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

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SHARED DECISION MAKING USING PERSONAL HEALTH RECORD TECHNOLOGY: A SCOPING REVIEW AT THE CROSSROADS

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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, CINAHL, 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 may 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 addressed a particular clinical condition, with 10 focused on diabetes and one-third offered 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 its intended complete process.

Conclusion

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

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 the pinnacle of patient–centred care, yet it has been difficult to implement in practice[2]. In a systematic review of patients' preference for shared decisions, 71% of the studies revealed that patients want to be an active and an involved partner with their care provider in making healthcare decisions[3]. In spite of patients wanting to participate, results of another systematic review on patient reported barriers and facilitators to SDM indicate they simply cannot participate due to the provision of inadequate 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 an ease of communications with care providers are needed to engage patients in self-management and decision-making.

Personal health record (PHR) technology could support patient–centred 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 communications, quality of care, and clinical outcomes[6],[7], the PHR is still strongly favored for use, but it is underutilized and presents a major opportunity for improvement in patient–centred 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 is little literature with methodological rigour on the provision of the SDM process using PHR technology; as such, it is the best fit for this research purpose with the emphasis placed 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 SDM via PHR design and

implementation issues, gaps in research and the types and sources of evidence, according to an enhanced Arksey and O'Malley's methodological framework as defined by Daudt et al.[9]. The five stages of a scoping review were carried out: (i) identify the research question, (ii) identify relevant studies, (iii) select articles, (iv) chart the data, and (v) 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 which involves the active participation of both patients and providers in healthcare treatment decisions which comprise exchange of information, discussion of best scientific evidence and patient preferences at a particular point in time, and the determination of treatment plans[10],[11]. PHR is a patient-facing electronic health record system through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure and confidential environment to support patient-centred 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-centred healthcare, 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 or PHR technology respectively and several editorial and opinion papers arguing for PHR as a solution to implementing SDM, there is little literature with methodological rigour on the provision of the 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 was SDM via PHR systems being developed for?
- What PHR architectural design 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 (CINAHL), Engineering Village (Compendex/ Inspec) and the Web of Science, then the grey literature (e.g. technical reports, organization websites, and conferences) to increase the capture of relevant material. The search was conducted between June-December 2015. Searches were limited to the English language and published between the years 2005-2015. This time restriction focused findings on more modern PHRs (e.g. accessible via mobile devices and advanced web application interactions). Searches of both the peer-reviewed and grey literature were adapted for each source and included combinations of keyword search terms (Table 1).

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”

Published RCT 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.

Table 2: Exclusion and Inclusion Criteria

	exclusion criteria	inclusion criteria
1st screen	• Use of medical terminology e.g. "portal" vein • Use of internet or health portals to search for health information • Only PHR and adoption, design methodology, implementation, usage, usability, privacy, health literacy, governance and policy, results delivery e.g. radiology • Electronic health record (EHR) addressing provider access only • Only SDM and adoption, implementation, usage, patient outcomes	• Electronic health records or portals with access by patients (and/or their designee) to their health information that address one or more elements of SDM process

2nd 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 one 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 focussed 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	

One researcher (SD) initially selected articles by screening titles/abstract using the 1st 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 two researchers (SD, AR) using the 2nd 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 may be supported in SDM via PHR, including original research, models, focused discussions or 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 multi-staged, involving the 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, article type and category, and identify themes. Initially, one researcher (SD) collected descriptive characteristics of the included articles such as general citation information, clinical condition, patient sub-group, 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, both quantitative and qualitative analyses of selected articles were completed, resulting in both 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 (referenced relevant descriptive supporting papers); 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][16][17][18][19]]. In the framework, the key enabling PHR functions by patient activity for SDM characteristics are identified and organized by the four 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 that is relevant to the decision. Options is 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 & colleagues[18], where actions are a consequence of the decision and expressed in an action plan with explicit follow-up to ensure the treatment decision respects preferences and to track outcomes of the decision. It is conceptualized that the integration of SDM via PHR in this way supports the patient during self-management through the sequential steps of the shared decision-making process with action planning and follow-up on 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 2013-2015; suggestive of a trend towards increased interest in SDM via PHR. The drive for SDM via PHR appears to be most directed from United States (US) as 60% of the articles originated in US (Figure 3) and a number of the articles identify key US organizations, agencies, acts and reports as promoting PHRs as an approach to facilitate the process of SDM[[20] [21], [22], [23], [24], [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), focussed 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; ten of which focussed on diabetes (Figure 4).

Twenty-one of the 38 articles identified a patient sub-population 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 architectural type, PHR functionality by patient activity for SDM, patient sub-group, and study design.

Summary: thematic analysis - design

PHR technology is provided to patients by a variety of arrangements including provider electronic health record 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 auto populates patient data from multiple health information systems). The standalone and tethered PHR types were most studied, often as a prototype system 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], plus one study protocol[27], and the motivation of articles categorized as 'methodological approach' and 'focussed discussion' of most recent

years. Along with shared patient-provider clinical decision support services, the interconnected PHR was argued as ideal for accessibility to consistent health information and improved patient self-management activities, care collaboration, decision making and quality of care.

The analysis of all articles resulted in the 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 four SDM elements and not a single article in the review had a PHR which operated using all SDM-enabled functionality as identified by the PHR functional subcategories.

Table 3: Enabling Functionality of PHR for SDM

SDM element	PHR function by patient activity	Total No. Articles	PHR functional subcategory (article Reference)
Choice	Receive decision-support	15	intelligent alerts [28], [29], [21], [30], [23], [31], [32], [33], [34], [35], [5], [36], [37], [38], [25]
		14	reminders [26], [23], [31], [22], [24], [27], [20], [39], [34], [35], [5], [36], [8], [37]
		1	SDM infobutton – initiate and track [28]
Options		23	personalized decision support [28], [29], [21], [26], [23], [31], [40], [22], [32], [41], [27], [42], [33], [20], [39], [34], [35], [8], [43], [44], [38], [45], [46]
		8	decision aid [23], [22], [47], [33], [20], [35], [28], [38]
		5	preference elicitation [28], [26], [23], [27], [34]
Decision	Access health information	27	knowledge base (educational resources) [21], [30], [26], [23], [31], [40], [22], [32], [24], [41], [27], [48], [42], [33], [49], [20], [39], [34], [35], [5], [50], [36], [8], [43], [25], [45], [46]
		25	integrated health data from multiple sources [29], [26], [40], [22], [24], [51], [52], [47], [48], [42], [33], [49], [20], [34], [35], [50], [36], [8], [43], [44], [53], [37], [25], [45], [46]
		17	intelligent presentation of data [29], [21], [35], [31], [40], [22], [32], [52], [33], [49], [20], [39], [35], [5], [8], [43], [44], [54], [38], [55], [46]
		12	care plan [28], [29], [21], [41], [27], [48], [35], [5], [43], [55], [46]
		4	provider clinical notes [52], [50], [8], [25]
		3	provider annotated clinical data [23], [39], [8]
	Communicate with others	25	message care team [28], [21], [23], [31], [32], [24], [41], [52], [47], [48], [33], [49], [20], [39], [50], [36], [8], [43], [54], [53], [37], [38], [55], [25], [45]
		10	virtual support group/ networks [23], [41], [52], [47], [33], [49], [20], [39], [8], [25]
		4	virtual assistant [23], [33], [20], [46]
		3	interactive bulletin board [41], [39], [55]
		2	useful data export [49], [37]
Action	Record health information	19	subjective self-report - manual entry by user [29], [30], [31], [40], [32], [41], [47], [33], [49], [34], [35], [5], [50], [8], [43], [44], [54], [38], [25]
		16	objective monitoring - integrated via devices or applications [29], [26], [23], [31], [27], [33], [49], [20], [34], [8], [43], [44], [54], [55], [25], [46]
		12	personal narratives and pictures [21], [31], [27], [33], [39], [5], [43], [54], [37], [38], [25], [46]
		11	co-author care plan [48], [28], [32], [27], [47], [33], [49], [34], [8], [40], [44]
		10	structured templates – observations of daily living [31], [22], [32], [24], [47], [49], [20], [35], [8], [44]

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 a EHR-tethered system including a solution to the initiation of SDM between patient and provider – i.e. use of 'infobutton'[28].

Options in this subcategory is 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 medical profile, preferences and goals, and provider 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 the decision making rather than an elicitation of preferences in context of all factors for the decision at hand, at that point in time. While the inclusion of decision aids in PHRs to support patients with decisions by weighing the benefits, harms and scientific uncertainties improve outcomes[38],[47], its use 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 the patient clinical profile and clinical practice guidelines, and delivered in a meaningful way to explain outcomes and probabilities to patients has proved challenging and hence the 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 of 'Access health information'. 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 illness such as a diabetes dashboard.

The PHR functional subcategory of ‘Communicate with others’ was identified in 26 articles. The subcategory ‘message care team’ included synchronous and asynchronous communications with care providers and with 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. The capture of personal narratives and media indicates emotional and psychological clues about the health and wellness of the patient[39], complements traditional signs and symptoms of disease[54], and its importance for improved decision making is increasingly being recognized[25]. The notion of a co-authored care plan was often described as relevant for increasing engagement in self-management and operationalized as either a plan of upcoming activities based on recent trends, authored by the patient, and shared with the provider[27],[33] or operationalized 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. Most salient design issues included privacy and security, system usability, patient health literacy, and system accessibility via mobile devices. While 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 which comprised all four PHR functions by patient activity for SDM. Three general types of patient outcomes were identified including: (i) affective-cognitive outcomes which related mostly to impact on patient-provider communications and patient knowledge, and satisfaction and ease of care; (ii) behavioural outcomes which related mostly to impact on patient decision-making, medication management and adherence to health behaviours; and (iii) health outcomes which related mostly to impact on physiological measures, quality of life, and symptom management.

DISCUSSION

The principle discoveries are discussed within three specific areas including SDM via PHR gap, opportunities and challenges.

SDM via PHR gap

Despite the widespread advocacy for SDM and promise of PHR technology, this scoping review reveals a scarcity of research with any methodological rigour on SDM via PHR to-date. This likely corresponds with the short timeframe in which electronic health record systems, and more specifically PHRs, have been in usual healthcare 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 the body of literature evaluating the use of SDM and its effectiveness as a mechanism to improve patient outcomes[1] and the adoption, use, and impact evidence of PHRs[13],[56]. Still, almost half of the articles in the review were categorized as either a conceptual framework, model or focused discussion to inform system design and implementation. Of the articles categorized as original research, a few focused on system design evaluation, often via a user-centred design approaches, and the larger portion of these articles investigated the effect of system use, revealing some evidence of patient outcomes.

Importantly and with the exception of four original research investigations[[5],[8],[21],[31], the articles in this review did not investigate PHR for SDM as the decision making process is intended. SDM process has been lost in translation – i.e. 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 the identification of a decision-making opportunity[36], patient access to health information and educational resources to support informed decision-making[50], provision of decision support tools to aid the patient with informed choice[[22],[38],[45], or varying communications functionality to support online patient-provider interactions for decision-making[53].

The review also exposed that current SDM via PHR investigations are focused on the provision of generic decision aids as opposed to computer-tailored ones, limited in the idea of tracking the patient through a SDM process, and non-existent on the topic of computerized elicitation of patient preferences in the context of a decision. 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 expanded the initial SDM-PHR conceptual framework through the addition of 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 share decision-making-personal health record [*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 care providers and across multiple settings, integrated access to health information and resources are necessary and the presentation of the information to the patient needs to take into consideration the continuous, inter-organizational care process in order for patients to make informed decisions and engage in their care[49]. Additionally, the interplay between multiple sources in one comprehensive electronic health records platform may not only improve patient self-management, it can transform the tradition of episodic care to

a more continuous, collaborative one 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 healthcare system as a whole, it offers a wide array of benefits[43]. PHRs need to be designed not as a repository of health information, but rather as an interactive tool 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 the value of the PHR lies in shared information and in the action they enable – e.g. decision-making. Separating the data from the applications enables greater innovation in the services which can facilitate that action[54], creating a secure 'ecosystem' of data sources, services and applications. From a systems design perspective, two articles in the review modelled independently developed, shared applications[28][34], identifying increased value in the provision of services to both patient and provider through the separation of 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 has characterized 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 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 research opportunity.

Only a small portion of articles provided empirical evidence of patient outcomes; mostly relating impact on affective-cognitive and behavioural outcomes with limited evidence of health outcomes. These finding

are consistent with the literature on SDM and patient outcomes[1] and on the impact of PHRs on patient outcomes[6]. While one-third of articles providing demonstration of patient outcomes focused on diabetes, 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 which 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 article urged researchers to aid in evolving this theoretical concept to practical application; a situation yet to be realized.

SDM via PHR challenge

Healthcare is a complex sociotechnical system which 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 the broader systems and the performance of knowledge intensive and case specific SDM tasks. Due to the nature of the tasks needed to be performed by the system, the integration of data and the coordination of communication and decision support services within and between users are required. This will undoubtable require changing such things as healthcare policy and governance and patients and providers' attitudes and expectations.

Other key challenges include the way EHR systems and innovative applications will be integrated using interoperability, communications, and privacy and security standards while keeping patient computing

mobility in mind. In addition, given that there is an imperative for the liquidity of clinical and self-reported patient data, information management and semantic interoperability related to data exchange are critical to ensure data quality.

Finally, system acceptability and usability from the users' perspective must be addressed. Traditionally, the SDM process has relied heavily on face-to-face communication between provider and patient and often builds on history of interactions together. When technology becomes a component of the communication process, questions are raised about the role of technology itself as a barrier 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 raises the question, will using a PHR for SDM encounter similar provider resistance related to a perceived lack of human touch?

LIMITATIONS

As part of 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 which was developed through synthesis of a preliminary literature review. While the results from this scoping review expanded the conceptual framework producing an enhanced framework, *i*SDM-PHR, a validation by users should be completed. Further, the quality of the evidence which identified the PHR functionality for SDM was not assessed, only the frequency of report in the literature was collected and analysed. While articles published between 2005 and 2015 were included in this review, it may be that 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 nor evaluate the quality of studies to report on impact of SDM via PHR in terms of patient outcomes.

CONCLUSION

To our knowledge, this is the first scoping review that has exclusively considered the topic of SDM via PHR relating design and outcomes evidence to date. The failure of electronic health record systems to provide patients access to their health information, incorporate patient self-reported data into interconnected systems, and support shared decision making both during and between face-to-face visits, may have undesired consequences for patient health[25]. Just as the PHR designed on an interconnected architecture has the potential to facilitate SDM through the creation of a complete, shared and balanced profile of the patient and the provision of personalized decision support and communications tools, so too does the 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 SDM in routine practice for patients and their providers within today's electronic health record environment.

SIGNIFICANCE

The research advances of 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.

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COMPETING INTERESTS

The authors declare that they have no competing interests.

PROVENANCE AND PEER REVIEW

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

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Supplemental File#1: Descriptive Characteristics of Included Articles

This file contains reference citations and descriptive data from the articles included in the scoping review.

Figure/ Illustration Captions

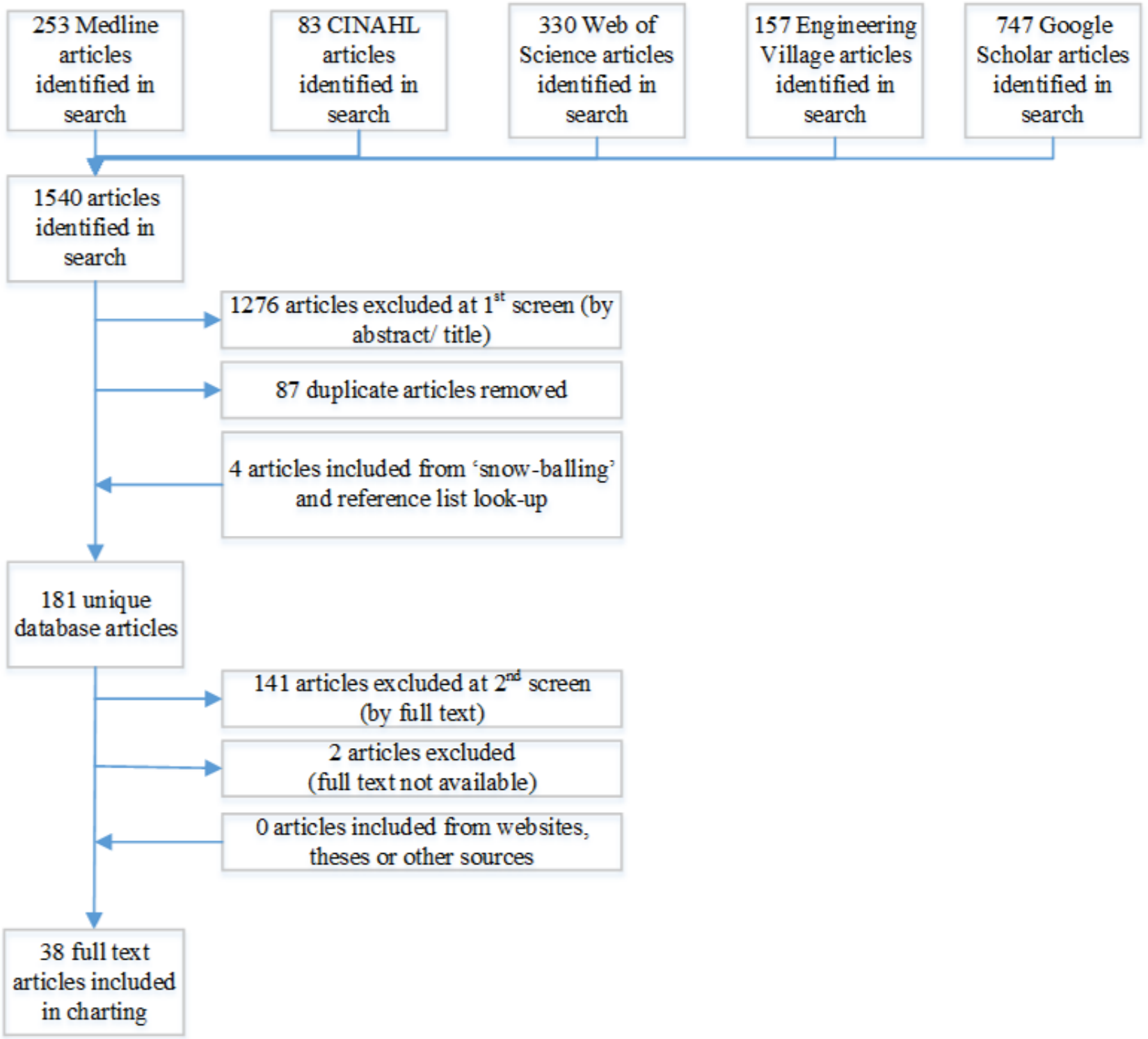
Figure 1: Flow diagram for Article Selection Process

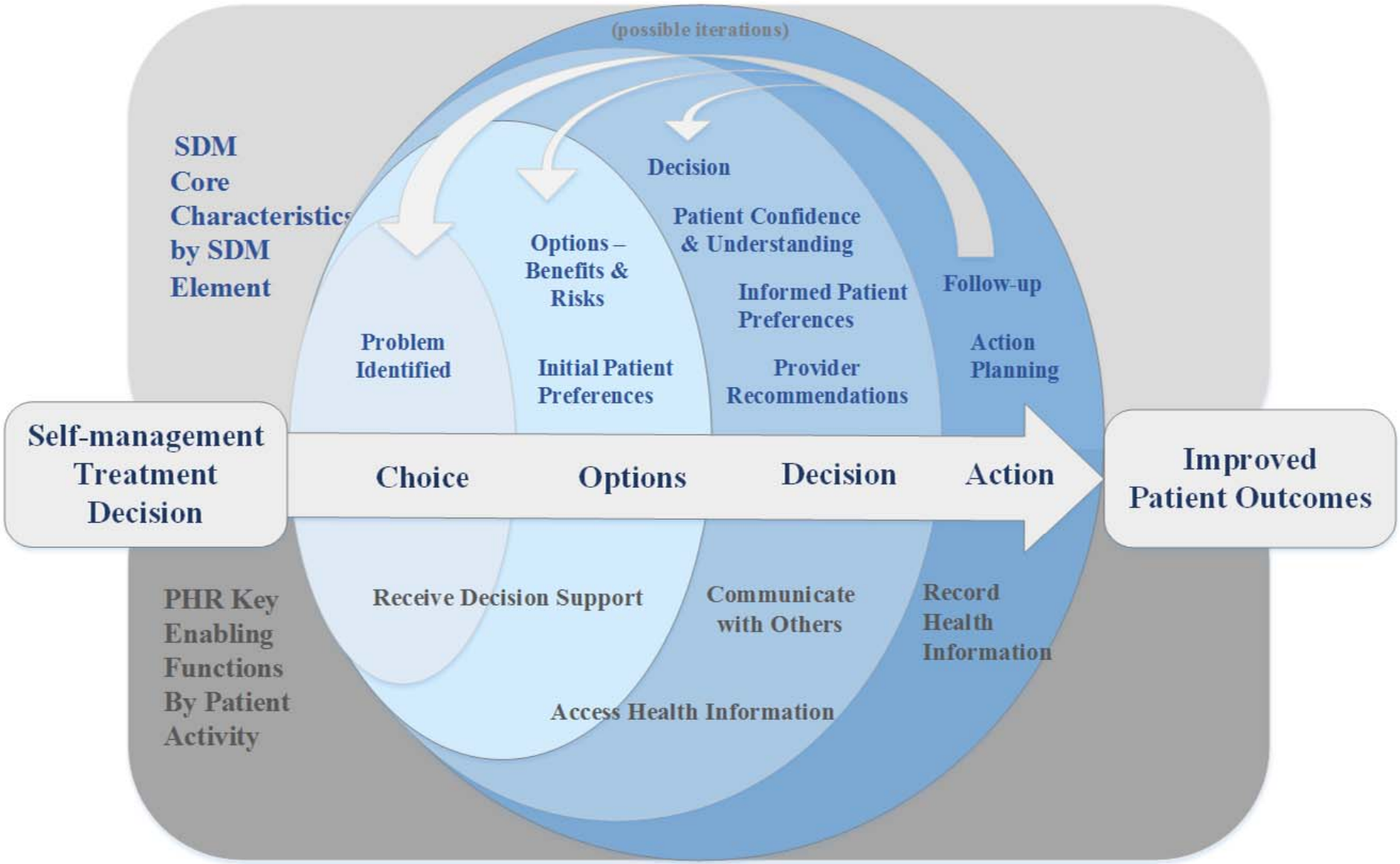
Figure 2: SDM-PHR Conceptual Framework

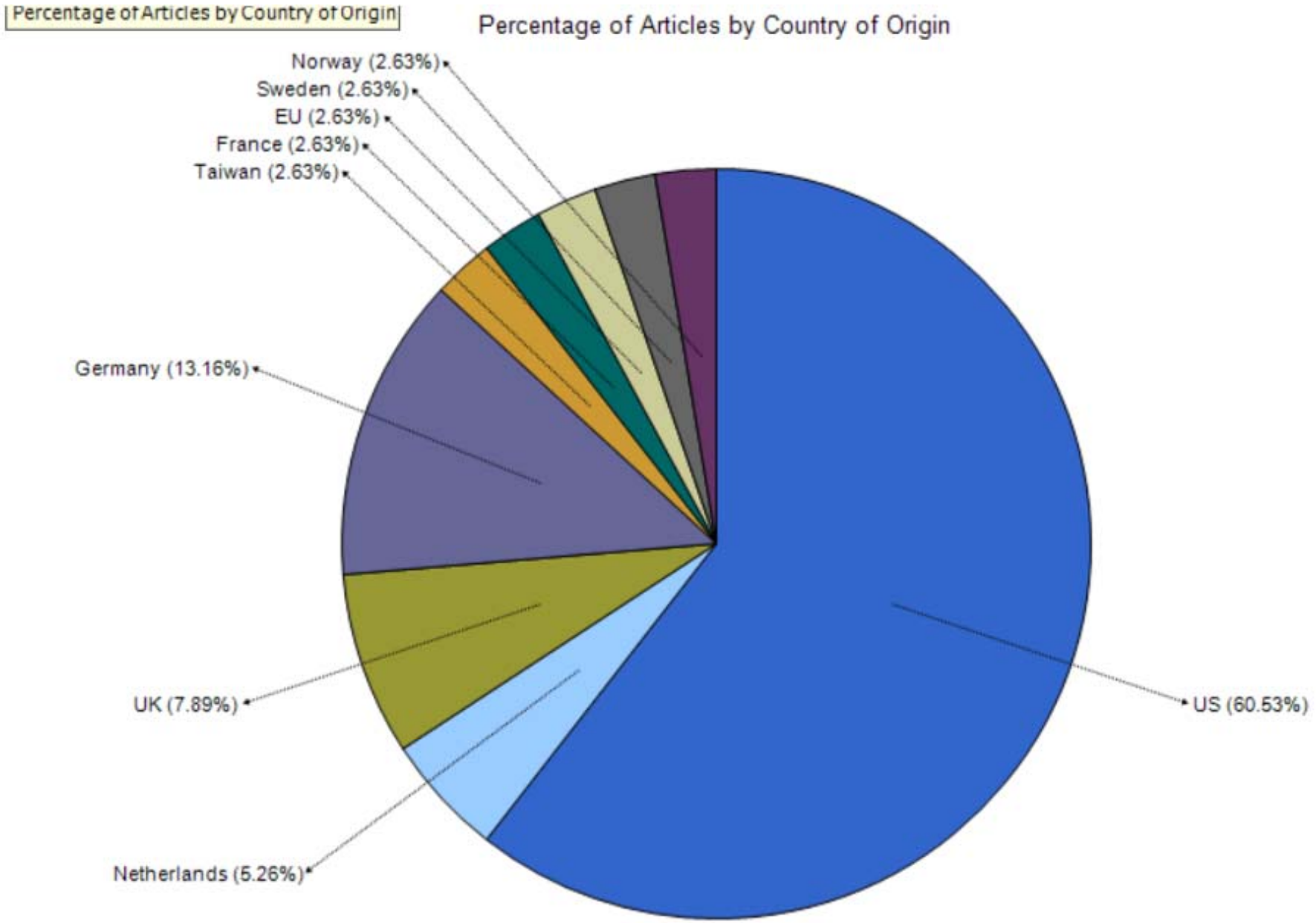
Figure 3: Percentage of Articles by Country of Origin

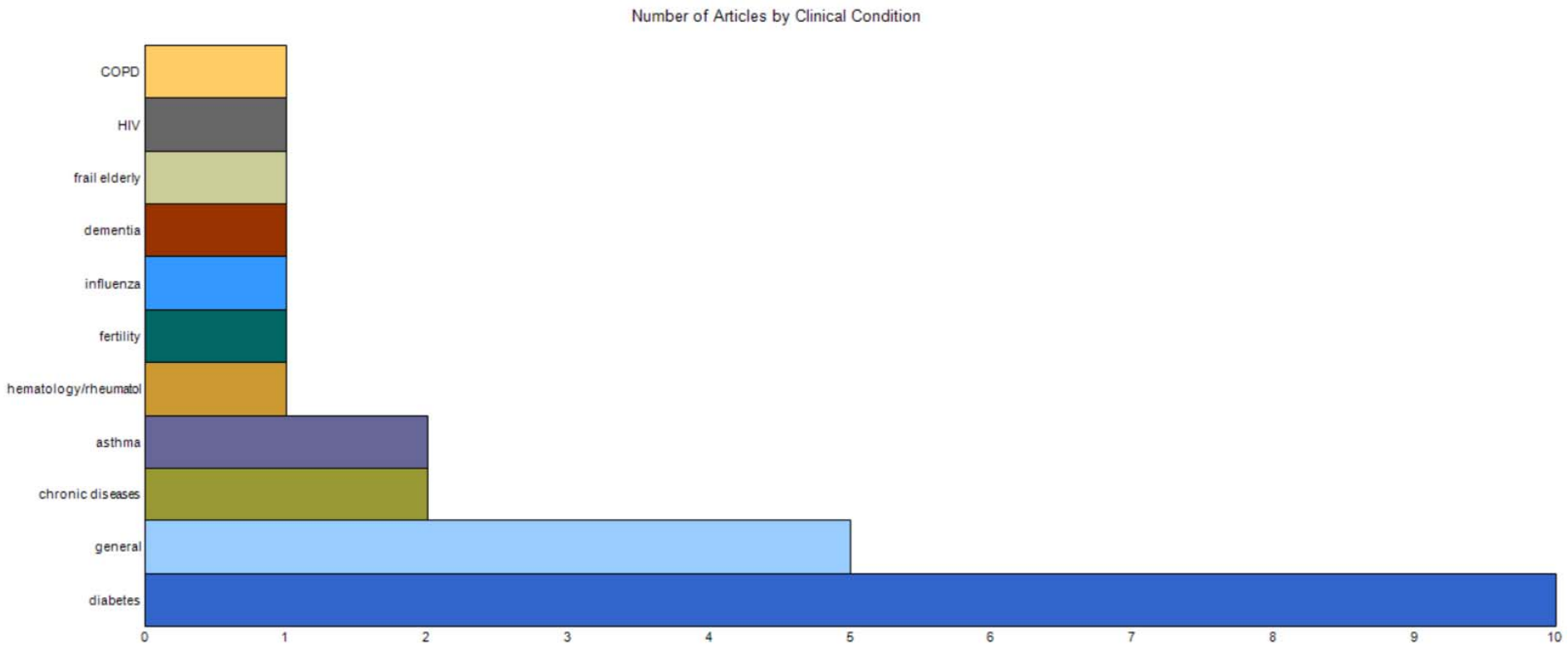
Figure 4: Number of Articles by Clinical Condition

Figure 5: *i*SDM-PHR Conceptual Framework


253 Medline articles identified in search
83 CINAHL articles identified in search
330 Web of Science articles identified in search
157 Engineering Village articles identified in search
747 Google Scholar articles identified in search
1540 articles identified in search
1276 articles excluded at 1st screen (by abstract/ title)
87 duplicate articles removed
4 articles included from 'snow-balling' and reference list look-up
181 unique database articles
141 articles excluded at 2nd screen (by full text)
2 articles excluded (full text not available)
0 articles included from websites, theses or other sources
38 full text articles included in charting


(possible iterations)
SDM Core Characteristics by SDM Element
Decision
Patient Confidence & Understanding
Options – Benefits & Risks
Informed Patient Preferences
Follow-up
Problem Identified
Initial Patient Preferences
Provider Recommendations
Action Planning
Self-management Treatment Decision
Choice
Options
Decision
Action
Improved Patient Outcomes
PHR Key Enabling Functions By Patient Activity
Receive Decision Support
Communicate with Others
Record Health Information
Access Health Information


Percentage of Articles by Country of Origin
Percentage of Articles by Country of Origin
Norway (2.63%)
Sweden (2.63%)
EU (2.63%)
France (2.63%)
Taiwan (2.63%)
Germany (13.16%)
UK (7.89%)
Netherlands (5.26%)
US (60.53%)


Number of Articles by Clinical Condition
COPD
HIV
frail elderly
dementia
influenza
fertility
hematology/rheumatol
asthma
chronic diseases
general
diabetes
0
1
2
3
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8
9
10

SDM Core Elements	Action						Choice		Options			Decision											
PHR Functional Sub-categories	Subjective self-report	Objective monitoring	Personal narratives and pictures	Co-author care plan	Structured templates	Reminders	Intelligent alerts	SDM info button - initiate and track	Personalized decision-support	Decision aid	Preference elicitation	Educational resources	Integrated health data from multiple	Intelligent presentation of data	Care plan	Provider clinical notes	Provider annotated clinical data	Message care team	Virtual support group/networks	Virtual assistant	Interactive bulletin board	Useful data export
PHR Core Functions by Patient Activity	Record health information						Receive decision-support					Access health information						Communicate with others				

Supplementary File #1: Descriptive Characteristics of Included Articles

Reference	Article Title	Category	Article Type	Study Design	Country	Clinical Condition	Patient Subgroup (for PHR use)	PHR function by patient activity for SDM (studied)*	PHR Type addressed**
(46)	Web-of-Things inspired e-Health platform for integrated diabetes care management	design	Methodological approach		UK	type 1 diabetes			interconnected
(31)	Continuous, Personalized Healthcare Integrated Platform	design + outcomes	original research	post-test with control	Taiwan	diabetes Type 1&2	adults	ALL	standalone
(43)	Personal health records: empowering consumers.	design	Focused discussion		US				interconnected
(33)	Improving diabetes management with electronic health records and patients' health records	design	Focused discussion		France	diabetes Type 1&2			tethered
(55)	Teaming up: feasibility of an online treatment environment for adolescents with type 1 diabetes	design + outcomes	original research	feasibility study: pre-post with control	Netherlands	type 1 diabetes	youth	access, communicate, record	standalone
(54)	Project HealthDesign: rethinking the power and potential of personal health records	design	Methodological approach		US				standalone
(47)	Expert patients	design	Focused discussion		UK				interconnected; tethered
(20)	Integrated personal health records: transformative tools for consumer-centric care.	design	Focused discussion		US				interconnected; tethered
(5)	Parent-reported outcomes of a shared decision-making portal in asthma: a practice-based RCT	design + outcomes	original research	Prospective RCT	US	asthma	child	ALL	tethered
(21)	A shared e-decision support portal for pediatric asthma.	design	original research	user-centered design: interviews and focus groups	US	asthma	child	ALL	tethered
(30)	Activation of persons living with HIV for treatment, the great study	design + outcomes	original research	pre-, post-test pilot; RCT protocol	US	HIV	adults	access, receive	standalone
(26)	Combining iGoogle and Personal	design	original research	user-	US	diabetes	adults	access,	interconnected

Reference	Article Title	Category	Article Type	Study Design	Country	Clinical Condition	Patient Subgroup (for PHR use)	PHR function by patient activity for SDM (studied)*	PHR Type addressed**
	Health Records to Create a Prototype Personal Health Application for Diabetes Self-Management			centered design: focus groups		Type 1&2		record, receive	
(37)	Standalone personal health records in the United States: meeting patient desires	design	original research	descriptive study	US	general		access, receive, communicate	standalone
(52)	e-Patients Perceptions of Using Personal Health Records for Self-management Support of Chronic Illness	design + outcomes	original research	interviews	US	Multiple chronic diseases	adults	access, communicate	tethered
(44)	Design and implementation of a web based patient portal linked to an ambulatory care electronic health record: Patient Gateway for diabetes collaborative care	design	Methodological approach		US	diabetes type 2			tethered
(40)	Practice-Linked Online Personal Health Records for Type 2 Diabetes Mellitus	design + outcomes	original research	RCT	US	diabetes Type 1&2	adults	access, record, receive,	tethered
(29)	A sensor-enhanced health information system to support automatically controlled exercise training of COPD patients	design	Model		Germany	COPD			interconnected
(36)	Patterns of Response to Patient-Centered Decision Support Through a Personal Health Record	design + outcomes	original research	post test	US	Diabetes (able to extract from article)	adults	receive	tethered
(23)	Consumer Health Informatics and Personal Health Records	design	Focused discussion		US				interconnected
(24)	Disruptive Digital Innovation in Healthcare Delivery: The Case for Patient Portals and Online Clinical Consultations	design	Focused discussion		US				tethered
(49)	Improving quality of life through eHealth - the patient perspective	design	Focused discussion		Sweden				interconnected
(35)	MyPreventiveCare: implementation and	design	original research	randomized cluster trial	US	general	adults	access, record,	tethered

Reference	Article Title	Category	Article Type	Study Design	Country	Clinical Condition	Patient Subgroup (for PHR use)	PHR function by patient activity for SDM (studied)*	PHR Type addressed**
	dissemination of an interactive preventive health record in three practice-based research networks serving disadvantaged patients—a randomized cluster trial			protocol				receive	
(22)	Designing a patient-centered personal health record to promote preventive care	design + outcomes	original research	post test	US	general	adults	access, record, receive	standalone; tethered
(28)	A model to support shared decision making in electronic health records systems.	design	Model		US				tethered
(27)	EMPOWER-support of patient empowerment by an intelligent self-management pathway for patients: study protocol	design	original research	RCT protocol	Germany & Turkey	type 1 & 2 diabetes	adults		interconnected
(51)	Embedding online patient record access in UK primary care: a survey of stakeholder experiences	design + outcomes	original research	post- survey	UK	general	adults	access	tethered
(39)	Living Profiles: an example of user-centered design in developing a teen-oriented personal health record	design	original research	user-centred design: interviews	US	Hematology and rheumatology disorders	youth	access, record	standalone
(34)	Making Healthcare More Accessible; Better; Faster; and Cheaper: The MobiGuide Project	design	Methodological approach		EU				interconnected
(48)	Filling the Gaps in a Fragmented Health Care System: Development of the Health and Welfare Information Portal (ZWIP)	design	original research	interviews	Netherlands	frail elderly	adults	access, record, communicate	tethered
(32)	Developing a shared electronic health record for patients and clinicians	design	Methodological approach		Norway				interconnected
(25)	Transforming health care delivery through consumer engagement, health data	design	Focused discussion		US				interconnected

Reference	Article Title	Category	Article Type	Study Design	Country	Clinical Condition	Patient Subgroup (for PHR use)	PHR function by patient activity for SDM (studied)*	PHR Type addressed**
	transparency, and patient-generated health information								
(38)	Tailored e-Health services for the dementia care setting: a pilot study of 'eHealthMonitor'	design + outcomes	original research	user centered design: interviews	Germany	dementia	adults	receive, record, communicate	standalone
(45)	Triaging patients at risk of influenza using a patient portal	design + outcomes	original research	post test	US	influenza	adults	access, receive	tethered
(41)	Empowering patients undergoing in vitro fertilization by providing Internet access to medical data	design + outcomes	original research	RCT	Netherlands	Fertiltiy	adults	access, communicate	standalone
(53)	Secure messaging and diabetes management: experiences and perspectives of patient portal users	design + outcomes	original research	interview and survey	US	Type 2 diabetes	adults	access, communicate	tethered
(8)	Personal Health Records for Patients with Chronic Disease	design	original research	interviews and survey	US	Chronic diseases	adults	ALL	tethered
(42)	Health Recommender Systems: Concepts, Requirements, Technical Basics and Challenges	design	Methodological approach		Germany				interconnected
(50)	Patient Experiences With Full Electronic Access to Health Records and Clinical Notes Through the My HealtheVet Personal Health Record Pilot: Qualitative Study	design + outcomes	original research	focus groups	US	general	adults	access	tethered

*access = access to health information; record = record health information; communicate = communicate with others, receive = receive decision-support; ALL= all four functions

**some articles addressed more than one PHR architectural type