Health Data Sharing Preferences of Consumers: Public Policy and Legal Implications of Consumer-Mediated Data Management

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Dedication

In appreciation of family members who provided unconditional support through my graduate studies and research. To my husband Tim, who encouraged me to complete my graduate degree in nursing information science. To my children, Kate, Trent, and Ian, who patiently supported my graduate studies as they grew into beautiful adults. To my father, who died from complex co-occurring medical conditions, often noting that no one in health care listened to his voice. To all health care consumers whose voices may be lost in the complexity of a system just now learning to adapt to consumer input, consumer choice, consumer control, and consumer sentiment. To a Learning Health System more closely aligned with the voice of the consumer.

Abstract

An individual's choice to share or have control of the sharing or withholding of their personal health information is one of the most significant public policy challenges associated with electronic information exchange. There were four aims of this study. First, to describe predictors of health data sharing preferences of consumers. Second, to test a hypothesized path diagram to understand the strength, path, and direction of relationships between and among the constructs of information privacy, data security, data sharing preferences, and consumer-mediated exchange (C-ME). Third, to create a theoretical model. Fourth, to make recommendations describing data governance structures needed for personally identifiable information in consumer-mediated data management. Study findings indicate two levels of health data sharing preferences exist (a) sharing between providers and (b) personal access to health information. The theoretical model showed data security and information privacy have a positive, direct relationship on consumer health data sharing preferences with respect to the types of data and mechanisms used to share personally identifiable health information. Results of this study were used to propose an integrated system approach to design, management, and control of consumer-mediated data management.

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Chapter 1: Introduction to the Study

Despite almost a decade of research and national initiatives aimed at understanding consumer information exchange attitudes, beliefs, and perceptions related to health care data, little is known regarding why consumers make the choice to share or withhold health information (Ancker, Edwards, Miller, & Kaushal, 2012; Anker, Silver, Miller, & Kaushal, 2013; Caine & Hanania, 2013; Campion, Edwards, Johnson, & Kaushal, 2013; Dhopeshwarkar, Kern, O'Donnell, Edwards, & Kaushal, 2012; Dimitropoulos & Rizk, 2009; Luchenski, 2012; Marquard & Brennan, 2009; O'Donnell, et al., 2011; Patel, Dhopeshwarkar, Edwards, Barrón & Likourezos, et al., 2011; Patel, Abramson, et al., 2011; Patel, Dhopeshwarkar et al., 2012; Ramos & Bakken, 2014; Teixeira, Gordon, Camhi, & Bakken, 2011; Wen, Kreps, Zhu, Miller, 2010). No research exists that describes predictors of health data sharing preferences of consumers. In addition, the researcher could not identify a theoretical model related to health data sharing preferences of consumers. The absence of a theoretical model to describe relationships among constructs of interest limits knowledge generation in a rapidly digitizing health care industry that has not integrated consumer-mediated processes into information exchange practices. New knowledge is needed regarding the public policy implications for consumer participation in information sharing.

Background of the Study

Data are an asset and a public good (McGinnis, Olsen, & Goodby, 2010). Health data (e.g., clinical, claims, and administrative) hold the potential to transform the health care industry into a learning health system (LHS) through the application and integration of bidirectional discoveries of actionable knowledge for research and health care practice

(Friedman, Wong, & Blumenthal, 2010; Greene, Reid, & Larson, 2012). Theoretically, people benefit because a LHS is likely to increase safety (avoiding misuse and harm from care) and promote effectiveness (avoidance of overuse or underuse and care grounded in evidence; Berwick, 2009; Kohn, Corrigan, & Donaldson, 2000). Justification for learning in health care originates from a morally essential feature of the health care system (Faden, Beauchamp, & Kass, 2011). Morally essential health rests on two empirical assumptions. First, a just health care system cannot be secured without continuous commitment to improving quality and efficiency of person-centered health services. Second, honoring this commitment depends on efficiently integrating into clinical service delivery a wide range of learning activities, including those conventionally classified as research (Faden et al., 2011; Institute of Medicine [IOM], 2009).

Health data provide significant insights to providers, consumers, and policy makers as data are transformed into usable information for treatment, evaluation of quality, and costs of care (Green et al., 2013; McGinnis et al., 2010; Tripathi, Delano, Lund, & Rudolph, 2009). Health care data offers the opportunity to fast-track evaluation on the six dimensions of quality care: safe, effective, person-centered, timely, efficient, and equitable (Berwick, 2009; Chaudhry et al., 2006; IOM, 2009). Still, additional evaluation metrics are needed, such as attention to information privacy, systems effectiveness, and legal and public policy support. Health information represents some of the most sensitive personal data available (Harper, 2014). The health data being recorded about people, when aggregated, provide a comprehensive picture of one’s health status and the health of populations of interest (Harper, 2014; Pritts, 2001).

Health information confidentiality, information privacy, and data security are fundamental rights (Markel Foundation, 2006). Confidentiality is the condition under which personal health information, obtained or disclosed within a confidential relationship, will not be re-disclosed without the permission of the individual (National Committee on Vital and Health Statistics, 2006). Information privacy refers to the ability of an individual to prevent certain disclosures of personal health information to any other person or entity (Markel Foundation, 2006). Data security are the protective measures (administrative, physical, and technical safeguards) that limit or grant access to personally identifiable information based on authorization or permissions, according to the Health Insurance Portability and Protection Act (HIPAA; Rothstein, 2007; U.S. Department of Health & Human Services, 2013).

Consumers want assurance that information they share about their health remains confidential, private, and secure (Markel Foundation, 2006). Health care professionals, including providers and health workers, must acknowledge that without assurances, consumers may withhold information (Moon, 2017). Theoretically, withholding information affects quality, safety, and care outcomes and reduces validity and reliability of actionable knowledge in a LHS. Health information at the point of care provides transparency, improves communication, and makes errors more transparent so that the negative effects can be mitigated (Makary & Daniel, 2016; Moon, 2017; Morey, Forbath, & Schoop, 2015).

Information privacy is a key component to health care quality and is necessary for meeting the Institute of Medicine’s (IOM) triple aim for health care (Berwick, 2009; Peel, 2007). If confidentiality and information privacy are missing, individuals will not have control of what others know about them (Olson, Grudin, & Horvitz, 2005). Individuals want to prevent undue surveillance, halt theft of personal identity, minimize embarrassment and stigma, protect what belongs to them, and limit risk to employment and insurance benefits (Harper 2014; Olson et al., 2005; Reed, 2007). Breaches are harmful, often leading to “privacy protective behavior” or situations where consumers avoid seeking health care services to protect their personal health information (Markel Foundation, 2006). Privacy protective behaviors may increase safety risks, increase medical errors, and lead to poor health outcomes.

Confidentiality and information privacy is deeply rooted in informed consent theory (Berg, Applebaum, Lidz, & Parker, 2001; Mayberry, 2003). Authorization to share or withhold information is based on characteristics found in informed consent: explanation, patient agreement, or refusal (expressed or implied), including disclosure of risks, benefits, and alternatives (Berg et al., 2001; Whitney, McGuire, & McCullough, 2004). Under HIPAA, individual consent or authorization is not required for disclosures related to treatment, payment, or health care operations (TPO; Rothstein, 2007; U.S. Department of Health & Human Services, 2013). Federal privacy and security protections are health care industry specific (covered entity, health care payer, and health care clearinghouse), but not all are easily managed in an information technology environment (Baumer, Earp, & Payton, 2000; Houser, Houser, & Shewchuk, 2007).

HIPAA regulation is not consumer centric (e.g., type of disclosure, purpose of disclosure, time limited disclosure) and does not include regulation specific to the management of health data sharing preferences of consumers. Much information, including wearable devices, applications, and patient generated data. in the health care system is left uncovered by information privacy or data security protections (Pritts, 2001, U.S. Department of Health and Human Services, 2016). Typically, health data are controlled by the collector, who is usually the owner of the electronic health record (EHR) or information system. Consequently, individuals have little control of the aggregation, disclosure, or secondary use of their health care data by the larger health care industry.

The application of electronic health information for uses outside direct care delivery and for purposes other than those for which they were originally collected is known as secondary use (Safran & Labkoff, 2007). Secondary users of health data include insurance payers, pharmacy benefit managers, the technology industry via vendor contracts, hospitals, quality assurance, improvement, research without consent, state and federal databases, registries, and population health initiatives. Secondary use has increased significantly since the digitization of health care records (Burke, 2014). Secondary use of health care data can enhance health care experiences for individuals, expand knowledge about disease and treatment, and help improve care quality and effectiveness (Peel, 2007; Rosenbaum, 2010; Safran & Labkoff, 2007). Complex ethical, political, policy, and social issues exist pertaining to the secondary use of health data. However, reducing secondary use is likely to affect quality of care and system integrity through decreasing efficiency, effectiveness, and insight—activities that rely on retrospective and comparative data analysis (Miriovsky, Shulman, & Abernethy, 2012).

Technology advancements related to the aggregation, re-use, and exchange of data outpace the development and adoption of policies, procedures, and processes essential for oversight of consumer health data secondary use (Rosenbaum, 2010; Safran

& Labkoff, 2007). Individuals are just beginning to know about widespread secondary uses of health information. However, many are not aware of how far outside the health care system their sensitive data flows (Harper, 2014; Reed, 2007). If patients do know, then secondary re-use may be one of many reasons consumers have anxiety related to information privacy. The positive result of this issue is that consumers are likely to engage in health care activities if information privacy, data security, and consent management include mechanisms for consumers to control access. The negative result of this issue is mechanisms that allow consumers to manage data sharing preferences (aggregation, access, and control), which require strong education regarding the benefits and risks of data sharing.

The Health Information Technology for Economic and Clinical Health (HITECH) Act, Title XIII of Division A and Title IV of Division B of the American Recovery and Reinvestment Act of 2009 (the Recovery Act; Pub. L. 111-5) supports the concept of consumers owning and controlling their personal health data. Technology needed to support this broad goal is in various stages of development. In the 21st century, health data sharing preferences of consumers are mostly managed through local “opt-in” or “opt-out” policies (Goldstein et al., 2010; Harper, 2014; Pritts, 2001). A consumer choosing to “opt-in” has all personally identifiable information in the shared record (Tripathi et al., 2009). A consumer choosing to “opt-out” has no personally identifiable information included in the shared record (Tripathi et al., 2009). However, it is unclear how the larger health care ecosystem encourages information exchange participation. Policy makers believe that the next generation of technology will rely on consumers being the intermediaries of their health data (Daniel, Deering, & Murray, 2014). A consumer who is a data intermediary owns, controls, and provides access to their health data based on individual preferences. A shift in understanding and practice begins with an environment that supports consumer-mediated exchange (C-ME).

Consumer-mediated exchange is one of only three types of health information exchange (directed, query, and C-ME) used to improve health care interoperability (Banning & Tritle, 2014; Daniel et al., 2014; Office of the National Coordinator [ONC], 2015). Direct exchange is electronic sharing between two information systems through one-way push transaction to a known, trusted entity (Banning & Tritle, 2014). Query exchange is both a push and pull transaction across a network and includes location, retrieval, and aggregation of information based on the end-user use case (ONC, 2015). Consumer-mediated exchange enables data aggregation and control, or access and use, of health information among providers, personal health records, and wearable health devices based on consumer preferences (ONC, 2015). Mechanisms that allow individuals to be data intermediaries are not readily available and the health care delivery environment is not equipped for full scale C-ME practices.

Consumer control of digital health information is characterized by desire for a high level of detail (i.e., granularity; Caine & Hanania, 2013; Dhopeshwarkar et al., 2012; Patel, Dhopeshwarkar, et al., 2011; Swartz, Caine, Alpert et al., 2015). A high level of detail is evidenced by digital information parsed and separated based on type of data and health data sharing preferences of consumers. The technical capability of C-ME resembles electronic data sharing capabilities found in financial services and online banking (Banning & Tritle, 2014). Individuals would serve as intermediaries of information exchange in the health care ecosystem (ONC, 2015). The recognition of C-

ME as an information exchange method acknowledges the powerful role that consumers play in health care transformation (Daniel et al., 2014; Williams, Mostashari, Mertz, Hogin, & Atwal, 2012). Successful C-ME relies on a complex system of data governance that relates to public policy, legal regulation, the health care industry, and consumer preferences. Similarly, C-ME requires a future state in which health data sharing preferences of consumers are operationalized as a standard technical capability in information exchange.

To make this happen, the regulatory environment must change. Federal regulations that govern health information are outdated, do not include consumers acting as data intermediaries, and are challenging to operationalize in a rapidly digitizing health care industry (Baumer et al., 2000; Daniel et al., 2014; Rothstein, 2007). The patchwork of state legal standards for disclosure of personally identified information has created confusion and variability in local interpretation and impeded information exchange (Baumer et al., 2000; Daniel et al., 2014; Pritts, 2001). Federal regulations, such as 42 CFR Part 2, protect sensitive data (e.g., chemical dependency, sexual health, and HIV or mental health information) and include rules written prior to health data digitization that cannot be managed in current technology environments (e.g., complex re-disclosure requirements). HIPAA focuses on simplification of administrative transactions for health care delivery and payers (U.S. Department of Health & Human Services, 2013). HIPAA does not reflect a current trend toward consumers aggregating, owning, and controlling their personal health data. Consequently, fragmentation of health records has become common place and secondary use of health information without individual consent is widespread (Baumer et al., 2000; Bourgeois, Olson, & Mandl, 2010; Harper, 2014).

Problem Statement

An individual’s choice to share or control the sharing or withholding of personal health information represents one of the most significant public policy challenges connected to electronic health information exchange (Goldstein et al., 2010; Faden et al., 2011; Harper, 2014). Personal identifiable information exchange is complex. The decision to share or withhold personally identifiable information is known as an information or data sharing preference (Olson et al., 2005). Affordable Care Act (ACA) policies strongly encourage the sharing of personally identifiable health care information between consumers and their providers (Berwick, 2009; Daniel et al., 2014; Patel et al., 2012). Consequently, health information sharing is used as a consumer engagement strategy to empower individuals to become active in managing their health and partnering in their health care (Daniel et al., 2014).

At issue is the absence of the consumer voice in policy and power structures that create legal regulation—the underpinnings of data governance needed for C-ME to become mainstream (Moon, 2017). The specific problem is factors that influence health data sharing preferences of consumers are not well understood (Moon, 2017). Limited understanding of predictors and the constructs of information privacy, data security, data sharing preferences, and C-ME exists. Consequently, these constructs are not integrated into an ecosystem sensitive to consumer preference or responsive to consumer choice. A theoretical model is needed to assist with information privacy, data security, health data sharing preferences, and C-ME. Theory helps provide a framework for analysis, is an efficient method for field development, and offers a clear explanation for the pragmatic world (Udo-Akang, 2012; Wacker, 1998). A theoretical model would help to formulate a logical, consistent, and mutually interdependent body of knowledge that supports evaluation and recommendations for change.

Purpose of the Study

The purpose of this study was to describe the interrelationships between the constructs of information privacy, data security, data sharing preferences and consumer-mediated exchange. The researcher used literature findings to develop a hypothesized path diagram of construct relationships (Ancker et al, 2012; Anker, Silver et al, 2013; Caine & Hanania, 2013; Campion et al, 2013; Dhopeshwarkar et al, 2012; Dimitropoulos & Rizk, 2009; Luchenski, 2012; Marquard & Brennan, 2009; O'Donnell, et al., 2011; Patel, Dhopeshwarkar et al., 2011; Patel, Abramson, et al., 2011; Patel, Dhopeshwarkar et al., 2012; Ramos & Bakken, 2014; Teixeira et al, 2011; Wen et al, 2010). This study used structural equation modeling (SEM) to test the hypothesized diagram to understand the strength, path and direction of relationship between predictor variables, observed variables and latent constructs.

Research Questions & Aims

The researcher examined the following research questions in this study.

Research Question 1. What factors predict affirmative and negative health data sharing preferences of consumers?

Research Question 2. What is the strength, path, and directionality of relationship between predictor variables and the antecedent constructs of information privacy and data security on health data sharing preferences of consumers and C-ME?

Building on previous researchers (Ancker et al., 2012; Ancker et al., 2013; Dhopeshwarkar et al., 2012; Luchenski, 2012; O'Donnell et al., 2012; O'Donnell et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015; Teixeira et al., 2011; Wen et al., 2010) who identified statistically significant factors that influence health data sharing preferences of consumers, the specific aims for this study included,

1. Describe predictors for health data sharing preferences of consumers;
2. Describe the strength, path, and directionality of relationship between predictor variables and the antecedent constructs of information privacy and data security on health data sharing preferences of consumers and C-ME;
3. Use the findings to test a path diagram in a developing theoretical model; and
4. Use the results to inform the development of more appropriate data governance policy recommendations in an era where consumers want to own and control their health data.

Theoretical Foundation

Consumer-mediated exchange is an interoperability method that relies on consumers to be data intermediaries (Branning & Tritle, 2014). Consumer-mediated exchange appears to be supported by multiple complex systems that create a data governance framework when integrated. Data governance is the exercise of authority, control, and shared decision-making (planning, monitoring, and enforcement) of the management of data assets (Mosley & Mosley, 2008). The complex systems that appear to support C-ME data governance are public policy, legal regulation, the health care industry, and consumer data sharing preferences. Complex systems theory provides a way to appreciate the interrelated and sometimes co-occurring nature of these complex systems needed for C-ME data governance (Mitchell, 2009, Morçöl, 2005). The researcher used integrated complex systems theory in two ways: (a) to understand implementation issues related to management of health data sharing preferences of consumers in a C-ME environment (e.g., systems organization, system dynamics, and systems networks and systems data or knowledge), and (b) application of new knowledge for a theoretical model that describes the relationships of the constructs of interest.

Study Design

The study was a retrospective descriptive observational study through which the researcher analyzed secondary data from a publicly available longitudinal data set on Health Information National Trends Survey (HINTS). The National Cancer Institute has been collecting HINTS data since 2003 (Nelson et al., 2004). The study design involved Structural Equation Modeling (SEM) to answer the research questions. Previous researchers explored the attitudes, beliefs, or perceptions of consumers using traditional regression methods (Ancker et al., 2012; Ancker et al., 2013; Dhopeshwarkar et al., 2012; Luchenski, 2012; O'Donnell et al., 2012; O'Donnell et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015; Teixeira et al., 2011; Wen et al., 2010). Through this study, the researcher explored the relationship of predictor variables on antecedent constructs (information privacy and data security) and their relationship to C-ME.

The dependent variable was the preference to share data between two health care providers. Independent variables were the 18 demographic characteristics captured in the HINTS 4 Cycle 4 data set. Descriptive statistics are presented through frequencies, percentages, means, and standard deviations. The researcher used a multinomial logistic regression to identify predictors of health data sharing preferences of consumers. Latent variables are identified as information privacy, data security, and C-ME. The researcher used confirmatory factor analysis (CFA) to find statistically significant predictors and observed variables to create a measurement model. The researcher used SEM to create a structural model. Through SEM, the researcher tested the direction, path, and strength of relationships between and among the predictors of health data sharing preferences of consumers and the antecedent concepts of information privacy, data security on the construct of health data sharing preferences, and C-ME in the hypothesized theoretical model.

Definitions

An *affirmative data sharing preference* indicates an individual's willingness to share digitized content in a networked computing environment.

A *negative data sharing preference* is the lack of willingness on the part of an individual to share digitized content in a networked computing environment.

Data sharing preference is the strength of importance assigned by a consumer to his or her individual data sharing preferences, as measured by three categories: very important, somewhat important, and not at all important (as measured by item D2b HINTS 4 Cycle 4).

Consumer-mediated exchange (C-ME) is defined as the ability for patients to aggregate and control the use of their health information among providers in the health care industry (ONC, 2015).

Data security is defined as the personal and electronic measures (administrative, physical, and technical safeguards to an information system) that grant access to personal health information to persons or entities authorized to receive the information and deny access to others (HIPAA Regulation).

Information privacy refers to the ability of an individual to prevent certain disclosures of personal health information to any other person or entity (Markel Foundation, 2006).

Assumptions

The study of predictors for health data sharing preferences of consumers is a relatively new domain of knowledge inquiry. Health data sharing preferences of consumers are based on consumer attitudes, beliefs, and perceptions. The researcher assumed a correlation existed between strength of predictors and the strength of the consumers' decision to share or not to share health data. Consumer attitudes, beliefs, and perceptions are assumed to be dynamic and changing over time based on condition, circumstance, and experience (Patel, et al., 2011). Data governance is a developing concept and not well defined in health care. The use of SEM to test theoretical models in nursing is a novel approach. Basic assumptions of SEM include multivariate normality, ensuring a large enough sample size, and the absence of multicollinearity (Hoyle, 2012). The study involved a publicly available data set. Future study should include data collected using a psychometrically tested instrument to increase reliability, validity, and generalizability of study findings.

Scope and Delimitations

Most research pertaining to health data preferences was conducted through observational methods (Ancker et al., 2012; Ancker et al., 2013; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Luchenski, 2012; Marquard & Brennan, 2009;

O’Donnell et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015; Wen et al., 2010) and nonrepresentative samples (Ancker et al., 2012; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Luchenski, 2012; Marquard & Brennan, 2009; O’Donnell et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015), and reported poor survey response leading to nonresponse bias and poor transferability of research findings (Moon, 2017). Previous researchers used nonvalidated survey instruments (no psychometric testing and no cognitive or pilot-testing), which limiting generalizability (Ancker et al., 2012; Ancker et al., 2013; Dimitropoulos et al., 2011; Marquard & Brennan, 2009; Patel et al., 2011; Patel et al., 2011; Schwartz et al., 2015; Wen et al., 2010). This study involved a large nationally representative sample to meet basic assumptions of SEM and analyze the interrelatedness of the constructs of interest. No theoretical model or conceptual framework is available for health data sharing preferences of consumers. The critical review of the literature assisted in developing a path diagram for a hypothesized theoretical model. The researcher used SEM to test a hypothesized theoretical model and determine model fit. Researchers do not use SEM to determine causation (Hoyle, 2012; Suhr, 2014), which limited the scope of this study.

Limitations

The HINTS is the only large longitudinal nationally representative survey on consumer health information technology trends. The HINTS did not contain observed variables necessary to test the entire hypothesized path diagram. However, the HINTS did include observed variables operationalized for three key latent constructs: information privacy, data security, and C-ME. The dependent variable was Item D2a (Share EHR), with response categories very important, somewhat important, and not at all important. Respondents were asked to indicate the strength of importance related to information sharing preferences in a treatment relationship. The item did not describe the data sharing preference as affirmative or negative. To arrive at affirmative or negative data sharing, the researcher measured strength, as higher level indicates affirmative data sharing preference, lower level indicates negative data sharing preference. This was a limitation of the study. Future study requires model validation using an instrument developed and psychometrically tested for the construct of data sharing preferences.

The study was limited by threats to selection bias, affecting internal validity. For example, HINTS used unweighted demographic distributions across years because of a decline in response rates using random-digital-dial techniques, which causes a disproportionate number of younger respondents to be excluded from the survey because the number of cellphones went up over time. HINTS also changed its survey instrument overtime. The overall objectives of the Medical Record Subset items have remained the same, but HINTS researchers added, deleted, or changed items over time. Refinement of items may reduce confidence that the difference in survey scores for longitudinal data is related to independent variable and not just instrumentation. To increase confidence in study findings, the researcher only used HINTS 4 Cycle 4, because it included the highest number of variables that could be operationalized to study constructs. The HINTS sample is taken from the National Cancer Institute database and the survey sample may draw from a larger than normal sample of cancer patients, so external validity may have been effected by volunteer or population bias.

Significance of the Study

Theory development requires (a) factor isolating (describe phenomenon), (b) factor relating (explain phenomenon), (c) situation relating (predict the relationships between phenomena), and (d) situation producing (control phenomena and relationships) (Nieswiadomy, 1998). To accomplish the critical steps of theory development, the researchers used SEM to test a hypothesized path diagram. The path diagram was used to explain relationships between study constructs of interest. First, the researcher described predictors health data sharing preferences. Second, the researcher investigated the strength, directionality, and path relationships between predictors and the constructs of information privacy, data security, and C-ME. Understanding the relationships between study constructs and health data sharing preferences enables interoperability models like C-ME to more closely align with consumer preferences for information exchange. Third, this researcher suggests future research regarding the effect of health data sharing preferences of consumers on larger goals of health care reform in a system that is just beginning to recognize the important role that consumers play in their own health care and the LHS.

Summary

Health information exchange will become an ever-present issue as the LHS develops. The perceived loss of autonomy and self-determination for individuals in a fully digitized health care system is an ever-present risk associated with information exchange. Coherent policies and a national framework for health data governance is needed. Data governance for C-ME requires an integrated complex systems approach that aligns public policy, legal regulation, health care delivery, and health data sharing preferences of consumers to meet consumer demands for granular control of their health data. An infrastructure of policies for data collection, storage, use, and exchange reinforced by national standards may be needed, but it may not be enough to support the necessary data sharing for a LHS. Study findings inform future public policy development to ensure data governance mechanisms are responsive to the increasing demands of consumers, including aggregation, control, and access to personal health data in an ecosystem that leverages C-ME. Chapter 2 presents the literature review for this study.

Chapter 2: Literature Review

Permission is obtained from a patient prior to accessing or sharing electronic protected health information (ePHI; Health Information Technology for Economic and Clinical Health Act, 2014; U.S. Department of Health & Human Services, 2013). Health care providers consider the release of information transaction a cursory legal requirement to obtain relevant patient information used in care delivery. Despite significant federal and state efforts to regulate the disclosure, use, and exchange of ePHI, consumers are beginning to demand more personal control of their health data (Caine et al., 2015; Dhopeshwarkar et al., 2012; O'Donnell et al., 2011; Patel, Abramson et al., 2011; Patel, Dhopeshwarkar et al., 2012; Schwartz et al., 2015). Consumer data sharing attitudes and preferences have been identified as a potential barrier in health information exchange (Ancker et al., 2012; Ancker et al., 2013; Caine & Hanania, 2013; Dhopeshwarkar et al., 2012; Dimitropoulos, Patel, Scheffler, & Posnack, 2011; O'Donnell et al., 2011; Patel Abramson et al., 2011; Patel, Dhopeshwarkar et al., 2011; Ramos & Bakken, 2014). Researchers have not thoroughly studied factors that influence consumers to share or withhold health information (O'Donnell et al., 2011; Patel et al., 2011). The literature review yielded a list of statistically significant factors that influence health data sharing preferences of consumers (see Table 1). Based on analysis and synthesis of the literature, a logic model was developed to inform and align public policy and legal regulation with consumer expectations related to the management of health data sharing preferences.

Literature Search Strategy

The HIPAA (2013) defines federal legal requirements for information privacy and data security of ePHI. In 2009, The HITECH Act, part of the American Recovery and

Reinvestment Act, promoted the adoption and meaningful use of health information technology, including the exchange of electronic health data across an expanded care continuum (HITECH, 2014). Subtitle D of the HITECH Act addresses concerns related to the electronic sharing of health information and strengthened the enforcement of HIPAA rules (HITECH, 2014). HIPAA modifications were codified in Omnibus Final Rule (2014), adding strength to limitations on use and disclosure of ePHI, expanding individuals' rights to receive electronic copies of their ePHI, increasing consumer notification practices and monetary penalties for unauthorized access, and redefining the "harm" threshold for unauthorized access of ePHI with objective standards (HIPAA, 2013). The researcher conducted the literature review within this historical legal and public policy context to identify factors that influence health data sharing preferences of consumers. Table 1 shows a legal regulation matrix to provide clarity regarding the influence of federal law on the management of health information. The legal regulation matrix includes federal regulations that apply to ePHI. Regulations described in the table include Health Information Portability and Accountability Act (HIPAA); 42CFR Part 2 (Sensitive Data); Genetic Information Non-Disclosure Act; and The Privacy Act of 1974, also known as the U.S. Freedom of Information Act.

The literature review involved use of electronic databases: Cumulative Index to Nursing & Allied Health Literature (CINAHL), PubMed, and applicable government websites. The researcher searched various key terms through CINAHL and PubMed: *release of information* AND *attitudes or preferences,* and combined keyword searches of *informed consent* AND *health information exchange*. The literature search included publications from the year 2000 through 2014, because the HIPAA Privacy Rule was published December 28, 2000 and Omnibus Final Rule was published February 3, 2013. The researcher reviewed 47 abstracts and publications, and removed any duplicates. Inclusion and exclusion criteria were applied. Articles included referred to HIPAA after 2009, patient consent related to release of information for electronic information exchange, and consumer attitudes or preferences for health data sharing. Articles were excluded if they included references to HIPAA prior to HITECH, or focused on informed consent for medical treatment or release of information for disclosure of sexually transmitted disease. The final systematic review included 18 articles, with 16 studies from three countries.

Table 1

Matrix of Federal Law Influencing Health Information

Regulation	Information Governed	Disclosures Without Authorization	Disclosures with Authorization	Regulated Entities
Health Information Portability & Accountability Act of 1996 (HIPAA) **Privacy Rule** *controls regulated entities disclosure of PHI:* *Regulated entity required to disclose PHI to the individual, their representative and HHS for enforcement* *Regulated entity must limit disclosure to the minimum necessary* **Security Rule** *requires regulated entities to maintain reasonable and appropriate safeguards to protect electronic PHI:*	Governs: Protected health information (PHI) Individually identifiable information relating to an individual's care or past, present, or future physical or mental health condition or payment for care Does Not Apply: De-identified information using the "safe harbor" method. Or if an expert determines that there is minimal risk of that information being used to identify an individual.	Regulated entities may disclose PHI without authorization to carry out the following activities: • Treatment – provision, management or coordination of health care and related services, consultation between providers and referrals. • Payment – determining eligibility, adjudicating claims, risk management, billing and collection, utilization review, coverage • Health care operations – quality assessment and improvement, evaluating provider / health plan performance, underwriting and other health insurance contract activities, medical review / auditing, business planning activities, business management and administrative activities. Regulated entities may also disclose PHI without authorization: • To facilitate another covered entity payment activities • To enable another provider treatment activities • If both covered entities have a relationship with the patient, for operation purposes	A covered entity may voluntarily choose, but ***is not required***, to obtain the individuals consent for it to use and disclose information about him or her for TPO. A covered entity that chooses to have a consent process has complete discretion under the Privacy Rule to design a process that works best for its business and consumers. Consent is the not the same as authorization to release information. Any disclosure not identified as required must have individual written authorization. Psychotherapy notes Sale of PHI	Covered entities' (health plans, healthcare clearing houses and most healthcare providers) And, their 'business associates' (entities that have access to or use PHI when performing certain functions or services for or on behalf of the covered entity) – collectively referred to herein as 'regulated entities'. All others are 'Non-covered entities'. A NCE is not a provider, payer, or clearinghouse as defined by HIPAA. A NCE could provide services such as peer health communities, online health management tools, and websites used to generate information for research, any of which might be accessed on computers or

Regulation	Information Governed	Disclosures Without Authorization	Disclosures with Authorization	Regulated Entities
Administrative – policies, procedures and processes for accessing e-PHI *Physical – environmental controls* *Technical – information system audit controls* *Organizational – BAA outlining all the applicable specifications for data use and disclosure* **Breach Notification Rule** *provides guidelines related to the prohibited use or disclosure of PHI that compromises the privacy and security of PHI.*		Regulated entities may also disclose PHI without authorization for Research Activities • If a decedents PHI is necessary for research purposes. • PHI necessary to prepare for research protocol and no physical movement or removal of data will be done • IRB waives the authorization requirements determining that the research could not be conducted without access to the PHI or that the use / disclosure presents minimal privacy risks to the individual. Regulated entities may also disclose PHI without authorization for Public Health: • PHI is used for activities related to quality, safety, or effectiveness of FDA-regulated products. • Public Health surveillance, intervention, or investigation Regulated entities are required to report breaches – related to unauthorized access of PHI to Office of Civil Rights based on perceived harm threshold.	Marketing uses / disclosure	smart phones and other mobile devices. NCE's are not subject to HIPAA and may collect, store, use data in ways that puts it at increased risk of privacy and security risk. m-Health devices used by covered entities are covered by HIPAA. All others fall under the FTC consumer protection regulations.
The Genetic Information Nondisclosure Act of 2008 (GINA)	Governs: An individual's genetic information	• Genetic information acquired by an employer can only be disclosed to an occupational, public health organization or health researcher in limited circumstances.	Authorization from individual is always required.	Health plans, issuers of health insurance and employers.
The Privacy Act of 1974 & United States Freedom of	Governs: Personal identifiable	• If a disclosure exemption exists, PII held or collected by the federal government can be used for statistical	Federal government may disclose information to	Federal Government

Regulation	Information Governed	Disclosures Without Authorization	Disclosures with Authorization	Regulated Entities
Information Act (FOIA)	information (PII) that is held or collected by the federal government.	research, agency-specific routine uses and as required by the FOIA. • FOIC exemption (6) prohibits disclosures of information about individuals would constitute a clear unwarranted invasion of personal privacy – like information found in personnel, medical or similar files.	individuals or their representatives with written consent.	
42 CFR Part 2	Governs: PHI that reveals individual received substance abuse treatment	Disclosure exemption: • Qualified researchers • Qualified Service Organization Agreement is a two-way agreement between a Part 2 program and the entity providing service Disclosure may be made: • The patient is accepted for treatment • The type or dosage of the drug has changed • The treatment is interrupted, resumed or terminated Disclosure is limited to: • PII • Type and dosage of the drug • Relevant dates • Central registries for preventing multiple enrollments into programs • Between detox or maintenance programs for preventing multiple enrollments into programs • A program may disclose information about a patient to the criminal justice system	Written consent is required for disclosure. A single consent form authorizes disclosure to multiple parties for multiple purposes Redisclosure statement must be present – prohibiting recipient from disclosing the information to other providers / organizations without consent Disclosures may not be made to central registry unless for preventing multiple enrollments or in connection with a	Federally assisted programs that provide substance abuse diagnosis, treatment or referral Programs that participate in Medicare US Drug Enforcement Administration (DEA) Federally tax-exempt

Regulation	Information Governed	Disclosures Without Authorization	Disclosures with Authorization	Regulated Entities
		which made participation in the program a condition of the criminal proceedings	criminal justice referral	

Theoretical Framework

Complexity science provides a lens to explore the complex system of public policy related to data governance. Public policy generally demonstrates the common sense and common conscience of the citizens and is applied to matters of public health, safety, and welfare (West’s Encyclopedia of American Law, 2008). Subsequently, public policy varies with changing social duties, economic needs, public opinion, and moral objectives of the people. Public policy influences the implementation, execution, and interpretation of legislation (West's Encyclopedia of American Law, 2008).

Mitchell (2009) defined a complex system as a “system in which large networks of components with no central control and simple rules of operation give rise to complex collective behavior, sophisticated information processing and adaptation via learning or evolution” (p. 200). Public policy could be considered a complex system because of its co-evolutionary nature and self-organizing behavior in the presence of strong government actors (Morçöl, 2010). Most public policy systems do not occur in isolation; instead, they co-exist with other systems, such as legal, social, economic systems, and are influenced by external and internal factors, including health data sharing preferences of consumers. Morçöl (2005, 2010) described the use of complexity theory in public policy as the conceptualization of relationships between micro processes (e.g., individual choices and behaviors) and macro policy processes (e.g., actions taken by the government).

Caldwell and Mays (2012) described this policy framework as taking into consideration the pace, direction and impact of organizational innovation and change by studying the interconnections between meanings across different organizational levels.

Using complexity theory to analyze both understanding and action at multiple levels influences public policy development and allows for clear interpretation of public policy (Caldwell & Mays, 2012). Information privacy, data security, and consumer consent management processes originate in public policy. Subsequently, legal regulation flows from public policy, forming the framework for data governance rules (Code of Fair Information Practices, 1973; U.S. Department of Health & Human Services, 2013; HITECH, 2014). Data governance is the core function of a data management framework (Mosley & Mosley, 2008. Data governance is a relatively new term in health care. Data governance is defined as the exercise of authority, control, and shared decision-making (planning, monitoring, and enforcement) of the management of data assets (Mosley & Mosley, 2008). Data governance in health care includes multiple complex systems: public policy, legal regulation (state and federal), technology infrastructure, health care delivery, and consumer behavior, beliefs, or perceptions (Moon, 2017). However, ensuring the consumer voice is present in public policy related to health data governance and the management of health data sharing preferences remains problematic.

Existing public policy and legal regulation recognizes the individual as the primary decision-maker in the release of information transaction (HITECH, 2014; U.S. Department of Health & Human Services, 2013). Federal public policy has more recently involved consumer engagement campaigns to organize consumer feedback pertaining to topics on consumer data management, such as how to view, download, and transmit that information (ONC, 2015). Research findings support consumer desire for granular control of their health care data (Caine et al., 2015; Dhopeshwarkar et al., 2012; Park et al., 2013; Patel et al., 2011; Schwartz et al., 2015). However, efforts have been hindered by outdated public policy, variation in interpretation of legal standards, and legal regulation that is difficult to operationalize in an electronic information management environment (Daniel et al., 2014). Consequently, public policy implementation in health care continues to be an issue, despite heavy incentives to digitize health data and create a learning health ecosystem.

One reason may be that typical public policy processes do not include feedback loop(s) that intentionally capture input from consumers or research findings, such as health data sharing preferences. System dynamics rely on reinforcing and balancing feedback (Cabrera & Cabrera, 2015). A resilient feedback loop restores balance to a system (Cabrera & Cabrera, 2015; Mitchell, 2009). A meta-resilient feedback loop allows a human to learn, create, design, and evolve programs (Mitchell, 2009). Resilient feedback loops in public policy may enable information, such as health data sharing preferences of consumers, to enter the system more quickly and ensure the next policy development cycle is better informed. Figure 1 shows a logic model that entails a “Resilient feedback loop: legal and public policy for consumer mediated data sharing model” (Moon, 2017). The logic model describes feedback loops that are critical to a dynamic, resilient system for public policy.

Health care public policy recently evolved to a point where consumers are considered stewards of personal health data (Daniel et al., 2014). Innovation has been slow for applications that provide access, control, or monitoring of personal health data based on preference. The public policy development framework for this study uses input from consumers’—the stewards of personal health data—and relevant research findings early in the development cycle. Evaluation to identify new, ongoing, or persistent systems gaps is important. Feedback loops allow for continuous rapid-cycle process improvement (Cabrera & Cabrera, 201; 5Mitchell, 2009). Evaluation findings can be used to support short- and long-term goals related to system change (Mitchell, 2009). Proactive processes ensure public policy reforms better align with consumer preferences. A dynamic public policy system driven by consumers' voices and preferences would create resilient and meta-feedback loop(s) that support a more coordinated, transparent, and consumer-centric health ecosystem responsive to consumer sentiment.

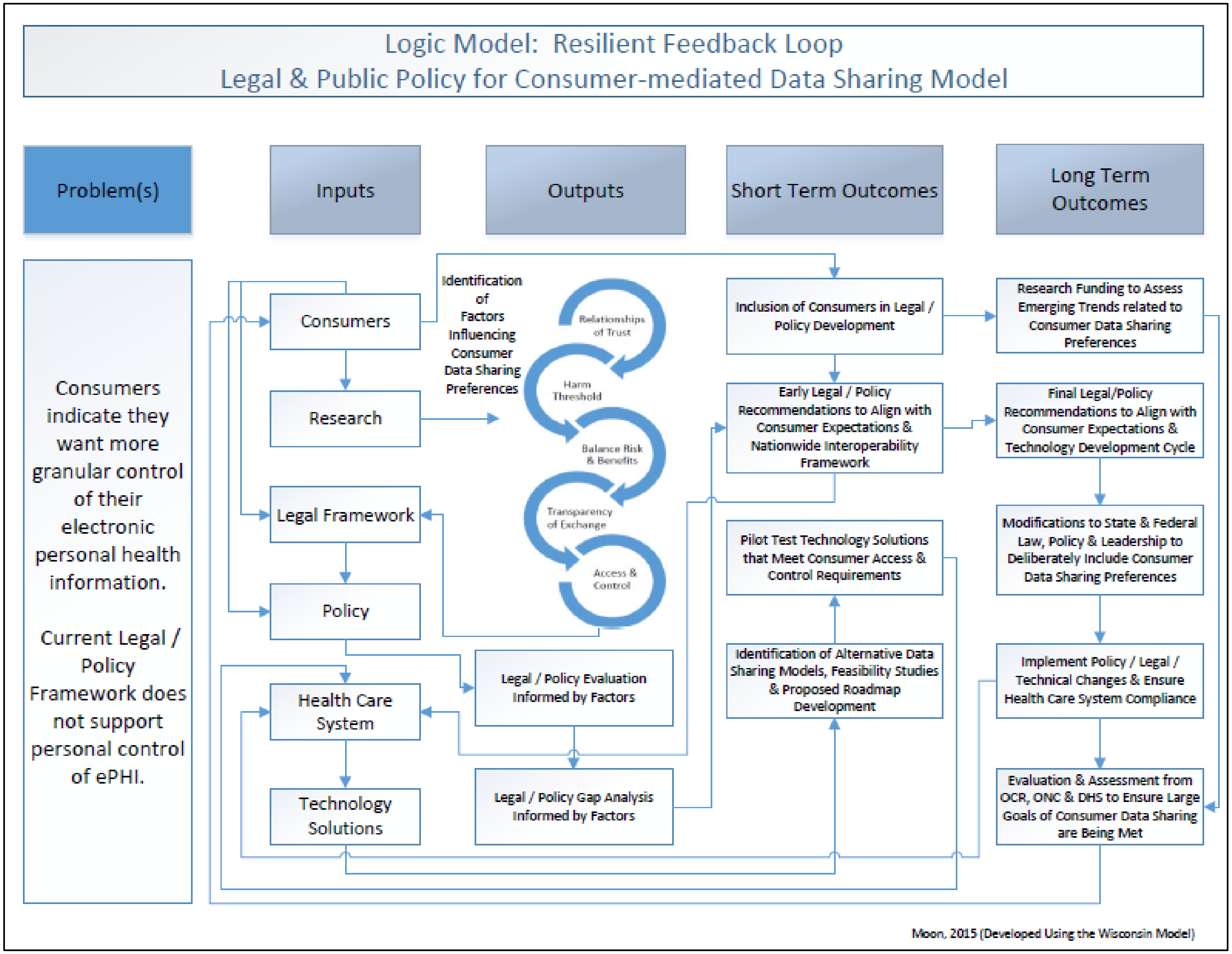

Figure 1. Logic model: Resilient feedback loop legal public policy for consumer mediated data sharing model.

Literature Review

Table 2 shows the 14 cross-sectional studies evaluated using Olsen and St. George's (2004) cross-sectional study design and data analysis framework and the two qualitative studies assessed using critically appraising qualitative research strategies (Kuper, Lingard, & Levinson, 2008). The researcher measured each of the 14 cross-sectional studies reviewed using a matrix of eight criteria: clearly identified variables, nationally representative sample, response rate > 20%, weighted scale survey tool, cognitive testing survey tool, pilot tested survey tool, survey bias, and clear data analysis description. An overall score of eight indicates high quality, score of four-six moderate quality, and score of three or less low quality.

Of the studies reviewed, 12 scored moderate quality ratings (Ancker et al., 2012; Ancker et al., 2013; Dhopeshwarkar et al., 2012; Luchenski, 2012; O'Donnell et al., 2012; O'Donnell et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015; Teixeira et al., 2011; Wen et al., 2010) and two rated with low quality ratings (Dimitropoulos et al., 2011; Marquard & Brennan, 2009). Lower overall quality ratings are attributed to (a) use of samples not nationally representative of the total population (Anker et al., 2012; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Luchenski, 2012; O'Donnell et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2011; Patel et al., 2012; Ramos & Bakken, 2014; Schwartz et al., 2015; Teixeira et al., 2011), (b) survey instruments not cognitively tested (Ancker et al., 2012; Ancker et al., 2013; Luchenski, 2012; Marquard & Brennan, 2009; Park et al., 2013; Patel et al., 2011; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015; Teixeira et al., 2011; Wen et al., 2010), (c) a low number of pilot tested instruments (Ancker et al., 2013;

Dimitropoulos et al., 2011; Marquard & Brennan, 2009; Schwartz et al., 2015; Teixeira et al., 2011; Wen et al., 2010) and (d) presence of survey bias (Ancker et al., 2013; Marquard & Brennan, 2009; Park et al., 2013).

Survey method advantages include low data collection cost and ability to provide standardized data-collecting procedures (Dillman et al., 2009). However, instrument validation through cognitive testing increases reliability of study results (Devellis, 2016). Validating the instrument through psychometrics ensures that summated scales are assessed for internal consistency (e.g., Cronbach Alpha) and that a set of variables or items measure a single construct (Devellis, 2016). The majority of the fourteen studies reviewed clearly identify variables of interest (Ancker et al., 2012; Ancker et al., 2013; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Luchenski, 2012; Marquard & Brennan, 2009; O'Donnell et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015; Wen et al., 2010), had response rates >20% (Ancker et al., 2012; Ancker et al., 2013; Dhopeshwarkar et al., 2012; Luchenski, 2012; Marquard & Brennan, 2009; O'Donnell et al., 2011; Park et al., 2013; Patel et al., 2011; Schwartz et al., 2015) and described data analysis methodology clearly (Ancker et al., 2012; Ancker et al., 2013; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Luchenski, 2012; O'Donnell et al., 2011; Patel et al., 2011; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015; Wen et al., 2010) which may increase the transferability of study findings.

Generalizability was limited by a nonrandomized study design (Ancker et al., 2012; Ancker et al., 2013; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Luchenski, 2012; Marquard & Brennan, 2009; O'Donnell et al., 2011; Park et al., 2013;

Patel et al., 2011; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015; Wen et al., 2010); a lack of representative samples, in which the minority participation is significantly lower than the national average (Ancker et al., 2012; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Luchenski, 2012; Marquard & Brennan, 2009; O'Donnell et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015); and weak instrument development (Ancker et al., 2012; Ancker et al., 2013; Dimitropoulos et al., 2011; Marquard & Brennan, 2009; Patel et al., 2011; Patel et al., 2011; Schwartz et al., 2015; Wen et al., 2010). Some surveys had high incidence of nonrespondent bias, including respondents not answering phones, screening calls, and phone lines dedicated to facsimiles, which leads to low response rates and nonrepresentative sampling, making it difficult to draw an inference about a population sample (Dimitropoulos et al., 2011; Patel et al., 2012; Wen et al., 2010).

Two of the qualitative studies reviewed, Caine and Hanania (2013) and Ramos and Bakken (2014), ranked high in quality because the samples were appropriate to the research question, data were appropriately collected, data were appropriately analyzed, and overall research aims were clear. Transferability is the degree to which the results of a qualitative study can be transferred to other contexts or settings (Guba & Lincoln, 1985). Both studies scored low for transferability of results, with a low number of males in the study samples and HIV clinic setting (Caine & Hanania, 2013; Ramos & Bakken, 2014), and Caine and Hanania's study lacked reflexivity. Reflexivity is the indication that a researcher performed self-reflection or acknowledgement of bias at every step of in study design (Guba & Lincoln, 1985). Lack of reflexivity may indicate skewedness on the part of the researcher toward a preconception, which limits the researchers’ ability to be a neutral observer in the qualitative research process.

Table 2

Literature Matrix and Statistically Significant Factors Influencing Health Data Sharing Preferences of Consumers

Reference	Purpose	Sample	Design	Factors Associated with Affirmative Health Data Sharing Preferences (95% Confidence Level)	Factors Associated with Negative Health Data Sharing Preferences (95% Confidence Level)
Ancker et al., 2012	Assess consumer perceptions of HIE in a state with an advanced HIE infrastructure	1120/800 RR = 71% New York Statewide	Cross-sectional Annual Telephone Survey (2011)	• Children in household • Education • Income >100,000 • Use of the Internet or e-mail • Perceived trustworthiness local business, large corporations, local government • Perceived trustworthiness of other people	• Age 40 to 65 • Privacy & security concerns • People more likely to lie in person than online
Ancker et al., 2013	Assess whether consumers' attitudes EHR/HIE are associated with doctors using EHR	1000/1603 RR = 63% National Sample Continental US	Cross-sectional Telephone Survey (2011)	• < 40 years of age; Improve Quality of Care • Doctor Uses EHR; Improve Quality of Care • < 40 years of age; EHR enhances privacy	• Electronic exchange across multiple physicians • Privacy & security concerns • High school education or less
Caine et al., 2015	Interviews to understand patient data sharing preferences	*N* = 30 Central Indiana Medical Clinic	Qualitative, Semi-structured interviews (2013)	• Personal control over access to ePHI • Notification when ePHI is accessed • Permission by patient prior to access • Restricting/blocking specific information • Time limits/temporal control • Access controls that support "need to know"	• Lack of personal control • Lack of knowledge of what information is being accessed, viewed or shared • Lack of systems that provide granular control for ePHI access

Reference	**Purpose**	**Sample**	**Design**	**Factors Associated with Affirmative Health Data Sharing Preferences (95% Confidence Level)**	**Factors Associated with Negative Health Data Sharing Preferences (95% Confidence Level)**
Campion et al., 2013	Assess HIE usage patterns in three communities	Data File of All HIE transactions	Cross-sectional study, retrospective cohort (2009-2011)	• N/A	• N/A
Dhopeshwarkar et al., 2012	Consumer preferences regarding the privacy and security of HIE.	170/190 RR = 85% Residents of Hudson Valley, NY	Cross-sectional Telephone Survey (2008)	• Decentralized portable devices with secure Internet Connection • Automatic database storage with clinicians only access • Males more willing to have data stored automatically in a central database • Trust provider to keep data private and secure in data base • Restricted access by visit type, information type, and clinician • Permission & greater personal privacy controls • Audit log capability to monitor access to ePHI • Controls in place to stop all viewing if needed	• Centralized Data Repository (CDR) password protected connection • Hispanic Ethnicity • Automatic storage of data • Lack of trust of health plan, hospital, or government • Unauthorized viewing • Trust only themselves to keep ePHI safe & secure
Dimitropoulos & Rizk, 2009	Assessment of state and organization privacy & security policy variations	42 Jurisdictions, including states and large health care organizations	Health Information Security & Privacy Collaborative Project	• N/A	• N/A

Reference	Purpose	Sample	Design	Factors Associated with Affirmative Health Data Sharing Preferences (95% Confidence Level)	Factors Associated with Negative Health Data Sharing Preferences (95% Confidence Level)
Dimitropoulos et al., 2011	Consumer **attitudes** regarding the perceived benefits of electronic **HIE**	1847/27831 RR = 15% National United States	Cross-sectional study, telephone survey (2010)	• Promise of better coordinated care • Promise to reduce the number of medical tests needed • Promise of improved medical care • Promise of improved quality of care • Benefits may outweigh the risks • Benefits of population and individual • Physician can override their personal privacy preferences in an emergency • Audit trail available to consumers • Permission needed to access ePHI	• Security of information exchange • Potential misuse of ePHI for fraud, identity theft or posting of ePHI on the Internet • Unauthorized access and viewing • Receipt of unsolicited junk mail • Discrimination, Black higher • Potential Loss of ePHI • Privacy concerns leading to denial of credit and employment • Information linked to wrong person • Release to wrong physician • Physician not involved in care • Sharing with friends, health plan or employer
Luchenski, J., 2013	Public views of integrated EHRs in the United Kingdom	2857/5331 RR = 54% 8 Hospital outpatient clinics & 8 general practices UK	Cross-sectional study, survey (2011)	• 25–34-year-old • Male • White • College education • Regular users of health care service • Full inclusion of health care history for PCP • Information made available for specific purpose	• Older adults • Female • Black & Asian • Healthy individuals
Marquard & Brennan, 2009	Assess consumer choice on using HIE for	*N* = 31 Neurology Clinic Patients	Cross-sectional study, onsite Computer-based survey	• Generally helping themselves, the patient • Preventing medication interactions	• Secondary re-use of information • Lack of choice to share or not share • Absence of trust in physician or health care system

Reference	Purpose	Sample	Design	Factors Associated with Affirmative Health Data Sharing Preferences (95% Confidence Level)	Factors Associated with Negative Health Data Sharing Preferences (95% Confidence Level)
	medication information only		tool & follow-up interview (2008)	• Generally helping other (patients or physicians) • Preventing potential side effects • Maintaining confidentiality of the information • Continuity of care • Increased convenience • Presence of trust in physician to keep information safe and private • Limited data set	• Privacy of information disclosure concerns • Security of information disclosure concerns • Lack of trust when sharing with insurance company
O'Donnell et al., 2011	To determine healthcare consumers' attitudes toward physician and personal use of HIE	170/199 RR = 88% Residents of Hudson Valley, NY	Cross-sectional study, telephone survey (2008)	• Use of Internet • Age > 65 • Income >100,000 • Improve the completeness of health record • Improved communication between physicians • Improved communication between physicians and patients • Caregiver of a chronically ill family member • Physician communication is perceived to be inadequate • Perceived improvement in privacy & security of ePHI	• Lack of personal control over health data • Females less likely to use or value PHR for HIE • Concern over multiple-viewers of their record • Those with chronic illness and higher health care utilization not likely to support HIE
Park et al., 2013	Examined patient's HIE preferences and perceived benefits and concerns	306/536 RR = 57% Seoul National University Bundang Hospital affiliated clinics	Pretest-Posttest, telephone survey (2008)	• Limited data set • Government Led HIE Initiative • Use of Internet • Restrict access by visit type, information type, and clinician	• Age 40 to 65 • Perceived improvement of cost • Perceived reduction of waste • Lower data sharing experience • System breakdown and lack of operational back-up • Complicated process to use the system

Reference	Purpose	Sample	Design	Factors Associated with Affirmative Health Data Sharing Preferences (95% Confidence Level)	Factors Associated with Negative Health Data Sharing Preferences (95% Confidence Level)
				• Reduced length of episode of care • Improved communication between physician and patient • Consent prior to data sharing • Improved quality of care; accurate diagnosis, expedited appointments • Benefits outweigh the risks • Increased convenience • Preferred physicians who had HIE capability • Trust provider to keep data private and secure in data base • Greater personal privacy controls	• Privacy and security breaches
Patel et al., 2011	Examined ethnically diverse attitudes towards HIE	*N* = 214 ED & 3 Ambulatory Care Sites served by the Brooklyn HIE	Cross-sectional study, onsite (2008)	• White, nonHispanic • Accessible by primary care doctor • Electronic sharing for emergency • Improved quality of care • Benefits outweigh risks • Improved accuracy of health records • Trust provider to keep data private and secure in data base • Restricted access by visit type, information type, and clinician	• NonWhite, Hispanic & Asian • Sharing ePHI over Internet connection • No improvement of privacy and security • Ethnically diverse lack trust of Internet mechanisms for sharing health data • Electronic sharing with health plan, employer, or government • Digital divide exists along economically challenged & ethnically diverse populations
Patel et al., 2011	Consumer attitudes towards	200/252 RR = 79%	Cross-sectional study,	• Internet access and use • Higher income • Employed	• Electronic sharing with health plan, employer or government

Reference	Purpose	Sample	Design	Factors Associated with Affirmative Health Data Sharing Preferences (95% Confidence Level)	Factors Associated with Negative Health Data Sharing Preferences (95% Confidence Level)
	PHRs and electronic data sharing	Residents of Hudson Valley, NY	telephone survey (2009)	• Younger Adults • Accessible by primary care doctor, designated family member or other healthcare provider • Greater personal privacy controls	• Lack trust of health plan, hospital, or government
Patel et al., 2012	Assessed consumer perceptions of HIT, HIE and PHRs	*N* = 117 Physician practices served by Rochester RHIO	Cross-sectional study, onsite survey (2009)	• Improved communication between physician and patient • Consent prior to data sharing • Improved accuracy of health records • Increase safety of care received • Emergency Access • Security safeguards in place • Exert personal control over ePHI data sharing & access • Able to audit who accessed or viewed medical date • Some college education	• Security of information sent over Internet
Ramos & Bakken, 2014	Evaluate patient consent workflow for HIE in an HIV clinic	Observations of Receptionist at HIV Clinic	Qualitative Study, contextual inquiry (2013)	• N/A	• N/A
Schwartz et al., 2015	Patient perceptions in controlling access to their ePHI	105/139 RR = 75% Patients primary care clinic	Prospective Cohort Study, Computer-based survey onsite (2013)	• Consent prior to data sharing • Restricted access by visit type, information type, and clinician • Patient control over who sees specific ePHI	• Sensitive information including mental health, drug/alcohol use, sexually transmitted disease & HIV • Limited sharing negatively impacts physician-patient relationship

Reference	Purpose	Sample	Design	Factors Associated with Affirmative Health Data Sharing Preferences (95% Confidence Level)	Factors Associated with Negative Health Data Sharing Preferences (95% Confidence Level)
				• Willingness to share nonsensitive information higher • Willingness to share is higher with primary care provider or specialty care provider	
Teixeira et al., 2011	HIV patient's willingness to share ePHI using a CCD	*N* = 93 HIV/Aids Patients, New York City	Cross-sectional study, onsite survey (2010)	• Trust provider to keep data private and secure in data base • Patient feels respected by care team • Education level • Hispanic • Increased willingness to share with physician and clinical staff • Trust government health insurers and programs • When trust is present, fear of stigma is less	• Sharing with nonclinical staff • Lack trust of private health insurers • Stigma increases when trust is low
Wen et al., 2010	Consumer perceptions about use of the Internet for PHR & HIE	*N* = 7674 US civilian noninstitutionalized adults	Cross-sectional study, Health Information National Trends Survey (HINTS, 2007)	• Age > 45 more likely to value exchange • Male • Trust provider to keep data private and secure	• No improvement of privacy and security • Female • Lack of trust in provider associated with perception of poor privacy and security controls for ePHI • Age 18-24 less likely to value importance of HIE

Note. Abbreviations: HIE, Health Information Exchange; ePHI, electronic Protected Health Information; CDR, Clinical Data Repository; PHR, Personal Health Record; HIT, Health Information Technology; RHIO, Regional Health Information Organization; HIV, Human Immunodeficiency Virus; CCD, Continuity of Care Document; UK, United Kingdom; EHR, Electronic Health Record; PCP, Primary Care Provider.

Health Data Sharing Preferences

The researcher reviewed each of the 16 studies to identify statistically significant ($p > 0.05$, 95% confidence interval) factors associated with health data sharing preferences of consumers. Identified factors were sorted into two categories: (a) factors influencing affirmative data sharing preferences and (b) factors influencing negative data sharing preferences (see Table 3). Factors related to descriptive characteristics were removed and classified into a single set of descriptive factors (see Table 4). The researcher sorted the remaining list of factors (affirmative and negative) into broad categories, removed redundant factors, and summarized them into a five-category classification schema. The classification schema that emerged shows a hierarchal and interdependent relationship between the factors that influence health data sharing preferences of consumers (see Figure 2). The researcher completed a review of the identified factors using this classification schema.

Table 3

Statistically Significant Factors Clustered

Factors	Factors Associated with Affirmative Health Data Sharing Preferences of Consumers	Factors Associated with Negative Health Data Sharing Preferences of Consumers
Trust	+ Perceived trustworthiness other people, local business, large corporations, local government + Trust provider to keep data private & secure + Primary care provider accesses & uses ePHI for authorized purposes only + When trust is present, fear of stigma is less + Trust providers to keep data private and secure in data base	– Absence or lack of trust of physician, health plan, hospital, health care system or government – Ethnically diverse lack trust of Internet mechanisms for sharing ePHI – People more likely to lie in person than online – Discrimination, Blacks higher – Denial of credit & employment
Patient Access & Control of Data	+ Consent, permission & personal control over access to ePHI + Restricting/blocking specific information, revealing only “need to know” + Restrict access by visit type, information type & clinician + Time limits/temporal control + Controls in place to stop all viewing if needed + Physician emergency override of personal privacy preferences	– Lack of choice to share or not share – Electronic exchange across multiple physicians – Lack of personal control & mechanisms for granular control – Trust only themselves to keep ePHI safe & secure – Fear release to wrong physician & sharing with friends, health plan or employer – Chronic illness or high health care utilizer may not can manage access & control of ePHI
Transparency of Data Exchange	+ Notification when ePHI is accessed + Audit log capability + Audit trail available to consumers + Information made available only for specific purpose + Limited data set + Decentralized portable devices with secure Internet connections + Limited sharing harms physician-patient relationship	– Lack of knowledge of what information is being access, viewed or shared – Secondary reuse of information – Multiple-viewers of record – Information linked to the wrong person & disclosure concerns – System breakdown & lack of operational back-up – Centralized data repository that is password protected – Automatic data storage & sharing data over Internet connection – Unauthorized access & misuse of ePHI for fraud, identity theft or posting of ePHI on the Internet – Security of information disclosure concerns & security breaches
Balance Risk and Benefits	+ Promise of quality of care, better coordinated care & continuity + Promise of improved medical care; reduce redundancy, + accuracy, expedited appointments & safety + Benefits to population & individual may outweigh risks + Increased convenience	– Relinquish personal control over ePHI – Perceived reduction in cost and reduction of waste that may negatively impact quality – Complicated system; what is created can’t be used by consumers

Factors	Factors Associated with Affirmative Health Data Sharing Preferences of Consumers	Factors Associated with Negative Health Data Sharing Preferences of Consumers
	+ Improved communication between provider & patient	
Sensitivity of Data	+ Willingness to share nonsensitive ePHI higher + Willingness to share ePHI with PCP or specialty care team higher + Patient feels respected by clinical care team + Trust government health insurers & programs	– Type of sensitive ePHI; mental health, drug/alcohol use, sexually transmitted disease & HIV – Sharing sensitive ePHI with nonclinical staff – Lack trust of private health insurers – Stigma increases when trust is low

Table 4

Statistically Significant Descriptive Characteristics Associated with Health Data Sharing Preferences of Consumers

	Factors Associated with Affirmative Consumer Data Sharing Preferences	**Factors Associated with Negative Consumer Data Sharing Preferences**
Descriptive Characteristics	+ Age < 40 years + Age > 65 years + Children in household + Caregiver + Education + Employed + Income > 100,000 + Internet Use + Male + White, nonHispanic + Hispanic + Regular utilizers of health care	– Age 18-24 years – lack understanding – Age 40 to 65 – managing chronic illness or caregiver – Age >65 years – managing chronic illness or digital divide – Education < high school – Female – Black & Asian – NonWhite, Hispanic & Asian – Healthy individuals – Low Internet use

Note. “Health Data Sharing Preferences of Consumers: Critical Review of Literature,” by L. Moon, 2017.

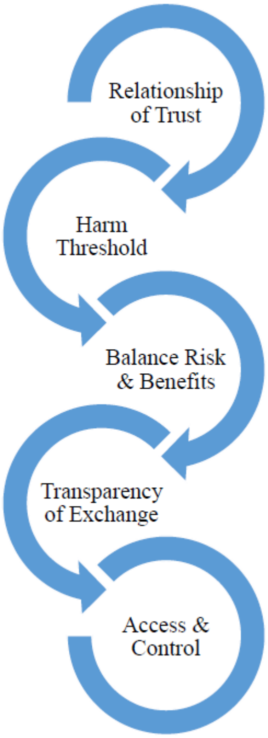

Figure 2. Nested classification schema factors influencing health data sharing preferences of consumers. Adapted from "Health Data Sharing Preferences of Consumers: Critical Review of Literature," by L. Moon, 2017.

Descriptive Characteristics

Bivariate analysis in three studies demonstrated that statistically significant descriptive factors associated with affirmative data sharing preferences include White nonHispanic (Patel et al., 2011), male gender (Ancker et al., 2012; Park et al., 2013), education, children in the household (Ancker et al., 2012), income level (Ancker et al., 2012; Park et al., 2013) and Internet use (Ancker et al., 2012; Park et al., 2013). Multivariate analysis completed in 14 studies yielded a list of descriptive characteristics associated with affirmative data sharing preferences, including age < 40 and age > 65 (Ancker et al., 2013; Luchenski, 2012; O'Donnell et al., 2011; Patel et al., 2011; Wen et al., 2010), White nonHispanic (Luchenski, 2012; Patel et al., 2011), number of children in household (Ancker et al., 2013), education level (Ancker et al., 2012; Luchenski, 2012;

Patel et al., 2012; Teixeira et al., 2011), employment status (Patel et al., 2011), income > 100,000 (Ancker et al., 2012; O’Donnell et al., 2011), male gender (Dhopeshwarkar et al., 2012; Luchenski, 2012; O’Donnell et al., 2011; Wen et al., 2010), Internet use (Ancker et al., 2012; O’Donnell et al., 2011; Wen et al., 2010), and regular users of the health care system (Luchenski, 2012; Marquard & Brennan, 2009).

To acquire a more comprehensive understanding of the polarity that exists between sharing and withholding ePHI, the researcher identified statistically significant negative descriptive characteristics. One main characteristic was age, and the studies included age 18–24 (lack understanding of health care system; Wen et al., 2010), age 40–65 (managing chronic illness or caregiver; Ancker et al., 2012; O’Donnell et al., 2011; Park et al., 2013), age > 65 (chronic illness present; O’Donnell et al., 2011). Other characteristics included education (high school or less; Ancker et al., 2012), female gender (Dhopeshwarkar et al., 2012; Luchenski, 2012; O’Donnell et al., 2012; Wen et al., 2010), Black (Dimitropoulos et al., 2011; Luchenski, 2012; Patel et al., 2011), Asian nonWhite and Hispanic (Dhopeshwarkar et al., 2012; Luchenski, 2012; Patel et al., 2011), healthy individuals (Luchenski, 2012), and low Internet use (Ancker et al., 2012; O’Donnell et al., 2011; Patel et al., 2011).

Descriptive characteristics found to be not statistically significant for data sharing in bivariate or multivariate analysis include marital status (Ancker et al., 2012; Ancker et al., 2013), political ideology (Ancker et al., 2012), physician use of electronic health record (Ancker et al., 2013), number of household members older than 65 (Ancker et al., 2011), urban residency (Ancker et al., 2012), and self-rated health (Ancker et al., 2012; Ancker et al., 2013). However, the majority of studies reviewed did not use a nationally representative sample (Ancker et al., 2012; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Luchenski, 2012; Marquard & Brennan, 2009; O'Donnell et al., 2012; Park et al., 2013; Patel et al., 2011; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015; Wen et al., 2010), only four studies oversampled for minorities (Ancker et al., 2012; Caine & Hanania, 2013; Patel et al., 2011; Schwartz et al., 2015) and one used a Spanish version (Patel et al., 2011) making it difficult to generalize findings to other populations. The remaining statistically significant affirmative and negative factors associated with health data sharing preferences of consumers were grouped into a classification schema of five broader categories: (a) trust relationship, (b) harm threshold, (c) balance risk and benefits, (d) transparency of data exchange, and (e) access and control of data. Figure 2 displays the nested classification schema.

Factors Associated with Trust Relationship

Trust relationships are essential in a digital health infrastructure. Consumers are expected to give permission for their ePHI to be accessed and shared; providers and organizations are expected to be responsible for safe and secure storage, use, and exchange of ePHI. Factors identified in the literature review as contributing to a positive trust relationship were perceived trustworthiness of other people, local businesses, large corporations (Ancker et al., 2011), and government (Ancker et al., 2011; Park et al., 2013; Teixeira et al., 2011); trust in providers to use the minimum set of information necessary (Caine & Hanania, 2013; Dhopeshwarkar et al., 2012; Luchenski, 2012; Park et al., 2013; Patel et al., 2011; Teixeira et al., 2011; Wen et al., 2010); belief that providers will keep data private and secure in their private practice databases and that providers act on behalf of patients and in their best interest when information is used and shared

(Ancker et al., 2013; Dimitropoulos et al., 2011; Marquard & Brennan, 2009); Patel et al., 2011; Patel et al., 2012); and consumer awareness that limited information sharing may harm the provider-patient relationship (Park et al., 2013). To reach an adequate level of consumer trust, providers and organizations must agree on a common set of shared policies and procedures, such as data use agreement, business associate agreement, and health information exchange (HIE) participant agreement, for data storage, use, and exchange to demonstrate that information privacy and data security protections are consistently applied and monitored (Ancker et al., 2012; Dimitropoulos & Risk, 2009). The health ecosystem is just beginning to highlight the influence of systematic, transparent, and purposeful protections on consumer trust and participation in health data exchange.

Factors associated with negative trust relationships include absence of confidence in the physician, health plan, hospital, health care system, and government (Dhopeshwarkar et al., 2012; Marquard & Brennan, 2009; Patel et al., 2011; Patel et al., 2011; Teixeira et al., 2011; Wen et al., 2010); fear of discrimination; denial of credit and denial of employment (Dimitropoulos et al., 2011; Patel et al., 2011); lack of trust by ethnically diverse populations when Internet mechanisms are used (Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Luchenski, 2012; Patel et al., 2011); and the increased likelihood that people will lie in-person when faced with stigma or embarrassment (Ancker et al., 2012). Increased education of health care providers, organizations, and consumers regarding the importance of implementing public policy that supports oversight and accountability in a consumer-mediated model is one way to establish trust across all parties. In addition, researchers need to make deliberate and ongoing efforts to identify gaps in public policy and legal regulation to provide the appropriate levels of safeguards for confidentiality.

Factors Associated with Harm Threshold

Harm includes physical, psychosocial, or mental injury. Assessing harm or risk of harm requires ongoing, continuous evaluation of mistreatment or injury and resulting damage (Berg et al., 2001). The HIPAA Final Rule establishes a threshold for measuring harm sustained by the unauthorized access of a consumer’s ePHI (U.S. Department of Health & Human Services, 2013). The National Committee on Vital and Health Statistics (2006) defined highly-sensitive information as pertaining to domestic violence, genetic information, mental health, reproductive health, and substance use. Unauthorized access to these types of data may contribute to the harm. Factors found to contribute to affirmative data sharing preferences related to harm include high personal willingness to share nonsensitive ePHI (Dimitropoulos et al., 2011; Luchenski, 2012; Marquard & Brennan, 2009; Park et al., 2013; Patel et al., 2012; Swartz, et al., 2015), high personal willingness to share ePHI with primary care physician or specialty care team (Dimitropoulos et al., 2011; Luchenski, 2012; Marquard & Brennan, 2009; Park et al., 2013; Patel et al., 2012; Swartz, et al., 2015), patients feeling respected by the clinical care team (Teixeira et al., 2011), and positive feelings of support from government programs meant to provide for medical needs (Teixeira et al., 2011). These factors appear to have a protective quality, allowing the recipient to measure personal experience against his or her risk tolerance related to information privacy or confidentiality.

Factors found to be statistically significant for negative data sharing preferences related to harm include data regarding a patient’s mental health, drug or alcohol use, sexually transmitted disease, and human immunosuppressive virus (Schwartz et al., 2015; Teixeira et al., 2011). In addition, risks to a patient’s harm include sharing data with nonclinical staff (Teixeira et al., 2011), fear of reprisal by private health insurers (Dhopeshwarkar et al., 2012; Marquard & Brennan, 2009; Patel et al., 2011; Teixeira et al., 2011), and stigma increases when trust is low (Teixeira et al., 2011). These factors may indicate that prior to engagement in HIE, consumers must form trust relationships to balance fear of stigma and embarrassment that can increase harm.

Factors Associated with Balance Risk and Benefit

The triple aim targets better quality, more coordinated care, increased patient satisfaction, and lower health care costs through the implementation of electronic health records and information exchange (ONC, 2014). Consumers are thought to be the primary beneficiaries of systematic changes that are transforming the delivery of health care (Berwick, 2009). Factors associated with affirmative data sharing preferences that balance risk and benefit include; the promise of better coordinated and improved quality of care (Ancker et al., 2013; Dimitropoulos et al., 2011; Marquard & Brennan, 2009; Park et al., 2013; Patel et al., 2011), elimination of redundancy (Dimitropoulos et al., 2011; Marquard & Brennan, 2009; Park et al., 2013; Patel et al., 2011; Patel et al., 2012), improved access, safety and increased population and individual benefits (Dimitropoulos et al., 2011; Marquard & Brennan, 2009), and perception of improved provider-patient communication if information is available (O’Donnell et al., 2011; Park, et al., 2011). To accomplish this transformation, policy makers realize that consumer health data must be accessible, sharable, and follow patients across the care continuum (Ancker et al., 2012; Ancker et al., 2013; Li, Yu, Ren, & Lou, 2010; Luchenski, 2012).

Factors associated with negative data sharing preferences to balance risk and benefit include the need to relinquish personal control of ePHI (Caine & Hanania, 2013; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; O'Donnell et al., 2011), the perceived ability to influence reduction in cost and waste associated with low quality care (Park et al., 2013), and the perception that new systems will be too complicated for consumers to use (Park et al., 2013; Patel et al., 2011). A more consumer-mediated data sharing model may neutralize some risk, allowing consumers to self-monitor access and sharing of ePHI, while mitigating some inherent risk in current systems.

Factors Associated with Transparency of Data Exchange

Transparency generally relates to the right to know and public access to information (Turilli & Floridi, 2009). Transparency is present when a consumer understands the type of information shared, with whom, for how long, and for what purpose (Morey et al., 2015). Consumers want the same level of health data transparency that they have come to expect with their credit card and financial information (Merz, 2013). Factors associated with affirmative data sharing preferences for data transparancy include availability of audit logs and audit trails (Caine & Hanania, 2013; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011), consumer notification when ePHI is accessed (Caine & Hanania, 2013; Dhopeshwarkar et al., 2012; Schwartz et al., 2015), use of decentralized data storage (Dhopeshwarkar et al., 2012), use of limited data sets for specific purpose (Caine & Hanaina, 2013; Dhopeshwarkar et al., 2012; Luchenski, 2012; Marquard & Brennan, 2009; Park et al., 2013; Patel et al., 2011; Schwartz et al., 2015) and the increased availability of consumer-accessible portable health care devices (Dhopeshwarkar et al., 2012). High levels of transparency do not exist because of technical challenges in providing an exchange system that is transparent to the patient, while limiting additional burden to the HIE.

Factors associated with negative data sharing and transparency of data exchange consist of low level of information available to consumers related to what parts of their health care record are shared (Ancker et al., 2012); secondary reuse of information (O'Donnell et al., 2011); multiple viewers of a record (Ancker et al., 2012; Dimitropoulos et al., 2011); chance of information linked to wrong person (Dimitropoulos et al., 2011); chance of information disclosed to wrong provider (Dimitropoulos et al., 2011; Teixeira et al., 2011); a centralized database (Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011); unauthorized access and misuse of data for fraud, identity theft, or posting ePHI on the Internet (Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2012); and fear of HIE system breakdown with no back-up available (Park et al., 2013). Although patients want more transparency of data exchange, care is mostly delivered in networks predisposing data to breaches because centralized control is lacking and the right technical safeguards are not present (Merz, 2013; Morey et al., 2015).

Factors Associated with Access and Control of Data

The meaningful use of electronic health records is endorsed by the Accountable Care Act and requires that consumers can view, download, and transmit their electronic ePHI (U.S. Department of Health & Human Services, 2017). This increases consumer ability to aggregate, access, and control their health information. Factors found to be associated with affirmative health data sharing preferences of consumers related to control and access include affirmative consent or permission on file (Caine et al., 2015;

Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015), personal control of access to ePHI (Caine et al., 2015; Dhopeshwarkar et al., 2012; Park et al., 2013; Patel et al., 2011; Schwartz et al., 2015), restricting or blocking specific information or revealing only “need to know” information (Caine et al., 2015; Dhopeshwarkar et al., 2012; Luchenski, 2012; Marquard & Brennan, 2009; Park et al., 2013; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015), application of time limits and temporal control (Caine et al., 2015; Dhopeshwarkar et al., 2012; Park et al., 2013), controls in place to prohibit all sharing if needed (Caine et al., 2015; Dhopeshwarkar et al., 2012), and physician emergency override of personal privacy preferences (Dimitropoulos et al., 2011; Patel., et al., 2011). These factors suggest that a centralized model of personal health record management that facilitates the storage, access, and sharing of ePHI is more attractive to patients (Li et al., 2010).

Factors associated with negative health data sharing preferences of consumers for access and control include sharing of data across multiple providers (Ancker et al., 2013; Patel et al., 2011); lack of choice to share or not share (Marquard & Brennan, 2009); feeling the lack of personal control (Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011); lack of mechanisms for granular control (Caine & Hanania, 2013; O’Donnell et al., 2011); fear of release of ePHI to wrong physician, friends, health plan, or employer (Dimitropoulos et al., 2011; Marquard & Brennan, 2009; Patel et al., 2011, Patel et al., 2011); and those with chronic illness or high health care utilizers may not be able to manage access and control (O’Donnell et al., 2011; Park et al., 2013). Study findings indicate consumers prefer permission is obtained prior to their health data being viewed through HIE (Caine & Hanania, 2013; Dhopeshwarkar et al., 2012; Dimitropoulos &

Rizk, 2009; Dimitropoulos et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015). These findings may suggest personal knowledge of how their health information is used and disclosed is equally as important as the issue of control of their data.

State of the Art and Science

Consumers are key stakeholders in the evolution of public policy related to health data collection, storage, use, and exchange. The Code of Fair Information Practices (1973) outlines five principles that must be present in order for consumers' information to be adequately managed: (a) no personal data kept on secret record keeping systems, (b) there must be a way for consumers to know what information is recorded and how it is used, (c) secondary uses of information require consumer consent, (d) consumers must be able to amend incorrect information, and (e) misuses of the information must be eliminated. These principles represent accepted guidelines for information management in the electronic marketplace. The Code of Fair Information Practices provide context for what is meaningful to consumers and expand the notion of the types of access and controls considered when defining the concept of granular consent preferences. Still, it is challenging for policy makers to consider how best to respect and include the voice of the consumer, given current challenges with health data interoperability.

Nurses and health care providers rely heavily on patient information to drive sound clinical decision-making at the bedside. Consumers choosing to share or withhold health care data from providers likely affect the safety of the care delivered. Not sharing health data limits the ability of consumers to receive coordinated care and increases adverse outcomes. Lack of data shared in an exchange environment reduces efficiency of population health opportunities and may negatively affect care management strategies deployed in total cost of care arrangements, such as value-based care, accountable care organizations, and risk-sharing arrangements.

Statistically significant factors show consumers (a) value relationships of trust, (b) desire knowledge related to harm when sharing of ePHI, (c) seek balance between risk and benefits of data sharing, (d) yearn for increased transparency of exchange, and (e) demand access controls for data sharing preferences (Ancker et al., 2012; Ancker et al., 2013; Dhopeshwarkar et al., 2012; Luchenski, 2012; O'Donnell et al., 2012; O'Donnell et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015; Teixeira et al., 2011; Wen et al., 2010). An interoperable health care system that includes these characteristics more closely resembles a consumer-mediated exchange model. Moving to C-ME will require new or modified public policy and legal regulation based on the health data sharing preferences of consumers. Likewise, the literature review showed public policy in a responsive system needs to include resilient feedback loops. Deliberate inclusion of health data sharing preferences of consumers and relevant research findings will provide input needed for such feedback loops to exist. A more integrated approach of consumer feedback and research could inform the modernization of a national public policy related to information privacy, data security, and consent management. Additionally, this feedback will support the development of consumer-centric information exchange models that promote the safe, secure, and interoperable exchange of health data based on consumer data sharing preferences.

Ethical Practice

Ethical practice in nursing and health care delivery is built on a foundation of trust. Personal health data are a tool used by providers to track, trend, and detect change in health over time. Ensuring that health data are managed in a way that supports ethical practice, public policy should include consumers as key stakeholders and citizen participants with a clear voting voice. In the 21st century, consumers are sideline participants. The literature review shows consumers becoming more aware of their right to make an informed choice regarding the sharing of their health care data (Ancker et al., 2012; Ancker et al., 2013; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Luchenski, 2012; Marquard & Brennan, 2009; O’Donnell et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2011; Patel et al., 2012; Schwartz et al., 2015; Teixeira, 2011; Wen et al., 2010). State and federal public policies and legal regulation support “opt-in” or “opt-out” models (Pritts, 2008). These models require consumers to make a choice to either include all information or exclude all information (Annas, 2003). No public policy or legal regulation exists that promotes granular management of electronic health data based on consumer preference.

The systematic review shows disparities exist in data sharing preferences related to race and ethnicity (Dhopeshwarkar et al., 2012; Luchenski, 2012; Patel et al., 2011; Teixeira et al., 2011), age (Ancker et al., 2012; Ancker et al., 2013; Luchenski, 2012; O’Donnell et al., 2011; Park et al., 2013; Wen et al., 2010), education (Ancker et al., 2012; Ancker et al., 2013; Luchenski, 2012; Patel et al., 2011; Patel et al., 2012; Teixeira et al., 2011), income level (Ancker et al., 2012; O’Donnell et al., 2011; Patel et al., 2011, Patel et al., 2011), and access to technology (O’Donnell et al., 2011; Park et al., 2013;

Patel et al., 2011; Patel et al., 2011). Minorities feel additional stigma is attached to personal health data, which decreases equal access to health care services, increases opportunity for unfavorable credit ratings, and decreases ability to obtain employment (Dimitropoulos et al., 2011). Public policy makers have an additional burden to provide needed education and security measures to build trust where little trust has historically existed because of structural racism.

Implications for ethical practice also exists for public policy development when populations or subgroups are targeted through population health initiatives. Consumer health and insurance claim data reused for population health management activities can detect individuals who are resource intensive. The purpose is to ensure all individuals and subgroups make the most efficient use of available health care resources (U.S. Department of Health & Human Services, 2017). A consumer who is targeted may feel that population health activities are punitive or increase feelings of mistrust and discrimination. Through the systematic review, the researcher found consumers want transparency regarding how their information is collected, used, and shared (Caine et al., 2015; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Luchenski, 2012; Marquard & Brennan, 2009; Park et al., 2013; Schwartz et al., 2015). Ethical practice concerns include both the risk and the benefit to the consumer. Subsequently, additional consumer education may allow knowledge acquisition to take place and key questions to be answered (i.e., how an individual is identified for high-risk outreach in care management programs) for consumers who participate in population health programs.

Limitations and Opportunities for Future Research

Research in this domain is limited by lack of experimental studies and use of small, mostly homogenous samples, which may decrease the generalizability. Only eight questionnaires in the 14 studies reviewed were pilot-tested (Ancker et al., 2012; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; O'Donnell et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2012). Pilot testing lacked rigor in most studies reviewed. Lack of rigorous pilot testing of the survey questionnaire can lead to study design bias, because researchers fail to identify validity (accuracy) and precision (reliability) problems when the survey instrument is not validated. These attributes ensure results of the study are replicable. Pilot testing can also increase concept clarity. When concepts are not well-defined, study participants may have poor understanding of the research questions. Lack of concept clarity may lead to poor study outcomes and lead to inconclusive findings during data analysis.

A limited number of studies regarding health data sharing preferences of consumers exist and most are observational studies (Ancker et al., 2012; Ancker et al., 2013; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Luchenski, 2012; Marquard & Brennan, 2009; O'Donnell et al., 2011; Park et al., 2013; Patel et al., 2012; Patel et al., 2012; Patel et al., 2012; Schwartz et al., 2015; Teixeira et al., 2011; Wen et al., 2010). Future research should focus on health data sharing preferences of consumers with the intent to inform public policy and meet C-ME expectations. Actively engaging consumers upfront in study design and rigorous research methodologies so that study findings are generalizable to larger populations and replicable will advance scientific knowledge. To increase reliability and strengthen study results, future research will benefit cognitive and psychometric testing for survey instruments. Future researchers need to use larger and more diverse samples to ensure study findings are transferable and identify emerging trends for health data sharing preferences of consumers. This requires allocation of research funds to support evaluation of public policy feedback loops and study of health data sharing preferences of consumers to inform public policy.

Conclusion

No deliberate mechanisms include consumers in the development of public policy related to health data sharing preferences or consumer-mediated data sharing. In addition, no resilient-feedback loop(s) exist to balance the complex public policy system. This literature review describes an analysis and synthesis of factors and issues associated with consumer data sharing preferences. Based on the analysis, the researcher proposed a logic model that deliberately includes consumer input and research early in public policy development cycles. The use of complexity theory allows for an approach to multidimensional public policy system review and the creation and evaluation of future data governance structures. Consumer input and research creates feedback loops to monitor gaps, identify opportunities, and modify current public policy as the health ecosystem moves toward a more consumer-mediated model of health data exchange in the learning health system. The researcher believes aligning public policy with health data sharing preferences of consumers will positively influence trust between consumers, the health ecosystem, and the aspirational goals of the health learning systems. Chapter 3 includes a discussion of the study methods.

Chapter 3: Methods

Previous researchers identified statistically significant factors that influence health data sharing preferences of consumers (see Table 2; Moon, 2017). No theoretical model exists to describe relationships between and among the constructs of information privacy, data security, C-ME, and interoperability. This study involved a publicly available data set and quantitative methods to describe predictors of health data sharing preferences of consumers. The researcher used SEM to test a hypothesized path diagram for model specification (Hoyle, 2012). Model specification is important when advancing new knowledge in a domain where little formal research has been completed and no theoretical model or framework exists (Suhr, 2014). Model specification began with analysis of available literature and the development of a hypothesized path diagram of a proposed theoretical model (see Figure 3). No previous researchers have completed this level of research inquiry.

Study Design

The study was a retrospective descriptive observational study using quantitative methods to analyze secondary data. This study, data were from a publicly available longitudinal data set regarding HINTS results. The dependent variable in this study was health data sharing preferences of consumers and independent variables were demographic factors. Latent variables were information privacy, data security, and C-ME.

Aim 1 of the study was to describe factors that predict health data sharing preferences of consumers. The gap in the literature is that no description of predictors for health data sharing preferences of consumers exist at this level. Available research indicates that consumers choose to share or withhold information based on personal preferences that include demographic characteristics (Patel, Barker & Siminerio, 2015). The goal was to describe predictors of health data sharing preferences of consumers. Aim 2 involved the predictors to test a hypothesized path diagram of constructs for information privacy (antecedent), data security (antecedent), health data sharing preferences of consumers, and C-ME—a form of interoperability (consequence). This aim supports ongoing work to understand the concept of health data sharing preferences of consumers using evolutionary concept analysis methods (Rodgers & Knafl, 1989). Findings are important to inform future public policy, legal regulation, and health care industry standards that respect and include the consumer's voice and preferences for information exchange.

Aim 2 was to determine the direction, path, and strength of relationship between the predictors (affirmative and negative) and antecedent concepts of information privacy, data security on the construct of health data sharing preferences of consumers, and C-ME. The gap is that no researchers have attempted to understand the direction, path, or strength of relationships between the constructs of interest for health data sharing preferences of consumers. The researcher used SEM, a quantitative method, to study three types of relationships between study constructs: (a) strength of association, (b) direct effect using directional relation between two variables, and (c) path as described by the indirect effect of independent variables on dependent variables through one or more intervening or mediating variables (Hoyle, 2012; Schumacker & Lomax, 2004).

SEM is a comprehensive statistical approach to testing hypotheses regarding relations among observed and latent variables (Hoyle, 2012). This modeling is a methodology for representing, estimating, and testing a theoretical network of mostly linear relationships between variables (Hoyle, 20112; Suhr, 2012). For example, the strength, directionality, and path of relationship between information privacy (antecedent), data security (antecedent), and health data sharing preferences of consumers are not well understood. The relationship between variables may show association, direct effect, or indirect effect, which are all important considerations for developing theoretical models (Hoyle, 2012; Schumacker & Lomax, 2004). Demonstrating how the construct of health data sharing preferences of consumers is influenced by variables that can be directly measured (e.g., education, income) or influenced by latent variables that mediate the effect on the construct of interest would be a significant advancement. This level of measurement is not available in studies of health data sharing preferences of consumers, because multilevel modeling approaches, such as CFA and SEM, have not been used to investigate health data sharing preferences of consumers (Ancker et al., 2012; Anker et al., 2013; Caine & Hanania, 2013; Campion et al., 2013; Dhopeshwarkar et al., 2012; Dimitropoulos & Rizk, 2009; Luchenski, 2012; Marquard & Brennan, 2009; O'Donnell et al., 2011; Park et al., 2013; Patel et al., 2011; Patel et al., 2012; Ramos & Bakken, 2014; Teixeira et al., 2011; Wen et al., 2010).

Aim 3 of the study was to use SEM model specification to test the hypothesized relationships in a path diagram (see Figure 3). The gap is that no theoretical model exists to describe construct relationships for health data sharing preferences of consumers. SEM specification begins with a path diagram of a proposed theoretical model (Hoyle, 2012). Model specification is important when advancing new knowledge in a research domain where little formal study has been completed and no theoretical model or framework exists. Theoretical models provide a framework for analysis, an efficient method for field development, and clear explanation of otherwise complex relationships between study constructs (Wacker, 1998). This is significant, because model specification provides information to ensure that the model (statistical statement of the relations among variables) is not under identified or over identified. SEM involves an iterative process to obtain an improved estimation of unknown free parameters within the specified model (Schumacker & Lomax, 2004). When the estimation procedure has converged, a single number is produced to summarize the degree of correspondence between expected and observed covariance matrices. Model fit is important for developing a theoretical model that describes the relationships between constructs (antecedent and consequence) that influence the latent variable of health data sharing preferences of consumers (Barrett, 2007; Browne & Cudeck, 1993).

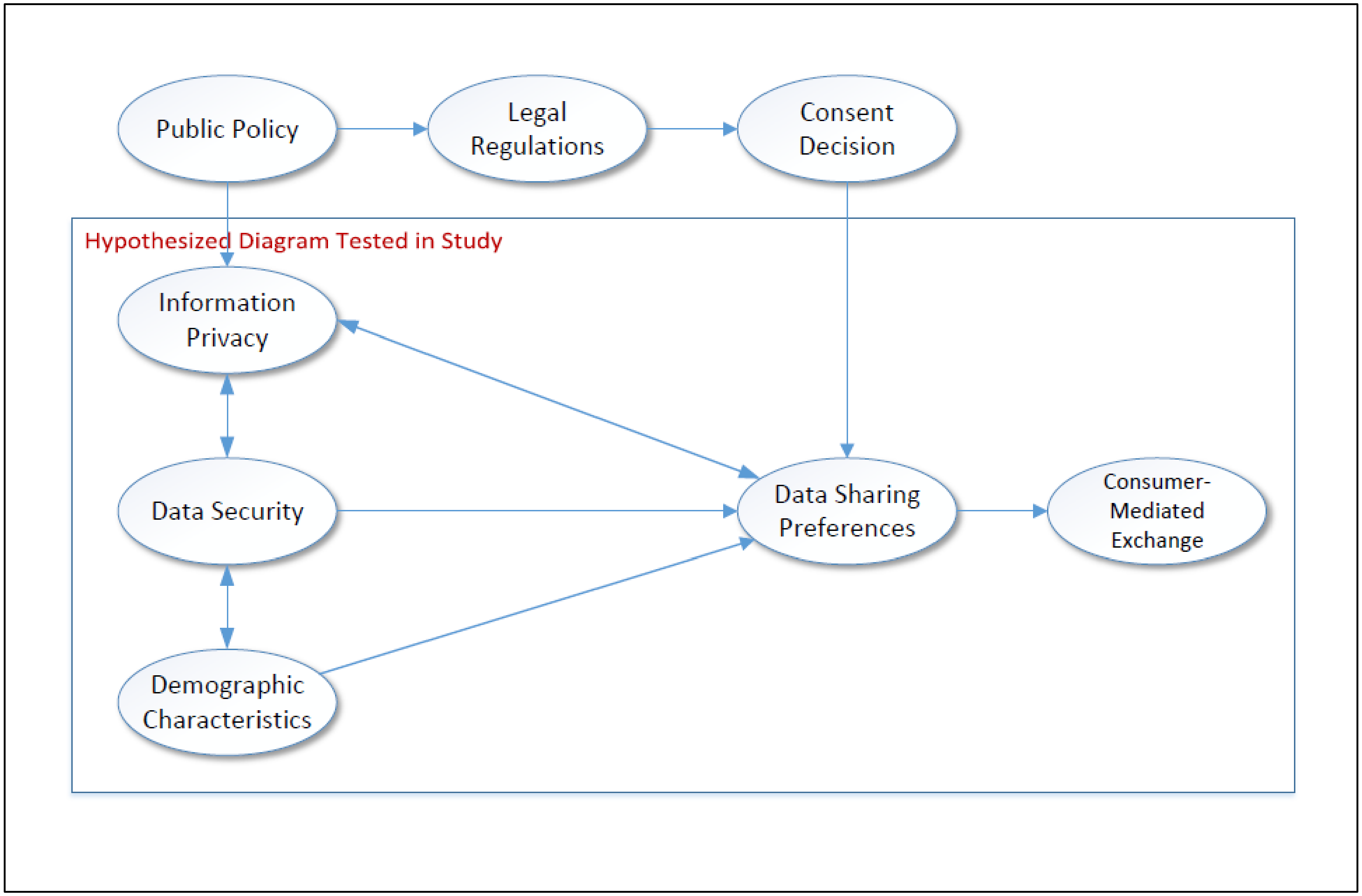

Figure 3. Hypothesized path diagram.

Aim 4 was to use study findings to describe the relationships of constructs in a developing theoretical model and consider implications on public policy related to C-ME data governance.

Data Source

HINTS data sets are categorized by year, cycle, and are available in three different formats (SPSS, SAS, and STRATA). Each data set has supporting documents that include analytic recommendations, historical document, methodology report, and the codebook for that cycle. The study data set includes data from the HINTS Cycle 4 in 2014 and the researcher used data from 2,000 survey participants. Data files included all completed survey responses of participants. For this study, only the participant responses for the medical information subset of items were used to operationalize study variables.

The National Cancer Institute formally sponsored HINTS; however, survey participants consist of patients with and without the medical condition of cancer. To ensure HINTS participants are representative of the general population and not just those who have a cancer diagnosis, HINTS includes a two-phased approach to select participants. The sample is stratified based on addresses from a database used by Marketing Systems Group, and then one adult is selected from each sampled household. The sampling frame of addresses is grouped into three sampling strata based on (a) addresses in areas with high concentrations of minority population, (b) addresses in areas of low concentrations of minority populations, and (c) addresses located in counties comprising central Appalachia, regardless of population (HINTS, 2015). HINTS use an equal-probability sample of addresses within each stratum and the minority frame is routinely oversampled to ensure a nationally representative sample could be attained.

A nationally representative sample, as defined by HINTS, is a sample that “looks like” the entire population of the United States (Nelson et al., 2004). To accomplish a nationally representative sample, the sample structure should reflect national proportions for gender, age, and race for each geographic region (Dillman et al., 2009). A total of four mailings exist in the HINTS fielding protocol and all households in the sample receive a first mailing, a reminder post-card, and the nonrespondents receive subsequent survey mailings following the Dillman approach (Dillman et al., 2009). Additionally, two toll-free telephone numbers were provided to respondents who needed technical assistance with the survey. HINTS Cycles 1–4 sample respondent numbers represented Years 2014 (3,677 respondents), 2013 (3,185 respondents), 2012 (3,630 respondents), 2011 (3,959 respondents) and 2009, (3,582 respondents).

Instrumentation

The Health Communication and Informatics Research Branch of the Division of Cancer Control and Population Sciences developed the HINTS. The HINTS is an outcome of the National Cancer Institute’s goal to better understand how individuals consume and use health care information to screen and decrease cancer risk. The HINTS instrument was first fielded in 2003 (HINT, 2015). The instrument includes a subset of items, such as the medical records section, to identify, monitor, and track developing trends related to health communication, health information technology, and information exchange. In this context, HINTS was an appropriate data set to study health data sharing preferences of consumers in this study. However, the original intent of HINTS was to understand the communication channels adults use to obtain and share vital health information about themselves and their loved ones within the context of cancer risk.

Therefore, a risk of sampling bias may affect generalization of study findings. Data science researchers have been using HINTS to create more effective strategies for health care information access, use, and exchange for several years (HINT, 2016). Subsequently, survey items in medical records section of HINTS were used to operationalize the constructs of information privacy, data security, data sharing preferences, and information exchange in this research study.

Researchers have fielded the HINTS instrument eight times since 2003. Some items in the questionnaire have been revised over time. The original HINTS instrument was pilot tested with 172 respondents, and revisions were made based on pilot test findings (Nelson et al., 2004). The HINTS survey instrument is used to collect 18 unique demographic characteristics through 3 to 5-point Likert scales to collect ordinal data regarding the 12 items in the medical record subset related to electronic medical records and information exchange. To ensure variables of interest were operationalized consistently for each survey year, the researcher assessed all survey items related to the constructs of interest (information privacy, data security, health data sharing preferences of consumers, and information exchange) for each survey year using a crosswalk tool. The survey instrument crosswalk showed demographic items were consistently applied for all the years, but key variables of interest could be operationalized through HINTS Cycles 1–4 (HINTS Cycle 1 included seven items of interest, Cycle 2 included two items of interest, Cycle 3 included five items of interest, and Cycle 4 included all 12 items of interest).

The HINTS instrument is available in two formats, depending on the year and method of survey fielding. HINTS used Random-Digit-Dial techniques in 2003, 2005, and 2008 and a self-administered mail questionnaire for HINTS 4 Cycle 1-4 Series from 2011 - 2014. The first three HINTS instruments were fielded as Random Digit Dial telephone surveys, using a computer assisted telephone interview format to accommodate complex skip patterns. When landlines overwhelmingly became replaced with cellphones, survey response rates were negatively affected. HINTS 4 Cycles 1–4 were collected using a single-mode mail survey and the next birthday method for respondent selection. The average response rate using the next birthday method was 34.44% (Salmon & Nichols, 1983).

Researchers have used HINTS data sets in a growing body of research to evaluate the effects of health communication, media, and health information technology on health and behavioral outcomes, health care quality, and health disparities (HINTS, 2015). In 15 peer-reviewed publications regarding the topic of information technology related to medical records, researchers used HINTS data. HINTS data has been studied in research showing the association between health information technologies and decision-making behaviors and outcomes in the U.S. population (HINTS, 2015). To increase generalizability to the U.S. population, survey weights were created to permit analysis.

HINTS is a population-level health survey. The HINTS instrument has not been used outside of the Division of Cancer Control and Population Sciences, but researchers have used the data sets in studies relating to health communication and information technology. The items used for this study did not come from a previously validated instrument or another national survey tool. The researcher could not find a test/retest or Cronbach’s Alpha as evidence of reliability. HINTS questions often measure complex constructs using single items that cannot be subjected to traditional measures of reliability, such as internal consistency. Some research shows single-item measures may have acceptable psychometric properties and are, therefore, a potentially viable alternative to multi-item scales for construct measurement purposes (Diamantopoulos, Sarstedt, Fuchs, Wilczynski, & Kaiser, 2012). The HINTS questions contain groups of items that could be considered a multi-item scale. Subsequently, independent researchers must decide if they want to use survey items separately or together. The HINTS team conducts rigorous cognitive testing of the items to ensure respondents understand the intent of the question and answer appropriately, and to ensure items are psychometrically sound (Nelson et al., 2004).

Operationalize Variables

The researcher operationalized all study variables using items from the HINTS medical records subset of the instrument. The study dependent variable was data sharing preferences. For this study, data sharing preferences referred to the willingness to share personally identifiable information with an outside entity or source in an electronic health record or information exchange. An *affirmative data sharing preference* indicates an individual’s willingness to share digitized content in a networked computing environment. A *negative data sharing preference* indicates the lack of willingness on the part of an individual to share digitized content in a networked computing environment. The dependent variable, data sharing preferences, was operationalized using HINTS medical records subset Item D2a (“Doctors and other health care providers should be able to share your medical information with each other electronically”); the variable was ordinal and treated as continuous. The researcher collected data on a Likert-type scale, ranging from 1 (*Very Important*) to 3 (*Not at all Important*). Question D2a asks respondents about the strength of importance for their decision to share medical information with health care providers. The question does not ask for an affirmative or negative data sharing preference. However, this is a secondary analysis of a publicly available data set. The researcher used the level of importance as a proxy measure for affirmative and negative data sharing preferences; higher level of importance was affirmative and lower level of importance was negative. Table 5 details the item number, item, variable type, and study variable.

Table 5

Item Number, Variable Name, Variable Type and Study Variable

Item No.	Item	Variable Type	Study Variable
N1	Age	Continuous	Independent variable
N2	Occupation Status	Categorical	Independent variable
N3	Active Duty Armed Forces	Categorical	Independent variable
N4	Received Care VA	Categorical	Independent variable
N5	Marital Status	Categorical	Independent variable
N6	Education	Categorical	Independent variable
N7	Born in USA	Dichotomous	Independent variable
N8	Year Came to USA	Dichotomous	Independent variable
N9	Speak English	Categorical	Independent variable
N10	Not Hispanic	Dichotomous	Independent variable
N11	Race	Categorical	Independent variable
N12	Total Household No.	Continuous	Independent variable
N13	Self-Gender	Dichotomous	Independent variable
N14	Children in Household	Continuous	Independent variable
N15	Rent or Own Home	Categorical	Independent variable
N16	Cellphone Use	Dichotomous	Independent variable
N17	Phone in Home	Dichotomous	Independent variable
N18	Income Ranges	Categorical	Independent variable
B7a	Medical Info - Email	Dichotomous	Observed variable - C-ME
B7b	Medical Info - Text	Dichotomous	Observed variable - C-ME
B7c	Medical Info - App	Dichotomous	Observed variable - C-ME
B7d	Medical Info - Video	Dichotomous	Observed variable - C-ME
B7e	Medical Info - Social Media	Dichotomous	Observed variable - C-ME
B7f	Medical Info - Fax	Dichotomous	Observed variable - C-ME

Item No.	Item	Variable Type	Study Variable
B7g	Medical Info - None	Dichotomous	Observed variable - C-ME
B8a	Interested Info_ApptReminder	Dichotomous	Observed variable - C-ME
B8b	Interested Info_GenHealth	Dichotomous	Observed variable - C-ME
B8c	Interested Info_MedRemind	Dichotomous	Observed variable - C-ME
B8d	Interested Info_LabResults	Dichotomous	Observed variable - C-ME
B8e	Interested Info Diagnostics	Dichotomous	Observed variable - C-ME
B8f	Interested Info_Vitals	Dichotomous	Observed variable - C-ME
B8g	Interested Info_Lifestyle	Dichotomous	Observed variable - C-ME
B8h	Interested Info_Symptoms	Dichotomous	Observed variable - C-ME
B8i	Interested Info_Images	Dichotomous	Observed variable - C-ME
D2a	Share EMR	Ordinal	Dependent variable
D2b	Access EMR	Ordinal	Observed variable
D3	Confident Info Safe	Ordinal	Observed variable - Data Security
D4	Confident Control Info	Ordinal	Observed variable - Information Privacy
D5	Withheld Info Privacy	Dichotomous	Observed variable - Information Privacy
D6	Fax Info Safe	Ordinal	Observed variable - Security
D7	Electronic Info Safe	Ordinal	Observed variable - Information Privacy

Latent variables were information privacy, data security, and C-ME—a form of interoperability. Information privacy refers to the ability of an individual to prevent certain disclosures of personal health information to any other person or entity and was operationalized by using HINTS medical records subset Item D4, D5, and D6. Data security was defined as the personal and electronic measures—the administrative, physical, and technical safeguards to an information system—that grant access to personal health information to persons or entities authorized to receive it and deny access to others. Data security was operationalized using HINTS medical records subset item D3 and D7. Consumer-medicated exchange is defined as the ability for patients to aggregate and control the use of their health information among providers in the health care industry (ONC, 2015). Consumer-medicated exchange was operationalized using HINTS medical records subset Items B7 and B8. An additional observed variable used was medical records subset Item D2b (Access EHR).

Data Analysis

The researcher entered data in SPSS Version 23.0 for Windows. The researcher conducted descriptive statistics to describe the sample demographics and the research variables used in the analysis. The researcher also calculated frequencies and percentages for categorical data, and calculated means and standard deviations for continuous data (Howell, 2010). The HINTS data are considered “clean,” but as a precaution, data was screened for accuracy, missing data, and outliers. The researcher tested the presence of outliers by the examination of standardized values. Standardized values represent the number of standard deviations the value is from the mean. Values higher than 3.29 and less than -3.29 standard deviations from the mean represent outliers and are removed from the data set (Tabachnick & Fidell, 2012). Missing data were examined for nonrandom patterns. Participants who did not complete major sections of the survey was excluded.

To examine the research questions, the researcher used SEM. Confirmatory Factor Analysis (CFA) specified the measurement model. This specification required that items were linked (loaded on) to each factor (observed variables, directly measured) and each item was linked to only one latent variable (not directly observed). When the measurement model was specified, SEM began. SEM is a type of statistical analysis based on the general linear model and is considered appropriate when multiple observed variables make up a latent variable and can be tested on another latent variable (Ullman, 2006). SEM allows for measured variables from a scale to be assessed as indicators of a latent construct and goodness of fit to be identified (Ullman, 2006). The latent construct is free of the measurement error associated with measured variables. The removal of measurement error leaves common variance, allowing for better measurement of reliability (Ullman, 2006). SEM allows for the testing of alternative models to the hypothesized model to analyze the best possible fit (Kahn, 2006).

The researcher used the SEM software AMOS to test the model fit. The software fit the data to the study model, and the results produced overall model fit statistics and parameter estimates. Through AMOS, the researcher used maximum likelihood estimation to estimate regression weights and fit data to the model (Kupek, 2005, 2006). Model fitting involved testing the predictive power of the variables while using the sample covariance matrix (Barrett, 2007; Gerstoft, Menon, Hodgkiss, & Mecklenbräuker, 2012).

Prior to analysis, the researcher assessed the assumptions of SEM. The assumptions of the SEM include multivariate normality, ensuring a large enough sample size, and the absence of multicollinearity (MacCallum, Browne, & Sagawara, 1996; Ullman, 2006). Multivariate normality assumes a normal bell curve distribution between the independent variables and the dependent variables. Researchers assess multivariate normality by examination of Q-Q plots (Tabachnick & Fidell, 2012). The absence of multicollinearity assumes that predictor variables are not too closely related and will be assessed with the covariates within the CFA. A power calculation showed that the appropriate sample size for this study was 237 participants, which was enough to ensure statistical validity and meet the assumption of a large sample (Kim, 2005). This study involved 2,000 cases.

Threats to Reliability & Validity

Experimental and quasi-experimental studies are concerned with external, internal, and construct validity (Shadish, Cook, & Campbell, 2002). Multilevel modeling (e.g., exploratory factor analysis, CFA, and SEM) involves concerns of threats to reliability and validity of the instrument used to test constructs, factors, and relationships (Schumacher & Lomax, 2010). SEM includes CFA (measurement model) and structural modeling. CFA represents the pattern of observed variables for latent constructs in the hypothesized model. CFA plays a role in validating and finding reliability of measurement where constructs are being tested (Schumacher & Lomax, 2010). Therefore, SEM can assist in testing hypothesized theoretical models to determine model fit, but SEM cannot be used to determine causation, which limited the scope of this study (Hoyle, 2012; Suhr, 2014).

Reliability. Reliability of an instrument is measured through indicators of internal consistency for scaled items (Schumacher & Lomax, 2010). Internal consistency is the confidence that the instrument will yield the same or similar results each time it is used (DeVellis, 2016). Reliability may be at risk, if the medical record subset items in the study instrument are unable to measure the construct of interest because of one or more items having low fit for use in data collection. The latent construct of interest is health data sharing preferences of consumers. Cronbach’s Alpha is a test of internal consistency and fit of an item to a scale (DeVellis, 2016). An item with a low Cronbach’s Alpha score (< 0.80) may need to be omitted from the instrument to increase internal consistency. Reliability is also affected by the number of cases; therefore, it is important to have an adequate sample size (Schumacher & Lomax, 2010). A small sample size could be a treat to reliability. The sample size for this study was 2,000 cases (recommended > 500), which increased the chance of the sample being representative for inferences to be made, as suggested by Schumacher and Lomax (2010). Additionally, split-half reliability tests can be applied to a sample as a test of reliability. Researchers can accomplish this reliability by splitting the sample number of cases into two parts and applying the same methodology used in the first CFA (first sample) on the second CFA run (second sample). This method ensures results gained on the first run can be replicated, which improves reliability in research that involves multilevel modeling approaches, such as SEM.

Construct validity. Factor analysis is used to identify the interrelationships between a set of variables and any underlying relationships, patterns, or structures between the variables (Schumacker & Lomax, 2004). Additionally, factors are interrelated variables that form clusters (one or more) on at least one dimension of a factor structure (Schumacher & Lomax, 2010). If the measure possesses all factors and the variables cluster on factor dimensions as the underlying theory describes, then there may be evidence of the theories construct validity (Suhr, 2014). However, interpretation of factors is subjective, which is a threat to validity. Subsequently, CFA and SEM require additional statistical empirical measures of variance-covariance, error, and communality, which provide important information that reduces chance of subjective error. For example, if variance-covariance matrices are under or overestimated, the result may not be valid (Suhr, 2012). Therefore, a researcher must be aware of tools within

CFA used to confirm or refute findings. For instance, principle component allows the researcher to rotate the factor structure using degrees of freedom (Schumacher & Lomax, 2010). Rotation enables the researcher to examine complex factor structures on an orthogonal axis to more clearly visualize the factor structure and ensure that loadings align as closely as possible to the axis (Schumacher & Lomax, 2010). Accurate analysis of factor loadings ensures construct validity.

A construct is more general than a specific variable (Hale & Astolfi, 2012). A construct is not directly observable. Instead, a construct is composed of multiple observed variables. Construct validity is the degree to which a test measures the construct that it claims to be measuring (DeVellis, 2016). A threat to construct validity may exist in a study if more than one construct is measured by a single item, causing correlated measurement error. Correlated measurement error may indicate complex factors exist, requiring additional tests to be run, and further simplifying the specified model and allowing fuller analysis to be completed. Confirmatory factor analysis is part of SEM and was one of the statistical methods used in this study to understand construct validity.

Ethical Procedures

The researcher obtained Institutional Review Board (IRB) approval before conducting the study. The study involved longitudinal data collected through HINTS that originates in the National Cancer Institute’s Division of Cancer Control and Population Sciences. The HINTS data are accessible with permission through an online formal process. All HINTS data are publicly available online through the HINTS website. The requester must register online at the HINTS website and agree to the data terms of use and provide an email address each time one enters the database (see Appendix A). The researcher accessed a limited data set with deidentified survey information. The data are stored in a secure password-protected, identity-validated, cloud-based storage solution called ShareFile that is HIPAA compliant. The researcher will destroy data following the research study in 2017.

Summary

The study was a retrospective descriptive observational study using quantitative methods to analyze secondary data. For this study, data were used from a publicly available longitudinal data set from the HINTS to meet the following specific aims: (a) describe predictors (affirmative and negative) for health data sharing preferences of consumers; (b) understand the strength, path, and directionality of relationships between predictor variables and the antecedent constructs of information privacy and data security on health data sharing preferences of consumers and interoperability; (c) use the findings to test a path diagram in a developing theoretical model; and (d) use the results to inform the development of data governance policy recommendations that are more appropriate in an era where consumers want to own and control their health data. SEM is a comprehensive statistical approach for testing hypotheses regarding relations among observed and latent variables (Hoyle, 2012). SEM is a methodology for representing, estimating, and testing a theoretical network of mostly linear relationships between variables (Hoyle, 2012). Subsequently, Chapter 4 presents the results of the statistical analysis.

Chapter 4: Results

This chapter presents findings for the two research study questions: (a) what factors predict affirmative and negative health data sharing preferences of consumers? and (b) what is the strength, path, and directionality of relationship between predictor variables and the antecedent constructs of information privacy and data security on health data sharing preferences of consumers and C-ME? In this chapter, the researcher also addresses the four study aims: (a) describe predictors for health data sharing preferences of consumers; (b) understand the strength, path, and directionality of relationships between predictor variables and the antecedent constructs of information privacy and data security on health data sharing preferences of consumers and interoperability; (c) use the findings to test a path diagram in a developing theoretical model; and (d) use the results to inform the development of more appropriate data governance policy recommendations in an era where consumers want to own and control their health data. To answer research questions and address study aims, the researcher conducted a multinomial regression, CFA on the scales, and SEM.

Demographic Characteristics

The following section presents demographic characteristics of the sample population (*N* = 2,000). Regarding participants' employment status, 992 (49.6%) were employed and 931 (46.6%) were unemployed. Regarding active duty service, 1,609 (80.5%) never served in the military and 264 (13.3%) had some level of recent military service. Regarding marital status, 912 (45.6%) were married, 69 (3.5%) were living as married, 336 (16.2%) were divorced, 205 (10.3%) were widowed, 55 (2.8%) were separated, and 323 (16.2%) were single, never married. For the highest level of schooling, 38 (2.4%) reported less than 8 years, 108 (5.4%) reported 8 through 11 years, 364 (18.5%) reported 12 years or completed high school, 147 (7.4%) reported post high school training other than college, 474 (23.7%) reported some college, 462 (23.1%) reported college graduate, and 310 (15.5%) reported postgraduate. Of the participants, 1,618 (80.9%) responded yes to being born in United States and 311 (15.6%) responded no. For how well do you speak English?, 1,610 (80.5%) reported very well, 173 (8.7%) reported not well 64 (3.2%), and 19 (1.0%) reported not at all. In terms of Hispanic ethnicity, participants reported 1,514 (75.7%) not Hispanic, 126 (6.3%) Mexican, 36 (1.8%) Puerto Rican, 22 (1.1%) Cuban, 97 (4.9%) Other Hispanic, and 11 (0.6%) multiple Hispanic ethnicities. Race was 1,310 (65.5%) White, 339 (17%) Black, 14 (0.7%) American Indian or Alaska Native, 68 (3.4%) multiple races selected, 6 (0.3%) Asian Indian, 25 (1.3%) Chinese, 15 (0.8%), Filipino 5 (0.3%) Japanese, 8 (0.4%) Korean, 10 (0.5%) Vietnamese, 9 (0.5%) other Asian, and 2 (0.1%) Native Hawaiian. Gender was 1,087 (54.4%) female and 754 (37.7%) male. Currently rent or own a home was 1,249 (62.5%), own 600 (30%) rent and 39 (2%) occupy without paying monetary rent. Working cellphone 1777 (88.9%) yes and 133 (6.7%) no. At least one telephone in your home that is not a cellphone 1189 (59.5%) yes and 723 (36.2%) no. Combined annual household income 168 (8.4%) $0 to $9,999, 130 (6.5%) $10,000 to $14,999, 120 (6%) $15,000 to $19,999, 261 (13.1%) $20,000 to $34,999, 247 (12.4%) $35,000 to $49,999, 298 (14.9%) $50,000 to $74,999, 217 (10.9%) $75,000 to $99,999, 247 (12.4%) $100,000 to $199,999, 94 (4.7%) $200,000 or more. Table 6 presents frequencies and percentages of the nominal demographic characteristics.

Table 6

Frequencies and Percentages of Demographical Data (N = 2,000)

Demographic	*n*	%
N2. Employment		
Response checked on form	992	49.6
Response not checked on form	931	46.6
Missing data	77	3.9
N3. Served on active duty		
Yes, now on active duty	15	.8
Yes, on active duty in the last 12 months but not now	4	.2
Yes, on active duty in the past, but not in the last 12 months	219	11.0
No, training for Reserves or National Guard only	26	1.3
No, never served in the military	1609	80.5
Missing data	127	6.4
N4. In past 12 months, have you received some or all your health care from a VA hospital or clinic.		
Inapplicable, coded 4 or 5 in ActiveDutyArmedForces	1292	64.6
Yes, all my health care	45	2.3
Yes, some of my health care	40	2.0
No, no VA health care received	166	8.3
Question answered in error (Commission Error)	343	17.2
Missing data	114	5.7
N5. What is your marital status?		
Married	912	45.6
Living as married	69	3.5
Divorced	336	16.8
Widowed	205	10.3
Separated	55	2.8
Single, never been married	323	16.2
Missing data	100	5.0
N6. What is the highest grade or level of schooling you completed?		
Less than 8 years	48	2.4
8 through 11 years	108	5.4
12 years or completed high school	369	18.5
Post high school training other than college (vocational or	147	7.4
Some college	474	23.7
College graduate	462	23.1
Postgraduate	310	15.5
Missing data	82	4.1
N7. Were you born in the United States?		
Yes	1618	80.9
No	311	15.6

Demographic	*n*	%
Missing data	71	3.6
N9. How well do you speak English?		
Very well	1610	80.5
Well	173	8.7
Not well	64	3.2
Not at all	19	1.0
Missing data	134	6.8
N10. Hispanic Ethnicity		
Not Hispanic	1514	75.7
Mexican	126	6.3
Puerto Rican	36	1.8
Cuban	22	1.1
Other Hispanic	97	4.9
Multiple Hispanic ethnicities selected	11	.6
Missing data	194	9.7
N11. Race		
White	1310	65.5
Black	339	17.0
American Indian or Alaska Native	14	.7
Multiple races selected	68	3.4
Asian Indian	6	.3
Chinese	25	1.3
Filipino	15	.8
Japanese	5	.3
Korean	8	.4
Vietnamese	10	.5
Other Asian	9	.5
Native Hawaiian	2	.1
Missing data	176	8.8
N13. Gender		
Multiple responses selected in error	1	.1
Male	754	37.7
Female	1087	54.4
Missing Data	158	7.9
N15. Do you currently rent or own a home?		
Multiple responses selected in error	3	.2
Own	1249	62.5
Rent	600	30.0
Occupied without paying monetary rent	39	2.0
Missing Data	109	5.5
N16. Does anyone in your family have a working cell phone?		
Yes	1777	88.9
No	133	6.7
Missing Data	90	4.5

Demographic	*n*	%
N17. Is there at least one telephone inside your home that is currently working and is not a cell phone?		
Yes	1189	59.5
No	723	36.2
Missing Data	88	4.4
N18. Thinking about members of your family living in this household, what is your combined annual income?		
$0 to $9,999	168	8.4
$10,000 to $14,999	130	6.5
$15,000 to $19,999	120	6.0
$20,000 to $34,999	261	13.1
$35,000 to $49,999	247	12.4
$50,000 to $74,999	298	14.9
$75,000 to $99,999	217	10.9
$100,000 to $199,999	247	12.4
$200,000 or more	94	4.7
Missing Data	218	10.9

Note. Due to rounding error, percentages may not always sum to 100%.

Ages of participants ranged from 18.00 to 98.00, with *M* = 54.92 and *SD* = 15.90. Total number of household members ranged from 1 to 14, with *M* = 2.37 and *SD* = 1.39. Total number of children in household ranged from 0 to 12, with *M* = 4.67 and *SD* = 0.99. Table 7 presents the descriptive statistics of continuous demographic variables.

Table 7

Descriptive Statistics of Continuous Demographic Variables (N = 2,000)

Continuous Variables	Min	Max	*M*	*SD*
N1. Age	18.00	98.00	54.92	15.90
N12. Total Household Members	1.00	14.00	2.37	1.39
N14. Children in household	0.00	12.00	4.67	0.99

The researcher examined the following research questions in this study.

Research Question 1. What factors predict affirmative and negative health data sharing preferences of consumers?

Research Question 2. What is the strength, path, and directionality of relationship between predictor variables and the antecedent constructs of information privacy and data security on health data sharing preferences of C-ME?

Study Findings

Medical Record Characteristics. The following section presents characteristics of the medical record item subset. Sharing health information between providers (D2a) was very important (65%), somewhat important (28.8%) and not important (6.1%). Personal access to health information (D2b) was very important (68.4%), somewhat important (23.9%), not important (7.7%). Confident in controls that protect medical records from unauthorized access (D3) was very concerned (22.1%), somewhat concerned (54.2%), not at all concerned (24.1%). Confident you have some say in who can collect, use, and share your medical information (D4) was very concerned (28.5%), somewhat concerned (47.3%), not at all concerned (24.1%). Kept information from provider due to privacy or security concerns (D5) was yes (13.9%) and no (86.1%). Information sent by fax viewed by unauthorized persons (D6) was not concerned (27%), somewhat concerned (44.2%), very concerned (28.7%). Electronic information protected by unauthorized viewing (D7) was not concerned (28.7%), somewhat concerned (51%) and very concerned (20.3%). Table 8 presents frequencies and percentages of the nominal medical record item characteristics variables.

Table 8

Frequencies and Percentages of Medical Characteristics

Demographic	*n*	%
D2a. Doctors and other health care providers should be able to share your medical information with each other electronically.		
Not important	119	6.1
Somewhat important	561	28.8
Very important	1265	65.0
D2b. You should be able to get to your own medical information electronically.		
Not important	147	7.7
Somewhat important	460	23.9
Very important	1314	68.4
D3. How confident are you that safeguards (including the use of technology) are in place to protect your medical records from being seen by people who aren't permitted to see them?		
Not concerned	463	23.7
Somewhat concerned	1060	54.2
Very concerned	431	22.1
D4. How confident are you that you have some say in who is allowed to collect, use, and share your medical information?		
Not concerned	475	24.1
Somewhat concerned	932	47.3
Very concerned	562	28.5
D5. Have you ever kept information from your health care provider because you were concerned about the privacy or security of your medical record?		
Yes	274	13.9
No	1694	86.1
D6. If your medical information is sent by fax from one health care provider to another, how concerned are you that an unauthorized person would see it?		
Not concerned	532	27.0
Somewhat concerned	871	44.2
Very concerned	566	28.7

Demographic	*n*	%
D7. If your medical information is sent electronically from one health care provider to another, how concerned are you that an unauthorized person would see it?		
Not concerned	564	28.7
Somewhat concerned	1004	51.0
Very concerned	400	20.3

Multinomial Logistic Regression

Aim 1 was to describe predictors for health data sharing preferences of consumers. To answer Research Question 1, the researcher conducted a multinomial logistic regression and examined the predictor variables of data sharing preferences. Results of the regression indicated the significant predictor variables of interest corresponded to employment (N2), received VA care (N4), marital status (N5), Education (N6), born in United States (N7), total household number (N12), gender (N13), cellphone use (N16), and income ranges (N18). The statistically significant variables were used in to the SEM to test the hypothesized path diagram (see Figure 3). Table 9 presents the final demographic variables included in the model.

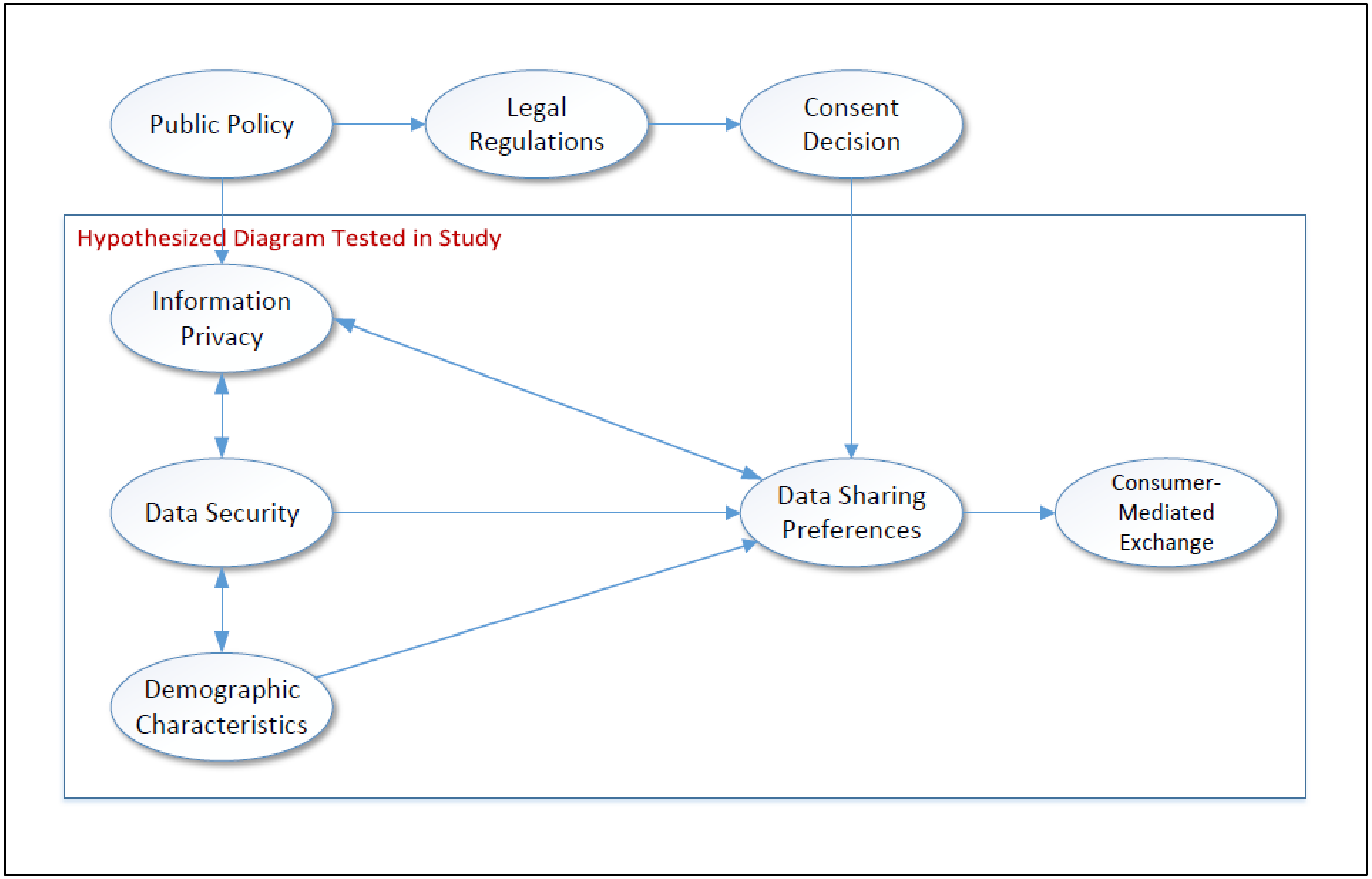

Figure 4. Hypothesized path diagram health data sharing preferences of consumers.

Table 9

Descriptive Characteristics HINTS for Share Electronic Health Records.

Statistically significant ($p < 0.05$)	Not statistically significant ($p > 0.05$)
Employed	Age
Marital status	Occupation status
Education	Active duty armed forces
Born USA	Year came to USA speak English
Total household number	Not Hispanic
Cellphone	Race
Income ranges	Rent or own home
Self-gender	
Received care VA	

Confirmatory Factor Analysis

Aim 2 involved the strength, path, and directionality of relationship between predictor variables and the antecedent constructs of information privacy and data security on health data sharing preferences of consumers and C-ME. To answer Research Question 2, the researcher performed CFA to see if the observed and latent variables in the model were a good fit. A good model fit is defined as having confirmatory fit indices (*CFI*) values higher than .90 and a root mean square error of approximation (*RMSEA*) value less than .08 (Kline, 2005). Confirmatory fit indices is used as a baseline comparison between alternative models as an indication of fit, because it is independent of sample size and behaves consistently across estimation methods (Schumacker & Lomax, 2004). The *RMSEA* is a standardized measure of error approximation. The study model consisted of three latent constructs. Information privacy (IP) was made up of three observed variables: D4, D7, and D5. Data security (DS) was made up of two observed variables: D3 and D6. Consumer-mediated exchange was made up of 16 variables: B7A–G and B8A-I. The initial results of the CFA showed a weak model fit, $\chi^2(186) = 6509.58$,

$p < .001$, $CFI = .71$, $RMSEA = .13$. To improve model fit, the researcher examined the modification indices to determine which parameter constraints were significantly limiting the model fit of the observed covariance structure.

Modification indices (MI) are indicators for how model structure can be improved. However, any modification of the model must be theoretically justifiable (Schumacker & Lomax, 2004). Modification indices for the study model indicated that the error terms of the observed variables for the latent construct C-ME could covary. The type of information shared and mechanism used to share information are related concepts. For this reason, the MI were used to improve the model. With the addition of the MI, the results of the CFA with the covariations showed significant improved fit, $\chi^2(171) = 2092.08$, $p < .001$, $CFI = .91$, $RMSEA = .08$. Table 10 presents a summary of the model iterations. Table 11 presents the final item breakdown for the CFA model. Figure 4 shows the CFA model with standardized values.

Table 10

Confirmatory Factor Analysis Fit Indices

CFA	χ^2	*df*	*p*	*CFI*	*RMSEA*
No MI	6509.58	186	< .001	.71	.13
MI	2092.08	171	< .001	.91	.08

Note. MI = Modification Indices

Table 11

Item Breakdown of Factors

Item No.	Label	Question
4	Information Privacy	
	D4	How confident are you that you have some say in who is allowed to collect, use, and share your medical information?
	D7	If your medical information is sent electronically from one health care provider to another, how concerned are you that an unauthorized person would see it?
	D5	Have you ever kept information from your health care provider because you were concerned about the privacy or security of your medical record?
3	Data Security	
	D3	How confident are you that safeguards (including the use of technology) are in place to protect your medical records from being seen by people who aren't permitted to see them?
	D6	If your medical information is sent by fax from one health care provider to another, how concerned are you that an unauthorized person would see it?
16	C-ME	
	B7	In the past 12 months, have you used any of the following to exchange medical information with a health care professional (email, text message, app on smartphone, video conference, social media, fax, none)?
	B8	How interested are you in exchanging the following types of medical information with a health care provider electronically (appointment reminders, general health tips, lab information, medication reminders, diagnostic information, vital signs, lifestyle behaviors, symptoms, digital images)?

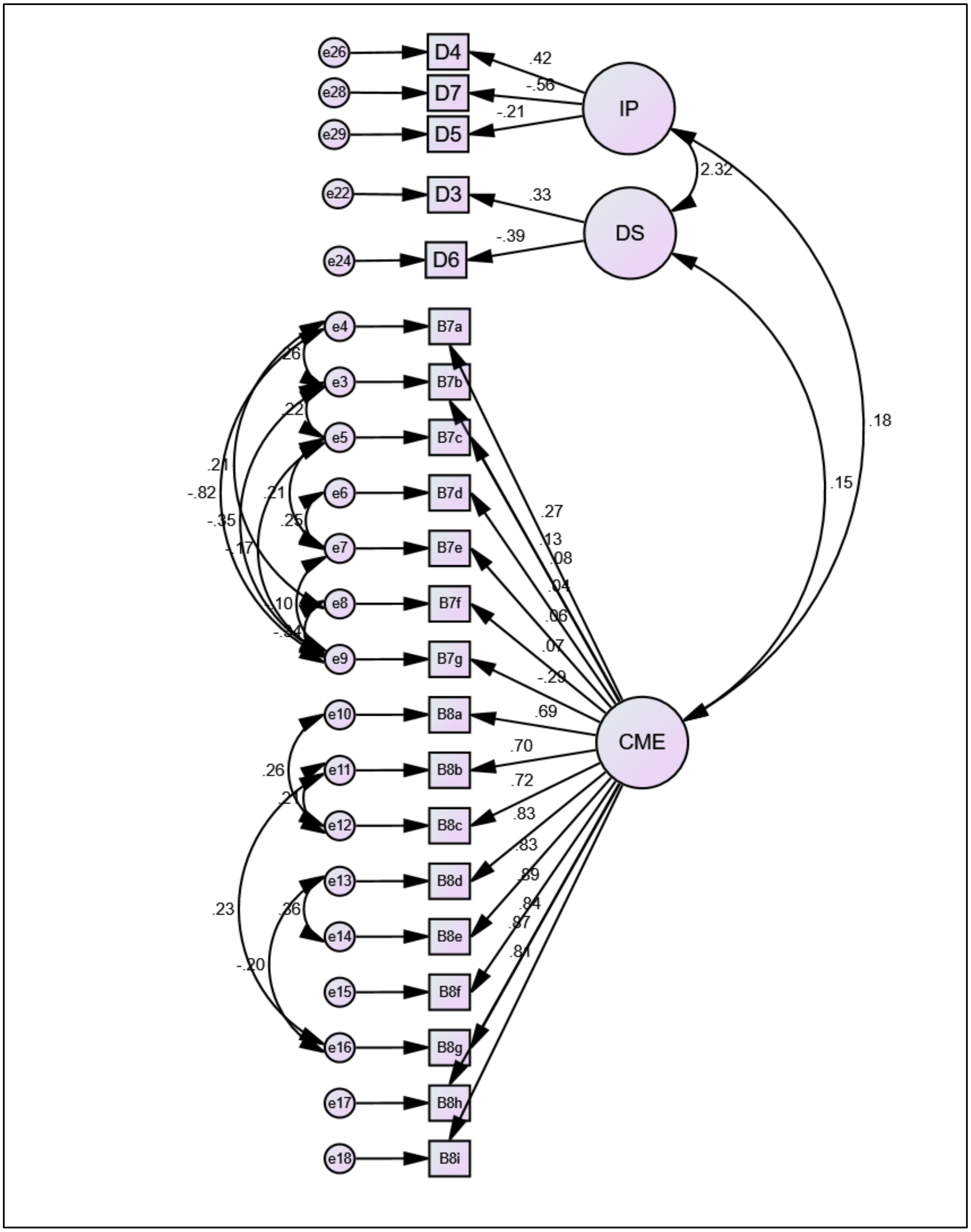

Figure 5. Standardized regression weights of final CFA model.

Structural Equation Model

Aim 3 involves the findings to test a path diagram in a developing theoretical model that begins to designate relationships between data governance structures in C-ME. The researcher conducted SEM to answer Research Question 2. The SEM involves use of Information privacy (IP), data security (DS), statistically significant demographic characteristics, data sharing preferences (D2a), data sharing access (D2b), and C-ME.

Model specification. The initial results of the model showed a weak model fit, $\chi^2(405) = 22397.09$, $p < .001$, $CFI = .09$, $RMSEA = .17$. A significant p value for the Chi-square test may not be indicative of model fit if the number of cases is higher than 400 (Schumacker & Lomax, 2004). This model involved 2,000 cases. Subsequently, this study involved standard measures of good model fit as: *CFI* value higher than .90 and a *RMSEA* value less than .08, as suggested by Kline (2005). The researcher examined modification indices to determine which parameter constraints were significantly limiting the model fit of the observed covariance structure. Again, the modification indices showed that the error terms of the observed variables for C-ME could covary. The results of the SEM with the covariations included showed significant improved fit, $\chi^2(127) = 6285.03$, $p < .001$, $CFI = .76$, $RMSEA = .09$. Although the *CFI* and *RMSEA* statistics did not reach the good model fit thresholds, the SEM is reasonably specified. A reasonably specified model is determined by *RMSEA*. The *RMSEA* values are classified into four categories: close fit (.00–.05), fair fit (.05–.08), mediocre fit (.08–.10), and poor fit (over .10). By examination of skewness and kurtosis, majority of the survey items met the univariate normality assumption. However, the multivariate normality assumption was not met. Table 12 provides a summary of the structural model.

Table 12

Model Fit Statistics for the Proposed Model

SEM	χ^2	*df*	*p*	*CFI*	*RMSEA*
No MI	22397.09	405	< .001	.09	.17
MI	6285.03	127	< .001	.76	.09

Note. MI = Modification indices.

Regression estimates. Aim 3 pertained to the findings to test a path diagram in a developing theoretical model. Regression weights were included in the model between each of the constructs. Information privacy ($p < .001$) and data security ($p < .001$) were statistically significant predictors of health data sharing preferences of consumers. In addition, the demographic factors employment ($p < .001$), education ($p = .066$), birth in the United States ($p = .006$), total household number ($p = .004$), cell phone use ($p < .001$), and income ranges ($p < .001$) were statistically significant predictors of health data sharing preferences.

The researcher further examined the regression weights for strength and directionality. Information privacy (β = .18) had a weak positive relationship with data sharing preferences. Data security (β = .97) had a strong positive relationship with data sharing preferences. The demographic factors of employment (β = -.10) and total household number (β = -.07) had weak inverse relationships with health data sharing preferences. The demographic factors of education (β = .04), birth in the United States (β = .06), cell phone use (β = .06), and income ranges (β = .11) had weak positive relationships with health data sharing preferences.

The researcher also examined regression weights between data sharing preferences, data access preferences, and C-ME. Data sharing preferences (β = .38, *p* <

.001) had a statistically positive relationship with data access preferences. Data sharing preferences (β = 1.00, *p* < .001) had a statistically positive relationship with C-ME. Table 13 presents a summary of regression results. Figure 6 presents a path diagram with the results of the model.

Table 13

Standardized Regression weights for the Proposed Model

Regression	β	*B*	*SE*	*C.R.*	*p*
D2a <- IP	.18	0.52	0.11	4.77	< .001
D4 < - IP	.29	1.00	-	-	-
D7 <- IP	-.63	-2.11	0.39	-5.40	< .001
D5 <- IP	-.38	-0.63	0.09	-6.85	< .001
D2a <- DS	.97	6.01	0.94	6.41	< .001
D3 <- DS	.14	1.00	-	-	-
D6 <- DS	.01	0.08	0.18	0.44	.663
D2a <- N2	-.09	-0.11	0.03	-3.95	< .001
D2a <- N5	.04	0.05	0.03	1.47	.141
D2a <- N6	.04	0.02	0.01	1.84	.066
D2a <- N7	.06	0.10	0.04	2.73	.006
D2a <- N12	-.07	-0.03	0.01	-2.87	.004
D2a <- N16	.06	0.15	0.05	2.94	.003
D2a <- N18	.11	0.03	0.01	4.48	< .001
D2b <- D2a	.38	0.40	0.02	18.40	< .001
C-ME <- D2b	1.00	0.04	0.01	3.69	< .001
B7a <- C-ME	.16	3.10	0.83	3.72	< .001
B7b <- C-ME	.08	1.00	-	-	-
B7c <- C-ME	.04	0.38	0.22	1.72	.086
B7d <- C-ME	.03	0.13	0.12	1.07	.286
B7e <- C-ME	.05	0.40	0.22	1.87	.062
B7f <- C-ME	.06	0.69	0.31	2.22	.026
B7g <- C-ME	-.17	-3.49	0.89	-3.92	< .001
B8a <- C-ME	.29	14.23	4.00	3.56	< .001
B8b <- C-ME	.24	11.97	3.42	3.50	< .001
B8c <- C-ME	.24	12.15	3.47	3.50	< .001
B8d <- C-ME	.33	18.44	5.13	3.60	< .001
B8e <- C-ME	.28	16.11	4.53	3.56	< .001
B8f <- C-ME	.30	16.43	4.60	3.57	< .001
B8g <- C-ME	.25	13.36	3.79	3.52	< .001
B8h <- C-ME	.27	14.26	4.03	3.54	< .001
B8i <- C-ME	.29	15.99	4.48	3.57	< .001

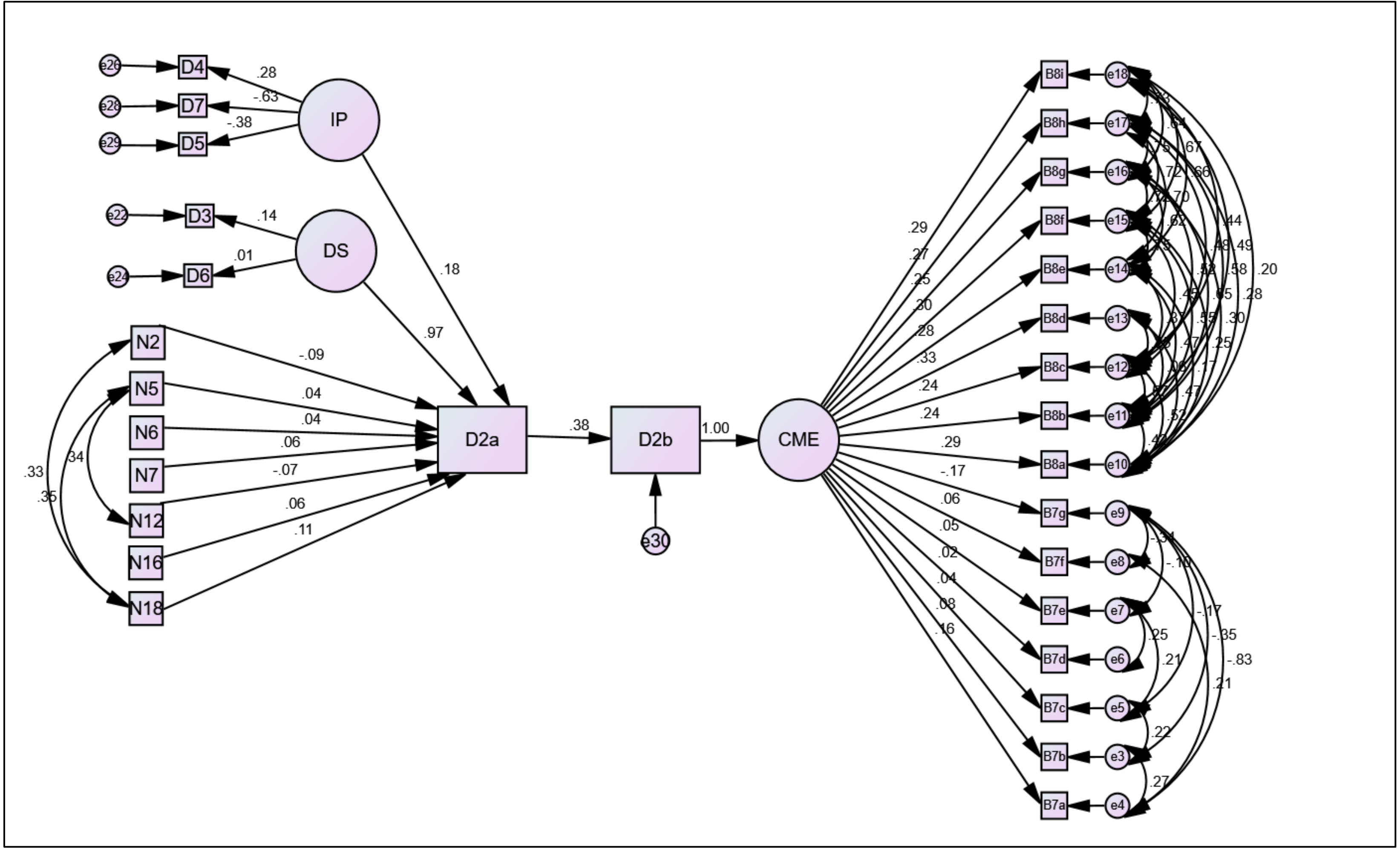

Figure 6. SEM diagram with standardized loadings.

Summary

The purpose of this research was to describe the interrelationships between the constructs of information privacy, data security, data sharing preferences and consumer-mediated exchange and to test a hypothesized path diagram. Figure 7 explanatory model presents the latent constructs (information privacy, data security, and C-ME) and data sharing preferences using SEM. Findings show latent constructs information privacy and data security, plus a subset of demographic characteristics, have a direct positive influence on data sharing preferences. However, the researcher found information privacy to have a weaker relationship than data security with data sharing preferences. No relationship was found between information privacy and data security. The data sharing preference Share EHR showed a stronger relationship on the latent construct C-ME when the observed variable Access EHR was added to the model. In Chapter 5, the researcher discusses findings and implications.

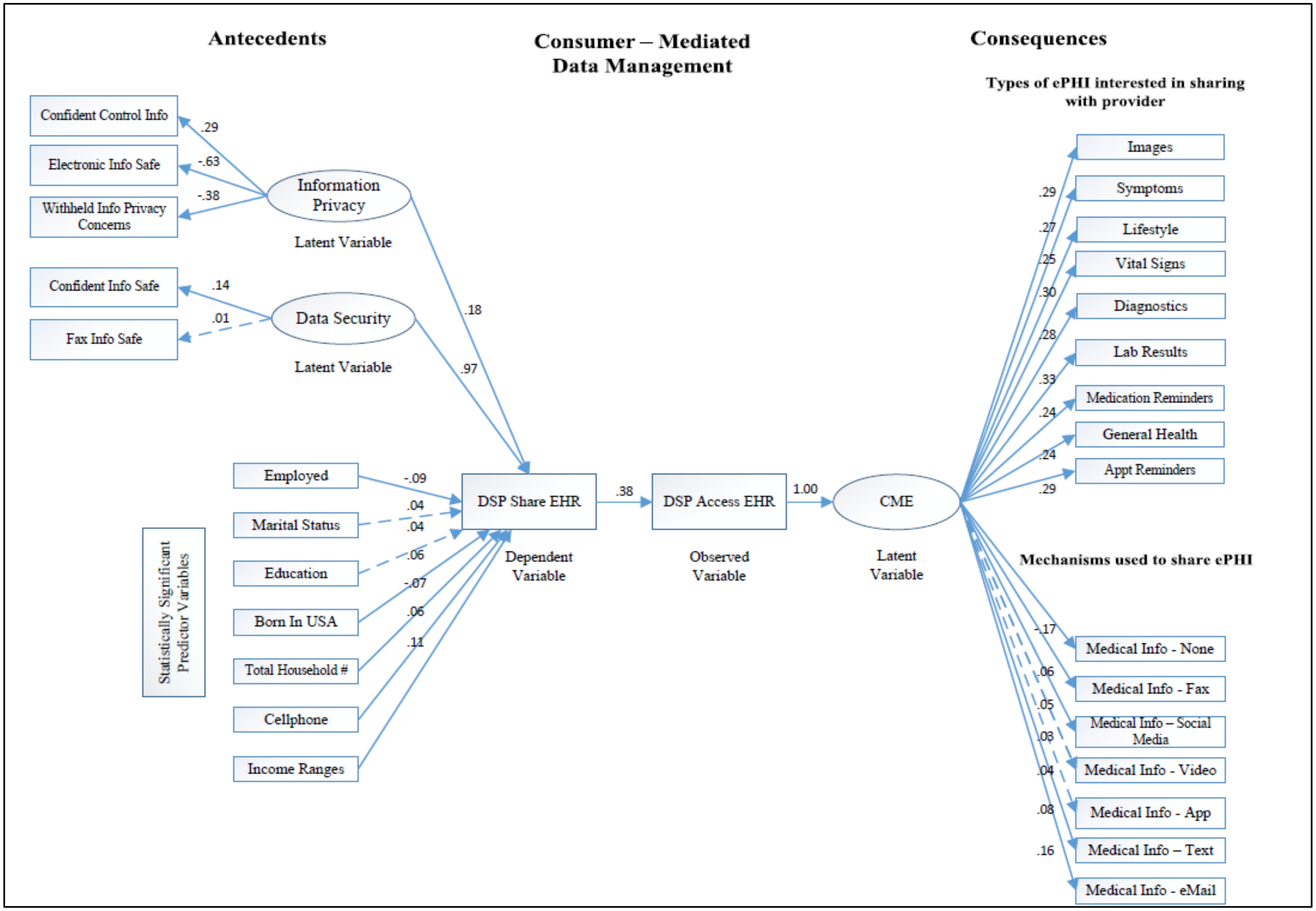

Figure 7. *Model health data sharing preference of consumers.*

Chapter 5: Discussion

Despite almost a decade of research and national initiatives aimed at understanding consumer information exchange attitudes, beliefs, and perceptions related to health care data, little is known regarding why consumers make the choice to share or withhold health information (Ancker, Edwards, Miller, & Kaushal, 2012; Anker, Silver, Miller, & Kaushal, 2013; Caine & Hanania, 2013; Campion, Edwards, Johnson, & Kaushal, 2013; Dhopeshwarkar, Kern, O'Donnell, Edwards, & Kaushal, 2012; Dimitropoulos & Rizk, 2009; Luchenski, 2012; Marquard & Brennan, 2009; O'Donnell, et al., 2011; Patel, Dhopeshwarkar, Edwards, Barrón & Likourezos, et al., 2011; Patel, Abramson, et al., 2011; Patel, Dhopeshwarkar et al., 2012; Ramos & Bakken, 2014; Teixeira, Gordon, Camhi, & Bakken, 2011; Wen, Kreps, Zhu, Miller, 2010). No research existed that describes predictors of health data sharing preferences of consumers. In addition, the researcher could not identify a theoretical model related to health data sharing preferences of consumers. The absence of a theoretical model to describe relationships among constructs of interest limits knowledge generation in a rapidly digitizing health care industry that has not integrated consumer-mediated processes into information exchange practices. New knowledge is needed regarding the public policy implications for consumer participation in information sharing.

There were four aims to this study. First, the researcher sought to describe predictors of health data sharing preferences of consumers. Second, the researcher tested a hypothesized path diagram to understand the strength, path, and directionality of relationships between and among the concepts of information privacy, data security, data sharing preferences, and C-ME. Third, the researcher created a theoretical model. Last, the researcher aimed to use the results to inform the development of more appropriate data governance policy recommendations in an era where consumers want to own and control their health data. The researcher answered two research questions: (a) What factors predict affirmative and negative health data sharing preferences of consumers? and (b) What is the strength, path and directionality of relationship between predictor variables and the antecedent constructs of information privacy and data security on health data sharing preferences of consumers and C-ME? This chapter presents the findings and suggests recommendations for consideration in public policy, legal regulation, health care providers, health care consumers and health care systems, as well as further research.

Interpretation of Findings

Predictor variables. Study findings show statistically significant predictor variables associated with health data sharing preferences include gender, employment status, marital status, education level, born in USA, received VA care, total number in household, cellphone use, and income level. Predictors not statistically significant in the 2014 HINTS were age, race, active duty armed forces, year came to USA, English speaking, and owning home. A critical review of research showed that age, race, and owning home were also statistically significant factors of data sharing preferences (Moon, 2017). No research to this point has included born in USA, received VA care, active duty armed forces, or year came to USA.

When compared to findings from the previous research, the shift in predictors of health data sharing preferences may be attributed to several factors. First, this study involved survey data collected in 2014 (most previous research collected data between 2008–2011). Second, the researcher used HINTS demographic items and additional variables (active duty armed forces, received care VA, born in USA, and year came to USA), but did not include demographic variables for health care utilization, health status, Internet use, or caregiver relationship. Last the researcher found mobile applications and social media eclipsed other communication methods by 2014. For instance, mobile applications and social media are primary modes of communication and ubiquitous in contemporary society, 2017. Previous researchers reported findings of low Internet use, low cellphone use, and higher landline use (Anker et al., 2012; Campion et al., 2013; Patel et al., 2011; Patel et al., 2011). For example, older communication methods include use of landline phones and dial-up Internet services that limit the use of online communication tools available, such as personal health portals linked to electronic health records or health applications that assist in the self-management of chronic disease (e.g., diabetes).

Sharing and withholding health data. Consumer-mediated exchange pertains to the sharing of electronic health information in a networked system by consumers of health care services (Daniel et al., 2014; Goldstein et al., 2010). Study findings suggest consumers who rate sharing of health data between providers as very important, also rate personal access to their health data as very important. This supports a move to a more consumer-centric approach of data sharing in health care (Caine et al., 2015; Dhopeshwarkar et al., 2012; Schwartz et al., 2015). Study findings also show that 75.8% of consumers are very concerned or somewhat concerned that they have some say in who can collect, use, and share their medical information. This finding indicates preference is an important dimension of C-ME. Conversely, only 24.1% of consumers were not concerned about having control of how their data was collected, used, or shared. This finding supports the view that C-ME must consider the preferences of all individuals. Consequently, C-ME requires individuals to be active participants in health data management (ONC Brief: Patient at the Center, 2014).

Path Diagram

Information privacy, data security, data sharing preference, and C-ME are complex multifaceted social constructs. The researcher found the path and direction of relationship between constructs of interest and dependent variables in the hypothesized path diagram to be true. Direct positive relationships between all observed and latent variables were found. However, no significant relationship existed between latent constructs information privacy and data security and no correlation existed between error terms. Correlated error indicates latent constructs may be complex or share something in common that is not represented in the specified model (Schumacker & Lomax, 2004). Previous researchers used survey instrument items that combined the construct of information privacy and data security, making it difficult to differentiate between the two concepts (Anker et al., 2012; Anker et al., 2013; Dimitropoulos et al., 2011). Consequently, lack of construct clarity between information privacy and data security affected generalizability of previous research findings.

The path diagram showed a direct relationship between latent constructs of information privacy, data security, and statistically significant predictors on the dependent variable Share EHR. The researcher identified a statistically significant and direct relationship between the dependent variable (Share EHR) and latent variable C-ME. A direct relationship was identified from C-ME to the 16 observed variables for types of information and mechanisms used to share information. This indicates a strong direct relationship may exist between data sharing preference, C-ME, and information sharing. However, 14 of 16 observed variables for the latent variable C-ME (types of information and mechanisms used) were not statistically significant until after the observed variable of Access EHR was added to the model. This may indicate that consumers consider health data sharing between providers to be important and want access to their health data to enjoy full benefits of control, access, and permissions related to data sharing preference.

Information Privacy

The researcher measured the latent construct of information privacy by three observed variables: confident control information, withheld information privacy concerns, and electronic information safe from unauthorized viewing. The path diagram showed direct positive and statistically significant relationships from the latent variable of information privacy to each observed variable: confident control information, $p > 0.000$; withheld information privacy concerns, $p > 0.000$; and fax information safe, $p > 0.000$. Regression weights indicate the strength of the relationship between variables of interest (fully saturated path is equal to 1.00; Schumacher & Lomax, 2012). Regression weights from the latent construct information privacy to observed variables were confident control information (0.28), withheld info privacy concerns (-0.38), and fax information safe from unauthorized viewing (-0.64).

Negative regression weights indicate that an inverse relationship exists between observed variables and latent constructs (Hoyle, 2012). For example, a negative regression weight between information privacy and the observed variable, withheld information privacy concerns, indicates individuals that withhold health information are more likely to believe information privacy is important. Likewise, respondents who believe that fax information is not safe from unauthorized viewing are more likely to rate information privacy as important. Regression weights also indicate that information privacy is enhanced by an individual's perception of confidence in controls that protect health care information. Controls that protect health care information are outlined in the HIPPA Security Rule (U.S. Department of Health & Human Services, 2013). Incentives, such as Meaningful Use (MU), require that security risk analysis be completed to ensure security safeguards are in place and vulnerabilities are mitigated.

Data Security

The latent construct of data security was measured by two observed variables: confident information safe (technical, administrative, and physical safeguards) and fax information safe. Regression weights from data security to observed variables were confident information safe (0.14) and fax information safe (0.03). The path diagram showed a direct, positive, and statistically significant relationship from the latent variable of data security to the observed variable, confident information safe (technical safeguards), $p > 0.000$. The direct path between data security to observed variable fax information safe was not statistically significant, $p > 0.294$, and the regression weight was low (0.03), indicating low confidence in security of fax health information. To reach an adequate level of consumer confidence, legal agreements and systematic technical safeguards that secure electronic health data must be consistently applied and proactively monitored (Ancker et al., 2012; Dimitropoulos & Risk, 2009).

Information Privacy & Data Security on Dependent Variables

Regression weights for latent constructs of information privacy and data security showed direct positive relationships on the dependent variable Share EHR in the path diagram. However, the regression weight for data security was significantly higher than information privacy, showing a stronger relationship exists between data security when compared to information privacy. This finding is significant. Information privacy has long been held by privacy experts as the stronger social concept affecting an individual's willingness to share or withhold health care information (Markel Foundation, 2006). However, a significant amount of health care information has moved to electronic format, while security breaches of electronic, online, and personal data from other sectors has increased simultaneously (Patel, Barker, & Siminerio, 2015). Individuals may place increased importance on technical, administrative, and physical safeguards in health care to enhance the overall confidentiality of electronic health information.

Dependent Variable and Consumer-Mediated Exchange

The dependent variable Share EHR had a direct positive relationship to Access EHR. Likewise, the researcher found a direct positive relationship between Access EHR and the latent variable C-ME. This indicates a preference to share between two providers, which positively influences the preference to access and subsequently control one's own health record. In the structural model, both preferences were strongly associated with exchange directed by the consumer. Lack of consumer control and knowledge about what information is being accessed, viewed, or shared has been shown to decrease participation in health exchange (Ancker et al., 2013; Caine et al., 2015; Dimitropoulos et al., 2011). New information regarding the importance of C-ME could support health care ecosystem change that integrates consumer-centric data management processes into practice.

The researcher measured the latent construct of C-ME by 16 observed variables from two groups: types of information and mechanisms used to share. Type of information was represented by images, symptoms, lifestyle, vital signs, diagnostics, lab results, medication reminders, general health, and appointment reminders. Mechanisms used to share health information included fax, social media, video, application, text, email, and none. Both features are important, because consumers trust providers to use the minimum set of information necessary for specified purposes (Caine et al., 2015; Dhopeshwarkar et al., 2012; Luchenski, 2012; Marquard & Brennan, 2009; Park et al., 2013; Patel et al., 2011).

All relationships between C-ME and types of information shared were direct and statistically significant. This finding indicates preferences to share a wide variety of information related to health care. However, medication reminders had the lowest regression weight and lab results had the highest regression weight in the model. This indicates some information may be more useful to share from the consumer perspective. Marquard and Brennan (2009) found sharing medication lists made sense to patients because it prevented medication interaction, prevented potential side effects, and assisted in continuity of care. This finding shows consumers understand that an inherent benefit exists. Swartz et al. (2014) found a consumer's key justification for granular control was to keep socially sensitive information that may be embarrassing or stigmatizing from being widely shared. Study findings confirm consumers may have preferences related to the type of health information shared.

All relationships between C-ME and mechanisms used to share information are positive and direct. However, only five out of seven direct paths were statistically significant (fax, social media, text, email, and none). The only negative regression weight for mechanism used to share was none, indicating that individuals who choose to not share health information are more likely to consider C-ME decisions to be important. The two direct paths not statistically significant for mechanisms used to share were video and applications. Regression weights were relatively low for all mechanisms used to share, including fax, social media, video, application, text, and email. This may indicate that no one specific mechanism exists; instead, health information sharing is important through multiple data sharing mechanisms. Likewise, this finding supports the notion that most patients agree with data sharing, especially in the presence of access controls (Schwartz et al., 2015). However, consumers may find some mechanisms (e.g., Internet or email) to share more mainstream or convenient (Ancker et al., 2012; Patel et al., 2011).

Study findings indicate individuals have two levels of data sharing preferences: (a) sharing between health care providers and (b) access to their own health information. Study findings show when both preferences are present, a strong, positive, direct relationship exists regarding the type of information and mechanism used to share information. This finding supports previous researchers who suggesed consumers believe the benefits of sharing heath data outweigh the risks (Ancker et al., 2013; Dimitropoulos et al., 2011; Marquard & Brennan, 2009; O'Donnell et al., 2011). Research shows that consumer trust increases especially in the presence of strong security safeguards, such as notifications when ePHI accessed, proactive monitoring, audit capabilities, security risk analysis, organizational policy and procedures (Caine et al., 2015; Dhopeshwarkar et al., 2012; Dimitropoulos et al., 2011; Marquard & Brennan, 2009; Park et al., 2013; Patel et al., Teixeira et al., 2011; Wen et al., 2010).

Study findings show 76.3% of respondents were very concerned or somewhat concerned about safeguards in place to protect records from unauthorized access. This finding supports the view that personal preference may be reliant on confidence in protections for the information privacy and data security of health information. Preserving consumer trust in information privacy and data security is a critical element in achieving an interoperable networked health IT infrastructure (Patel, Barker, Hughes, & Moon, 2015; Moon, 2017). However, only 13.9% of study respondents indicated they had withheld information from health care providers because of information privacy or data security concerns. This finding supports a recent study, showing only a minority of consumers chose to restrict access by their health care providers because of information privacy concerns (Schwartz et al., 2015). In addition, the study theoretical model shows data security has a stronger relationship to data sharing preferences. The strong, direct, and positive relationship between the latent construct of data privacy on data sharing preference is a significant finding. This finding relates to the development and integration of new data government public policies and resulting legal standards related to safe, secure, interoperable health data in a vibrant learning health system.

Consumer Input, Choice, Control, and Sentiment

If individuals are to be active participants in the access, aggregation, creation, use and, exchange of health data, then consumer-mediated data management may be a more appropriate label than C-ME. This section presents the framework of consumer input, consumer choice, consumer control, and consumer sentiment to describe how best to include consumers in health data sharing arrangements.

This researcher recognized consumer-mediated data management as a central tenant in the developing learning health system. Factors influencing trust, harm threshold, balancing risk and benefits, transparency, access, and control are considered key features (Moon, 2017). Figure 8 shows an integrated systems approach to consumer-mediated data management. The integrated systems approach shows a dynamic pattern of consumer-mediated data management and secondary use *reliant* on health data sharing preferences of consumers, and integral data governance principles to balance the needs of consumers (access and control, permission and use, risk and benefit, and transparency) in a LHS. Based on complexity science, this perspective is characterized by adaptive behaviors and continuous reinforcing and balancing feedback loops (Cabrera & Cabrera, 2015). These features are important when considering new methods that inform public policy, legal regulation, and data governance related to the constructs of interest.

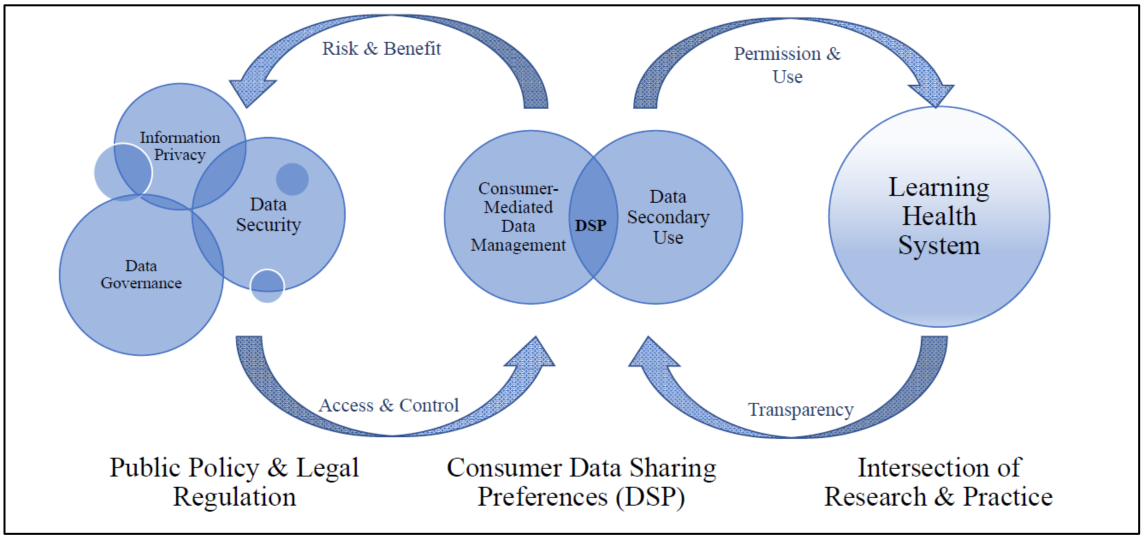

Figure 8. Integrated systems approach to consumer-mediated data management.

Consumer Input

Traditional public policy cycles are sequential (agenda setting, policy formulation, policy implementation, and policy evaluation) and rely on established decision-makers internal to the public policy system (Morçöl, 2010). A dynamic learning health system would systematically apply consumer input and research for public policy issues to become responsive to both consumer demand and sentiment. Study findings suggest consumer input (e.g., importance of data security > information privacy) captured methodically can inform issues important to public policy. Consumer panels and advisory boards are mostly used as a mechanism to collect feedback (Arnstein, 1969). Still, public policy informed by the consumer voice continues to lag consumer sentiment (Faden et al., 2011; Goldstein et al., 2012; Harper, 2014). This delay in public policy informed by consumer sentiment raises two issues. First, it raises questions about the reliability of current mechanisms used to capture consumer input. Second, it creates a need for an organized approach to determine where and how consumer input is collected to inform public policy. This approach is necessary because public policy is a complex system spanning multiple perspectives and different organizational levels (Caldwell & May, 2012). An integrated systems approach may more aptly fit contemporary public policy needs, such as data governance requirements for a LHS. The aim of using consumer sentiment is to better represent the consumer voice in public policy on topics, including health data sharing preferences.

Consumer Choice

In a learning health system, a natural exists tension between individual choice in the form of health data sharing preferences, and the larger macro policy processes that drive secondary use (e.g., government required quality activities) for health care purposes. Morçöl (2010) described the conceptualization of relationships between micro processes (e.g., individual choices and behaviors) and macro policy processes (actions taken by the government) as important governance components (Morçöl, 2005, 2010). Existing public policy acknowledges the powerful role consumers play as intermediaries of their health data (Williams et al., 2012; Daniel et al., 2014; Goldstein et al., 2010). Consensus in the public policy community also shows informed and engaged consumers have a vital role in improving quality of care that the health ecosystem delivers (AHRQ, 2007; Arnold, 2007; Daniel et al., 2014). Study findings show respondents rated both levels of consumer choice as very important: sharing health data between providers (65%) and personal access to health information (68%). Consequently, consumer choice must be a key feature of data governance policy related to health data sharing preferences.

The Code of Fair Information Practices adopted by the Office of the National Coordinator in 2008 includes individual choice as one of its five principles (Blumenthal, 2014; Code of Fair Information Practices, 1973). In a networked environment, decisions related to data sharing preferences could be executed by several parties, including consumers, health care providers, provider organizations (quality), government agencies, the research community, or other legal entities (Goldstein et al., 2010). These determinations are rarely made by the individual. Instead, they are most often driven by federal law (HIPAA) under treatment, payment, and operation (TPO) provisions (U.S. Department of Health & Human Services, 2013). For example, consumer data collected for health care purposes, such as TPO, can be used without individual permission for secondary purposes (research, quality, safety, case management, care coordination, fraud & abuse detection, and public health activities; U.S. Department of Health & Human Services, 2013). Therefore, while consumers may demand more control of health data sharing preferences, current federal regulation may not recognize or protect such preferences.

Consumer Control

In the meantime, consumers have begun to demand granular (e.g., detailed, segmented, and parsed) control of their health care data (Caine et al., 2015; Dhopeshwarkar et al., 2012; Park et al., 2013; Patel et al., 2011; Schwartz et al., 2015). Meaningful use incentives placed low expectations (10% of patients) on consumer participation, while national public policy continues to push for consumers to own their health data (HITECH, 2012). At the same time, government research surveys showed that one in three consumers experience gaps in information exchange during routine health care visits (Patel, Barker, & Siminerio, 2014). Three out of 10 individuals who accessed information online rated available health information as only somewhat helpful (Patel et al., 2014). Significant disparities exist, such as individuals with lower incomes and less education are 50% less likely to be offered access to their health information (Patel et al., 2015). While the volume of electronic health record data is high, the availability of health data at the consumer level is low. Consequently, no fully vetted C-ME exists for individuals to aggregate, control, segment, and exchange data ongoing.

In 2009, Meaningful Use regulations required health care covered entities and eligible providers to adopt, use, and exchange electronic health information (HITECH, 2009). By 2012, national public policy makers recognized that health information would not be liberated for use in health care delivery by health care covered entities, eligible providers, and technical vendors alone. A public policy shift to focus health information control strategies on the individual quickly followed (Ricciardi, Mostashari, Murphy, Daniel, & Siminerio, 2013). Meaningful Use Stage 2 program objectives enabled individuals to view, download, and transmit their health data (Daniel et al., 2014). The goal was to support consumer engagement (psychological, personal health, and data management) and drive market demand for information exchange (Patel et al., 2014). In 2013, HIPAA final rule was released, supporting public policy position that consumers should have limited rights to their data (U.S. Department of Health & Human Services, 2013). Policy levers, such as Meaningful Use, incentivized health covered entities and eligible providers to work with technical vendors to develop and implement a limited set of information exchange protocols and data standards. Unfortunately, most covered entities and eligible providers implemented minimum requirements, interpreting the rules as terms of compliance, collecting the incentives, and often turning off the exchange capabilities when funding was exhausted (Information Blocking Report, 2015). The result is an underappreciated, poorly articulated tension between information exchange and the health data sharing preferences of consumers that is driven by policy, regulation, and practice.

Consumer Sentiment

This is the first study of relationships between constructs of information privacy, data security, data sharing preferences, and C-ME. Integrated complex systems theory provides context for the theoretical model describing relationships between and among the constructs of interest (Mitchell, 2009; Morçöl, 2005). Limited understanding of relationships between information privacy, data security, and health data sharing preferences can lead to public policy not aligned with consumer expectations (Moon, 2017). Public policy not aligned with consumer expectations may result in legal regulations that do not follow shifting consumer sentiment. For example, confidentiality concerns have driven public policy makers to focus mostly on information privacy (Markel Foundation, 2006; Mayberry, 2003; National Committee on Vital and Health Statistics, 2006; Pritts, 2001; Rothstein, 2007). Meanwhile, data security breaches have been escalating at an alarming rate (Burke, 2014).

Study findings indicate information privacy, a historical lynch-pin of early data governance efforts, showed a significantly weaker relationship on health data sharing preferences in the theoretical model. Data security showed a strong, positive, and direct relationship on health data sharing preferences ($\beta = 0.96$). Privacy showed a weaker but positive direct relationship with health data sharing preferences ($\beta = 0.21$). Subsequently, public policy may need to shift to respond to the growing concerns of consumers related to health information security protections. This result is an example of a possible realignment of public policy (and potentially legal regulation) based on consumer sentiment. An integrated system of consumer-mediated data management would help ensure (a) a dynamic pattern of consumer-mediated data management and secondary use *reliant* on health data sharing preferences of consumers, and (b) the integral nature of data governance principles needed to balance the needs of consumers (access and control, permission and use, risk and benefit, and transparency) in a LHS.

Ethical Nursing Implications

The LHS relies on secondary use of large data, known as big data, sets for research and practice. The use of large data sets is a growing approach for nursing information science (Delaney & Westra, 2017). Big data are not just about technology, it is about sociological transformation of knowledge-based innovation (Dereli, Coskun, Guner, & Agirbasli, 2014). Zwitter (2014) goes as far as to suggest that individual moral agency must be reimagined in the context of big data. Traditional ethics emphasize moral responsibility of the individual, known as moral agency. Individual moral agency is determined by causality, knowledge, and choice. Big data introduces distributed morality, or the effects of many actors contributing to an action (Zwitter, 2014). Therefore, individual moral agency (free will and individualism) is challenged in networked ecosystems. The concept of power is crucial to ethics and moral responsibility. Networked ecosystems create a network definition of power (Dereli et al., 2014). Therefore, free will of the individual is proportionally diminished by the larger the networked ecosystem.

The health data sharing preferences of a consumer could be an aspect of moral agency, or free will and individualism. Individual preference is part of choice. The ONC Issue Brief: Person at the Center (2014) lists the optimization of individual self-determination as a core value. Having individual preferences respected is key to autonomy and self-determination. Networked ecosystems require mechanisms to manage choice of individuals whose health data are aggregated, stored, and used in community records. Moral agency is a unidimensional concept in networked ecosystems. The choice is binary, where an individual can only choose to opt-in or opt-out of the record location, data aggregation, and exchange in developing information collaborative arrangements (e.g., Minnesota Health Records Act, 2015).

Distributed networks are beginning to develop. A distributed network would use defined procedures within a set scope to limit risk of harm (Brown et al., 2010). However, in a distributed network, no guarantee exists that individual health data sharing preference is known, available, or managed. New technology, such as Blockchain, is under development and may address moral agency in future distributed networks. Blockchain is a distributed ledger technology that maintains a continuously growing list of ordered records called blocks—each timestamped, kept in a registry, and inherently resistant to modification of data. The financial industry has started to use Blockchain to track ownership of assets with the need for a central authority. Because health data are an asset, Blockchain may be useful to health care data management. Until then, nurses and other health care providers must pay close attention to the preferences of consumers (data sharing or otherwise) applying strong ethical principles to ensure that justice (equal distribution of resources based on benefits and burdens), beneficence (desire to do good), and autonomy (self-determination and individual preference) are preserved.

Recommendations

Public policymakers. Based on study findings, public policymakers need to consider the following recommendations.

- Develop pragmatic data governance principles and technical standards that can be fully operationalized in health care delivery systems, including the evolving learning health system.

- Include participatory mechanisms in public policy development cycle to systematically collect consumer sentiment on a wide variety of data governance topics related to information privacy, data security, and consent management.
- Support consumer choice through granular consent and information privacy controls for electronic health information to meet social expectations and ethical considerations in networked environments.

Legal experts and regulators. Based on study findings, legal experts and regulators need to consider the following recommendations.

- Focus on data security enforcement, while balancing transparency for consumers and data liquidity requirements for an evolving LHS. This includes incentivizing innovation of technical safeguards and the subsequent generalization of such tools, only after they have been piloted tested in health care ecosystem.
- Modification of rules (a) for permissions (HIPPA, 42CFR Part 2, state laws) to include consumer-mediated data management provisions, especially where secondary use is prevalent; (b) that cannot be operationalized in electronic environment, such as complex re-disclosure requirements for sensitive data; (c) that are difficult to enforce, such as the minimum necessary rule and harm thresholds; and (d) the addition of rules to cover third-party applications that collect personal health data, are at increased risk of information privacy or data security breach, and use consumer data for secondary purposes.

Health care providers. Based on study findings health care providers need to consider the following recommendations.

- Inclusion of education and shared decision-making related to health data sharing preferences as part of the provider-patient relationship.
- Focus on enhanced security safeguards to minimize vulnerabilities and mitigate risk of unauthorized access.
- Resource and human capital allocation to support proactive compliance practices to create a culture of compliance across enterprise or organization.
- Become an active participant in the LHS.

Health care consumer. Based on study findings health care consumers will want to consider the following recommendations.

- Know your rights to access, aggregate, control, exchange, and use personal health information.
- Voice your concerns, as well as your personal preferences for access, aggregation, control, exchange, and use of your personal health information.
- Drive demand for transparent exchange mechanisms and data segmentation based on individual preference in the developing LHS.
- Become knowledgeable about secondary use of health data and the public good of comparative effectiveness research in the developing LHS.

Health care systems. Based on study findings health care systems will want to consider the following recommendations.

- Ensure organizational policies, procedures, and practices protect consumer health data and mitigate organization and personal risk to health care consumers.
- Disseminate best practices and collaborate as partners with market-based competitors, to ensure consumer health data are safe, secure, protected, and used for purposes that promote the public good.
- Reduce variation of interpretation related to public policy and legal regulation related to information privacy, data security, and consumer consent management in health care ecosystem.
- Drive innovation that is pilot-tested prior to dissemination into health care ecosystem. Include user-centered design principles that focus on health care workers and consumers.

Study Limitations

This was a secondary data analysis of an existing public data set from HINTS. The survey instrument items were closely matched to constructs of interest in this study. However, the study may be limited by a small group of variables collected on an ordinal scale. This limitation is because SEM output is optimized by continuous variables used to perform estimations necessary for the measurement and structural model. To mitigate this issue, outside expertise was sought from a University of Minnesota psychometrician who recommended that ordinal variables were treated as continuous. Additionally, survey instrument Item D2a used for the dependent variable did not explicitly ask the data sharing preference question in a binary form. Subsequently, to answer Research

Question 1, the researcher scaled responses and used very important as an indicator of affirmative data sharing preferences.

Future Research

Multiple implications for future research exist. Because information privacy, data security, and C-ME are complex social constructs, a need exists for a psychometric and cognitive tested survey instrument specific to the study of health data sharing preferences of consumers. Weak instrument development was found in eight of the 14 studies reviewed for this research (Ancker et al., 2012; Ancker et al., 2013; Dimitropoulos et al., 2011; Marquard & Brennan, 2009; Patel et al., 2011; Patel et al., 2011; Schwartz et al., 2015; Wen et al., 2010). Instrument validation through cognitive testing increases reliability of study results (Devellis, 2016). Validating the instrument through psychometrics ensures that summated scales are assessed for internal consistency (e.g., Cronbach Alpha) and that a set of variables or items measures a single construct (Devellis, 2016).

Second, future research considerations should include the use of sentiment analysis, through crowd sourcing methods. Using advanced methods, such as machine learning and vector analysis, would allow for close to real-time data collection of consumer sentiment on topics relevant to public policy. Topics, including health data sharing preferences of consumers, would benefit from real-time sentiment analysis. The systematic, near real-time capture of consumer sentiment would enhance adaptive complex system approaches like the one proposed in this study. The advanced information science methods would aid in creating feedback loops for collecting and then using consumer sentiment information. These will be key to moving to a consumer-mediated data management approach in the LHS.

Conclusion

The interrelationship between the complex social constructs of information privacy, data security, data sharing preferences, and C-ME has been poorly understood. New knowledge was needed, given the public policy implications for consumer participation in information sharing. Knowledge generation based on theory is important in a rapidly digitizing health care industry that has not fully integrated consumer-centric processes into information exchange practices. The researcher used SEM to analyze a secondary data set and develop a theoretical model. Study findings provide information not previously available to research and public policy makers, such as enhanced concerns about data security and the identification of two levels of health data sharing preferences (sharing between providers and personal access). These are both important concepts as the LHS develops.

Study findings also support the notion that consumer sentiment may be key in an adaptive complex system needed for consumer-mediated data management. Consumer input, consumer choice, consumer control, and consumer sentiment are integral features of an adaptive complex system that aligns with consumer preference. Results of this study are used to propose an integrated perspective systems approach to design, manage, and control consumer-mediated data management. However, change begins with an environment that supports C-ME. The consumer voice is a catalyst for that change. Moreover, consumer preference is integral to any system changes so that data governance policy more closely aligns with consumer preference to ensure the ecosystem becomes adaptive to consumer voice.

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Appendix A: HINTS Data Terms of Use

It is of utmost importance to ensure the confidentiality of survey participants. Every effort has been made to exclude identifying information on individual respondents from the computer files. Some demographic information such as sex, race, etc., has been included for research purposes. NCI expects that users of the data set will adhere to the strictest standards of ethical conduct for the analysis and reporting of nationally collected survey data. It is mandatory that all research results be presented/published in a manner that protects the integrity of the data and ensures the confidentiality of participants.

In order for the Health Information National Trends Survey (HINTS) to provide a public-use or another version of data to you, it is necessary that you agree to the following provisions.

1. You will not present/publish data in which an individual can be identified. Publication of small cell sizes should be avoided.
2. You will not attempt to link nor permit others to link the data with individually identified records in another database.
3. You will not attempt to learn the identity of any person whose data are contained in the supplied file(s).
4. If the identity of any person is discovered inadvertently, then the following should be done;
    a. no use will be made of this knowledge,
    b. the HINTS Program staff will be notified of the incident,
    c. no one else will be informed of the discovered identity.
5. You will not release nor permit others to release the data in full or in part to any person except with the written approval of the HINTS Program staff.
6. If accessing the data from a centralized location on a time-sharing computer system or LAN, you will not share your logon name and password with any other individuals. You will also not allow any other individuals to use your computer account after you have logged on with your logon name and password.
7. For all software provided by the HINTS Program, you will not copy, distribute, reverse engineer, profit from its sale or use, or incorporate it in any other software system.
8. The source of information should be cited in all publications. The appropriate citation is associated with the data file used. Please see Suggested Citations in the Download HINTS Data section of this Web site, or the Readme.txt associated with the ASCII text version of the HINTS data.
9. Analyses of large HINTS domains usually produce reliable estimates, but analyses of small domains may yield unreliable estimates, as indicated by their large variances. The analyst should pay particular attention to the standard error and coefficient of variation (relative standard error) for estimates of means, proportions, and totals, and the analyst should report these when writing up results. It is important that the analyst realizes that small sample sizes for particular analyses will tend to result in unstable estimates.
10. You may receive periodic e-mail updates from the HINTS administrators.

☐ Marking this box indicates that I agree to comply with the above stated provisions.

Please enter your email: