

# The role of patient engagement in patient-centric health information exchange (HIE) initiatives: an empirical study in the United States

Role of patient  
engagement in  
HIE

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## Abstract

**Purpose** – Patient-centric exchanges, a major type of Health Information Exchange (HIE), empower patients to aggregate and manage their health information. This exchange model helps patients access, modify and share their medical information with multiple healthcare organizations. Although existing studies examine patient engagement, more research is required to investigate patients' attitudes and willingness to play an active role in patient-centered information exchange. The study's main objective is to develop a model based on the belief-attitude-intention paradigm to empirically examine the effects of patients' attitudes toward engagement in care on their willingness to participate in patient-centric HIE.

**Design/methodology/approach** – The authors conducted an online survey study to identify the antecedents and consequences of patients' attitudes toward engagement in care. To empirically test the research model, the authors collected data from a national sample ( $n = 357$ ) of individuals in the United States. The data were analyzed using structural equation modeling (SEM).

**Findings** – The proposed model categorizes the antecedents to patients' attitudes toward engagement in patient-related and healthcare system factors. The results show that patient-related factors (perceived health literacy and perceived coping ability) and health system factors (perceived experience with the healthcare organization and perceived patient-provider interaction) significantly shape patient attitude toward care management engagement. The results indicate that patients' attitudes toward engaging in their healthcare significantly contribute to their willingness to participate in medical information sharing through patient-centric HIE initiatives. Moreover, the authors' findings also demonstrate that the link between patient engagement and willingness to participate in HIE is stronger for individuals who perceive lower levels of privacy and security concerns.

**Originality/value** – The authors validate the proposed model explaining patients' perceptions about their characteristics and the healthcare system significantly influence their attitude toward engaging in their care. This study also suggests that patients' favorable attitude toward engagement can bring patient-centric HIE efforts onto a path to success. The authors' research attempts to shed light on the importance of patients' roles in adopting patient-centric HIE initiatives. Theoretical and practical contributions of this study are noticeable since they could result in a deeper understanding of the concept of patient engagement and how it may affect healthcare services in an evolving digital world. The authors' findings can help healthcare organizations provide public citizen-centric services by introducing user-oriented approaches in healthcare delivery systems.

**Keywords** Patient-centric HIE, Citizen-oriented services, Patient engagement, Patient-related factors, Healthcare system factors, Privacy and security concerns

**Paper type** Research paper

## 1. Introduction

Offering incentives for adoption of certified Electronic Health Record (EHR) systems and Health Information Exchange (HIE) projects, the Health Information Technology for Economic and Clinical Health Act (HITECH) caused a primary shift in the US's Health



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Information Technology (HIT) (Vest *et al.*, 2015) and HIE policies (Tripathi *et al.*, 2009). HIE, which involves technologies such as EHRs, supports the electronic capture and sharing of patients' health information for effective healthcare delivery (Kim *et al.*, 2015). HIEs offer public health benefits such as early detection of infectious diseases resulting in an improved tracking of chronic disease management, reducing medical errors, enhancing healthcare quality and lowering healthcare costs (Erickson *et al.*, 2003).

The three forms of HIE models are direct, query-based and patient-centric exchange mechanisms. The national coordinator's office for HIT defined direct model as exchanging health information electronically between care providers through a secure network (Williams *et al.*, 2012). The query-based exchange occurs where healthcare organizations can look up the patient data in a centralized HIE architecture and data repository (Campion *et al.*, 2013). Finally, patient-centric exchanges are those where patients can access, manage, aggregate and control the use of their health information among care providers (Esmaeilzadeh and Mirzaei, 2018). Patient-centric HIE gives control to the patients to review health records to ensure their medical and billing information is correct and complete. Using this patient-centric HIE, patients can protect, monitor and track their health. In the US, patients reserve the right to be a part of HIE by using the opt-in policy, whereby a patient is required to sign a consent form for his/her clinical data to be uploaded into the HIE community database (Tripathi *et al.*, 2009).

Despite providing potential benefits, widespread adoption of HIE networks across healthcare providers and organizations faces several challenges (Eden *et al.*, 2016). Sharing information across geographically apart and commercially separate entities has raised major patient privacy issues, data security and data integrity concerns (Winkler *et al.*, 2016). Studies have identified patients' security issues and privacy risks as the most critical barriers to their willingness to participate in HIE efforts, thereby affecting HIE's widespread adoption (Wen *et al.*, 2010). HIE improves communication among providers by transmitting information across a wide range of care settings to provide safer and more efficient care. However, other varieties of challenges have impeded widespread adoption of HIE efforts, including technical standards, cost, workflow and information blocking practices by patients (Klein *et al.*, 2017). These concerns support the need for a patient-centric exchange model, which empowers patients by giving them a choice to share their health information in the care process (Klein *et al.*, 2015).

Previous studies on HIE's usefulness highlight the patient-centric HIE as the best way to achieve an effective, scalable, and sustainable health information infrastructure and help provide comprehensive electronic patient records when and where required (Cimino *et al.*, 2014). Moreover, a healthcare survey reported that roughly 70% of the public and 65% of doctors support the idea of patient's access to and control over their health information (Zarcadoolas *et al.*, 2013). A recent study compared patients' attitudes towards the different models of HIE and empirically found that patient-centric HIE is the most preferred model with a higher number of patients willing to participate in exchange activities by making opt-in decisions (Esmaeilzadeh and Mirzaei, 2018). These findings highlight the patients' preferences to have greater control over medical information sharing procedures (Nair *et al.*, 2004). Despite offering potential benefits, patient-centric HIE has not seen a desired adoption rate in the industry due to specific factors such as the incompleteness of records, patients' reluctance to participate and physicians' caution to accept patient-centric HIE (Esmaeilzadeh, 2018c; Zwaanswijk *et al.*, 2013). In this context, it is essential to understand the factors affecting patients' attitudes towards engagement in their care and their willingness to participate in a patient-centric HIE.

Patients are viewed as both crucial stakeholders and beneficiaries of patient-centric HIE efforts. Achieving a nationwide adoption of patient-centric HIE depends on patients' participation in electronic information exchange. Therefore, successful implementation of HIE networks will not be feasible without patients' positive beliefs and attitudes towards engaging in their care, specifically in the context of patient-centric HIE systems (Goldstein and Rein, 2010).

The Institute of Medicine designated “patient-centeredness” as one of the six goals for the 21<sup>st</sup>-century health care system. The Patient Protection and Affordable Care Act (PPACA), with an increased focus on patient engagement, is transforming the face of healthcare delivery in the US (Millenson and Macri, 2012). In conventional healthcare models, patients were more passive recipients of medical information during consultations and treatment processes. However, the recent patient-centric models ushered in a new healthcare delivery era where patients are expected to be more involved and engaged in their care practices (Ellins and Coulter, 2005). Patient engagement can be described as an individual’s involvement in his/her care to make competent and well-informed decisions about his/her healthcare and take actions to modify or support such decisions (Rockville *et al.*, 2012). Engagement is often viewed as a multi-faceted strategy to achieve the “triple aim” of improved patient care and experience, better health outcomes, and reduced healthcare costs (James, 2013). Studies have demonstrated that patients who are actively engaged in the management of their healthcare obtained more favorable clinical outcomes when compared to those patients who are disengaged and passive (Hibbard *et al.*, 2007; Frosch and Elwyn, 2011; Greene and Hibbard, 2012; Barello *et al.*, 2015). Patient engagement is also considered the linchpin of efforts to improve healthcare delivery (Tripathi *et al.*, 2009).

A rise in technology-enabled patients who desire greater control over their health has paved the way to a stream of research on patients’ attitudes toward patient-held medical records (Sartain *et al.*, 2015; Mamra *et al.*, 2017). Despite the vital role of patients in healthcare systems, prior studies call for more research to investigate patients’ attitudes towards participation in HIE efforts (Whiddett *et al.*, 2006). There is a lack of substantial empirical evidence on identifying factors driving and impeding patients’ desire to be involved in improving their treatment process. Moreover, compared to other traditional sharing models (such as fax, mail, phone), existing studies have still paid less attention to the role of patient’s attitudes towards engagement in electronic exchange of information through patient-centric HIE. Further, in our literature review, we hardly found a comprehensive study examining the antecedents and consequences of patient engagement in the context of patient-centric HIE. Our study by profoundly investigating the factors influencing the patient’s attitude toward engagement, their willingness to participate in patient-centric HIE, and the role of privacy and security concerns is unique from previous research. This work attempts to develop and empirically test a research model based on a belief-attitude-intention paradigm (Fishbein and Ajzen, 1977; Ajzen, 1991) to shed light on the importance of patients’ role in adopting patient-centric HIE. Consequently, this study addresses the following research questions:

- RQ1. What are the factors shaping patients’ attitudes toward their engagement in healthcare?
- RQ2. Does the patients’ attitude toward engagement contribute to their willingness to participate in patient-centric HIE?
- RQ3. Do perceived privacy concerns moderate the relationship between patients’ attitudes toward engagement in healthcare and their willingness to participate in patient-centric HIE?

Based on the mentioned research questions, our study can contribute new and meaningful knowledge related to patients’ engagement in their healthcare, particularly in patient-centric HIE, as a key component of healthcare and patient experience. As patient-centered care is becoming more firmly established, our study provides needed empirical evidence of patients’ engagement attitudes, including those related to privacy and security of personal health information. Patient buy-in and participation are crucial to successful HIE adoption and, therefore, it is necessary to understand patients’ perspectives regarding their engagement with HIE. It is important to note that we do not aim to examine the action of participating in

medical information sharing through HIE initiatives. That is why this study's primary focus is on attitude and willingness to participate, and the actual authentic behavior is not included in our model.

## 2. Research model and hypotheses development

### 2.1 Theoretical foundations

The theories of reasoned action (TRA) (Fishbein, 1979) and planned behavior (TPB) (Ajzen, 1985, 1991) predict an individual's attitudes and intentions toward a specific target behavior. The belief-attitude-intention (BAI) paradigm drawn from these theories has successfully predicted the behavioral intention or willingness to engage in target behaviors in various contexts like consumer marketing (Ting *et al.*, 2016), management (Fishbein and Ajzen, 1977; Davis, 1989) and medicine (Yzer, 2012) among others. According to this paradigm, an individual's cognitive structure, composed of beliefs about the behavior and the use of an expectancy-value model, determines attitude toward that behavior. Further, attitude toward a behavior is regarded as following upon beliefs about the behavior, which yields intentions to carry out the target behavior. Our study adopts the general structure of the BAI paradigm that has psychological variables under the realms of beliefs, attitudes, and intentions. Fishbein and Ajzen (1977) noted the importance of first identifying the beliefs associated with engaging in target behavior to operationalize the cognitive structure. We conducted an extensive literature review to determine the salient beliefs associated with the attitude towards patient engagement. The following section details the proposed hypotheses development.

The term "patient engagement" is used in literature to refer to patient actions and behaviors such as self-management of health conditions (Rodriguez, 2013), accessing services (Basta *et al.*, 2008), retention with services (Couper *et al.*, 2010), motivation to participate in interventions (Kortte *et al.*, 2007), experiences with physicians (Berry *et al.*, 2008), role in goal setting and treatment decision making (Stacey *et al.*, 2008) and patient safety (Davis *et al.*, 2007). The varied definitions of engagement highlight the context-specific nature of patient engagement. We refer to a patient's active role in their healthcare management as patient engagement in this study.

Studies identified a variety of antecedents to attitude towards patient engagement in different contexts. An engagement model classified the factors influencing patient and family engagement into those related to patients, organizations and society (Carman *et al.*, 2013). A study categorized the factors influencing patient safety into patient-related, illness-related, healthcare setting-related and healthcare professional-related dimensions (Davis *et al.*, 2007). A framework distinguished between intrinsic variables (health literacy, depression and others) and extrinsic factors (family influences, financial capabilities, and others) affecting patient engagement in diabetes self-management (Rodriguez, 2013). Another study labeled the factors influencing patient involvement in healthcare decision making as patient-related, disease-related, healthcare expert-related and healthcare setting-related (Vahdat *et al.*, 2014). A similar study categorized the factors influencing racial and linguistic minority engagement in hospital safety into patient-related (demographic characteristics, literacy, language proficiency), illness-related, healthcare professional-related and healthcare setting related (Johnstone and Kanitsaki, 2009).

In a systematic literature review of studies on patients' perspectives toward active engagement in their care and safety (in terms of reducing medical errors), researchers identified illness, individual cognitive characteristics, clinician-patient relationship and healthcare organizational factors as the main factors influencing patient engagement in their care (Doherty and Stavropoulou, 2012). We argue that it is important to investigate patients' perceptions of the healthcare system deriving from their experience and physician-patient

communication. More recently, researchers employed an extended technology acceptance model to predict patients' attitudes toward using personal health records (PHRs) and found that attitude towards usage behavior mediated individuals' perceptions and behavioral intention to use PHRs (Razmak and Bélanger, 2018).

To deliver a comprehensive understanding of patient engagement, we propose a classification of key factors shaping patients' engagement in their healthcare. Our extensive literature review identified six major factors influencing the patient's engagement in their care process. We classify these factors into two main categories: (1) patient-related factors and (2) healthcare system factors. Patient-related factors consist of perceived health literacy, perceived medical errors, perceived health status, and perceived coping ability. Healthcare system factors include the perceived importance of experience with the healthcare organization and patient-provider interaction. A significant qualitative study found that patients who were active in their care engagement (in terms of making health-related decisions) were more receptive to responsibly managing their health information than those who were passive in their care management (Forsyth *et al.*, 2010). We aim to empirically test this relationship between attitude toward engagement and willingness to participate in patient-centric HIE in our study. In the following section, we highlight related studies, develop hypotheses, and finally propose a conceptual research model.

## 2.2 Patient-related factors

**2.2.1 Perceived health literacy.** Perceived health literacy is defined as the degree to which individuals believe that they can obtain, process, understand, and communicate health-related information to make informed health decisions to promote and maintain good health (Berkman *et al.*, 2011). Affordable Care Act notes that engaging patients in their care fundamentally relies on health literacy (Koh *et al.*, 2013). Medical knowledge, jargon, specialized language, and terminology can be extremely confusing in the healthcare area. A study found that patients prefer to be more involved in those aspects of their health that do not require medical knowledge (Thompson *et al.*, 1993). A systematic review study reported a significant association between low health literacy and reduced treatment adherence, increased risk of having a chronic disease, decreased use of preventive services and poor health outcomes (Berkman *et al.*, 2011). A study indicated that individuals with low health literacy are less likely to engage in shared decision-making with their healthcare providers and ask fewer questions (Paasche-Orlow and Wolf, 2007). Based on Levinson *et al.* (2005), most patients prefer to leave the final clinical decisions to physicians and only rely on physicians to receive medical knowledge rather than seek out information themselves. Recent research proposed a model which linked beliefs about health literacy and patient engagement and highlighted how improved health literacy results in increased patient engagement (McCormack *et al.*, 2017). According to Deber *et al.* (2007), familiarity with medical procedures and potential treatments increases patients' willingness to participate in the health-related decision-making process. Therefore, perceived medical knowledge may encourage the patient to be engaged in finding the best diagnostic options, care planning, and treatment choices. Thus, we hypothesize:

*H1.* Perceived health literacy positively influences patients' attitudes towards engagement in their care.

**2.2.2 Perceived medical errors.** Medical error, which could be fatal, is a preventable adverse effect of healthcare (Wu *et al.*, 1991). A medical error may refer to the administration of wrong drugs or inappropriate dosages, errors in medical record transcription, unnoticed adverse reactions, and failure to communicate crucial information. While addressing these technical errors and complex issues is critical to eliminate the number of adverse events experienced by patients, recent studies and campaigns have targeted the patient as an integral team member

in reducing medical errors (Scobie and Persaud, 2010). For instance, patients are encouraged to ask healthcare professionals for more clarification when they do not understand the treatment process and are afraid of possible medical errors (Schwappach and Wernli, 2010). Understanding patients' role in patient safety and engaging patients in patient safety practices will help reduce adverse events (Schwappach, 2010). Previous literature indicates that patients could make essential contributions to their safety by participating in error-prevention strategies (Davis *et al.*, 2008). A sense of worry about medical errors may increase the patient likelihood of engaging in error prevention behaviors (Peters *et al.*, 2006). Thus, increased perception of risk and preventability can enhance patient involvement in healthcare decision making (Fisher *et al.*, 2019).

Patients generally believe they have a role in preventing medical errors (Rockville *et al.*, 2012). In a study conducted on consumers' views of patient safety, one-third of individuals shared their experience of a medical staff induced preventable medical error (Kaiser Family Foundation, 2006). They further reported that these errors often resulted in severe health consequences such as pain or long-term disability. A study highlights that patients seem to have some awareness of medical errors (Gallagher *et al.*, 2003). This awareness, combined with the perceived personal vulnerability to medical error, is a powerful determinant of their willingness to monitor and engage in their care. A patient is more likely to hold a positive attitude toward engagement in his/her care due to the perception of risk and vulnerability associated with medical errors that could endanger patient safety. Patients who strongly believe that medical errors and safety incidents are likely to occur at the hospital level are more prone to be engaged in their healthcare process to reduce possible errors. Thus, to lower the prevalence rates of medical errors and hospital-acquired infections, patients will increase the number of interventions and interactions with providers (McGuckin *et al.*, 2001; Weingart *et al.*, 2004). For instance, patients may engage more often to correct erroneous health information stored in hospitals' databases. Formally stated:

*H2. Perceived medical errors positively influence patients' attitudes towards engagement in their care.*

*2.2.3 Perceived health status.* Perceived health status gives an overall assessment of an individual's health in general. Individuals with different health conditions have different attitudes toward engagement in care management, such as data sharing (Zhang *et al.*, 2018). Previous research has indicated perceived health status to be an important determinant of an individual's ability to initiate and adhere to prescribed medical regimens, which are necessary for actively managing his/her health (Fowles and Walker, 2009; Hibbard and Cunningham, 2008; Hibbard *et al.*, 2007; Hibbard and Mahoney, 2010). A study shows that patients who perceive themselves healthy exhibit a more positive attitude toward engaging in their healthcare matters (McCabe *et al.*, 2018). Another study found a positive association between the number of chronic conditions, a measure of perceived health status, and patient engagement, suggesting that individuals who perceive their health as poor are more engaged in their care (Alexander *et al.*, 2012). Hibbard and Cunningham (2008) propose that people with multiple chronic conditions may be more positive to take a greater role in self-management of their health and therefore be more engaged in their care planning.

Moreover, health care providers may be more driven in equipping the patients with multiple conditions with self-managing skills and behaviors, which may enhance attitude toward engagement among such patients. A study examines chronic patients' participation in medical consultations and shows that many chronically ill patients feel confident in medical interactions (Henselmans *et al.*, 2015). Another study investigates why some patients are more involved than others, and they highlight that seriousness of illness may increase patient eagerness in involvement and participation in health care consultations (Thompson, 2007). A study indicates that people who considered themselves unhealthy are more prone to



engage in information sharing with physicians (Esmailzadeh, 2018b). Patients with severe illness are in constant need of support and care from providers to ensure that illness is under control and does not cause life-changing threats. For instance, patients with chronic diseases may become more likely to participate in consultations and information exchange with healthcare providers. Therefore, we posit that in the presence of poor health conditions, individuals may feel that higher levels of engagement in self-care management are essential for them compared to people with minor illnesses. Thus, we hypothesize:

*H3.* Perceived health status negatively influences patients' attitudes towards engagement in their care.

*2.2.4 Perceived coping ability.* The concept of patient engagement extends from the tenets of self-determination theory, which states that individuals are naturally motivated to improve their well-being (Mccarley, 2009). However, stressful events in life, such as an illness, may trigger negative emotions like anxiety and depression, which may, in turn, discourage the patient from being actively engaged in his healthcare. Coping with negative emotions such as anger, despair, shame, fear, and grief triggered by a chronic condition poses a significant challenge that may contribute to patients' sense of losing control over their lives. Consequently, this can discourage them from further engaging in their care (Bodenheimer et al., 2002). Active coping strategies can thus encourage an individual to be optimistic about taking an influential role in his/her healthcare and shape a positive attitude toward engagement in managing his/her health. In support, a study suggesting that patients with active coping strategies are more likely to prefer a leading role in decision making about care planning (Arora and Mchorney, 2000). Another study identified patients' psychological problems, including hostility and depression, to inhibit the development of therapeutic relationships (Broome et al., 1999). A study proposes that depression, a passive coping style, is highly associated with lower patient engagement (McCabe et al., 2018). According to American Diabetes Association (ADA), an active and healthy coping style is one of the most important self-care behaviors, and patients with higher levels of active-coping strategies are more likely to engage in diabetes self-management programs (Rodriguez, 2013; Rose et al., 2002). This evidence leads us to posit the following hypothesis.

*H4.* Perceived coping ability positively influences patients' attitudes towards engagement in their care.

## 2.3 Healthcare system factors

*2.3.1 Perceived importance of patient-provider interaction.* Healthcare providers have different approaches to interacting with their patients. Some may actively seek and pay careful attention to patients' questions, preferences, and concerns and efficiently address their needs by providing a clear explanation about health conditions and care planning. By patient-provider interaction, we mean patient-physician interaction at the user-level. Positive patient-provider interactions can create a supportive environment for patients to transform from their traditional passive recipient role to the one where they desire to be actively engaged in their care (Blanquicett et al., 2007; Berry et al., 2008). High-quality physician communication skills such as explaining, soliciting, listening, coaching and questioning have been associated with higher levels of patient adherence with treatment plans, higher recall of crucial medical information, improved self-management of diseases, and enhanced mental and physical health consequences (Ratanawongsa et al., 2008). A study articulated that patients who experienced positive and greater quality interpersonal exchanges with their physicians exhibited a more favorable attitude toward engagement in the care process (Alexander et al., 2012). These results highlight that collaborative partnerships between patients and physicians are an essential predictor of feelings about patient engagement for

improving care. A study indicated that patients prefer to consult a sympathetic physician interested in listening to their concerns and expectations and discussing both the problem and potential treatments with them (Little *et al.*, 2001). Literature provided evidence to support that clinical communications and effective interactions between patients and providers significantly impact how patients view engagement to influence healthcare outcomes (Di Blasi *et al.*, 2001). These studies showed that patients' beliefs about the quality of interaction with healthcare providers are considered necessary in shaping their attitude towards care engagement. Lubetkin *et al.* (2010) suggested that complementary physician-patient roles help patients realize room to improve their health. Thus, they begin to solicit or be receptive to information about the actions to be performed to maintain their well-being, thereby enhancing their feelings about engagement. Formally stated:

H5. The perceived importance of patient-provider interaction positively influences patients' attitudes towards engagement in their care.

*2.3.2 Perceived importance of experience with the healthcare organization.* Agency of Healthcare Research and Quality (AHRQ) defines patient experience as a process that encompasses a range of interactions that patients have with the healthcare system, including their care from health plans, nurses and medical staff in hospitals, and other healthcare facilities (Carman *et al.*, 2013). The patient experience reflects the occurrences and events that take place across the continuum of care. Getting timely appointments, good communication with physicians, nurses, hospital staff and easy access to information may characterize a patient's perceived experience with attention and respect. Studies suggest that if the procedures of receiving care in healthcare organizations do not cause anxiety for patients, they have more confidence to successfully navigate the healthcare system, which allows them to have a better experience and be engaged in their care (Hibbard *et al.*, 1999; Berry *et al.*, 2003). Realizing the opportunity to benefit from active patient engagement, healthcare organizations devote considerable effort to enable patients to experience no difficulty communicating with hospital staff. A study indicates that patients' experience should guide the development of tools and services in healthcare organizations to result in patient engagement (Graffigna *et al.*, 2013). In a study conducted to explore the links between patient experience with hospitals and clinical effectiveness outcomes, the results highlighted the positive associations between patient experience with healthcare organizations' policies and practices and higher levels of participation in care management (Doyle *et al.*, 2013).

A systematic literature review found that patients with a better experience with the healthcare setting are better able to know what to expect in the healthcare organization about diagnostic and treatment services than those with less experience (Corlett and Twycross, 2006). Then, the positive experience with the organizational factors will allow them to know more about the steps of care delivery, which, in turn, enhances attitude toward patient engagement (Little *et al.*, 2004). In contrast, negative experiences, which result from less familiarity with a health care setting, can act as inhibitors to feelings about patient engagement (Sainio *et al.*, 2001). Enhancing the patient experience with organizational factors will lead to increased care and improved health outcomes (Hibbard *et al.*, 2004). Thus, the patient's experience with the healthcare organization is perceived to be one of the most important factors affecting their care involvement. Therefore, we propose the following hypothesis:

H6. The perceived importance of experience with the healthcare organization positively influences patients' attitudes towards engagement in their care.

#### *2.4 Attitude toward patient engagement and willingness to participate in patient-centric HIE*

The two important strategies proposed by the Office of National Coordinator to fulfill its goal to empower and engage people in their health improvement through HIT are to increase



patient's access to their health information and enable patients to take action with such information (Ricciardi *et al.*, 2013). Patient-centric HIE supports these strategies. However, despite the expected advantages, the HIE projects have not witnessed the healthcare industry's desired adoption rate as a preferred data exchange mechanism (Esmailzadeh, 2018a). Since patients' consent is the critical requirement to render information exchange among providers, policymakers are increasingly paying more attention to increasing patient engagement in HIE initiatives. In particular, patient engagement is considered as a prerequisite for a successful implementation of patient-centric HIE. Literature indicates that patients' favorable beliefs and support will be essential to gain HIE's potential benefits (Patel *et al.*, 2012). Sands and Wald (2014) show that patients' access to their health information offers an excellent opportunity for improved patient engagement and team-based care. However, very few studies have investigated patients' attitudes towards patient-centric HIE efforts and their willingness to adopt it (Dhopeswarkar *et al.*, 2012). Patient engagement is an integral part of patient-centric HIEs, and health information cannot be shared with other healthcare providers without patients' active participation (Wen *et al.*, 2010).

Evidence from the literature shows very few empirical studies discussed how patients make opt-in decisions toward HIE (Goldstein and Rein, 2010). For instance, Ancker *et al.* (2013) suggest that patients' attitude toward engagement in care can influence their choice of physicians, perceived healthcare quality, and intention to endorse HIE initiatives. This finding implies that patients with favorable feelings about engagement in care may be more likely to accept a role in a patient-centric HIE project and, in turn, become more inclined to share their health information with providers. Patients who think engagement in healthcare is beneficial to solve health-related issues may exhibit more willingness to participate in a network to exchange their medical information electronically. Patient-centric HIE delegates a greater authority and control over medical records to patients by empowering them to access, aggregate, and manage their health information from a wide range of providers. Thus, patient-centric HIE mainly seeks to increase patient engagement in the process of delivery of care. Patients who are actively engaged in their healthcare are more willing to participate in patient-centric HIE. Accordingly, we posit that a more favorable attitude toward engagement in care will result in patients' increased willingness to participate in exchanging information electronically through patient-centric HIE models. Formally stated:

- H7.* Patients' attitude toward engagement in care positively influences their willingness to participate in patient-centric HIE.

## 2.5 Privacy and security concerns

Based on the national survey commissioned by the Institute of Medicine (IOM), only 1% of the respondents were comfortable with sharing their medical information without their consent (Detmer *et al.*, 2008). Consumer concerns about misuse of their health information stem from a variety of factors such as hospitals' collection practices, the likelihood of privacy violations (e.g., unauthorized access or hacked personal data), secondary use of medical records (e.g., data mining purposes), lack of control over how medical records are collected and how such information will be used (Agaku *et al.*, 2014; Chen and Xu, 2013; Perera *et al.*, 2011). Information privacy concerns may influence HIEs' patient databases' validity and completeness, resulting in wasteful investment, inaccurate treatments, erroneous care planning and higher mortality rates (Whiddett *et al.*, 2006). To avoid such issues, HIE networks should assure patients that their medical records would be well protected. Thus, privacy and security issues will influence consumers' beliefs about HIE initiatives.

Previous studies emphasize that patients are concerned about losing control over the ways HIE systems handle their personal health information (Kim *et al.*, 2015). According to Dimitropoulos and Rizk (2009), Information privacy in healthcare is an individual's desire or

ability to have the choice of control over their medical information, and the violation of this choice can result in privacy concerns. HIE initiatives utilize sharing mechanisms with which health information is transmitted electronically among healthcare providers; thus, many security concerns and privacy risks may entail (Campion *et al.*, 2013). When a technology (e.g. HIE) deals with sharing sensitive information and may exacerbate privacy concerns, patients' information disclosure willingness is not dependent only on their overall engagement in care.

Prior studies highlight the importance of privacy and security concerns in the context of HIE implementation (Dimitropoulos and Rizk, 2009; Park *et al.*, 2013). Patients are willing to participate in HIE when their health records are collected, stored and exchanged confidentially (Abdulnabi *et al.*, 2017). According to Wright *et al.* (2010), if a patient's privacy and security needs concerning a data exchange mechanism are not met, he/she will become more likely to hide further health information from healthcare providers. Favorable perceptions about participation in the patient-centric HIE system is a result of a solid match between the HIE mechanisms and security/privacy requirements (Campion *et al.*, 2013). If a privacy policy is perceived transparent, patients can learn about health information sharing between providers, types of exchange mechanisms (e.g., direct and look-up), the sensitivity of information exchanged through the HIE, access to shared data.

People with different perspectives on information disclosure privacy concerns will exhibit different adoption behaviors (Acquisti *et al.*, 2015). Patients are more willing to participate in sharing activities through an HIE network if assured that the exchange mechanism secures their health information privacy (Ancker *et al.*, 2012). Extant literature indicates that patients expect improved transparency and greater awareness about entities that can access their information and security measures in place to protect such information (Dimitropoulos *et al.*, 2011). Improved transparency about the information accessing and sharing entities will result in patients experiencing lesser privacy and security concerns.

In this study, we examine whether the relationship between attitude-intention in the context of patient-centric HIE is contingent on individual risk perceptions. We posit that this relationship is stronger when the risk factor (i.e., privacy and security concern) affecting patients' adoption behavior exerts fewer effects. Therefore, under low privacy and security concerns about exchange mechanisms, a positive attitude toward engagement will significantly influence a patient's willingness to participate in patient-centric HIE initiatives. We argue that patients' attitudes toward engagement in care can positively affect willingness to participate in patient-centric HIE, but the strength of that relationship may vary based on their privacy and security concern levels. Furthermore, when patients perceive higher privacy and security concerns associated with patient-centric HIE, they may display a less desirable attitude towards engaging in their care and be less likely to participate in patient-centric HIE.

*H8. Patients' information privacy and security concerns moderate the relationship between their attitude toward engagement in healthcare and their willingness to participate in patient-centric HIE.*

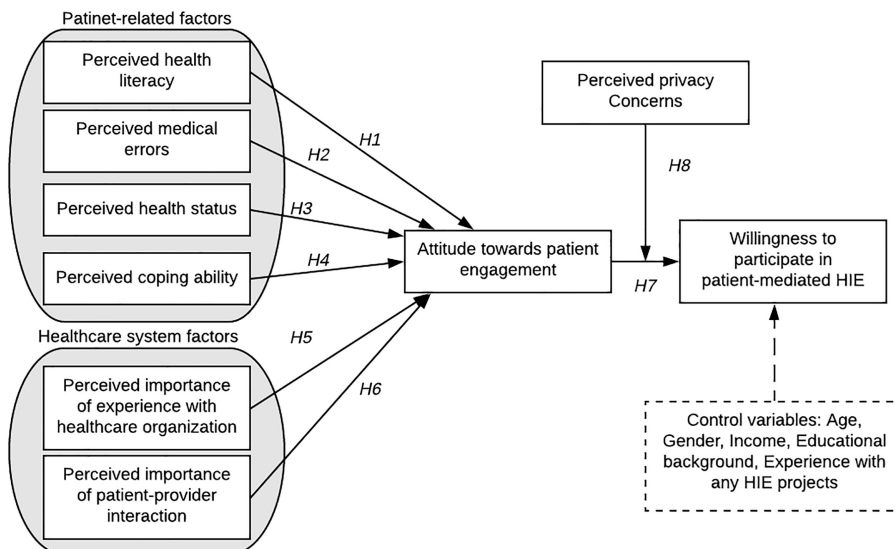
## 2.6 Control variables

Those factors not represented by core variables (variables included in the research model) but may influence the interrelationships between the core variables were controlled in the study. Previous literature indicates that individuals differ in their desire for engagement in care based on their demographic characteristics such as age, gender, income, and education levels (Arora and Mchorney, 2000). Several studies examined the relationship between patients' age and their engagement preferences in care. For instance, recent trend reports indicate an increase in the number of older adults who prefer to access health information online (Zickuhr

and Madden, 2012). A study demonstrated that a higher percentage of older respondents reported Internet usage for managing online personal health information (Lustria *et al.*, 2011). Gender plays a vital role in determining the engagement behavior with females desiring more engagement than males (Beaver *et al.*, 1996; Stiggelbout and Kiebert, 1997). This finding is consistent with women being more active in seeking care and asking questions during visits (Wallen *et al.*, 1979; Nathanson, 1977; Mechanic, 1978). Furthermore, it is consistent with identifying women as health advocates for the rest of their family (Mazur and Hickam, 1997). Women desire a more active role than men in medical decision-making (Arora and Mchorney, 2000).

Highly educated people may opt for more engagement in their care than their less academic peers (Arora and Mchorney, 2000). Conceptual knowledge, numeracy, and computer skills are important measures of an individual's literacy that contribute to successful and increased patient engagement via a patient portal (Haun *et al.*, 2014; Haggstrom *et al.*, 2011; Monkman *et al.*, 2013; Taha *et al.*, 2014). Previous studies argue that people at low-income levels face additional challenges, such as limited English proficiency and cognitive decline, which discourage them from actively engaging in their care (Carman *et al.*, 2013). Moreover, the levels of engagement in care management are low for people with low income (Hibbard and Cunningham, 2008). Moreover, previous studies indicate that experience with HIE projects is considered a factor affecting patient engagement in exchanging health information (Tripathi *et al.*, 2009). The degree to which people are familiar with HIE systems' mechanisms to share health information electronically may lead to a greater positive attitude toward HIE (Esmailzadeh, 2019). Thus, a higher familiarity level (previous experience with an HIE network) will likely encourage patients to engage in their health care by participating in information sharing initiatives.

Figure 1 presents the proposed conceptual model in this study. The model is mainly built upon a belief-attitude-intention perspective to explain the antecedents and consequences of patient engagement in care. The framework describing the casual link begins with patient-related factors and healthcare system factors to attitude toward patient engagement. Finally, it ends with a willingness to participate in patient-centric HIE. In this study, we controlled for age, gender, income, level of education, and level of experience with HIE projects in our model.



**Figure 1.**  
Proposed  
research model

### 3. Materials and methods

#### 3.1 Measurement design

The measurement of constructs included in the research model was based on the existing measures and instruments validated by other researchers. We adapted the survey measures from the existing literature and made minor changes to fit the HIE context. Items measuring willingness to participate in patient-centric HIE were adapted from [Venkatesh et al. \(2003\)](#) and [Angst and Agarwal \(2009\)](#). The scales used to measure privacy and security concerns were adapted from studies conducted by [Stewart and Segars \(2002\)](#) and [Van Slyke et al. \(2006\)](#). To measure the attitude toward patient engagement construct, we adapted the items reported by [Davis et al. \(2007\)](#) and [Gruman et al. \(2010\)](#). We drew on existing patient engagement studies to measure patient-related and situational factors. The items indicating perceived health status were adapted from [Bansal and Gefen \(2010\)](#). Perceived medical errors were measured based on a study conducted by [Blendon et al. \(2002\)](#). Our study adopted items to measure perceived coping ability from studies by [Arora and Mchorney \(2000\)](#) and [Sinclair and Wallston \(2004\)](#). Items reflecting perceived health literacy were adapted from [Chinn and McCarthy \(2013\)](#). Items measuring the perceived importance of physician-patient interaction were adapted from [Vieder et al. \(2002\)](#). To measure the perceived importance of experience with the healthcare organization, we adapted items suggested by [Corlett and Twycross \(2006\)](#) and [Little et al. \(2004\)](#). The complete survey questions are provided in [Appendix](#).

It should be highlighted that the two constructs used in this study (i.e., attitude toward patient engagement in care and willingness to participate in patient-centric HIE) are two different concepts. The first one refers to beliefs about technologies in which patients collect, manage and share their medical records with others. This construct is specifically a health IT phenomenon. The latter is a broad term that refers to patients' participation in their health care, and it is a medical phenomenon.

The survey questionnaire instrument was pre-evaluated in a pilot study involving 74 graduate students at a large Southeastern university in the US to assess the reliability and validity of the survey instrument in the context of HIE. Each construct's Cronbach's alpha was computed to evaluate the internal consistency of items (willingness to participate in patient-centric HIE:  $\alpha = 0.91$ , privacy and security concerns:  $\alpha = 0.90$ , attitude toward patient engagement:  $\alpha = 0.89$ , perceived health status:  $\alpha = 0.88$ , perceived medical errors:  $\alpha = 0.85$ , perceived coping ability:  $\alpha = 0.88$ , perceived health literacy:  $\alpha = 0.84$ , perceived importance of physician-patient interaction:  $\alpha = 0.89$ , perceived importance of experience with the healthcare organization:  $\alpha = 0.92$ ). All the constructs in the model showed good performance in terms of internal consistency as Cronbach's alpha values were well above the 0.7 cut-off value ([Hair et al., 2011](#)), indicating a significant correlation between the items for each of the constructs. This study uses five-point Likert scales with anchors ranging from (1) strongly disagree to (5) strongly agree.

#### 3.2 Data collection procedure

We designed and used an online version of the questionnaire (custom-developed using Qualtrics software) and utilized Amazon's Mechanical Turk (MTurk) platform to survey a national sample of patients. MTurk has been used in several studies as a reliable and acceptable source of subject participants ([Marge et al., 2010](#)) to analyze the perceptions of samples that are quite representative of the general population of interest, including a broad range of ages, income levels, ethnicities, and work experiences ([Behrend et al., 2011](#)). The survey was posted to MTurk in October 2019, and the respondents' location was limited to the United States. The incentive for participation was a monetary reward (\$1). Since this study's main objective is to examine the effects of patient engagement on willingness to participate in patient-centric HIE, we used a scenario that clearly explained HIE. Thus, at the beginning of the survey, a detailed description of patient-centric HIE technology was provided to ensure

that respondents completely comprehended the study's context and purpose. Three hundred seventy-one individuals within the United States attempted the survey. We used [Soper's \(2020\)](#) tool that uses the principals of lower bounds on SEM sample size ([Westland, 2010](#)) to identify the adequate sample size for this study. Given this study's characteristics and anticipating effect sizes small to medium effect sizes (between 0.2 and 0.3), the statistical power of 0.8 and probability level of 0.05, the adequate sample size ranges from 180 to 460. We acknowledge that the sample size we acquired for this study may not be adequate to detect small effect sizes.

As mentioned in previous studies, one general concern in data collection is the potential lack of attention and random responses ([Huang et al., 2012](#)). Consistent with other studies, we used "captcha" questions to prevent and identify careless, hurried, or haphazard answers ([Mason and Suri, 2012](#)). Based on the answers to these questions, we dropped fourteen responses. Previous studies that collected data using MTurk reported a similar ratio of dropped responses ([O'leary et al., 2014](#)). Thus, concerns that online respondents might reply randomly or haphazardly to complete the survey quickly were alleviated. The responses that failed the quality assessment were excluded, and the final set of valid responses that could be used in the study comprised 357 samples. The average time for survey completion was found to be 10.3 min. In terms of timing and number of questions, the mean response time implies that the answers can be acceptable.

### 3.3 Measurement model analysis and instrument validation

Confirmatory Factor Analysis (CFA) was performed on all the constructs to assess the measurement model and validate the survey instrument. Analyses were carried out using IBM SPSS AMOS (Version 22) to find evidence for convergent validity and discriminant validity. The results of model fit indices for measurement model demonstrated a good fit with goodness of fit indices [ $\chi^2/df = 2.34$ , Goodness-of-fit index (GFI) = 0.89, Adjusted goodness of fit index (AGFI) = 0.93, Comparative fit index (CFI) = 0.90, Normed-fit index (NFI) = 0.93, Incremental Fit indices (IFI) = 0.91, Standardized RMR (SRMR) = 0.03, and RMSEA = 0.04] all meeting their respective common acceptance levels.

According to [Gefen et al. \(2000\)](#), convergent validity can be ascertained by examining the measures such as standardized factor loading, composite reliability, and the Average Variance Extracted (AVE). The convergent validity test results are tabulated in [Table 1](#). The composite reliability value for each of the constructs was found to be greater than 0.89, well above the threshold acceptance value of 0.7, highlighting the adequate reliability of constructs ([Chin, 1998](#)). The reported standardized factor loading for each of the constructs in the model was found to be greater than 0.7, and according to [Hair et al. \(2006\)](#), a factor loading of 0.7 or greater is acceptable. The AVE was calculated using the values of standardized factor loading for each of the constructs. All AVE's values were also found to be greater than 0.64, well above the minimum acceptable value of 0.5 ([Segars, 1997](#)). The values of these measures provide evidence that the constructs exhibit acceptable convergent validity.

Then, we assessed the discriminant validity of the model constructs. In [Table 2](#), the off-diagonal elements denote the inter-construct correlation coefficients, and the values in italic along the main diagonal denote the square root of the AVEs. The constructs' adequate discriminant validity is demonstrated if AVE's square root for each of the constructs exceeds 0.7 and is greater than the inter-construct correlations in corresponding rows and columns ([Fornell et al., 1982](#)). Our results fulfill that requirement, and therefore, our constructs exhibit discriminant validity.

Although the correlations among constructs were not very noticeable, we computed the Variance Inflation Factor (VIF) and tolerance values to identify any multicollinearity evidence among the variables. The VIF values were below the cutoff value of 5, ranging between 1.074 and 1.940. The tolerance values, a reciprocal of VIF, ranged between 0.931 and

Construct	Items	Standardized factor loading (>0.7)	Composite reliability (>0.7)	AVE (>0.5)
Perceived health literacy	PHL1	0.81	0.916	0.646
	PHL2	0.80		
	PHL3	0.79		
	PHL4	0.83		
	PHL5	0.81		
	PHL6	0.78	0.902	0.698
	PME1	0.82		
	PME2	0.83		
	PME3	0.80		
	PME4	0.89		
Perceived health status	PHS1	0.88	0.896	0.682
	PHS2	0.85		
	PHS3	0.79		
	PHS4	0.78		
Perceived coping ability	PCS1	0.89	0.930	0.727
	PCS2	0.88		
	PCS3	0.81		
	PCS4	0.86		
	PCS5	0.82		
Perceived importance of patient-provider interaction	PPI1	0.80	0.922	0.662
	PPI2	0.82		
	PPI3	0.86		
	PPI4	0.81		
	PPI5	0.78		
	PPI6	0.81		
Perceived importance of experience with the healthcare organization	EHO1	0.85	0.944	0.707
	EHO2	0.83		
	EHO3	0.80		
	EHO4	0.86		
	EHO5	0.87		
	EHO6	0.79		
	EHO7	0.88		
Attitude toward patient engagement	PE1	0.87	0.934	0.669
	PE2	0.80		
	PE3	0.81		
	PE4	0.79		
	PE5	0.78		
	PE6	0.81		
	PE7	0.86		
Privacy and security concerns	PSC1	0.85	0.952	0.738
	PSC2	0.83		
	PSC3	0.87		
	PSC4	0.90		
	PSC5	0.85		
	PSC6	0.85		
	PSC7	0.86		
Willingness to participate in HIE	WP1	0.85	0.943	0.806
	WP2	0.89		
	WP3	0.93		
	WP4	0.92		

**Table 1.**  
Results of convergent  
validity



Construct	PHL	PME	PHS	PCS	PPI	EHO	PE	PSC	WP	Role of patient engagement in HIE
PHL	0.803									
PME	0.301	0.835								
PHS	0.112	-0.100	0.825							
PCS	0.285	0.237	0.202	0.852						
PPI	0.379	0.385	0.034	0.406	0.813					
EHO	0.422	0.378	0.049	0.422	0.455	0.840				
PE	0.510	0.342	0.083	0.506	0.580	0.445	0.817			
PSC	0.207	0.271	0.018	0.135	0.082	0.150	0.153	0.859		
WP	0.219	0.215	0.092	0.221	0.304	0.285	0.270	-0.339	0.897	

**Note(s):** PHL = Perceived health literacy; PME = Perceived medical errors; PHS = Perceived health status; PCS = Perceived coping ability; PPI = Perceived importance of patient-provider interaction; EHO = Perceived importance of experience with the healthcare organization; PE = Attitude toward patient engagement; PSC = Privacy and security concerns; WP = Willingness to participate in HIE

**Table 2.**  
Results of discriminant validity

0.515, exceeding the cutoff value of 0.1 (Hair *et al.*, 2011). Thus, we found no evidence of multicollinearity issues in the study.

To address the concerns of common method variance commonly associated with the self-report survey method (employed in the study), we examined the potential for common method bias (CMB) (Sharma *et al.*, 2009). We performed Harmon's single factor test to test if CMB is of concern to our study (Cenfetelli *et al.*, 2008). We found that none of the nine factors individually accounted for the majority of covariance (<20%), while they could explain 73.024% of the total variance. The results revealed that CMB posed a non-significant threat in our data sample.

## 4. Results

### 4.1 Descriptive statistics

Table 3 summarizes the demographic information in our final dataset. The demographic characteristics show that the majority of respondents were female (68%), White (71%), with a full-time job (63%), and had a bachelor's degree (50%). Age range and income were fairly scattered; however, age range between 30 and 39 (33%) and an annual household income between \$25,000 and \$49,999 (27%) was greater among provided categories. All participants are from the US, and most of them resided in suburban areas (47%). Finally, the majority of participants (68%) did not experience an HIE project offered by healthcare organizations.

Table 4 presents the number of items as well as descriptive statistics per construct.

### 4.2 Structural model analysis

We tested the hypotheses using IBM SPSS AMOS (Version 22) within a Structural Equation Modeling (SEM) framework. Ho (2006) notes that the structural model's overall fit can be assessed using the goodness of fit indices. The findings indicated that the  $\chi^2$  of the model was 2533.511, with 1,195 degrees of freedom ( $\chi^2/\text{df} = 2.12$ ). The indices values for GFI = 0.951, AGFI = 0.90, CFI = 0.920, NFI = 0.916, RFI = 0.917, and TLI = 0.934 were above 0.9 and the SRMR = 0.033 and RMSEA = 0.045 were below 0.08 (Byrne, 2001). The values of all these indices were found to be in the acceptable range. As the results indicate, at least four indices met the minimum recommended values, supporting a good fit between the observed data and hypothesized model in accordance with Kline (2015). Consider the path diagram presented in Figure 2, displaying the standardized path coefficients between different constructs in the structural model. The significant predictors of attitude towards engagement as well as willingness to participate in patient-centric HIE are illustrated.

ITP

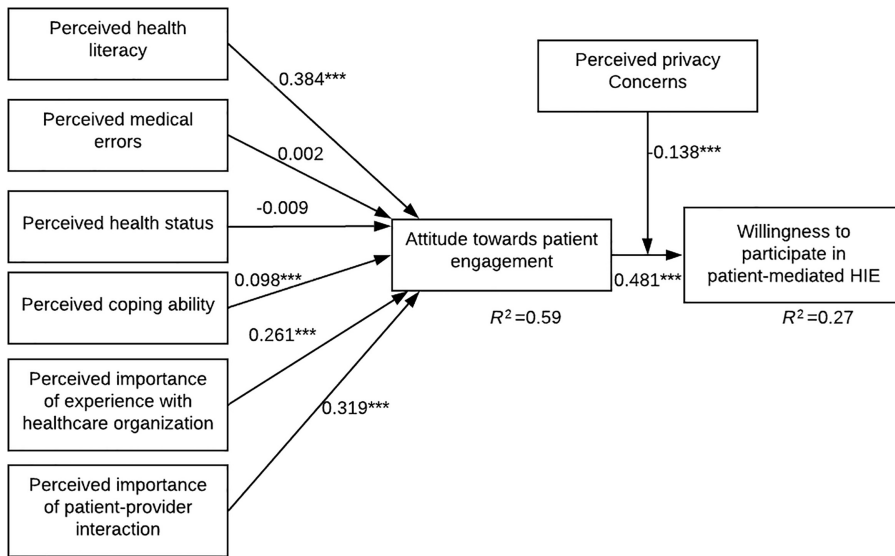
Variable	Categories	Percentage (%)
Gender	Male	32
	Female	68
Age	Under 20	2
	20–29	29
	30–39	33
	40–49	15
	50–59	11
	60 or older	10
	Others	3
Race	White/caucasian	71
	Black or African American	11
	Hispanic or Latino	6
	Asian	9
	Others	3
Level of education	Less than high school	2
	High school graduate	10
	Some college	26
	2-years degree	8
	4-years degree	50
	Doctorate	4
Residency area	Urban	34
	Suburban	47
	Rural	19
Employment	Full time	63
	Part-time	16
	Unemployed	13
	Retired	5
	Student	3
Income	Less than \$25,000	22
	\$25,000-\$49,999	27
	\$50,000-\$74,999	24
	\$75,000-\$99,999	14
	\$100,000 or more	13
Experience with any HIE projects	Yes	32
	No	68

**Table 3.**  
Demographic  
characteristics

Constructs	Number of items	Mean	SD
Perceived health literacy	6	3.85	0.78
Perceived medical errors	4	3.46	0.75
Perceived health status	4	3.68	0.87
Perceived coping ability	5	4.03	0.85
Perceived importance of patient-provider interaction	6	4.22	0.77
Perceived importance of experience with the healthcare organization	7	4.32	0.80
Attitude toward patient engagement	7	4.19	0.80
Privacy and security concerns	7	3.27	0.99
Willingness to participate in HIE	4	3.59	1.03

**Table 4.**  
Descriptive statistics of  
constructs

The results of hypotheses testing are summarized in [Table 5](#). [H1](#) is supported where higher health literacy leads to enhanced attitude toward patient engagement ( $\beta = 0.384, p < 0.001$ ). However, we found no support for [H2](#), which indicates that perceived medical errors would significantly reinforce attitude toward patient engagement. [H3](#), which posits that perceived



**Figure 2.**  
Results

health status would directly affect patient engagement, is also not supported. The analysis demonstrates that individuals' perceived coping style positively influences their attitude toward patient engagement ( $\beta = 0.098, p < 0.001$ ), and this positive linkage support [H4](#).

The path coefficient of the relationship between the perceived importance of experience with the healthcare organization and attitude toward patient engagement is significant, supporting [H5](#) ( $\beta = 0.261, p < 0.001$ ). Moreover, the effect of perceived importance of patient-provider interaction on attitude toward patient engagement is significant, supporting [H6](#) ( $\beta = 0.319, p < 0.001$ ). [H7](#) argues a positive relationship between attitude toward patient engagement and willingness to participate in patient-centric HIE, which is supported ( $\beta = 0.481, p < 0.001$ ).

Furthermore, we analyzed the interaction term to examine whether privacy and security concerns moderate the impact of attitudes toward patient engagement on willingness to participate in patient-centric HIE. The path goes from the interaction term (privacy and security concerns \* attitude toward patient engagement) to the willingness to participate in patient-centric HIE to test whether the moderating effect ([H8](#)). This analysis indicates that the moderation hypothesis is supported ( $\beta = -0.138, p < 0.01$ ).

Among the demographic characteristics (i.e. age, gender, education level, income, and experience with HIE projects), the findings show that only age has a significant positive relationship with attitude toward patient engagement ( $\beta = 0.086, p < 0.01$ ) and willingness to participate in HIE ( $\beta = 0.131, p < 0.01$ ). Thus, older patients hold a positive attitude toward engagement in their healthcare, and they also present a significantly higher willingness to participate in HIE. As mentioned before, we controlled the effects of age in our model. Moreover, we did not find any significant impact of other control variables in the model.

Finally, the variables explained 59% of the variance in attitude toward patient engagement and 27% of the variance in willingness to participate in patient-centric HIE. The  $R^2$  scores reflected that the model provides adequate explanatory power to predict the variance in the patient engagement attitude and intentions to participate in patient-centric HIE.

Hypothesis	Path	Standardized coefficient	Standard error	Critical ratio	Results
H1	PHL→PE	0.384***	0.055	6.987	Supported
H2	PME→PE	0.002	0.071	0.028	Not supported
H3	PHS→PE	−0.009	0.029	−0.302	Not supported
H4	PCS→PE	0.098***	0.027	3.597	Supported
H5	EHO→PE	0.261***	0.037	7.122	Supported
H6	PPI→PE	0.319***	0.045	7.134	Supported
H7	PE→WP	0.481***	0.104	4.615	Supported
H8	PE→WP (Moderating effect of PSC)	−0.138**	0.041	3.365	Supported

Attitude toward patient engagement  $R^2$ : 0.59  
Willingness to participate in HIE  $R^2$ : 0.27  
**Note(s):** PHL = Perceived health literacy; PME = Perceived medical errors; PHS = Perceived health status; PCS = Perceived coping ability; PPI = Perceived importance of patient-provider interaction; EHO = Perceived importance of experience with the healthcare organization; PE = Attitude toward patient engagement; PSC = Privacy and security concerns; WP = Willingness to participate in HIE  
Model paths \*\* $p < 0.01$ , \*\*\* $p < 0.001$

Table 5.  
SEM results

5. Discussion

5.1 Primary findings and implications for research

This research suggests several implications for theory. First, since previous studies propose patient engagement as an important variable in the context of HIE rollout (Furukawa *et al.*, 2014), it is crucial to add and empirically test patient engagement and its antecedents in the HIE adoption research stream. Patients are considered crucial stakeholders of HIE efforts. HIE projects’ widespread implementation will not be feasible without their positive beliefs, supporting attitudes, and active engagement in the exchange procedures (Yeager *et al.*, 2014). This study is among the first to investigate the role of attitude toward engagement in healthcare, its antecedents, and its consequences in the HIE rollout from patients’ views. This study proposes a research model that is mainly based on a belief-attitude-intention framework to explain causal relationships. The links begin with the beliefs shaped based on patient-related factors and healthcare system factors (perceptions) to attitude toward patient engagement (attitude) and finally end with the willingness to participate in HIE (behavioral intention). The findings indicate that individuals’ attitudes toward engaging in their healthcare significantly contributed to their decisions to participate in HIE projects. Concerning the role of patient engagement, our results are consistent with extant literature suggesting that patient participation in the process of care, decision making about treatment options, and care planning can increase the likelihood of commitment to information sharing with healthcare providers (Makoul and Clayman, 2006). The results further point to the importance of the direct effect of patient-related factors and healthcare system factors in enacting patient engagement in the context of HIE.

Second, this study differentiates between the perceptions resulting from patients’ characteristics and the beliefs derived from healthcare systems to shed light on patient engagement concerning patient-centric HIE efforts. Relying on the importance of patient-related factors, this study implies that the strength of attitude toward patient engagement amplifies for individuals who hold a positive and active coping style. This result is consistent with arguments posited in prior patient engagement studies that positive emotions, such as being optimistic about healthcare services, encourage patients to be actively engaged in their healthcare process (Davis *et al.*, 2007). Our findings related to the important role of health

literacy are in line with previous studies' propositions. These studies emphasize that patients with adequate medical knowledge are more likely to interpret medical treatments and medications and are more prone to accept an active role in their treatment process (Say *et al.*, 2006). Several prior studies suggest that patient-related factors such as age, gender, income, and educational background are positively associated with beliefs about engagement in healthcare (Arora and Mchorney, 2000) and their willingness to participate in HIE efforts (Park *et al.*, 2013). Our study shows that patients' age is the only demographic variable affecting attitude toward engagement in care and willingness to share information electronically. Older patients are more likely to engage in shared healthcare decisions by exchanging information with providers. This result is consistent with Caine and Hanania (2013), which demonstrates that age is the only demographic variable that impacts information-sharing preferences. According to Esmaeilzadeh and Sambasivan (2017), older individuals are more likely to believe that HIE networks can improve healthcare quality and are more willing to support the exchange of their health information through HIE. Our study extends prior studies by confirming that older patients will be more engaged in helping providers to share medical information with other healthcare organizations.

Third, contrary to our expectations, the findings show that perceived medical errors do not directly shape attitude toward patient engagement. This result is not consistent with previous studies, which indicated that patients might want to be more involved in their care to prevent medical errors such as death, disability, or prolonged treatments (Blendon *et al.*, 2002). Medical errors may occur in a physical hospital setting, in information sharing among physicians, or in interactions between physicians and patients (such as failure to communicate essential medical records). Patients may be more involved in their health to reduce the rates of medical errors occurring in healthcare organizations. However, beliefs about medical errors may not be an important factor in the context of patient-centric HIE. One plausible justification for this could be related to respondents' belief that HIE networks will enable effective sharing of health information among different healthcare entities to improve care quality, care coordination, patient safety, and reduced mortality rates (Miller and Tucker, 2014). Thus, a patient may perceive HIE projects to inherently minimize delays in care delivery, aid physicians in choosing appropriate treatment and medication regimes, thus avoiding adverse drug-drug interactions and redundant tests (Patel *et al.*, 2012). This perception can lead to reduced medical errors. Accordingly, minimizing medical errors is one of HIE's integral characteristics, and perceived medical errors may not be an influencing factor for patients to engage in this context.

Although prior studies suggest that individuals' characteristics (such as current health status) may impact the way patients analyze the utility of using an IT (Bansal and Gefen, 2010). Our results concerning the impact of perceived health status on patient engagement point out that overall individual health will not significantly contribute to patient attitude toward engagement in the HIE context. Contrary to our hypothesis, results suggest that personal beliefs may not influence attitude toward patient involvement in care. The first plausible justification for this result could be the lack of wide-range health conditions since most respondents were healthy with minor health issues or chronic problems. The second possible explanation is that respondents may have been impacted by the scope of this study (i.e., HIE efforts). Thus, both healthy and unhealthy individuals may exchange their health information with hopes of receiving the expected benefits of HIE projects. Unhealthy individuals, such as those with chronic conditions, are perceived to be more anxious and vulnerable to digital devices and services surrounding them due to infirmity strain (Zhang *et al.*, 2018). Nevertheless, in the context of our study, even individuals who consider themselves unhealthy may become likely to invest in interacting with HIE networks to achieve public health benefits such as improved care coordination, early detection of disease outbreaks, enhanced analysis of risk factors, and public health threats identification

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(Simon *et al.*, 2009). On the other hand, patients who consider themselves healthier may also shape a positive attitude toward engagement in care because they may believe that sharing health information with providers would help monitor and control their health conditions.

Fifth, this work contributes to engagement studies by highlighting the significant role of healthcare system factors in shaping patient attitudes toward information sharing engagement. Our research identifies two factors to capture the associations between patients and the healthcare system (i.e., interactions with physicians and experience with healthcare organizations). Prior studies indicate that collaborations between patients and healthcare providers are critical for the success of HIE efforts (Safran *et al.*, 2007). Our findings empirically confirm it by explaining that effective dialogue and active collaboration in the patient-provider interactions can resolve possible issues associated with information-sharing efforts. The collaborative activities may be more noteworthy in the HIE context than in traditional exchange methods (e.g., fax, mail). It is more likely that patients become worried about the unknown when unfamiliar technology is used by providers to share sensitive health records electronically. Our results also enrich the patient engagement literature by demonstrating that the perceived effectiveness of processes and transparency of procedures used by healthcare organizations to deliver care services will significantly contribute to patient engagement in information-sharing projects. This finding is in harmony with prior studies suggesting that hospitals' meaningful policies and practices for sharing health information will encourage patients to take an active role in HIE networks (Carman *et al.*, 2013). Our work contributes to the research area in the patient-centric HIE implementation by identifying significant antecedents that can reduce patients' awareness of the unknown information exchange procedures among healthcare entities.

Finally, this study uses the patient engagement perspective to explain the theorization of HIE adoption by capturing the dynamics of the patient-engagement building process. To better articulate this dynamism, our research advances the theoretical development in this field. It also adds to the existing literature by investigating the role of privacy and security concerns associated with HIE projects. We examined the moderating effect of privacy and security concerns in the relationship between patient engagement and intention to adopt HIE. In existing studies, privacy and security concern has been considered in relation to information disclosure activities. Several studies examined the direct or indirect effects of privacy concerns on an individual's intention to disclose information (Bansal and Gefen, 2010; Zhang *et al.*, 2018). Our study empirically supports that privacy and security concern has a moderation effect on patient willingness to participate in HIE. In particular, the result suggests a negative moderating effect of privacy and security concerns on the relationship between attitude toward engagement and willingness to exchange information with providers. This study's results contribute to the current HIE literature by indicating that attitude toward engagement in care management on participation in information sharing is different between patients who perceive high and low levels of privacy and security concerns associated with HIE efforts.

### *5.2 Implications for practice*

The findings in this study have important managerial implications for those tasked with developing and managing patient-centric HIEs. First, our study is one of the first attempts to furnish evidence that patient engagement can be potentially leveraged as a factor to enhance patient-centered information-sharing efforts. This work highlights that healthcare organizations in different settings need a principal strategy, such as adopting a patient-centered model to address quality and efficiency challenges around care delivery. Moving toward a patient-centered care model has recently received healthcare organizations' attention to identify patients' preferences better and focus on their needs (Davis *et al.*, 2005). Involving patients during the exchange of clinical information leads to improved accuracy of



information required for care planning and safer patient-centered care. Including patients in the care circle allows them to participate in care delivery and correct their portals' records (Muething *et al.*, 2007). Patient-centric HIE systems provide premier technology to support clinical decision-making, coordinate care between various healthcare organizations and engage patients in their care process. This study highlights that HIE projects need strong and trusting relationships with patients who are an important party that drives advantage from HIE efforts and that their uptake can significantly influence the nationwide implementation of HIEs. Practitioners and policymakers should design more powerful persuasion techniques based on factors affecting patient participation in HIE efforts.

Second, results show that health literacy is the most significant factor in enhancing attitude toward engagement in care management. Patients with higher awareness and health literacy will hold a positive attitude toward participating in information exchange with healthcare providers. The higher the degree to which individuals can obtain, process, and understand basic health information needed to make appropriate health decisions, the more likely they accept active roles in their safety, treatment processes, and health care. Based on this result, a significant barrier to patient engagement in healthcare and patient safety practices is an individual's lack of awareness and understanding of necessary medical information. If public health literacy is low, individuals will become less prone to participate in HIE projects. This finding is consistent with literature indicating that patients with higher medical knowledge, skills, and confidence to make informed decisions about their health are more engaged in their care planning and finding more appropriate treatment options (Irizarry *et al.*, 2015). Thus, research should address involving patients in patient safety and informed decision-making through further education and awareness.

Patients as health care consumers may seek information in the hope of learning and understanding the details of their medical records. Patient-centric HIE administrators should leverage patient management tools such as patient portals to provide them with educational resources (Otte-Trojel *et al.*, 2015). This initiative may help patients better understand the disease-specific medical care requirement and steps to be taken in case of complications, especially in an emergency. Educational information via the portal can be an important feature to increase the health literacy of patients. The portals should advance proper educational material and information for patients to gain an insight into their results and the doctor's notes. The information can be shared by providing links with educational material or creating a section of the portal where disease-specific information such as symptoms, treatment, side effects, and follow up can be accessed.

Moreover, sufficient resources are required to maintain the portal. For instance, there may be a need to hire new staff to enter and transcribe the medical information into an easier and more straightforward language for the patients to comprehend, which will reduce the time that physicians need to spend on the portal and may increase the use of the portal. Lastly, the portal should present health information in additional user-friendly formats (e.g. images, videos, and audio). As suggested by prior studies, video sharing can increase the effectiveness of health information exchange (Househ *et al.*, 2014).

Third, the significant role of perceived interactions with providers and experience with healthcare organizations and the moderating effect of privacy and security concerns suggest that healthcare providers with a good reputation can practically advance patient engagement in HIE efforts. In contrast, patients are less likely to support and participate in HIE efforts if developed or managed by providers with a relatively poor reputation due to previous data breaches. Consistent with Lu *et al.* (2011), lack of interactions between patients and healthcare providers can become a significant barrier in the implementation of HIE projects. Thus, the participation of trusted providers in the implementation of HIE initiatives and contributions of reputable healthcare organizations to the development of transparent privacy policies should be highlighted in HIE projects to enhance patients' attitudes toward engagement in

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information-sharing activities. Patient engagement enables a healthcare provider to expand from traditional information-sharing methods to patient-centric HIE models (Esmailzadeh and Mirzaei, 2018). Healthcare providers should look for opportunities to nurture their patients' participation in projects designed to exchange health information electronically. They should consider using tactics to increase the HIE privacy policy's transparency to mitigate privacy and security concerns and develop campaigns to leverage the power of image and reputation.

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Finally, HIE officials are required to launch a comprehensive marketing strategy to improve patients' perceptions about the accountability and accuracy of privacy policies, fostering patients' attitudes toward participation in HIE services. Research implications suggest that managers of patient-centric HIE initiatives should consider maximizing the transparency of privacy policy dimensions to encourage patients to disclose their health information. As our study shows the moderating role of privacy and security concerns in building a positive attitude toward engagement in sharing information, a systematic strategy can be adopted by healthcare entities to better demonstrate the dimensions of HIE's privacy statement. For instance, national educational programs, health conferences, and webinars that are easily accessible to a wide range of people can be advocated to publicize the key goals and policies of patient-centric HIE efforts. Educational forums available on official health websites, online tutorials accessible on patient portals or online health communities, and computerized help programs can be used by healthcare organizations to improve the transparency of HIE efforts, broadcast their privacy policies, and increase public awareness of digital exchange mechanisms.

### *5.3 Limitations and future study*

Our research has some limitations which call for additional studies. First, our study used an online survey to recruit participants digitally. Thus, we only considered individuals who accessed the internet and were healthy enough to participate in the online survey. Future studies can use larger sample sizes and use other data collection means and sampling strategies to reach out to a generalizable sample to a wide range of healthcare consumers and produce more reliable results.

Second, it is important to note that the study is based only on a sample of respondents drawn from the United States. Some practical solutions (such as privacy policy development and strategies related to patient health literacy) can be used in other countries developing and implementing patient-based HIE. However, caution should be exercised when generalizing this study's results to users of patient-centric HIE in other countries. Future studies should consider drawing samples from wider geographical areas, including other developed countries and developing countries where technological infrastructures and Internet services are less developed than in the United States. While investigating the cultural factors is beyond this study's scope, future research can examine the role of cultural dimensions in facilitating and improving patient engagement. For example, it is interesting to identify whether individualism or collectivism may create different levels of information exchange participation in the context of patient-centric HIE. Our work also opens the door to future cross-cultural studies on health information sharing behaviors through HIE networks.

Third, we used patient-centric HIE as the context of our study and collected the data from patients concerning the proposed HIE model. While the findings provide valuable insights on how patient-related and healthcare system factors influence patients' willingness to participate in information sharing, the results may not generalize to other types of HIE (i.e., direct model and query-based exchange). Further research is required to investigate patients' motivations to participate in information sharing through different HIE platforms.

Fourth, future research could leverage our findings to investigate the possible interaction effects between information exchange intentions, personality traits (e.g., agreeableness,

conscientiousness, extraversion, neuroticism, openness), and patient engagement. Fifth, the results indicate that together, the factors could explain 59% of the variance in patient engagement and 27% of the variance in willingness to adopt patient-centric HIE. Another research avenue to consider is examining additional factors that may enhance the amount of variance explained in patient participation in HIE initiatives. Future studies should include factors such as subjective norms, type of health information, satisfaction with treating doctors, and trusting beliefs into the model. Also, as this paper's primary focus is on patients' attitudes and willingness to participate, we did not examine the actual behavior of participating in medical information sharing through HIE initiatives. Further research can extend our study scope by adding actual behavior in their model as a latent variable or conducting a longitudinal study. Finally, future research should more deeply compare the effects of specific health status (e.g. physical and mental health stability) to articulate whether a lack of physical and mental health stability can exert different effects on information exchange intention and its relationship with patient engagement.

## 6. Conclusion

Patient engagement is an important consideration for healthcare systems that may influence medical service quality. Extant literature highlighted the role of patients in promoting patient-centered care models. However, more research is required to investigate the effects of patient engagement in the context of patient-centric HIE. This study develops a research model based on a belief-attitude-intention perspective to explain the antecedents and consequences of patients' attitudes toward engagement in the process of care. To do so, we propose two groups of antecedents, which may impact patient approaches to participation in healthcare-related issues, patient-related, and healthcare systems factors. The results show that two dimensions of patient-related factors (i.e., perceived health literacy and perceived coping ability) and health system factors (i.e., experience with a healthcare organization and patient-provider interaction) significantly shape patient attitude toward care management engagement. Of the mentioned factors, perceived health literacy is the most significant predictor of attitude toward patient engagement in our study. The findings provide evidence to articulate the mechanism in which beliefs about engagement in health care will enhance patients' willingness to participate in patient-centric HIE. Finally, our results suggest that the link between attitude toward engagement and resultant intentions (willingness to participate in HIE) is stronger for individuals who perceive lower levels of privacy and security concerns. This study's findings provide insights into the phenomenon of patient engagement and add to the literature on HIE efforts, e-health, self-management tools, and health informatics. Thus, HIE managers and healthcare organizations participating in HIE networks may need to put their efforts into increasing patient engagement and reinforcing organizational factors to encourage a wide range of patients to participate in HIE. This study's theoretical and practical contributions are noticeable since they could result in a deeper understanding of what patient engagement means and how it may affect healthcare services in an evolving digital world.

## References

- Abdulnabi, M., Al-Haiqi, A., Kiah, M.L.M., Zaidan, A., Zaidan, B. and Hussain, M. (2017), "A distributed framework for health information exchange using smartphone technologies", *Journal of Biomedical Informatics*, Vol. 69, pp. 230-250.
- Acquisti, A., Brandimarte, L. and Loewenstein, G. (2015), "Privacy and human behavior in the age of information", *Science*, Vol. 347, pp. 509-514.
- Agaku, I.T., Adisa, A.O., Ayo-Yusuf, O.A. and Connolly, G.N. (2014), "Concern about security and privacy, and perceived control over collection and use of health information are related to withholding of health information from healthcare providers", *Journal of the American Medical Informatics Association*, Vol. 21, pp. 374-378.

- Ajzen, I. (1985), "From intentions to actions: a theory of planned behavior", in Kuhi, J. and Beckmann, J. (Eds), *Actionôcontrol: From Cognition to Behavior*, Springer, Heidelberg, 11639.
- Ajzen, I. (1991), "The theory of planned behavior", *Organizational Behavior and Human Decision Processes*, Vol. 50, pp. 179-211.
- Alexander, J.A., Hearld, L.R., Mittler, J.N. and Harvey, J. (2012), "Patient–physician role relationships and patient activation among individuals with chronic illness", *Health Services Research*, Vol. 47, pp. 1201-1223.
- Ancker, J.S., Edwards, A.M., Miller, M.C. and Kaushal, R. (2012), "Consumer perceptions of electronic health information exchange", *American Journal of Preventive Medicine*, Vol. 43, pp. 76-80.
- Ancker, J.S., Silver, M., Miller, M.C. and Kaushal, R. (2013), "Consumer experience with and attitudes toward health information technology: a nationwide survey", *Journal of the American Medical Informatics Association*, Vol. 20, pp. 152-156.
- Angst, C.M. and Agarwal, R. (2009), "Adoption of electronic health records in the presence of privacy concerns: the elaboration likelihood model and individual persuasion", *MIS Quarterly*, Vol. 33, pp. 339-370.
- Arora, N.K. and Mchorney, C.A. (2000), "Patient preferences for medical decision making: who really wants to participate?", *Medical Care*, Vol. 38 No. 3, pp. 335-341.
- Bansal, G. and Gefen, D. (2010), "The impact of personal dispositions on information sensitivity, privacy concern and trust in disclosing health information online", *Decision Support Systems*, Vol. 49, pp. 138-150.
- Barello, S., Graffigna, G., Vegni, E., Savarese, M., Lombardi, F. and Bosio, A.C. (2015), "Engage me in taking care of my heart': a grounded theory study on patient–cardiologist relationship in the hospital management of heart failure", *British Medical Journal Open*, Vol. 5, p. e005582.
- Basta, T., Shacham, E. and Reece, M. (2008), "Psychological distress and engagement in HIV-related services among individuals seeking mental health care", *AIDS Care*, Vol. 20, pp. 969-976.
- Beaver, K., Luker, K.A., Owens, R.G., Leinster, S.J., Degner, L.F. and Sloan, J.A.J.C.N. (1996), "Treatment decision making in women newly diagnosed with breast cancer", *Cancer Nursing*, Vol. 19, pp. 8-19.
- Behrend, T.S., Sharek, D.J., Meade, A.W. and Wiebe, E.N. (2011), "The viability of crowdsourcing for survey research", *Behavior Research Methods*, Vol. 43, p. 800.
- Berkman, N.D., Sheridan, S.L., Donahue, K.E., Halpern, D.J. and Crotty, K. (2011), "Low health literacy and health outcomes: an updated systematic review", *Annals of Internal Medicine*, Vol. 155, pp. 97-107.
- Berry, L.L., Seiders, K. and Wilder, S.S. (2003), "Innovations in access to care: a patient-centered approach", *Annals of Internal Medicine*, Vol. 139, p. 568.
- Berry, L.L., Parish, J.T., Janakiraman, R., Ogburn-Russell, L., Couchman, G.R., Rayburn, W.L. and Grisel, J. (2008), "Patients' commitment to their primary physician and why it matters", *The Annals of Family Medicine*, Vol. 6, pp. 6-13.
- Blanquicett, C., Amsbary, J., Mills, C. and Powell, L. (2007a), "Examining the perceptions of doctor-patient communication", *Human Communication*, Vol. 10, pp. 421-436.
- Blendon, R.J., Desroches, C.M., Brodie, M., Benson, J.M., Rosen, A.B., Schneider, E., Altman, D.E., Zapert, K., Herrmann, M.J. and Steffenson, A.E. (2002), "Views of practicing physicians and the public on medical errors", *New England Journal of Medicine*, Vol. 347, pp. 1933-1940.
- Bodenheimer, T., Lorig, K., Holman, H. and Grumbach, K. (2002), "Patient self-management of chronic disease in primary care", *Journal of the American Medical Association*, Vol. 288, pp. 2469-2475.
- Broome, K.M., Flynn, P.M. and Simpson, D.D. (1999), "Psychiatric comorbidity measures as predictors of retention in drug abuse treatment programs", *Health Services Research*, Vol. 34, p. 791.
- Byrne, B.M. (2001), "Structural equation modeling: perspectives on the present and the future", *International Journal of Testing*, Vol. 1, pp. 327-334.

- 
- Caine, K. and Hanania, R. (2013), "Patients want granular privacy control over health information in electronic medical records", *Journal of the American Medical Informatics Association*, Vol. 20, pp. 7-15.
- Campion, T.R., Edwards, A.M., Johnson, S.B. and Kaushal, R. (2013), "Health information exchange system usage patterns in three communities: practice sites, users, patients, and data", *International Journal of Medical Informatics*, Vol. 82, pp. 810-820.
- Carman, K.L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C. and Sweeney, J. (2013), "Patient and family engagement: a framework for understanding the elements and developing interventions and policies", *Health Affairs*, Vol. 32, pp. 223-231.
- Cenfetelli, R.T., Benbasat, I. and Al-Natour, S. (2008), "Addressing the what and how of online services: positioning supporting-services functionality and service quality for business-to-consumer success", *Information Systems Research*, Vol. 19, pp. 161-181.
- Chen, Y. and Xu, H. (2013) "Privacy management in dynamic groups: understanding information privacy in medical practices", *Proceedings of the 2013 Conference on Computer Supported Cooperative Work*, ACM, San Antonio Texas, pp. 541-552.
- Chin, W.W. (1998), "The partial least squares approach to structural equation modeling", *Modern Methods for Business Research*, Vol. 295, pp. 295-336.
- Chinn, D. and McCarthy, C. (2013), "All Aspects of Health Literacy Scale (AAHLS): developing a tool to measure functional, communicative and critical health literacy in primary healthcare settings", *Patient Education and Counseling*, Vol. 90, pp. 247-253.
- Cimino, J.J., Frisse, M.E., Halamka, J., Sweeney, L. and Yasnoff, W. (2014), "Consumer-mediated health information exchanges: the 2012 ACMI debate", *Journal of Biomedical Informatics*, Vol. 48, pp. 5-15.
- Corlett, J. and Twycross, A. (2006a), "Negotiation of parental roles within family-centred care: a review of the research", *Journal of Clinical Nursing*, Vol. 15, pp. 1308-1316.
- Couper, M.P., Alexander, G.L., Maddy, N., Zhang, N., Nowak, M.A., McClure, J.B., Calvi, J.J., Rolnick, S.J., Stopponi, M.A. and Little, R.J. (2010), "Engagement and retention: measuring breadth and depth of participant use of an online intervention", *Journal of Medical Internet Research*, Vol. 12, p. e52.
- Davis, F.D. (1989), "Perceived usefulness, perceived ease of use, and user acceptance of information technology", *MIS Quarterly*, Vol. 13 No. 3, pp. 319-340.
- Davis, K., Schoenbaum, S.C. and Audet, A.M. (2005), "A 2020 vision of patient-centered primary care", *Journal of General Internal Medicine*, Vol. 20, pp. 953-957.
- Davis, R.E., Jacklin, R., Sevdalis, N. and Vincent, C.A. (2007), "Patient involvement in patient safety: what factors influence patient participation and engagement?", *Health Expectations*, Vol. 10, pp. 259-267.
- Davis, R., Koutantji, M. and Vincent, C. (2008), "How willing are patients to question healthcare staff on issues related to the quality and safety of their healthcare? An exploratory study", *BMJ Quality and Safety*, Vol. 17, pp. 90-96.
- Deber, R.B., Kraetschmer, N., Urowitz, S. and Sharpe, N. (2007), "Do people want to be autonomous patients? Preferred roles in treatment decision-making in several patient populations", *Health Expectations*, Vol. 10, pp. 248-258.
- Detmer, D., Bloomrosen, M., Raymond, B. and Tang, P. (2008), "Integrated personal health records: transformative tools for consumer-centric care", *BMC Medical Informatics and Decision Making*, Vol. 8, p. 45.
- Dhopeswarkar, R.V., Kern, L.M., O'donnell, H.C., Edwards, A.M. and Kaushal, R. (2012), "Health care consumers' preferences around health information exchange", *The Annals of Family Medicine*, Vol. 10 No. 5, pp. 428-434.
- Di Blasi, Z., Harkness, E., Ernst, E., Georgiou, A. and Kleijnen, J. (2001), "Influence of context effects on health outcomes: a systematic review", *The Lancet*, Vol. 357, pp. 757-762.

- 
- Dimitropoulos, L. and Rizk, S. (2009), "A state-based approach to privacy and security for interoperable health information exchange", *Health Affairs*, Vol. 28, pp. 428-434.
- Dimitropoulos, L., Patel, V., Scheffler, S. and Posnack, S. (2011), "Public attitudes toward health information exchange: perceived benefits and concerns", *American Journal of Managed Care*, Vol. 17, pp. SP111-SP116.
- Doherty, C. and Stavropoulou, C. (2012), "Patients' willingness and ability to participate actively in the reduction of clinical errors: a systematic literature review", *Social Science and Medicine*, Vol. 75 No. 2, pp. 257-263.
- Doyle, C., Lennox, L. and Bell, D. (2013), "A systematic review of evidence on the links between patient experience and clinical safety and effectiveness", *British Medical Journal Open*, Vol. 3, p. e001570.
- Eden, K.B., Totten, A.M., Kassakian, S.Z., Gorman, P.N., Mcdonagh, M.S., Devine, B., Pappas, M., Daeges, M., Woods, S. and Hersh, W.R. (2016), "Barriers and facilitators to exchanging health information: a systematic review", *International Journal of Medical Informatics*, Vol. 88, pp. 44-51.
- Ellins, J. and Coulter, A. (2005), *How Engaged are People in Their Health Care? Findings of a National Telephone Survey*, Picker Institute Europe, Oxford.
- Erickson, S.M., Wolcott, J., Corrigan, J.M. and Aspden, P. (2003), *Patient Safety: Achieving a New Standard for Care*, The National Academies Press, Washington DC.
- Esmailzadeh, P. (2018a), "Challenges and opportunities of health information exchange (HIE) from health consumers' perspective", *International Journal of E-Health and Medical Communications*, Vol. 9, pp. 20-42.
- Esmailzadeh, P. (2018b), "The effects of public concern for information privacy on the adoption of health information exchanges (HIEs) by healthcare entities", *Health Communication*, Vol. 34 No. 10, pp. 1202-1211.
- Esmailzadeh, P. (2018c), "Healthcare consumers' opt-in intentions to Health Information Exchanges (HIEs): an empirical study", *Computers in Human Behavior*, Vol. 84, pp. 114-129.
- Esmailzadeh, P. (2019), "The process of building patient trust in health information exchange (HIE): the impacts of perceived benefits, perceived transparency of privacy policy, and familiarity", *Communications of the Association for Information Systems*, Vol. 45, p. 21.
- Esmailzadeh, P. and Mirzaei, T. (2018), "Comparison of consumers' perspectives on different health information exchange (HIE) mechanisms: an experimental study", *International Journal of Medical Informatics*, Vol. 119, pp. 1-7.
- Esmailzadeh, P. and Sambasivan, M. (2017), "Patients' support for health information exchange: a literature review and classification of key factors", *BMC Medical Informatics and Decision Making*, Vol. 17 No. 1, p. 33.
- Fishbein, M. (1979), "A theory of reasoned action: some applications and implications", *Nebraska Symposium on Motivation*, Vol. 27, pp. 65-116.
- Fishbein, M. and Ajzen, I. (1977), "Belief, attitude, intention, and behavior: an introduction to theory and research", *Journal of Business Venturing*, Vol. 5, pp. 177-189.
- Fisher, K.A., Smith, K.M., Gallagher, T.H., Huang, J.C., Borton, J.C. and Mazor, K.M. (2019), "We want to know: patient comfort speaking up about breakdowns in care and patient experience", *BMJ Quality and Safety*, Vol. 28, pp. 190-197.
- Fornell, C., Tellis, G.J. and Zinkhan, G.M. (1982), "Validity assessment: a structural equations approach using partial least squares", *Proceedings of the American Marketing Association Educators' Conference*, Chicago, IL, USA, pp. 1-5.
- Forsyth, R., Maddock, C.A., Iedema, R.A. and Lassere, M. (2010), "Patient perceptions of carrying their own health information: approaches towards responsibility and playing an active role in their own health—implications for a patient-held health file", *Health Expectations*, Vol. 13, pp. 416-426.
- Fowles, E. and Walker, L. (2009), "Maternal predictors of toddler health status", *Journal for Specialists in Pediatric Nursing*, Vol. 14, pp. 33-40.



- 
- Frosch, D.L. and Elwyn, G. (2011), "I believe, therefore I do", *Journal of General Internal Medicine*, Vol. 26 No. 1, pp. 2-4.
- Furukawa, M.F., King, J., Patel, V., Hsiao, C.-J., Adler-Milstein, J. and Jha, A.K. (2014), "Despite substantial progress in EHR adoption, health information exchange and patient engagement remain low in office settings", *Health Affairs*, Vol. 33, pp. 1672-1679.
- Gallagher, T.H., Waterman, A.D., Ebers, A.G., Fraser, V.J. and Levinson, W. (2003), "Patients' and physicians' attitudes regarding the disclosure of medical errors", *The Journal of the American Medical Association*, Vol. 289, pp. 1001-1007.
- Gefen, D., Straub, D. and Boudreau, M.-C. (2000), "Structural equation modeling and regression: guidelines for research practice", *Communications of the Association for Information Systems*, Vol. 4, p. 7.
- Goldstein, M.M. and Rein, A.L. (2010), "Consumer consent options for electronic health information exchange: policy considerations and analysis", *Office of Policy and Planning: Office of the National Coordinator for Health IT*.
- Graffigna, G., Barello, S. and Riva, G. (2013), "Technologies for patient engagement", *Health Affairs*, Vol. 32 No. 6, p. 1172.
- Greene, J. and Hibbard, J.H. (2012), "Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes", *Journal of General Internal Medicine*, Vol. 27 No. 5, pp. 520-526.
- Gruman, J., Rovner, M.H., French, M.E., Jeffress, D., Sofaer, S., Shaller, D. and Prager, D.J. (2010), "From patient education to patient engagement: implications for the field of patient education", *Patient Education and Counseling*, Vol. 78, pp. 350-356.
- Hagstrom, D.A., Saleem, J.J., Russ, A.L., Jones, J., Russell, S.A. and Chumbler, N.R. (2011), "Lessons learned from usability testing of the VA's personal health record", *Journal of the American Medical Informatics Association*, Vol. 18, pp. i13-i17.
- Hair, J.F., Black, W.C., Babin, B.J., Anderson, R.E. and Tatham, R.L. (2006), *Multivariate Data Analysis*, Humans: Critique and reformulation. Journal of Abnormal Psychology, 6th ed., Pearson Prentice Hall, New Jersey, Vol. 87, pp. 49-74.
- Hair, J.F., Ringle, C.M. and Sarstedt, M. (2011), "PLS-SEM: indeed a silver bullet", *Journal of Marketing Theory and Practice*, Vol. 19, pp. 139-152.
- Haun, J.N., Lind, J.D., Shimada, S.L., Martin, T.L., Gosline, R.M., Antinori, N., Stewart, M. and Simon, S.R. (2014), "Evaluating user experiences of the secure messaging tool on the Veterans Affairs' patient portal system", *Journal of Medical Internet Research*, Vol. 16 No. 3, p. e75.
- Henselmans, I., Heijmans, M., Rademakers, J. and Van Dulmen, S. (2015), "Participation of chronic patients in medical consultations: patients' perceived efficacy, barriers and interest in support", *Health Expectations*, Vol. 18, pp. 2375-2388.
- Hibbard, J.H. and Cunningham, P.J. (2008), "How engaged are consumers in their health and health care, and why does it matter", *Research Briefs*, Vol. 8, pp. 1-9.
- Hibbard, J.H. and Mahoney, E. (2010), "Toward a theory of patient and consumer activation", *Patient Education and Counseling*, Vol. 78, pp. 377-381.
- Hibbard, J.H., Greenlick, M., Jimison, H., Kunkel, L. and Tusler, M. (1999), "Prevalence and predictors of the use of self-care resources grading system", *Evaluation and the Health Professions*, Vol. 22, pp. 107-122.
- Hibbard, J.H., Stockard, J., Mahoney, E.R. and Tusler, M. (2004), "Development of the patient activation measure (PAM): conceptualizing and measuring activation in patients and consumers", *Health Services Research*, Vol. 39, pp. 1005-1026.
- Hibbard, J.H., Mahoney, E.R., Stock, R. and Tusler, M. (2007), "Do increases in patient activation result in improved self-management behaviors?", *Health Services Research*, Vol. 42, pp. 1443-1463.
- Ho, R. (2006), *Handbook of Univariate and Multivariate Data Analysis and Interpretation with SPSS*, CRC Press Taylor & Francis Group, Boca Raton, FL.

- 
- Househ, M., Borycki, E. and Kushniruk, A. (2014), "Empowering patients through social media: the benefits and challenges", *Health Informatics Journal*, Vol. 20, pp. 50-58.
- Huang, J.L., Curran, P.G., Keeney, J., Poposki, E.M. and Deshon, R.P. (2012), "Detecting and deterring insufficient effort responding to surveys", *Journal of Business and Psychology*, Vol. 27, pp. 99-114.
- Irizarry, T., Dabbs, A.D. and Curran, C.R. (2015), "Patient portals and patient engagement: a state of the science review", *Journal of Medical Internet Research*, Vol. 17, p. e148.
- James, J. (2013), "Health policy brief: patient engagement", *Health Affairs*, 14 February 2013, available at: [https://www.healthaffairs.org/doi/10.1377/hpb20130214.898775/full/healthpolicybrief\\_86.pdf](https://www.healthaffairs.org/doi/10.1377/hpb20130214.898775/full/healthpolicybrief_86.pdf), doi: 10.1377/hpb20130214.898775.
- Johnstone, M.-J. and Kanitsaki, O. (2009), "Engaging patients as safety partners: some considerations for ensuring a culturally and linguistically appropriate approach", *Health Policy*, Vol. 90, pp. 1-7.
- Kaiser Family Foundation and Agency for Healthcare Research and Quality (2006), *Consumers' Views of Patient Safety and Quality Information*, Kaiser Family Foundation Publication, Washington DC, #7559, available at: [www.kff.org/kaiserpolls/pomr092706pkg.cfm](http://www.kff.org/kaiserpolls/pomr092706pkg.cfm).
- Kim, K., Joseph, J.G. and Ohno-Machado, L. (2015), "Comparison of consumers' views on electronic data sharing for healthcare and research", *Journal of the American Medical Informatics Association*, Vol. 22, pp. 821-830.
- Klein, D.M., Fix, G.M., Hogan, T.P., Simon, S.R., Nazi, K.M. and Turvey, C.L. (2015), "Use of the Blue Button online tool for sharing health information: qualitative interviews with patients and providers", *Journal of Medical Internet Research*, Vol. 17, p. e199.
- Klein, D.M., Pham, K., Samy, L., Bluth, A., Nazi, K.M., Witry, M., Klutts, J.S., Grant, K.M., Gundlapalli, A.V. and Kochersberger, G. (2017), "The veteran-initiated electronic care coordination: a multisite initiative to promote and evaluate consumer-mediated health information exchange", *Telemedicine and e-Health*, Vol. 23, pp. 264-272.
- Kline, R. (2015), *Principles and Practice of Structural Equation Modeling*, 4th ed., Guilford Publications, New York.
- Koh, H.K., Brach, C., Harris, L.M. and Parchman, M.L. (2013), "A proposed 'health literate care model' would constitute a systems approach to improving patients' engagement in care", *Health Affairs*, Vol. 32, pp. 357-367.
- Kortte, K.B., Falk, L.D., Castillo, R.C., Johnson-Greene, D. and Wegener, S.T. (2007), "The Hopkins rehabilitation engagement rating scale: development and psychometric properties", *Archives of Physical Medicine and Rehabilitation*, Vol. 88, pp. 877-884.
- Levinson, W., Kao, A., Kuby, A. and Thisted, R.A. (2005), "Not all patients want to participate in decision making: a national study of public preferences", *Journal of General Internal Medicine*, Vol. 20 No. 6, pp. 531-535.
- Little, P., Everitt, H., Williamson, I., Warner, G., Moore, M., Gould, C., Ferrier, K. and Payne, S. (2001), "Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations", *British Medical Journal*, Vol. 323, pp. 908-911.
- Little, P., Dorward, M., Warner, G., Moore, M., Stephens, K., Senior, J. and Kendrick, T. (2004), "Randomised controlled trial of effect of leaflets to empower patients in consultations in primary care", *British Medical Journal*, Vol. 328, p. 441.
- Lu, Y., Yang, S., Chau, P.Y. and Cao, Y. (2011), "Dynamics between the trust transfer process and intention to use mobile payment services: a cross-environment perspective", *Information and Management*, Vol. 48, pp. 393-403.
- Lubetkin, E.I., Lu, W.-H. and Gold, M.R. (2010), "Levels and correlates of patient activation in health center settings: building strategies for improving health outcomes", *Journal of Health Care for the Poor and Underserved*, Vol. 21, pp. 796-808.
- Lustria, M.L.A., Smith, S.A. and Hinnant, C.C. (2011), "Exploring digital divides: an examination of eHealth technology use in health information seeking, communication and personal health information management in the USA", *Health Informatics Journal*, Vol. 17, pp. 224-243.

- 
- Makoul, G. and Clayman, M.L. (2006), "An integrative model of shared decision making in medical encounters", *Patient Education and Counseling*, Vol. 60, pp. 301-312.
- Mamra, A., Sibghatullah, A.S., Ananta, G.P., Alazzam, M.B., Ahmed, Y.H. and Doheir, M. (2017), "Theories and factors applied in investigating the user acceptance towards personal health records: review study", *International Journal of Healthcare Management*, Vol. 10, pp. 89-96.
- Marge, M., Banerjee, S. and Rudnicki, A.I. (2010), "Using the Amazon Mechanical Turk for transcription of spoken language", *2010 IEEE International Conference on Acoustics, Speech and Signal Processing*, IEEE, pp. 5270-5273.
- Mason, W. and Suri, S. (2012), "Conducting behavioral research on Amazon's Mechanical Turk", *Behavior Research Methods*, Vol. 44, pp. 1-23.
- Mazur, D.J. and Hickam, D.H. (1997), "Patients' preferences for risk disclosure and role in decision making for invasive medical procedures", *Journal of General Internal Medicine*, Vol. 12 No. 2, pp. 114-117.
- Mccabe, P.J., Stuart-Mullen, L.G., Mcleod, C.J., Byrne, T.O., Schmidt, M.M., Branda, M.E. and Griffin, J.M. (2018), "Patient activation for self-management is associated with health status in patients with atrial fibrillation", *Patient Preference and Adherence*, Vol. 12, p. 1907.
- Mccarley, P. (2009), "Patient empowerment and motivational interviewing: engaging patients to self-manage their own care", *Nephrology Nursing Journal*, Vol. 36 No. 4, pp. 409-413.
- Mccormack, L., Thomas, V., Lewis, M.A. and Rudd, R. (2017), "Improving low health literacy and patient engagement: a social ecological approach", *Patient Education and Counseling*, Vol. 100, pp. 8-13.
- Mcguckin, M., Waterman, R., Storr, J., Bowler, I., Ashby, M., Topley, K. and Porten, L. (2001), "Evaluation of a patient-empowering hand hygiene programme in the UK", *Journal of Hospital Infection*, Vol. 48 No. 3, pp. 222-227.
- Mechanic, D. (1978), "Sex, illness, illness behavior, and the use of health services", *Social Science and Medicine Part B Medical Anthropology*, Vol. 12, pp. 207-214.
- Millenson, M.L. and Macri, J. (2012), *Will the Affordable Care Act Move Patient-Centeredness to Center Stage*, Urban Institute, Washington, DC, pp. 1-10.
- Miller, A.R. and Tucker, C. (2014), "Health information exchange, system size and information silos", *Journal of Health Economics*, Vol. 33, pp. 28-42.
- Monkman, H. and Kushnir, A. (2013), "A personal health record", *Enabling Health and Healthcare Through ICT: Available, Tailored and Closer*, Vol. 183, p. 179.
- Muething, S.E., Kotagal, U.R., Schoettler, P.J., Del Rey, J.G. and Dewitt, T.G. (2007), "Family-centered bedside rounds: a new approach to patient care and teaching", *Pediatrics*, Vol. 119, pp. 829-832.
- Nair, K., Willison, D., Holbrook, A. and Keshavjee, K. (2004), "Patients' consent preferences regarding the use of their health information for research purposes: a qualitative study", *Journal of Health Services Research and Policy*, Vol. 9, pp. 22-27.
- Nathanson, C.A. (1977), "Sex, illness, and medical care: a review of data, theory, and method", *Social Science and Medicine*, Vol. 11 No. 1, pp. 13-25.
- O'leary, M.B., Wilson, J.M. and Metiu, A. (2014), "Beyond being there: the symbolic role of communication and identification in perceptions of proximity to geographically dispersed colleagues", *MIS Quarterly*, Vol. 38, pp. 1219-1243.
- Otte-Trojel, T., De Bont, A., Aspria, M., Adams, S., Rundall, T.G., Van De Klundert, J. and De Mul, M. (2015), "Developing patient portals in a fragmented healthcare system", *International Journal of Medical Informatics*, Vol. 84, pp. 835-846.
- Paasche-Orlow, M.K. and Wolf, M.S. (2007), "The causal pathways linking health literacy to health outcomes", *American Journal of Health Behavior*, Vol. 31, pp. S19-S26.
- Park, H., Lee, S.-I., Kim, Y., Heo, E.-Y., Lee, J., Park, J.H. and Ha, K. (2013), "Patients' perceptions of a health information exchange: a pilot program in South Korea", *International Journal of Medical Informatics*, Vol. 82, pp. 98-107.

- 
- Patel, V.N., Dhopeswarkar, R.V., Edwards, A., Barrón, Y., Sparenborg, J. and Kaushal, R. (2012), "Consumer support for health information exchange and personal health records: a regional health information organization survey", *Journal of Medical Systems*, Vol. 36, pp. 1043-1052.
- Perera, G., Holbrook, A., Thabane, L., Foster, G. and Willison, D.J. (2011), "Views on health information sharing and privacy from primary care practices using electronic medical records", *International Journal of Medical Informatics*, Vol. 80, pp. 94-101.
- Peters, E., Slovic, P., Hibbard, J.H. and Tusler, M. (2006), "Why worry? Worry, risk perceptions, and willingness to act to reduce medical errors", *Health Psychology*, Vol. 25, p. 144.
- Ratanawongsa, N., Roter, D., Beach, M.C., Laird, S.L., Larson, S.M., Carson, K.A. and Cooper, L.A. (2008), "Physician burnout and patient-physician communication during primary care encounters", *Journal of General Internal Medicine*, Vol. 23 No. 10, p. 1581.
- Razmak, J. and Bélanger, C. (2018), "Using the technology acceptance model to predict patient attitude toward personal health records in regional communities", *Information Technology and People*, Vol. 31 No. 2, pp. 306-326.
- Ricciardi, L., Mostashari, F., Murphy, J., Daniel, J.G. and Siminerio, E.P. (2013), "A national action plan to support consumer engagement via e-health", *Health Affairs*, Vol. 32, pp. 376-384.
- Rockville, M., Maurer, M., Dardess, P., Carman, K.L., Frazier, K. and Smeeding, L. (2012), "Guide to patient and family engagement: environmental scan report", *Prepared by American Institutes for Research under Contract HHSA*, Agency for Healthcare Research and Quality, Rockville, MD.
- Rodriguez, K.M. (2013), "Intrinsic and extrinsic factors affecting patient engagement in diabetes self-management: perspectives of a certified diabetes educator", *Clinical Therapeutics*, Vol. 35, pp. 170-178.
- Rose, M., Fliege, H., Hildebrandt, M., Schirop, T. and Klapp, B.F. (2002), "The network of psychological variables in patients with diabetes and their importance for quality of life and metabolic control", *Diabetes Care*, Vol. 25, pp. 35-42.
- Safran, C., Bloomrosen, M., Hammond, W.E., Labkoff, S., Markel-Fox, S., Tang, P.C. and Detmer, D.E. (2007), "Toward a national framework for the secondary use of health data: an American medical informatics association white paper", *Journal of the American Medical Informatics Association*, Vol. 14, pp. 1-9.
- Sainio, C., Lauri, S. and Eriksson, E. (2001), "Cancer patients' views and experiences of participation in care and decision making", *Nursing Ethics*, Vol. 8 No. 2, pp. 97-113.
- Sands, D. and Wald, J. (2014), "Transforming health care delivery through consumer engagement, health data transparency, and patient-generated health information", *Yearbook of medical informatics*, Vol. 23, pp. 170-176.
- Sartain, S.A., Stressing, S. and Prieto, J. (2015), "Patients' views on the effectiveness of patient-held records: a systematic review and thematic synthesis of qualitative studies", *Health Expectations*, Vol. 18, pp. 2666-2677.
- Say, R., Murtagh, M. and Thomson, R. (2006), "Patients' preference for involvement in medical decision making: a narrative review", *Patient Education and Counseling*, Vol. 60, pp. 102-114.
- Schwappach, D.L. (2010), "Engaging patients as vigilant partners in safety: a systematic review", *Medical Care Research and Review*, Vol. 67, pp. 119-148.
- Schwappach, D. and Wernli, M. (2010), "Medication errors in chemotherapy: incidence, types and involvement of patients in prevention. A review of the literature", *European Journal of Cancer Care*, Vol. 19, pp. 285-292.
- Scobie, A.C. and Persaud, D.D. (2010), "Patient engagement in patient safety: barriers and facilitators", *Patient Safety and Quality Healthcare*, Vol. 7, pp. 42-47.
- Segars, A.H. (1997), "Assessing the unidimensionality of measurement: a paradigm and illustration within the context of information systems research", *Omega*, Vol. 25, pp. 107-121.

- 
- Sharma, R., Yetton, P. and Crawford, J. (2009), "Estimating the effect of common method variance: the method—method pair technique with an illustration from TAM research", *MIS Quarterly*, Vol. 33 No. 3, pp. 473-490.
- Simon, S., Evans, J.S., Benjamin, A., Delano, D. and Bates, D. (2009), "Patients' attitudes toward electronic health information exchange: qualitative study", *Journal of Medical Internet Research*, Vol. 11, p. e30.
- Sinclair, V.G. and Wallston, K.A. (2004), "The development and psychometric evaluation of the brief resilient coping scale", *Assessment*, Vol. 11, pp. 94-101.
- Soper, D.S. (2020), "A-priori sample size calculator for structural equation models [software]", available at: <https://www.danielsoper.com/statcalc>.
- Stacey, D., Samant, R. and Bennett, C. (2008), "Decision making in oncology: a review of patient decision aids to support patient participation", *CA: A Cancer Journal for Clinicians*, Vol. 58, pp. 293-304.
- Stewart, K.A. and Segars, A.H. (2002), "An empirical examination of the concern for information privacy instrument", *Information Systems Research*, Vol. 13, pp. 36-49.
- Stiggelbout, A.M. and Kiebert, G.M. (1997), "A role for the sick role: patient preferences regarding information and participation in clinical decision-making", *CMAJ: Canadian Medical Association Journal*, Vol. 157, p. 383.
- Taha, J., Sharit, J. and Czaja, S.J. (2014), "The impact of numeracy ability and technology skills on older adults' performance of health management tasks using a patient portal", *Journal of Applied Gerontology*, Vol. 33, pp. 416-436.
- Thompson, A.G. (2007), "The meaning of patient involvement and participation in health care consultations: a taxonomy", *Social Science and Medicine*, Vol. 64, pp. 1297-1310.
- Thompson, S.C., Pitts, J.S. and Schwankovsky, L. (1993), "Preferences for involvement in medical decision-making: situational and demographic influences", *Patient Education and Counseling*, Vol. 22, pp. 133-140.
- Ting, M.S., Goh, Y.N. and Isa, S.M. (2016), "Determining consumer purchase intentions toward counterfeit luxury goods in Malaysia", *Asia Pacific Management Review*, Vol. 21 No. 4, pp. 219-230.
- Tripathi, M., Delano, D., Lund, B. and Rudolph, L. (2009), "Engaging patients for health information exchange", *Health Affairs*, Vol. 28, pp. 435-443.
- Vahdat, S., Hamzehgardeshi, L., Hessam, S. and Hamzehgardeshi, Z. (2014), "Patient involvement in health care decision making: a review", *Iranian Red Crescent Medical Journal*, Vol. 16 No. 1, e12454.
- Van Slyke, C., Shim, J., Johnson, R. and Jiang, J.J. (2006), "Concern for information privacy and online consumer purchasing", *Journal of the Association for Information Systems*, Vol. 7, pp. 415-444.
- Venkatesh, V., Morris, M.G., Davis, G.B. and Davis, F.D. (2003), "User acceptance of information technology: toward a unified view", *MIS Quarterly*, Vol. 27, pp. 425-478.
- Vest, J.R., Kern, L.M., Silver, M.D., Kaushal, R. and Investigators, H. (2015), "The potential for community-based health information exchange systems to reduce hospital readmissions", *Journal of the American Medical Informatics Association*, Vol. 22, pp. 435-442.
- Vieder, J.N., Krafchick, M.A., Kovach, A.C. and Galluzzi, K.E. (2002), "Physician-patient interaction: what do elders want?", *Journal of the American Osteopathic Association*, Vol. 102, p. 73.
- Wallen, J., Waitzkin, H. and Stoeckle, J. (1979), "Physician stereotypes about female health and illness: a study of patient's sex and the informative process during medical interviews", *Women and Health*, Vol. 4 No. 2, pp. 135-146.
- Weingart, S.N., Toth, M., Eneman, J., Aronson, M.D., Sands, D.Z., Ship, A.N., Davis, R.B. and Phillips, R.S. (2004), "Lessons from a patient partnership intervention to prevent adverse drug events", *International Journal for Quality in Health Care*, Vol. 16 No. 6, pp. 499-507.

- Wen, K.-Y., Kreps, G., Zhu, F. and Miller, S (2010), "Consumers' perceptions about and use of the internet for personal health records and health information exchange: analysis of the 2007 health information national trends survey", *Journal of Medical Internet Research*, Vol. 12 No. 4, p. 73.
- Westland, J.C. (2010), "Lower bounds on sample size in structural equation modeling", *Electronic Commerce Research and Applications*, Vol. 9 No. 6, pp. 476-487.
- Whiddett, R., Hunter, I., Engelbrecht, J. and Handy, J. (2006), "Patients' attitudes towards sharing their health information", *International Journal of Medical Informatics*, Vol. 75, pp. 530-541.
- Williams, C., Mostashari, F., Mertz, K., Hogin, E. and Atwal, P. (2012), "From the Office of the National Coordinator: the strategy for advancing the exchange of health information", *Health Affairs*, Vol. 31, pp. 527-536.
- Winkler, T.J., Ozturk, P. and Brown, C.V. (2016), "Sustainability strategies for regional health information organization startups", *Health Policy and Technology*, Vol. 5 No. 4, pp. 341-349.
- Wright, A., Soran, C., Jenter, C.A., Volk, L.A., Bates, D.W. and Simon, S.R. (2010), "Physician attitudes toward health information exchange: results of a statewide survey", *Journal of the American Medical Informatics Association*, Vol. 17, pp. 66-70.
- Wu, A., Folkman, S., Mcphee, S.J. and Lo, B. (1991), "Do house officers learn from their mistakes?-", *The Journal of the American Medical Association*, Vol. 265 No. 16, pp. 2089-2094.
- Yeager, V.A., Walker, D., Cole, E., Mora, A.M. and Diana, M.L. (2014), "Factors related to health information exchange participation and use", *Journal of Medical Systems*, Vol. 38, p. 78.
- Yzer, M. (2012), "The integrative model of behavioral prediction as a tool for designing health messages", in Cho, H. (Ed.), *Health Communication Message Design*, SAGE Publications, Thousand Oaks.
- Zarcadoolas, C., Vaughn, W.L., Czaja, S.J., Levy, J. and Rockoff, M.L. (2013), "Consumers' perceptions of patient-accessible electronic medical records", *Journal of Medical Internet Research*, Vol. 15, p. e168.
- Zhang, X., Liu, S., Chen, X., Wang, L., Gao, B. and Zhu, Q. (2018), "Health information privacy concerns, antecedents, and information disclosure intention in online health communities", *Information and Management*, Vol. 55, pp. 482-493.
- Zickuhr, K. and Madden, M. (2012), *Older Adults and Internet Use*, Pew Research Center, Washington, DC, Vol. 6.
- Zwaanswijk, M., Ploem, M., Wiesman, F. and Verheij, R. (2013), "Understanding health care providers' reluctance to adopt a national electronic patient record: an empirical and legal analysis", *Medicine and Law*, Vol. 32, p. 13.

## Appendix

The Appendix is available online for this article.

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