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LITERATURE REVIEW

Factors influencing health data sharing preferences of consumers: A critical review

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KEYWORDS

Informed consent;
Release of information;
Health information
exchange;
Consumer attitudes;
Consumer health data
sharing preferences;
Health information
exchange public policy

Abstract

The purpose of this critical review is to synthesize available literature and identify factors influencing consumer data sharing preferences, while presenting a logic model for legal / public policy development that aligns with consumer expectations for management of ePHI. Eighteen articles were included for the critical review; including 16 studies from three countries. The fourteen cross-sectional studies were evaluated using Olsen and St. George's (2004) Cross-sectional Study Design and Data Analysis framework and two qualitative studies were assessed using Kuper, Lingard, & Levinson (2008) [14] Critically Appraising Qualitative Research strategies. An emerging classification schema of statistically significant factors identified in this critical review shows that, (1) Trust relationship, (2) Harm Threshold, (3) Balance Risk and Benefits, (4) Transparency of Data Exchange and (5) Access and Control of Data are important when considering how to best include the consumer voice in the development of legal / public policies related to the privacy, security and consent management of ePHI.

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Contents

Introduction	2
History and review of literature	2
Descriptive characteristics	6
Factors associated with trust relationship	6
Factors associated with harm threshold	14
Factors associated with balance risk and benefit	14

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Factors associated with transparency of data exchange	15
Factors associated with access and control of data	15
State of the art and science.	15
Theory	16
Logic model	16
Ethical practice	16
Limitations and opportunities for future research	17
Conclusion	17
Funding	18
Competing interests.	18
Ethical approval	18
Acknowledgements	18
References	18

Introduction

Permission is obtained from a patient prior to accessing or sharing electronic protected health information (ePHI) [11,12]. Health care providers consider the release of information (ROI) transaction to be 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 [5,8,22,25-28,31]. Consumer data sharing attitudes and preferences have been identified as a potential consumer engagement barrier in health information exchange [2,3,5,8,10,22,27-29]. Factors that influence consumer's to share or withhold health information are not well studied [22,28]. The purpose of this critical review is to synthesize available literature and identify factors influencing consumer data sharing preferences, while presenting a logic model for legal / public policy development that aligns with consumer expectations for management of ePHI.

History and review of literature

The Health Insurance Portability and Accountability Act (HIPAA) defines federal legal requirements for privacy/security of protected health information [12]. In 2009, The Health Information Technology for Economic and Clinical Health (HITECH) Act, part of the American Recovery and Reinvestment Act (ARRA) promoted the adoption and meaningful use of health information technology including the exchange of electronic health data across an expanded care continuum [11]. Subtitle D of the HITECH Act addresses concerns related to the electronic sharing of health information and strengthened the enforcement of HIPAA rules [11]. HIPAA modifications were codified in Omnibus Final Rule (2014), adding strength to limitations on use and disclosure of ePHI, expanding individual's 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 [12]. It is within this historical legal/public policy context that the literature search was conducted to identify factors that

influence consumer data sharing preferences. Table 1 shows the applicable legal regulations.

The literature review used electronic databases: Cumulative Index to Nursing & Allied Health Literature (CINAHL), PubMed, and applicable government websites. The search strategy used for CINAHL and PubMed; (release of information) AND (attitudes or preferences) or combined keyword search (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. Forty-seven abstracts and publications were reviewed. Duplicates were removed and inclusion/exclusion criteria were applied. Articles included referred to HIPAA after 2009, patient consent related to ROI for electronic information exchange and studied consumer attitudes or preferences for health data sharing. Articles were excluded if they included references to HIPAA prior to HITECH, focused on informed consent for medical treatment or ROI for disclosure of sexually transmitted disease. Eighteen articles were included for the critical review; including 16 studies from three countries.

The fourteen cross-sectional studies [2,3,8,10,16,17,22,25-28,31,32,34] were evaluated using Olsen and St. George's (2004) Cross-sectional Study Design and Data Analysis [23] framework and two qualitative studies [5,29] were assessed using Kuper, Lingard, and Levinson (2008) Critically Appraising Qualitative Research strategies [14]. Each of the fourteen cross-sectional studies reviewed was measured using 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, 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. Twelve studies reviewed scored moderate quality ratings [2,3,8,16,22,25-28,31,32,34] and two rated with low quality ratings [10,17]. Lower overall quality ratings are attributed to use of samples not nationally representative [2,8, 10,16,17,22,25-29,31,32], survey instruments not cognitively tested [2,3,16,17,25-28,31,32,34], low number of pilot tested instruments [3,10,17,31,32,34], and presence of survey bias [3,17,25]. Survey method advantages include low data collection cost and ability to provide a standardized data-collecting procedures. However, validating

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