Journal of the American Medical Informatics Association, 0(0), 2017, 1–11
doi: 10.1093/jamia/ocw172
Review

Review

Shared decision-making using personal health record technology: a scoping review at the crossroads

Selena Davis,[1] Abdul Roudsari,[1] Rebecca Raworth,[2] Karen L Courtney,[1] and Lee MacKay[3]

[1]School of Health Information Science, University of Victoria, Victoria, Canada, [2]University of Victoria Libraries, Victoria, Canada and [3]Kootenay Lake Hospital Diabetes Clinic and Kootenay Boundary Division of Family Practice, Nelson, BC, Canada

Corresponding Author: Selena Davis, School of Health Information Science, University of Victoria, PO Box 1700, HSD A202, Victoria, BC, Canada, V8W 2Y2. E-mail: daviss@uvic.ca, Phone: 250-505-7866

Received 8 July 2016; Revised 8 November 2016; Accepted 29 November 2016

ABSTRACT

Objective. This scoping review aims to determine the size and scope of the published literature on shared decision-making (SDM) using personal health record (PHR) technology and to map the literature in terms of system design and outcomes.

Materials and Methods. Literature from Medline, Google Scholar, Cumulative Index to Nursing and Allied Health Literature, Engineering Village, and Web of Science (2005–2015) using the search terms "personal health records," "shared decision making," "patient-provider communication," "decision aid," and "decision support" was included. Articles ($n = 38$) addressed the efficacy or effectiveness of PHRs for SDM in engaging patients in self-care and decision-making or ways patients can be supported in SDM via PHR.

Results. Analysis resulted in an integrated SDM-PHR conceptual framework. An increased interest in SDM via PHR is apparent, with 55% of articles published within last 3 years. Sixty percent of the literature originates from the United States. Twenty-six articles address a particular clinical condition, with 10 focused on diabetes, and one-third offer empirical evidence of patient outcomes. The tethered and standalone PHR architectural types were most studied, while the interconnected PHR type was the focus of more recently published methodological approaches and discussion articles.

Discussion. The study reveals a scarcity of rigorous research on SDM via PHR. Research has focused on one or a few of the SDM elements and not on the intended complete process.

Conclusion. Just as PHR technology designed on an interconnected architecture has the potential to facilitate SDM, integrating the SDM process into PHR technology has the potential to drive PHR value.

Key words: personal health records, shared decision-making, self-management, patient-centered care, decision support.

BACKGROUND

Shared decision-making (SDM) has been promoted as the optimal approach to making health care decisions, associated with evidence of patient benefits[1] and touted as the pinnacle of patient-centered care, yet it has been difficult to implement in practice.[2] In a systematic review of patient preference for shared decisions, 71% of the studies revealed that patients want to be active and involved partners with their care providers in making health care decisions.[3] Despite patients wanting to participate, results of another systematic review on patient-reported barriers to and facilitators of SDM indicate that they simply cannot participate, with inadequate provision of information as the most significant barrier.[4] Access to personalized education and decision-support tools resulting from the integration of all patient health data and ease of communication with care providers are needed to engage patients in self-management and decision-making.

Personal health record (PHR) technology could support patient-centered care by making all relevant information and tools available, and it is a promising approach for overcoming barriers to implementing SDM in practice.[5] Despite the lack of strong empirical evidence that PHRs increase patient engagement, provide better care coordination, and improve patient-provider communication, quality of care, and clinical outcomes,[6,7] they are still strongly favored, but are underutilized, and present a major opportunity for improvement in patient-centered care, patient engagement, and self-management decision-making.[8]

To date, few studies, and no systematic or scoping reviews, have addressed the design and implementation of SDM with the use of PHR technology. A scoping study was chosen because an initial appraisal of the literature indicated that there was little with methodological rigor on use of the SDM process using PHR technology. As such, it is the best fit for this research, with an emphasis on the scoping technique to map relevant literature in terms of potential size and scope. Specifically, a scoping review was carried out to identify key design and implementation issues, gaps in research, and types and sources of evidence, according to an enhanced Arksey and O'Malley methodological framework as defined by Daudt et al.[9] The 5 stages of a scoping review were carried out: (1) identify the research question, (2) identify relevant studies, (3) select articles, (4) chart the data, and (5) collate, summarize, and report the results.

Operational definitions

For the purpose of this scoping review, the following definitions were employed. SDM is a collaborative process that involves the active participation of patients and providers in health care treatment decisions, which comprise exchange of information, discussion of best scientific evidence and patient preferences at a particular point in time, and determination of treatment plans.[10,11] PHR is a patient-facing electronic health record system through which individuals can access, manage, and share their own health information (and that of others for whom they are authorized), in a private, secure, and confidential environment to support patient-centered care.[12,13]

OBJECTIVE

The research aim was to determine the size and scope of the published literature on SDM via PHR in terms of system design and effect. The rationale behind this broad objective was the increased relevance of patient-centered health care, specifically SDM in clinical practice, the increased use of patient-facing innovative health information technologies, and the current lack of consensus in the literature on how best to design these tools to support self-management and decision-making.

Research questions

Although there is extensive literature on SDM and PHR technology and several editorial and opinion papers arguing for PHR as a solution to implementing SDM, there is little literature with methodological rigor on provision of SDM via PHR. Therefore, based on a combination of informal discussions and a preliminary review of the published topics, the following focus areas and research questions were developed for this scoping review:

i. Design theme for implementing SDM via PHR
   - Was SDM as a whole process being studied or only certain elements of the SDM process?
   - What patient subgroups and clinical conditions were SDM via PHR systems being developed for?
   - What PHR architectural designs for SDM have been investigated?
   - What was the enabling functionality of PHR for SDM?
   - What other SDM-PHR design and/or implementation issues were identified?

ii. Outcomes theme of SDM via PHR
   - Has implementing SDM via PHR demonstrated outcomes, specifically an improvement in patient outcomes?
   - What types of patient outcomes were investigated?
   - Was SDM via PHR relevant for a particular patient subgroup or disease?

MATERIALS AND METHODS

Identifying relevant articles

The identification of articles was approached in multiple steps, first targeting the electronic literature databases of Medline, Google Scholar, Cumulative Index to Nursing and Allied Health Literature, Engineering Village (Compendex/Inspec), and the Web of Science, then the gray literature (eg, technical reports, organization websites, and conferences) to increase the capture of relevant material. The search was conducted between June and December 2015. Searches were limited to the English language and published between 2005 and 2015. This time restriction focused findings on more modern PHRs (eg, accessible via mobile devices and advanced Web application interactions). Searches of both the peer-reviewed and gray literature were adapted for each source and included combinations of keyword search terms (Table 1).

Published randomized controlled trial protocols were included, but research in progress, editorials, and commentaries were not. Articles were not limited to any particular patient subgroup, disease, or clinical setting. The goal was to conduct a sensitive rather than specific search of the literature. A range of "snowballing" techniques were used, including reference list follow-up. One research librarian (RR) was consulted to confirm the selection of databases, search terms, and search strategy to identify potential articles.

Article selection

A screening tool was developed with specific inclusion and exclusion criteria (Table 2), based on the focus areas identified with the research questions.

One researcher (SD) initially selected articles by screening titles/abstracts using the first screen inclusion and exclusion criteria. Then full-text papers were pulled for those that passed initial screening, and 179 full-text articles were reviewed by 2 researchers (SD, AR) using the second screen inclusion and exclusion criteria to select the final set of 38 articles. Seven conflicts related to article selection were resolved through discussion. Final inclusion criteria dictated that the article address ways patients can be supported in SDM via PHR, including original research, models, focused discussions, and methodological approaches, and/or the efficacy or effectiveness of PHRs with SDM elements in relation to engaging patients in self-care and decision-making. Study sample size was not used as an exclusion criterion. Figure 1 illustrates the article selection process.

Charting the data

The charting process was multistaged, involving extraction of information from individual articles into QSR NVivo 11 Pro software for data extraction and management. Two researchers (SD, AR) met regularly to iteratively reach consensus on code definitions and article type and category, and identify themes. Initially, 1 researcher (SD) collected descriptive characteristics of the

Table 1. Keyword search strategy

PHR keyword search terms (synonyms using OR)	AND	SDM keyword search terms (synonyms using OR)
"personal health records," "PHR," "Health Records, Personal" [MeSH], "patient-controlled electronic health record," "patient portal"		"shared decision making," "Decision Making" [MeSH], "patient-provider communication," "decision aid," "decision support"

Table 2. Exclusion and inclusion criteria

	Exclusion criteria	Inclusion criteria
First screen	Use of medical terminology, eg, "portal" vein Use of Internet or health portals to search for health information Only personal health record (PHR) and adoption, design methodology, implementation, usage, usability, privacy, health literacy, governance and policy, results delivery (eg, radiology) Electronic health record (EHR) addressing provider access only Only shared decision making (SDM) and adoption, implementation, usage, patient outcomes	EHRs or portals with access by patients (and/or their designees) to their health information that address one or more elements of SDM process
Second screen	Original research, models, or methodological approaches on efficacy or effectiveness or design or implementation of single component systems: Decision aids Clinical decision-support systems Remote patient monitoring Internet-based coaching interventions Secure messaging Patient access to provider EHR during the encounter only Conceptual models focused on optimizing health service delivery or interoperable EHRs Work in progress, editorials, or commentaries	At least 1 of the PHR keyword search terms AND at least one of the study SDM keyword search terms had to be somewhere in the article Original research, conceptual model, methodological approach, or focused discussion (which referenced relevant descriptive supporting papers) on the design or implementation of PHR technology for one or more elements of SDM Evidence of outcomes of one or more elements of SDM via PHR
Limits	Articles published 2005–2015 English-language articles	

included articles such as general citation information, clinical condition, patient subgroup, country of origin, and study design. Two researchers (SD, AR) charted the data, including PHR architectural type and functions for SDM elements and key findings on outcomes. Comparisons were made and any coding conflicts were resolved through discussion.

Collating and summarizing

In line with scoping studies and the aim of this study, quantitative and qualitative analyses of selected articles were completed, resulting in a descriptive numerical summary and a thematic analysis.[14] Predefined descriptive classifications were applied to the initial coding of all articles, including:

i. Article type
   a. Model (an explicit conceptual representation of concepts designed to guide further research);
   b. Methodological approach (an explicit framework designed to guide future research activity);
   c. Focused discussion (relevant descriptive supporting papers were referenced); or
   d. Original research (primary source article describing purpose, methods, results, and interpretation of study findings).

ii. Article category
   a. Design (PHR system attributes for one or more elements of SDM) or
   b. Design + outcomes (evidence of patient outcomes).

All articles in this review reported on PHR system attributes for one or more elements of SDM and, as such, were categorized as contributing to the "design" theme, while only those articles that reported original research evidence of patient outcomes were categorized as contributing to the "impact" theme.

In order to commonly classify the scoping review findings, the study utilized a conceptual framework (Figure 2), which was synthesized from the preliminary literature, linking the SDM process with the enabling PHR technology. The conceptual framework was used to guide data collection and analysis. The framework was conceived from recommendations of relationships between characteristics and elements of the SDM process and key enabling PHR functions by patient activity based on the work of several groups of authors.[15–19] In the framework, the key enabling PHR functions by patient activity for SDM characteristics are identified and organized by the 4 core SDM elements: choice, options, decision, and action. Choice is a recognition that a decision is required and is characterized by the retrieval of personal information relevant to the decision. Options is

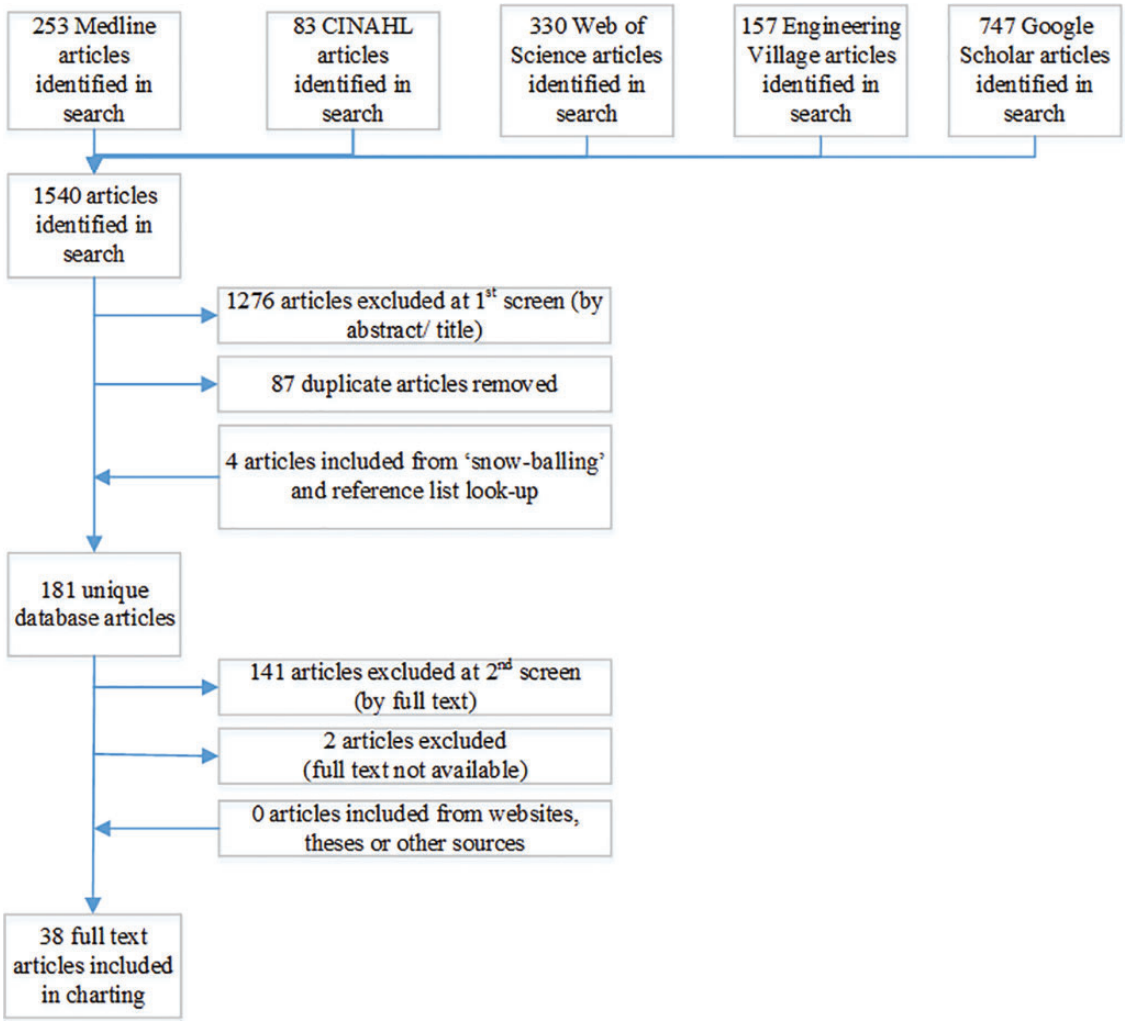

Figure 1. Flow diagram for article selection process

the presentation and possible interpretation of relevant evidence for the decision. The decision element is characterized by an exploration and inclusion of personal preferences and values related to the decision. The addition of an action element adapts and expands the SDM model by Elwyn and colleagues,[18] where actions are a consequence of the decision and expressed in an action plan with explicit follow-up to ensure that the treatment decision respects preferences and to track outcomes of the decision. It is conceptualized that integrating SDM via PHR in this way supports patients during self-management through the sequential steps of the shared decision-making process, with action planning and follow-up of the ensuing action to improve outcomes. Follow-up may give way to the need to loop back into one of the activities along the shared decision-making path to (re-)evaluate the decision.

RESULTS

Summary: descriptive characteristics

Of the 38 articles in this review, more than half (21 articles) were published in the last 3 years, between 2013 and 2015, suggestive of a trend toward increased interest in SDM via PHR. The drive for SDM via PHR appears to be coming mostly from the United States, as 60% of the articles originated there (Figure 3), and a number of articles identify key US organizations, agencies, acts, and reports promoting PHR as an approach to facilitate the SDM process.[20–25]

All 38 articles in the scoping review contributed to the design theme and were categorized as conceptual model (2 articles), methodological approach (6 articles), focused discussion (8 articles), and original research (22 articles). Only 14 articles indicated empirical evidence of patient outcomes and contributed to the outcomes theme. Twenty-six articles addressed a particular clinical condition, 10 of which focused on diabetes (Figure 4).

Twenty-one of the 38 articles identified a patient subpopulation for which the technological system of study was designed, with most systems being designed for adults (17 articles).

A complete list of descriptive characteristics of the articles is found in Supplemental File 1, covering citation information, category and type, country of origin, clinical condition, PHR architecture type, PHR functionality by patient activity for SDM, patient subgroup, and study design.

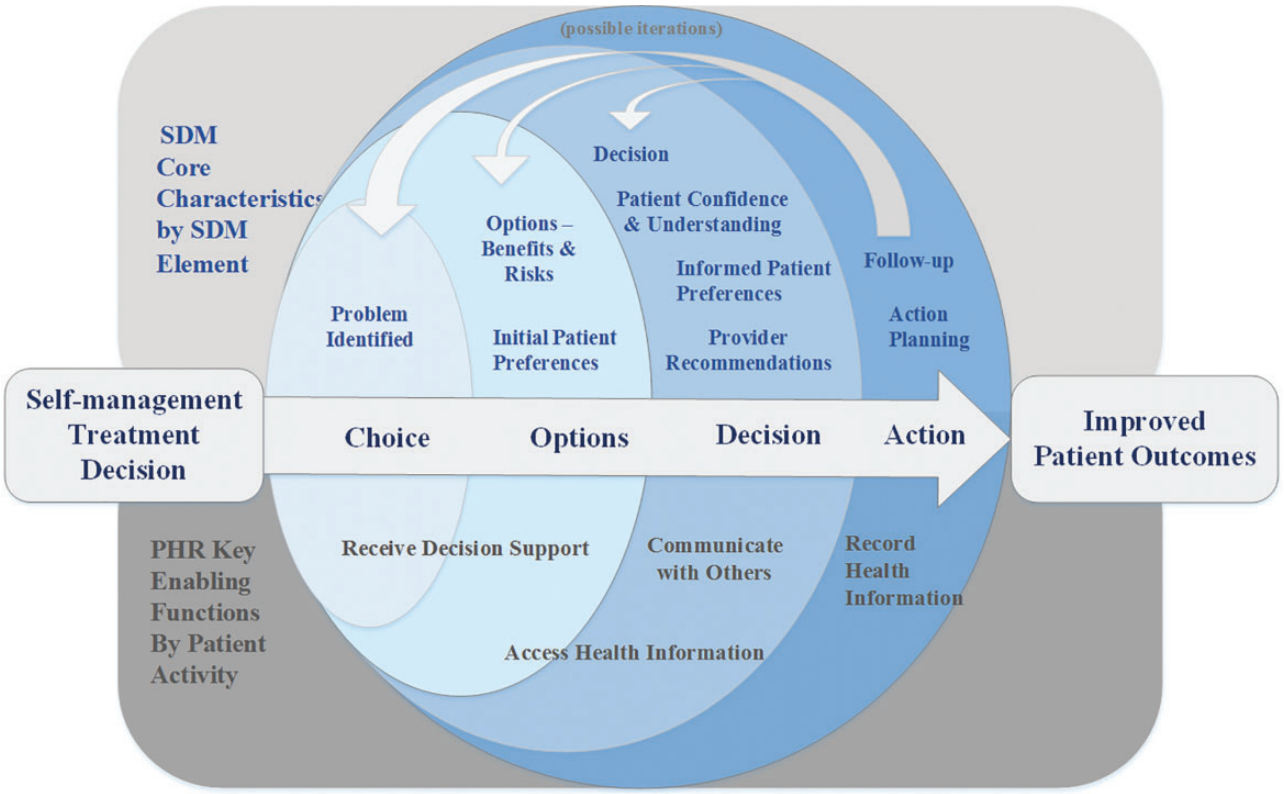

Figure 2. SDM-PHR conceptual framework

Summary: thematic analysis – design

PHR technology is provided to patients by a variety of arrangements, including electronic health record (EHR) vendors, provider organizations, private entities, and public eHealth websites. The most common PHR architectural types are standalone, tethered (linked to a specific provider's health information system), and interconnected (gathers and autopopulates patient data from multiple health information systems). The standalone and tethered PHR types were most studied, often as prototype systems or in pilot implementation, and comprised 91% of the original research articles. In contrast, the interconnected PHR type was the focus of just one original research article[26] and one study protocol,[27] and the motivation of articles categorized as "methodological approach" and "focused discussion" of most recent years. Along with shared patient-provider clinical decision-support services, the interconnected PHR was argued to be ideal for accessibility to consistent health information and improved patient self-management activities, care collaboration, decision-making, and quality of care.

Analysis of all articles resulted in expansion of the SDM-PHR conceptual framework through the addition of PHR functional subcategories (Table 3). Only 4 articles examined a PHR whose functionality met all 4 SDM elements, and not a single article in the review had a PHR using all SDM-enabled functionalities as identified by the PHR functional subcategories.

SDM concept of choice and options

Thirty-one of 38 articles identified at least one PHR functional subcategory of "Receive decision support." Choice in this subcategory is recognized as the use of intelligent alerts, reminders, or infobuttons. Just one article modelled the integration of SDM into an EHR-tethered system, including a solution to initiate SDM between patient and provider; ie, by use of an infobutton.[28]

Options in this subcategory are recognized by the use of personalized decision support, decision aids, and preference collection. One article specifically identified the relevance of personalizing decision support and action planning with a combination of the patient's medical profile, preferences, and goals and the provider's recommendations[27]; however, in common with the few other articles that identified the importance of patient preferences to guide action, previously collected patient preferences are often used to guide decision-making rather than eliciting preferences in the context of all factors for the decision at hand at that point in time. Including decision aids in PHRs to support patients by weighing the benefits, harms, and scientific uncertainties of decisions improves outcomes,[38,47] but this has been limited and varied, and depends on the complexity and intelligence of the integrated decision-support system.[22,23] Computer-tailoring a decision aid based on patient clinical profiles and clinical practice guidelines and delivered in a meaningful way to explain outcomes and probabilities to patients has proved challenging, hence a computerized generic paper form was often the default.[23] Yet decision-support services in the form of context-specific decision aids are the future of decision-making.[49]

SDM concept of decision

All articles in this review identified at least one PHR functional subcategory related to the patient activity "access health information."

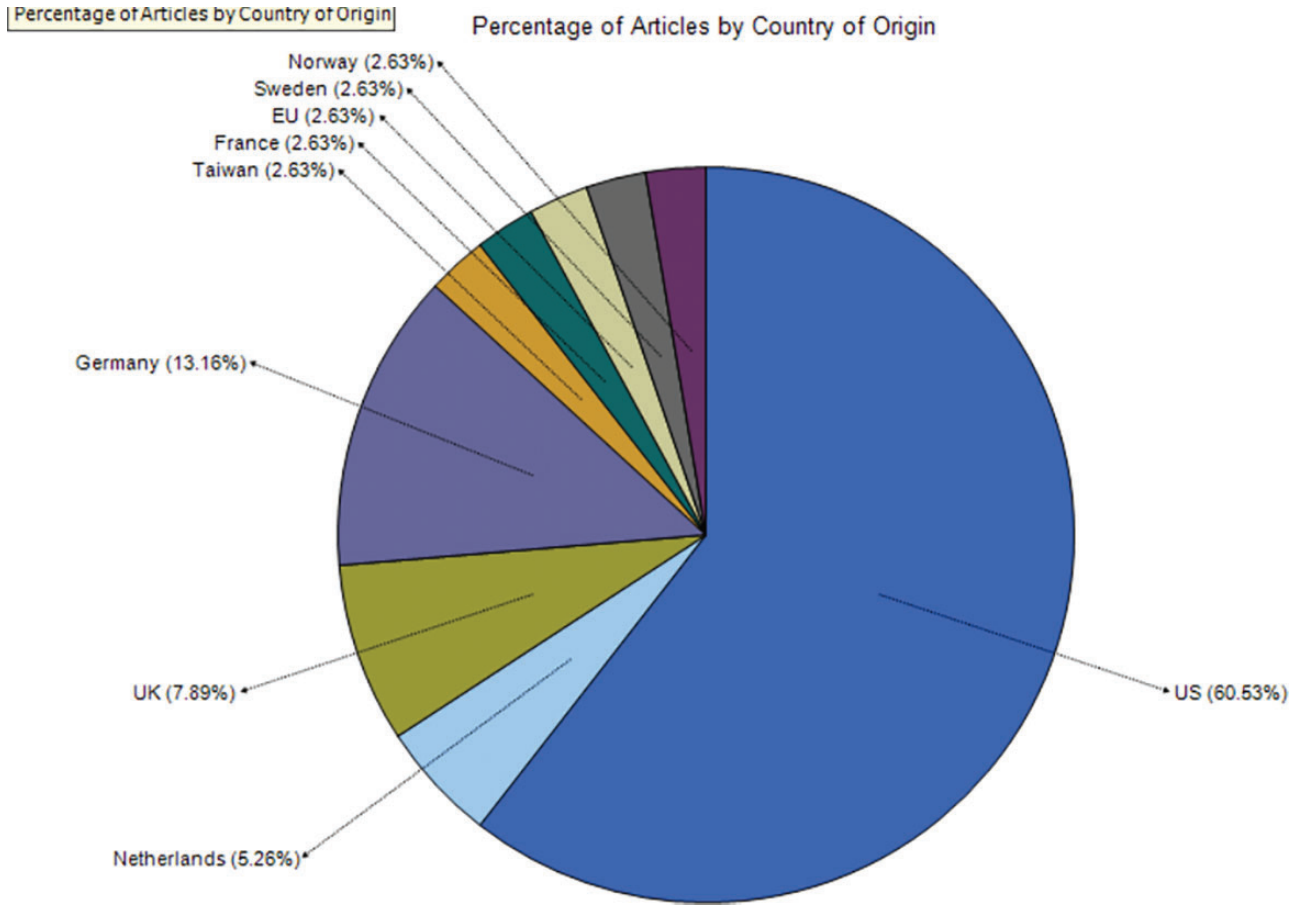

Figure 3. Percentage of articles by country of origin

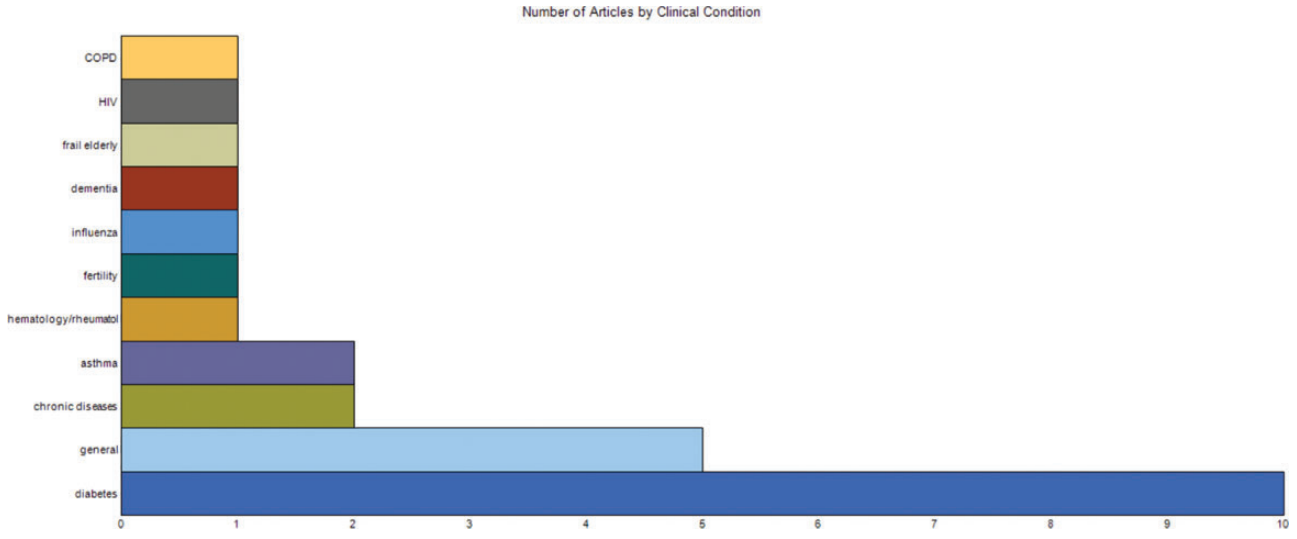

Figure 4. Number of articles by clinical condition

The subcategory "access to educational resources" included access to documents, videos, risk calculators, and external resource links, while the subcategory "integrated health data from multiple sources" included integrating data from all EHR systems. Finally, the subcategory "intelligent presentation of patient information" included data visualization trends and an overview customized to specific illnesses, such as a diabetes dashboard.

The PHR functional subcategory "communicate with others" was identified in 26 articles. The subcategory "message care team" included synchronous and asynchronous communications with care

Table 3. Enabling functionality of PHR for SDM

SDM element	PHR function by patient activity	Total no. of articles	PHR functional subcategory (article reference)
Choice	Receive decision support	15	Intelligent alerts[5,25,21,23,28–38]
		14	Reminders[5,8,20,22–24,26,27,31,34–37,39]
		1	SDM infobutton – initiate and track[28]
Options		23	Personalized decision support[8,20–23,26–28,29,31–35,38–46]
		8	Decision aid[20,22,23,28,33,35,38,47]
		5	Preference elicitation[23,26–28,34]
Decision	Access health information	27	Knowledge base (educational resources)[5,8,20–27,30,31–36,39–43,45,46,48–50]
		25	Integrated health data from multiple sources[8,20,22,24–26,29, 33–37,40,42–53]
		17	Intelligent presentation of data[5,8,20–22,29,31–33,35,38–40,43,44,46,49,52,54,55]
		12	Care plan[5,21,27–29,35,41,43,46,48,55]
		4	Provider clinical notes[8,25,50,52]
		3	Provider annotated clinical data[8,23,39]
	Communicate with others	25	Message care team[8,20,21,23–25,28,31–33,41,43,45,47–49, 36–39,50,52–55]
		10	Virtual support group/networks[8,20,23,25,33,39,41,47,49,52]
		4	Virtual assistant[20,23,33,46]
		3	Interactive bulletin board[39,41,55]
		2	Useful data export[37,49]
Action	Record health information	19	Subjective self-report – manual entry by user[5,8,25,29–35,38,40,41,43,44,47,49,50,54]
		16	Objective monitoring – integrated via devices or applications[8,20,25,29,26,27,23, 31,33,34,43,44,46,49,54,55]
		12	Personal narratives and pictures[5,21,25,27,31,33,37–39,43,46,54]
		11	Co-author care plan[8,27,28,32,33,34,40,44,47–49]
		10	Structured templates – observations of daily living[8,20,22,24,31,32,35,44,47,49]

providers and social networks. Such communications increased patient engagement and resulted in productive patient-provider interactions necessary for improved patient outcomes.[41,52]

SDM concept of action

Thirty-three of 38 articles identified at least one PHR functional subcategory of "record health information." The subcategory "personal narratives and media" included recording preferences, goals, values, moods, and events through pictures, videos, music, and stories. Capturing personal narratives and media indicates emotional and psychological clues about the health and wellness of the patient[39] and complements traditional signs and symptoms of disease,[54] and its importance to improved decision-making is increasingly being recognized.[25] The notion of a co-authored care plan was often described as relevant to increasing engagement in self-management and was operationalized as either a plan of upcoming activities based on recent trends, authored by the patient and shared with the provider,[27,33] or as patient responses to structured questions and incorporated into a care plan.[40]

Other SDM-PHR design and implementation issues were identified in the articles. The most salient design issues included privacy and security, system usability, patient health literacy, and system accessibility via mobile devices. Implementation issues included patient and provider expectations, system policy and governance, provider workflow and workload, and patient and provider upskilling.

Summary: thematic analysis – outcomes

About one-third of the articles (14 articles) indicated empirical evidence of patient outcomes. The PHR function by patient activity for SDM most studied was "access to health information." Just 2 of the studies used PHRs that comprised all 4 PHR functions by patient activity for SDM. Three general types of patient outcomes were identified: (1) affective-cognitive outcomes, which related mostly to impact on patient-provider communication and patient knowledge, and satisfaction and ease of care; (2) behavioral outcomes, which related mostly to impact on patient decision-making, medication management, and adherence to health behaviors; and (3) health outcomes, which related mostly to impact on physiological measures, quality of life, and symptom management.

DISCUSSION

The principal discoveries are discussed within 3 specific areas: SDM via PHR gap, opportunities, and challenges.

SDM via PHR gap

Despite widespread advocacy for SDM and the promise of PHR technology, this scoping review reveals a scarcity of research with any methodological rigor on SDM via PHR. This likely corresponds to the short time frame in which EHR systems, and more specifically PHRs, have been in health care practice. The review does reveal an upward trend in numbers of articles on the topic within the last 5 years, which is in line with the recent exponential growth in literature evaluating the use of SDM and its effectiveness as a mechanism to improve patient outcomes[1] and the evidence of adoption, use, and impact of PHRs.[13,56] Still, almost half of the articles were categorized as either a conceptual framework, a model, or a focused discussion to inform system design and implementation. Of the articles categorized as original research, a few focused on system design evaluation, often via user-centered design approaches, and the larger portion investigated the effect of system use, revealing some evidence of patient outcomes.

Importantly, and with the exception of 4 original research investigations,[5,8,21,31] the articles in this review did not investigate PHR for

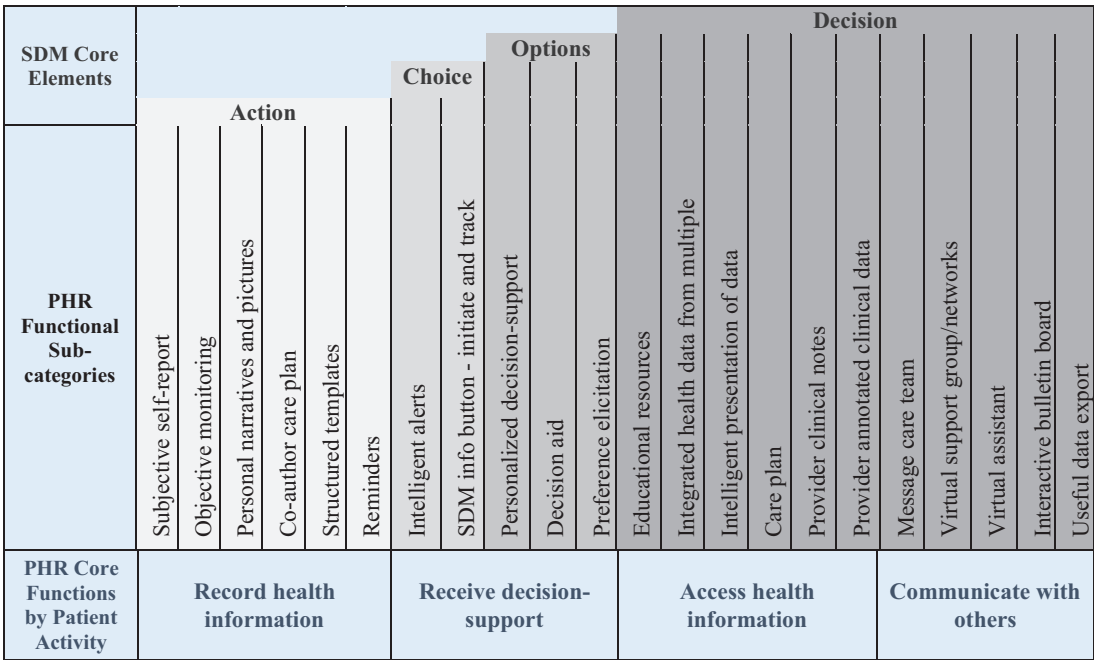

Figure 5. *i*SDM-PHR conceptual framework

SDM as the decision-making process is intended. The SDM process has been lost in translation; ie, research has focused on one or a few of the SDM elements and not on the complete process. Articles in the review focused, by way of differing PHR architectural and functional designs, on such topics as the provision of alerts for identifying decision-making opportunities,[36] patient access to health information and educational resources to support informed decision-making,[50] provision of decision-support tools to aid patients with informed choice,[22,38,45] and varying communication functionalities to support online patient-provider interactions for decision-making.[53]

The review also exposed that current investigations of SDM via PHR are focused on the provision of generic decision aids as opposed to computer-tailored ones, limited in the idea of tracking patients through the SDM process, and nonexistent on the topic of computerized elicitation of patient preferences in the context of a decision. This is not surprising, as these system tasks require intelligent decision support and interconnected PHR technology. Further, the review revealed that prototype standalone systems were being used to investigate the inclusion of patient data from objective monitoring devices and applications such as wearable technology and home biosensors and the integration of virtual networks.

SDM via PHR opportunity

The scoping review expands the initial SDM-PHR conceptual framework by adding PHR functional subcategories. Deriving benefit from an expanded framework and a system designed on the interconnected PHR architectural type, future research may be able to draw on the integrated shared decision-making–PHR (*i*SDM-PHR) conceptual framework (Figure 5).

The interconnected PHR architecture is a design solution considered to be the most sophisticated, comprehensive, and valuable.[57] Because care is increasingly received from multiple providers and across multiple settings, integrated access to health information and resources is necessary, and the presentation of information to patients needs to take into consideration the continuous, interorganizational care process in order for them to make informed decisions and engage in their care.[49] Additionally, the interplay between multiple sources in one comprehensive EHR platform can not only improve patient self-management, but also transform traditional episodic care to more continuous, collaborative care supporting decision-making, care coordination, and communication between providers and patients.[27,42] As an unconnected collection of personal health information, the PHR is limited, but as an interconnected account with the health care system as a whole, it offers a wide array of benefits.[43] PHRs need to be designed not as repositories of health information, but rather as interactive tools to engage patients in their own care.[37] PHRs must provide information that is useful to individuals caring for their health as well as to providers, as their value lies in shared information and in the action they enable, eg, decision-making. Separating the data from the applications enables greater innovation in the services that can facilitate that action,[54] creating a secure "ecosystem" of data sources, services, and applications. From a systems design perspective, 2 articles in the review modeled independently developed shared applications,[28,34] identifying increased value in the provision of services to patients and providers by separating patient data from decision support and communication services, because it affords opportunities in innovative design, sophistication of services, and care coordination across systems.

Diabetes was identified as the most commonly studied clinical condition in this review. This finding is in line with the literature, which characterizes diabetes as a condition sensitive to PHR intervention.[15] The most common patient population studied was adults. Just one article focused on diabetic youth, providing evidence of system feasibility, but found that while the standalone PHR intervention provided knowledge, a virtual environment for contact with a diabetes care team, peer support, and insight in treatment goals, it lacked integration with other eHealth systems, which limits its use and benefit.[55] Given the widespread adoption of various technologies by youth[58] and the recognition of the importance of involving youth in decision = making,[59] system design research vis-à-vis the

application of SDM via PHR for this age group is a promising opportunity.

Only a small portion of articles provided empirical evidence of patient outcomes, mostly relating to impact on affective-cognitive and behavioral outcomes, with limited evidence of health outcomes. These findings are consistent with the literature on SDM and patient outcomes[1] and on the impact of PHRs on patient outcomes.[6] One-third of articles demonstrating patient outcomes focused on diabetes, but the evidence is still limited and, as such, it is questionable whether SDM via PHR is relevant for a particular clinical condition. Likely outcomes will remain mixed until a PHR system is optimally designed and implemented to support SDM within its broader yet interconnected EHR systems environment.

To date, the value of the PHR itself has been varied, and most research has been carried out using PHR systems that often do not meet the necessary architecture or functionalities required for widespread adoption and impact.[60] The time may be ripe to take patient engagement in health self-management and decision-making to the next level using innovative, interconnected, patient-facing PHR technology.[23,24] In 2008, Detmer et al.[20] identified interconnected PHRs as promoting active, ongoing patient collaboration and decision-making and coordinated care delivery, and the article urged researchers to help evolve this theoretical concept to practical application, a situation yet to be realized.

SDM via PHR challenge

Health care is a complex sociotechnical system that presents a challenging environment in which to implement promising yet disruptive technology like *i*SDM-PHR, not only because it involves a variety of users, such as care providers, patients, organizational providers, and system developers, but also because it requires integration with broader systems and performing knowledge-intensive and case-specific SDM tasks. Due to the nature of tasks the system needs to perform, integrating data and coordinating communication and decision-support services within and between users will be required. This will undoubtedly require changing such things as health care policy and governance, as well as patients' and providers' attitudes and expectations.

Other key challenges include the way EHR systems and innovative applications will be integrated using interoperability, communication, and privacy and security standards while keeping patient computing mobility in mind. In addition, given the imperative for liquidity of clinical and self-reported patient data, information management and semantic interoperability related to data exchange will be critical to ensure data quality.

Finally, system acceptability and usability from the user's perspective must be addressed. Traditionally, the SDM process has relied heavily on face-to-face communication between providers and patients and often builds on a history of interactions together. When technology becomes a component of the communication process, questions are raised about its role as a barrier to or facilitator of communication. In telehealth studies, providers have been concerned that the use of technology in care could reduce the "human touch," although this is typically less of a concern for patients.[61] But this raises the question of whether using a PHR for SDM will encounter similar provider resistance related to a perceived lack of human touch.

LIMITATIONS

As part of our analysis, a qualitative directed content analysis approach was used to map SDM elements with PHR functionality. The directed aspect of the content was based on a conceptual framework that was developed by synthesizing a preliminary literature review. While the results from this scoping review expanded the conceptual framework to produce an enhanced framework, *i*SDM-PHR, validation by users should be done. Further, the quality of the evidence that identified the PHR functionality for SDM was not assessed; only the frequency of report in the literature was collected and analyzed. While articles published between 2005 and 2015 were included in this review, articles dated pre-2005 or other literature sources might lead to additional insights. Finally, this research did not exclude original studies based on sample size or evaluate the quality of studies to report on the impact of SDM via PHR in terms of patient outcomes.

CONCLUSION

To our knowledge, this is the first scoping review to exclusively consider the topic of SDM via PHR relating to design and outcomes evidence. The failure of EHR systems to provide patients with access to their health information, incorporate patient self-reported data into interconnected systems, and support SDM both during and between face-to-face visits could have undesired consequences for patient health.[25] Just as a PHR designed on an interconnected architecture has the potential to facilitate SDM by creating a complete, shared, and balanced profile of the patient and providing personalized decision-support and communications tools, so too does integration of the SDM process into the PHR have the potential to drive the value and adoption of the PHR. The state of SDM is not a question of whether we should do it, rather how can we integrate it into routine practice for patients and their providers within today's EHR environment.

SIGNIFICANCE

This research advances our understanding of the system design requirements of SDM via PHR. Future research may be able to draw on the in *i*SDM-PHR conceptual framework.

FUNDING

This work is funded, in part, through the Denis and Pat Protti Endowment Fund, whose support permitted some of the research time of the corresponding author. No organizations or agencies provided funds for this research

COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHOR CONTRIBUTIONS

SD led the research, including research design, data collection, and analysis; was responsible for knowledge modeling; drafted the original manuscript; and led revisions to the manuscript based on initial review

AR supported the research study, including data collection and analysis, and provided original manuscript edits.

RR contributed subject matter expertise and original manuscript edits.

KC provided edits to both the original and revised manuscripts.

LM contributed subject matter expertise.

PROVENANCE AND PEER REVIEW

This research was presented as a poster at the eHealth 2016 conference in Vancouver, BC, Canada. Not commissioned; externally peer-reviewed

ACKNOWLEDGMENTS

The authors acknowledge the support of Carol Gordon, research librarian, University of Victoria, and the very helpful comments of the reviewers in improving the quality of this paper.

SUPPLEMENTARY MATERIAL

Supplementary material is available online at *Journal of the American Medical Informatics Association*.

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