope of this study covers the testing and evaluation of EHR sharing as a design artifact to improve patient empowerment. In the proposed design, we highlight AI-embedded capabilities (intelligent agents) as a design principle in the implementation of the artifact. AI is conceptualized as an intelligent agent—a tool that can scan and understand text and voice inputs and automatically provides users with the needed information (Edmunds & Morris, 2000). This study utilizes an integrated technique that caters for the needs of the patients (patient empowerment) and also helps physicians incorporate EHR systems into their practices. Relevant to this study are the roles of shared screen and AI agents. The role of shared screen is to improve communication efficiency, increase comprehension of patient information, and eliminate doubts about the authenticity of patient health data. It can facilitate involvement in the care process and understanding in decision-making regarding treatment options. Intelligent tools on the other hand are software programs that function at the backend but enhance human computer interaction through voice recognition and response through intelligent options for the user of the EHR to make decisions using the suggested option made available by the intelligent options.

Therefore, we believe that designing an interactive system that is embedded with intelligent agents can facilitate interaction between physicians and patients and with the system at the same time. This intelligent system can help overcome the problem of information overload; and can aid in the decision-making process by capturing user information, learning about user preferences, and predicting what the user needs (Belfour & Furner, 1997) through voice commands, voice recognition, and shared screen options. The following research questions are addressed in this study. 1) *How can patients be empowered through their perceptions of access to health information, choice options, interaction with the physician, and physician naturalness during the care process?* 2) *What is the role of shared screen and intelligent agents in facilitating physicians' use of electronic health record systems and empowering patients during the healthcare process?*

The aim is to design and evaluate an artifact to measure the effectiveness of EHR screen sharing towards patient empowerment. To do this, we compared the effectiveness of implementing the artifact using both the traditional paper-based approach to our proposed new approach (enhanced EHR system). We used a multi-group analysis approach and a diabetes scenario to demonstrate the artifact design. There were 77 participants in the study, and each was exposed to 2 treatments. So together the sample size was 154. Results reveal that there was a significant difference between the traditional and current designs. Our results suggest that patients are more empowered when they have access to their health information, interact with the physicians, have choice options to make decisions, and when the physician blends with patient in a more natural way. Next, we discuss on the artifact design methodology, followed by the evaluation process. Lastly, we discuss the findings of our analysis and provide contributions of how the artifact design enhances our knowledge base.

2. Justificatory Knowledge

Patient-centered care (PCC) is one of the key domains of high-quality care as prescribed by the Institute of Medicine that focuses on patient empowerment. PCC is seen as a quality relationship among patients, clinicians, and the health systems (Epstein & Street, 2011). Prior study has shown that patient-centeredness was achieved by the patients finding a common ground for communication with the physicians (Meredith et al., 2001). In setting a vision for patient-centered care, research has underscored the need for clinician-patient relationship enhanced by “computer-based guidance and communications systems (Davis et al., 2005). The study suggests access to care, patient engagement, systems that support care, care coordination, shared decision making as attributes that should be considered for patient-centered care. We believe that high quality patient-centered care can be achieved by instituting systems that lessens cognitive burdens on patients and clinicians while helping them interact with each other and with the system using less efforts.

We establish our theoretical underpinning on the Minimally Disruptive Medicine (MDM) care model framework, a theory-based, patient-centered and context-sensitive approach focused on a patient's life

and health goals while imposing the smallest possible treatment weight (May et al., 2009). MDM seeks to advance patients' goals for health (*perceived empowerment*) by helping patients have access (*perceived access*) to health information, helping them make appropriate choices (*perceived choice*), helping them interact with physicians (*perceived interaction*), and having the physician facilitate the care process (*perceived naturalness*) that imposes less load on the patient (May et al., 2009; Schattner et al., 2015). The MDM approach uses effective tools to help providers and patients use integrative health systems and techniques to improve health and wellbeing. To accommodate patients' needs and preferences, MDM requires adjusting protocols and practice guidelines. MDM has two goals: identifying the right care and making the right care happen. Studies have shown that identifying the right care focuses on improving value-based system of care and patient centered care by making patient care more meaningful, efficient, and impactful (see Lateef, 2011). On the other hand, making the right care happen focuses on patient empowerment by increasing patients' efficacy, knowledge, and involvement in the care process (see Tuil et al., 2007). These aims are accomplished when the goal of the care is elicited, when patients are involved in the decision making, when we can track the patient outcome, when efforts are directed to improving care and medication management, and connecting patients to community resources (May et al., 2009).

Our main variable of investigation is *patient empowerment*, which is broader concept than patient centeredness. Both concepts are complementary and do not oppose each other. Although literature is disjointed with respect to the general definition of patient empowerment, the concept is *linked to patients' access and knowledge to information, their involvement in the decision process, their interaction with the physicians, and the role of the physician in enabling a meaningful care process* (Tuil et al., 2007; Anderson et al., 1991; Corrigan et al., 1999). It has been shown that promoting patients' access to health records improves empowerment (Ross & Lin, 2003). Furthermore, the approach of providing access to personal health information (PHI) through the paper-based method is still disputable in terms of its effectiveness (Lovell et al., 1987). But, HIT systems have promoted patient empowerment by increasing patients' knowledge and access to information and patient-physician interaction (Tuil et al., 2007). Studies have concluded that patient empowerment is achieved in the process of providing a patient centered care (Holmström & Röing, 2010; Castro et al., 2016). Consequently, we investigate patient empowerment on the basis of this theoretical underpinning. To do this, we design an artifact that facilitates access to patient health information, interaction between patients and physicians, choice options for decision making, and patient's perceptions of how natural physicians are in the care process. Our design follows the design science research methodology for information systems (Peffer et al., 2008).

3. Artifact Design

This study adapts and applies the design science research methodology process model suggested by Peffer, et al. (2008). Following the suggested process, research in design science identifies and solves a problem by designing and developing artifact solutions that are relevant and add knowledge to the context and field of study. Through this process model, design theories, methods, or models can be invented or improved. A proposed new design approach of EHR shared screen option for patient empowerment is tested by evaluating and comparing the functionality and effectiveness of implementing the traditional paper-based approach toward the care process to the current suggest approach. By EHR sharing, we mean physicians get to share their screen with the patients during healthcare visits. This artifact is relevant in that, 1) it gives patients the opportunity to have a good knowledge of their health situation so that they can be involved in the care process and 2) it encourages the physicians to instantly and consistently use the EHR system.

Designing an artifact that seeks to enhance patient empowerment requires a framework and an intelligent system that address the needs for high quality care and minimal efforts on the part of both the physicians and the patients. The MDM care model (May et al., 2009) provides the basis by facilitating legitimate patient-physician partnership, respecting patients' and physicians' values and preferences, and is an innovative method for leveraging meaningful interactions. It takes into consideration the actors and their interaction with the system to produce high-quality care outcomes. In this study we are interested in how the goal of the MDM care model (i.e., making the right care happen) is accomplished. Thus, our design focuses on facilitating the interaction between patients and physicians through a shared decision-making mechanism (in our case, an AI-embedded EHR system) to generate a patient-centric outcome—patient

empowerment. The EHR system is embedded with AI capabilities—intelligent tools, to provide access, choice options, improve patient-physician interaction and enhance EHR use. The system uses the proposed IT artifacts, shared screen for patients to have access to their health information or report, voice recognition for communication with the system, intelligent decision options as patients' choice empowerment, and communication and coordination as a medium of interaction. As we will see later, our proposed model demonstrates a design that facilitates simultaneous interaction between the physician and patient, who interact with the system as well, to produce a patient centric outcome and also enhances the use of EHR systems. Both the traditional paper-based record system and the EHR standalone design do not provide patients with full access to their information. The paper-based and non-shared EHR systems are shown and explained in Figure 1. In the paragraphs that follow, we describe the artifact design by using evaluation methods, measures, and metrics, which are crucial components of design science research based on the generate/test cycle (Henver et al., 2004).

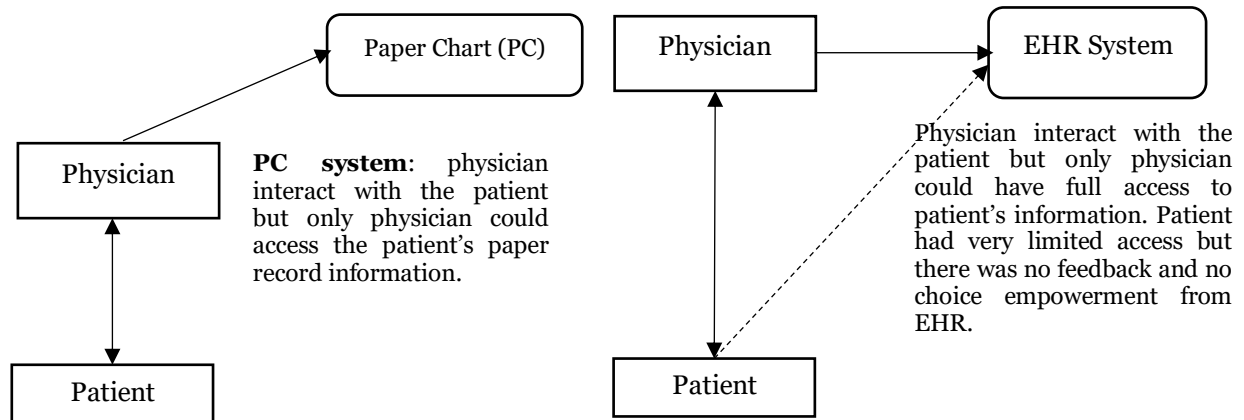


Figure 1: Paper Chart vs. EHR

There are three design artifacts produced in this study for our proposed model (see Figure 2). First, *shared screen* (for access). It describes the object used by both patients and physicians for information access. Patient information are stored in the EHR system that can be accessed by both actors through the shared screen as opposed to the traditional paper system and the non-shared EHR system that only the physicians had access and the patients were left out. With this shared screen option, patients can participate in the decision-making process and their options and preferences are respected by the physician, thus, improving patient-centered care. Second, *voice recognition* (for communication) capabilities. This artifact describes the ability of the EHR technology to recognize voice input from the actors, understand their needs, and provide options to the system users based on specific requirements. Voice recognition can be embedded into the EHR system using AI machine learning algorithms (algorithms that computer systems use to perform specific tasks). Voice recognition is important because it reduces the burden of clicking and manual typing of information into the system. The system does much of the work by understanding the voice commands, transcribes them, and provides options that the users can choose from. This way, it eases use of the system, make the interaction and treatment move faster, and the physician pays more attention to the patient, which lead to better patient-centered care. Third artifact is *decision options* (choice). The choice option in this design empowers the patient to participate in the care process with their needs and preferences considered. This artifact is designed in such a way that the system provides different possibilities depending on triggers from the users. Triggers could be in the form of questions.

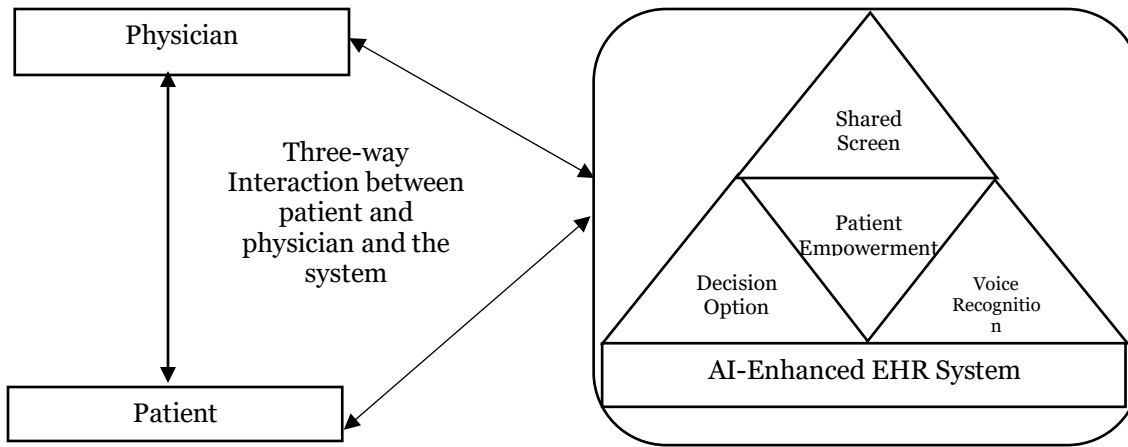


Figure 2: Proposed EHR Sharing Model for Patient Empowerment

The systems are design in compliance with regulatory standards stipulated by regulatory boards such as the Health Insurance Portability and Accountability Act (HIPAA), a United States legislation that regulates the processing and use of patient health data to meet privacy and security requirements (Murray et al., 2011). The architectural design serves to transfer and process information for use by physicians and patients during a hospital visit (Marceglia et al., 2015). This architecture (Figure 3) combines a set of technologies: IoT devices, database management systems, and cloud computing, divided into three component layers: human interaction layer, AI-Assisted EHR layer, and cloud and database layer.

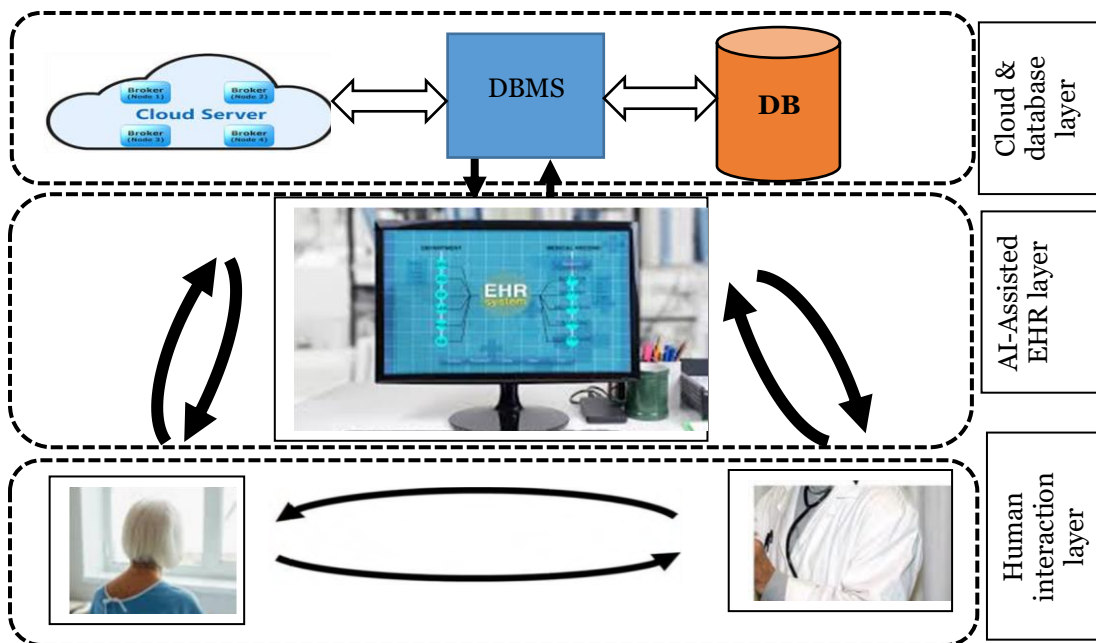


Figure 3: Architectural design of EHR enhanced system with components and relationships.

The human interaction layer provides an environment for effective communication and interaction between physicians and patients. The role of the AI-Assisted EHR layer is to capture patient's data from the human interaction layer through voice recognition and mouse clicking, encrypt it, and then send it to be stored in the EHR systems. The cloud and database (DB) layer provides a high computing capacity and a distributed storage. Organizations can embed artificial intelligence capabilities to recognize, analyze, and interpret patient data in order to identify possible reasons for abnormal results on diseases diagnosis, suggest treatments options, generate proactive predictions for possible future complications.

4. Demonstration

To demonstrate the design, we used a flow chart (Figure 4) and considered a hypothetical patient's lab report (diabetes) with the out-of-range values. The physician shares his/her screen with the patient showing the lab results. This way the patient can have access to their health information.

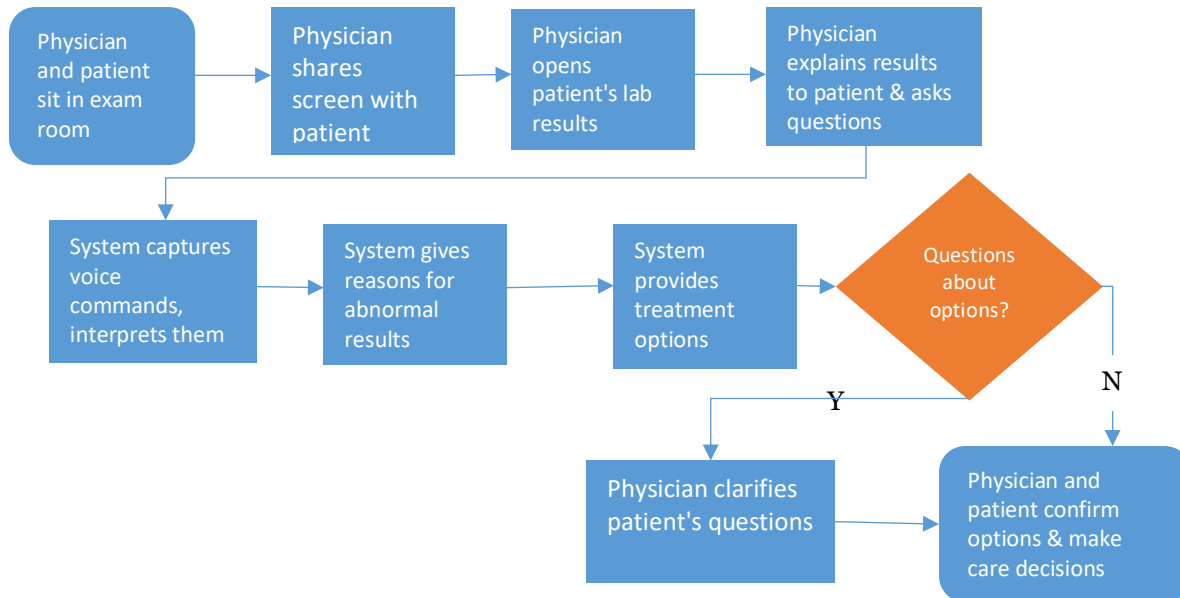


Figure 4: Flow chart showing procedure for illustration of design principles for EHR Sharing.

Once the cursor is moved over or clicked on an out-of-range value, a list of possible reasons will show up generated by the intelligent tool. Depending on the reasons for the “out of range” numbers, the physician can ask the patients some questions to confirm the possible reasons generated by the system. This question and answer session helps to improve interaction between the patient and the physician. Finally, based on the reasons for the high numbers, the system provides treatment options and/or life modifications for consideration by the patients. This serves as a choice options for decision making.

Target Participants/Subjects

The artifact will be setup in a typical clinical setting. For this study, subjects were patients randomly screened for the possibilities of diabetes. Subjects were assessed via a focus group technique in a classroom setting. Subjects were males and females, ages ranging from 24 to 39. This class of patients are able to understand critical health events and could make decisions and/or participate in health decision-making processes.

Measurement

An integration framework is designed to allow AI capabilities to be embedded into an EHR system to recognize users' conversations through voice recognition and the options are displayed and accessed via a shared screen. The system then intelligently provides the users with options that relate to the users' needs. Based on the design, we assume that the patient has been tested and his/her lab result needs further investigation by the physician to determine the cause of the diabetes, if the patient was rightly diagnosed, and what treatment options are appropriate. Looking at a patient's lab report, the physician shares his/her screen with the patient, and the AI capability highlights the tests figures that are beyond the normal range. AI features also provide some further recommendations based on the report values. When

prompted, the physician asks some questions to the patients and based on the responses, the AI system then provides possible reasons for the high values and any treatment options available.

5. Evaluation

In this section, the artifact is evaluated to demonstrate its worth with evidence addressing criteria such as validity, utility, quality, and efficacy. We tested the design using a specific scenario for application (in our case, diabetes). We evaluated the artifact design by using a focus group approach and gather data to examine the effectiveness and applicability of the solution. The effectiveness of the design was evaluated by assessing the interaction between patients and physicians, users' interaction with the system, the system's ability to enhance usage, and the overall degree to which patients express satisfaction regarding the visit. Additionally, regarding the evaluation of the design, we measured patients' perceptions of access, choice, interaction, naturalness, and empowerment. We now discuss the evaluation process below.

Focus group techniques (Tremblay et al., 2010) has been shown to provide a means to evaluate design science research (DSR) projects across a wide range of settings including healthcare because of the flexible format it entails. It provides direct interaction between the researcher and the respondents, it helps us gain richer understanding of the large amounts of data available, and the group setting allows for emergence of varied ideas and opinions. From the start, we clearly formulated the research problem and identified the research goals. We designed an exploratory and confirmatory focus groups to incrementally improve the artifacts and demonstrate the artifact's utility in the healthcare setting respectively. A sample frame was identified with at least one pilot group and two confirmatory focus groups (CFG). The size or number of participants of the groups were within the recommended range (4-12) and participants were selected based on their characteristics in relation to the topic under investigation. Participants are familiar with the application environment and are potential users of the proposed artifact.

Based on their understanding of the technical aspect of the artifact, the researchers were identified as the moderator and second observer respectively. The focus group was conducted in a friendly environment and the artifact design was communicated effectively. The moderator was respectful, listened well and controlled different views of the discussion. A pretest questioning was done to set the discussion route aligned with the research objectives. Questions were based on a broad explanation of the scenario where participants have the ability to utilize and evaluate the artifact. Before the focus group was conducted, participants filled out demographics and informed consent forms (IRB). In the data collection, participants were shown two demonstrations and then were asked to fill out a survey based on the demonstration of the artifact utilization. We implemented the artifact using the current design was shown and the participants filled out the first part of the survey. Then, the traditional design was demonstrated, and the participants filled out the second part of the survey. In total, a sample size of 76 observations was obtained.

6. Statistical Analyses and Results

We obtained data from the same population to test the null hypothesis (H_0): that *the means between the traditional design and the new design relating to access, choice, interaction, naturalness, and empowerment are the same*. For each construct, we first calculated the average of each construct in our model design. The main statistical approach to test the difference between two groups is to apply a t-test (Jeanmougin et al., 2010). A t-test is a type of inferential statistic used to determine if there is a significant difference between the means of two groups. We analyzed our data using a t-test statistics to see whether there is a significant difference between the traditional and current designs. It allows us to compare the average values of the two data sets and determine if they came from the same population. Comparing the average of the t-test statistics for each of the five constructs in our model, the results show that the new proposed design is significantly different from the old traditional design at $p < 0.01$ level. The summary results are shown in Table 1. From the results, we fail to accept the null hypothesis, indicating that the data readings are strong and are not by chance.

Variable	Traditional Approach (t-test)	Current Approach (t-test)	Difference in t-tests	p-value	Number of observations
Access	3.87	6.11	2.24	<0.01	154
Choice	4.06	6.05	1.99	<0.01	154
Interaction	3.82	6.07	2.25	<0.01	154
Naturalness	3.81	6.09	2.28	<0.01	154
Empowerment	3.96	6.17	2.21	<0.01	154

Table 1: t-test statistics results

7. Implications and Conclusion

Human-computer interaction (HCI) is one of the theories that make up the socio-economic software intensive systems (SIS) theories. HCI focuses on the design, implementation, and evaluation of IT and interaction between users and computers. It is a multidisciplinary field that includes computer science, cognitive science and human factors engineering. HCI is a broad field which overlaps with areas such as user-centered design, user interface design and user experience design. Scientifically, HCI focuses on research and development of empirical understanding about users and their interaction with systems. Based on the proposed artifact in this research, we suggest the following design principles. First, embedding or integrating specially designed artificial intelligence systems into electronic health records will be a novel way of implementing and improving HCI (Kotzé et al., 2008). This will not only improve the EHR quality but will also improve the physician-patient interaction and the performance of physicians in terms of efficiency and effectiveness.

Second, implementing HCI should consider the quality of the interaction and the usability of the system to achieve effectiveness, efficiency and satisfaction in specified contexts. Designers should consider if the HCI is appropriate and suitable in the context of its application, whether the environmental and organizational factors do encourage or promote/support HCI, and whether the HCI system is effective in its use in a typical work environment. In brief, HCI implementation needs to consider the needs of the specific context in which it is to be applied, be usable and supports a collaborative and interactive environment between the users and the systems.

Third, managing complexity (technical, human and societal) would be the key intellectual driver in the design. AI systems are very abstract and complex to design and implement. Therefore, gleaning knowledge and insights from other fields would provide solid grounds to demystify the complexity in developing artifacts that are robust but usable. Designing models and methods for managing complexity will require creative ideas for new information technology (IT) abstractions, representations, and languages. It is assumed that having accurate system specification at the initial stage will produce a system that fits users' needs. This may not be true in all cases as a complex system (e.g. systems properties such as, performance, reliability, security, usability, and sustainability) may change or alter a user's behavior towards its use. There is a need to come up with new ways of understanding and conceptualizing how IS qualities can be measured and evaluated. Managing complexity is important because the IT artifacts and the integrated systems containing these artifacts need to be reliable, adaptable, and sustainable. Due to the innovative and novel contribution of AI capabilities in our work systems today, we see the complexity driver as the most appropriate driver to be used for the design of innovative artifacts and the development of rigorous theories to rethink the development, evolution, and adaptation of future information systems.

This current study only tested the design artifact in a classroom setting using medical students as subjects for the demonstration. It is possible that the results could be different if we place in a perfect hospital setting. Further research should consider implementing the design artifact in a typical clinical setting and observe how the results might change with real-time subjects and artifacts in use. We also acknowledge that the phenomenon under investigation might reveal some significant findings if an empirical investigation is performed to assess the impact of perceived access, perceived choice, perceived interaction, and perceived naturalness on patient empowerment. Therefore, we call on further investigation to empirically test the effects of these factors on the patient empowerment. Moreover, in our model/artifact development, we introduced AI-based electronic health record (EHR) systems as a design principle for consideration when implementing the current approach in a real-world scenario. Thus, we

recommend that caution should be applied when interpreting our results. For an effective implementation of the proposed artifact, future research should actually test the artifact with an EHR system that is fully embedded with AI capabilities.

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