

Prerequisites of Personal Health Record for Chronic Kidney Disease: A Scoping Review and Evaluation of the Content Validity

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Abstract. Background: It is obvious that the Personal Health Record (PHR) is a major cornerstone for “improving the self-management of patient”. However, lack of an effective and comprehensive personal health record system prohibits the widespread use of PHRs. The aim of this study was to identify the core data sets and required functionalities for designing a PHRs for chronic kidney disease (CKD) management and assess their validity. **Methods:** It was a study including two phases. In the initial phase, a scoping review was conducted with the aim of determination the core data sets and required functionalities for designing PHRs. Then in the second phase, the validity of data items and functionalities was determined by 25 multidisciplinary experts. **Results:** 22 studies were eligible after screening 1335 titles and abstracts and reviewing 88 full texts. We determined 20 core data set and 8 required functionalities of PHRs. From the perspective of experts, ‘health maintenance’ and ‘advance directives’ were most often marked as useful but not essential, while ‘test and examination’, ‘medication list’ and ‘diagnosis and comorbid conditions’ were predominantly considered as essential by all experts (n=25,100%). **Conclusion:** This research is a step that we have taken to identify prerequisites that could be used for the design, development, and implementation of an effective and comprehensive electronic personal health record.

Keywords. Chronic Kidney Disease, Personal Health Record, PHR, CKD, Core data sets

1. Introduction

Significant social and economic burdens of chronic diseases have led to a shift in the health policy, involving a focus on health promotion, chronic disease prevention, and self-management [1]. Chronic kidney disease (CKD) is a major public health concern [2-

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4]. More than 70 million individuals worldwide have CKD, and according to estimates, the prevalence will further increase as will the already enormous impact CKD has on health system resources related to its care [5,6]. Health information technologies (ITs) have the potential to significantly increase the engagement of patients by using personal health records (PHRs) to electronically connect them to their health information and clinical team and continuity of care [7]. PHR is a tool that has the potential to change and possibly to improve patient-provider relationship and enable the healthcare system to evolve a more personalized medical model and promising results to address some of these challenges [8-10]. Unfortunately, designing and developing programs that improve patient care and obtaining complete and high-quality data in nephrology have remained a challenge [11]. The literature does not yet adequately describe the potential functions and prerequisites of PHRs design [12-15]. So, the objectives of these study were to derive core data sets and functionalities specifically for PHRs for patients diagnosed with CKD and determine the validity of these core data sets and functionalities.

2. Method

This review was guided by Arksey and O'Malley's 6-stage scoping review framework [16]. We searched for relevant articles written in English between 1990 and Jan 2021 using PubMed, Science Direct, Web of Science and Embase databases, and the related websites such as guideline.gov, IEEE, and WHO. A combination of keywords and Medical Subject Headings (MeSH) were used as follows: group A included PHR-related terms and group B included terms related to "kidney failure chronic." We considered all the full text papers with quantitative, qualitative, or mix method designs and full reports that studied PHRs and determined the data elements and functionalities of chronic kidney disease PHR. However, the papers in the formats of letter to editor, short communication and commentary, and articles in non-English language or those with English abstracts published in languages other than English were excluded. Additionally, if the study was about a personal electronic record but had not the state data items and functionalities, it was excluded from the study. After searching the studies from all databases and eliminating duplicates, the studies were independently reviewed and screened by two members of the research team (FS and RSH) in three phases by title, abstract, and then the full text of the articles. Studies meeting the inclusion criteria were critically reviewed using Arksey and O'Malley's summative analysis method [16] according to the frequency of the items in the included studies. To validate the core data sets and functionalities, we formed an expert panel. The panel consisted of 25 multidisciplinary experts that were recruited base purposive sampling. In this way, the experts are requested to specify whether the core data sets and functionalities is necessary for designing a PHR for CKD or not via email. To this end, they are requested to score each item from 1 to 3 with a three-degree range of "not necessary, useful but not essential, essential" respectively. The formula of content validity ratio is $CVR = (N_e - N/2) / (N/2)$, in which the N_e is the number of panelists indicating "essential" and N is the total number of panelists. The numeric value of content validity ratio is determined by Lawshe table [17]. Ethical approval was received from the Shiraz University of Medical Sciences by Dr Abbas Rezaeianzadeh, (Ethical number: IR.SUMS.REC.AC.IR.1399.1310).

3. Results

In total, 1335 studies were selected after searching the databases. After removing the duplicates, screening, and applying inclusion and exclusion criteria, 88 studies were eligible for further full-text review. Thereafter, 16 articles, 4 reports, and 2 guidelines were selected for the final analysis.

Most studies were journal article ($n=16$, 76%), published in the USA ($n=10$, 45%), and published between 2012 and 2018 ($n=15$, 71%) (Table1).

Table1. Description of included study

First author name & [Ref]	Resource type	Publication Date	Country/Institution
Venuthurupalli [18]	Article (Cross sectional)	2017	Australia
Navaneethan [19]	Article (Cross sectional)	2012	USA
Nakashima [10]	Article (Cross sectional)	2019	Japan
Mendu [6]	Article (Prospective study)	2014	USA
Drawz [20]	Article (RCT)	2012	USA
Mendu [21]	Article (Cross sectional)	2019	USA
Drawz [22]	Article (Review)	2015	USA
Khan [23]	Article (Cross sectional)	2013	USA
Venuthurupalli [24]	Article (Cohort)	2018	Australia
Bruland [25]	Article (Case report)	2016	Germany
Do [26]	Article (project report)	2011	USA
Archer [9]	Article (Review)	2011	Canada
Kaelber [11]	Article (Cross sectional)	2008	USA
Gearon [27]	Report	2007	California
Tran [28]	Guideline	2012	USA
Burke-Bebee [29]	Report	2010	USA
Johnston [30]	Report	2007	AMIA
Roehrs [31]	Article (Review)	2017	Brazil
Tang [32]	Article	2006	USA
Dickinson [33]	Guideline	2014	USA
Unknown [34]	Report	2012	European
Katehakis [35]	Article (Review)	2017	Greece

Table2. Core data sets for designing PHRs for chronic kidney disease based on evidence and expert panel.

Core Data Sets	Frequency (%)	Expert Panel			CVR*	Interpretation
		Essential	Useful not essential	Unnecessary		
Problem list	7(31.81%)	24(96%)	1(4%)	0	0.92	Remained
Surgical procedures	2(9.00%)	23(92%)	1(4%)	1(4%)	0.84	Remained
Diagnosis/comorbid conditions	9(40.90%)	25(100%)	0	0	1	Remained
Medications list	12(54.54%)	25(100%)	0	0	1	Remained
Risk factors & allergies	8(36.36%)	23(92%)	2(8%)	0	0.84	Remained
Demographics data	9 (40.90%)	24(96%)	1(4%)	0	0.92	Remained
Health maintenance	1(4.54%)	16(64%)	7(28%)	2(8%)	0.28	Eliminated
Disease characteristic	2(9.00%)	24(96%)	1(4%)	0	0.92	Remained
Advance directives	2(9.00%)	17(68%)	2(8%)	6(22%)	0.36	Eliminated
Physical examination	2(9.00%)	22(88%)	2(8%)	1(4%)	0.76	Remained
Wellness management	3(13.62%)	22(88%)	3(12%)	0	0.76	Remained
Care plan	2(9.00%)	23(92%)	1(4%)	1(4%)	0.84	Remained
Health summary	6 (27.27%)	23(92%)	2(8%)	0	0.84	Remained
Family record& history	7 (31.81%)	24(96%)	1(4%)	0	0.92	Remained
Genetic data	2(9.00%)	20(80%)	3(12%)	2(8%)	0.60	Remained
Health patterns	7(31.81%)	20(74%)	4(14%)	1(4%)	0.60	Remained
Test and examination	17(77.27%)	27(100%)	0	0	1	Remained
Functional status	2(9.00%)	21(84%)	3(12%)	1(4%)	0.68	Remained

Finally, 124 data items were identified from the literature that classified in 20 core data set. "Test and examination" was the most common core data set examined ($n = 17$) in the included studies. Other common core data item examined included medication list ($n=12$), "diagnosis and comorbid conditions", "preventive care & immunization" and "demographics data" ($n=9$). About data sets, 'health maintenance', and 'advance directives' were most often marked as useful but not essential or unnecessary, while 'test

and examination', 'medication list' and 'diagnosis and comorbid conditions', were predominantly considered as essential by all experts (n= 25, 100%) (Table2).

Table 3. Required functionality in designing PHRs for CKD based on evidence and expert panel.

Required functionality	Sub items	Frequency	Expert plan			CVR*
			Essential	Useful, not essential	Unnecessary	
Historical data	Manage historical clinical data	4(18.18%)	24(96%)	1(4%)	0	0.92
Management observations	Manage clinical observations	3(13.62%)	18(72%)	7(28%)	0	0.44
	Manage test results	3(13.62%)	25(100%)	0	0	1
	Manage provider care plans	2(9.00%)	23(92%)	1(4%)	1(4%)	0.84
	Manage health calendar	2(9.00%)	23(92%)	1(4%)	1(4%)	0.84
	Manage medication	9(40.90%)	25(100%)	0	0	1
Management of decision support	Manage drug interaction checking	3(13.62%)	18(72%)	7(28%)	0	0.44
	Manage guidelines and protocols	2(9.00%)	21(84%)	2(8%)	2(8%)	0.68
	Manage health alerts	3(13.62%)	23(92%)	2(8%)	0	0.84
	Manage health reminders	6(27.27%)	23(92%)	0	2(8%)	0.84
Management of patient support	Manage custom patient education	6(27.27%)	23(92%)	2(8%)	0	0.84
	Manage family education	2(9.00%)	23(92%)	2(8%)	0	0.84
	Manage data input errors	3(13.62%)	24(96%)	1(4%)	0	0.92
	Manage trading patterns	2(9.00%)	21(84%)	2(8%)	2(8%)	0.68
	Manage shared patient experience	4(18.18%)	15(60%)	1(4%)	9(36%)	0.20
Management of security	Manage results notification	2(9.00%)	23(92%)	2(8%)	0	0.84
	Manage secure the access to PHR	2(9.00%)	24(96%)	1(4%)	0	0.92
	Manage entity authentication	2(9.00%)	24(96%)	1(4%)	0	0.92
	Manage entity authorization	2(9.00%)	24(96%)	1(4%)	0	0.92
	Manage secure data exchange	2(9.00%)	24(96%)	1(4%)	0	0.92
	Manage patient privacy	4(18.18%)	24(96%)	1(4%)	0	0.92
	Manage secure messaging	3(13.62%)	24(96%)	1(4%)	0	0.92
	Manage consents and authorizations	2(9.00%)	23(92%)	1(4%)	1(4%)	0.84
	Manage data masking for sensitive	2(9.00%)	22(88%)	3(12%)	0	0.76
	Manage a registry of actors	2(9.00%)	24(96%)	1(4%)	0	0.92
Management of administrative issues	Manage demographics information	3(13.62%)	24(96%)	1(4%)	0	0.92
	Manage scheduling	7(31.81%)	24(96%)	1(4%)	0	0.92
	Manage advance care directives	2(9.00%)	17(68%)	2(8%)	6(24%)	0.36
	Manage insurance eligibility	3(13.62%)	21(84%)	1(4%)	3(12%)	0.68
	Manage clinical trial recruitment	2(9.00%)	22(88%)	0	3(12%)	0.76
	Manage multiple views of data	2(9.00%)	22(88%)	3(11%)	0	0.76
	Manage donor information	2(9.00%)	16(64%)	5(20%)	4(16%)	0.28
	Manage access to public health	2(9.00%)	20(80%)	4(16%)	1(4%)	0.60
	Manage clinical research	2(9.00%)	24(96%)	0	1(4%)	0.92
	Manage clinical dashboard	3(13.62%)	22(88%)	2(8%)	1(4%)	0.76
Management of electronic communication	Manage team coordination	2(9.00%)	23(92%)	2(8%)	0	0.84
	Manage of communication	9(40.90%)	25(100%)	0	0	1
	Manage contact information	5(22.72%)	23(92%)	2(8%)	0	0.84
	Manage referral authorizations	3(13.62%)	16(64%)	6(24%)	3(12%)	0.28
Management health monitoring	Manage Home monitoring	8(36.36%)	23(92%)	2(8%)	0	0.84
	Manage wellness, preventive, life style	4(18.18%)	23(92%)	1(4%)	1(4%)	0.84

NOTE: *CVR or Content Validity Ratio = (N_c-N₂)/ (N/2) with 25 persons at the expert panel (N=25), the items with the CVR bigger than 0.37 remained at the instrument and the rest eliminated.

In terms of required functionalities, 'manage of communication, 'manage medications' and 'manage test and examination' were considered as essential by all experts (n= 25, 100%). Management of clinical research information and clinical trial recruitment were other functionalities recommended by experts. According to result of expert panel, 2 items out of core data sets items (health maintenance & advance directives) and 4 items out of functionalities (manage shared patient experience, manage advance directives, manage donor information & manage referral authorizations) were eliminated (Table 2&3).

4. Discussion

Based on the results of our study, 20 core data sets were determined. Core data items proposed by this study covered all 11 data components essential for PHRs that were prepared by consensus set of standards of CCD, CCA, CCR, AHIMA, AMIA, DICOM, immunizations, medications, allergies, family history, lab/test results, and procedures/surgeries [28,32]. The corresponding PHRs for CKD, ‘advanced directives’, was checked as unnecessary in most of responses by experts. Considering that advanced directives are not popular in Iran, the number was expected. These findings contrast with other countries which “advanced directives” is very important and, indeed, the legal right of the patient [28,36]. These differ may be due to cultural differences between Iran and other countries might influence the choice of key data sets/functionalities. Essential functionalities that recommended by experts in designing PHRs for CKD were consistent with the results of other on literature [6,10,11,18,19,26,28,29]. An innovative function under strong focused of experts is the “custom patient education”. Health care delivery moves towards a more consumer focused, personalized care, patients and individuals’ roles grow, and many potential advantages of the PHR have been portrayed [37].

5. Conclusions

We propose pre-requisites of personal health record consisting of 20 core data sets and 8 main functionalities for CKD patient. These pre-requisites could be used for designing and implementing effective and comprehensive PHRs for chronic kidney disease management.

Acknowledgment

This article is adopted from a PhD dissertation approved by Shiraz University of medical sciences, Shiraz, Iran

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