Are Personal Health Records (PHRs) Facilitating Patient Safety? A Scoping Review

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Abstract. Personal Health Records (PHRs) are poised to improve patient safety, however the mechanism(s) in which they improve safety is not clear. To this end, we conducted a scoping review with the following objectives: 1) explore the extent of the evidence that PHRs improve patient safety, 2) determine where PHR research has been done per International Medical Informatics Association (IMIA) Represented Region [1], 3) to identify the PHR naming convention(s) used per IMIA Region [1]. The findings revealed that there is limited evidence that PHRs improve patient safety. The results also revealed heterogeneity in PHR nomenclature and how they were used in healthcare settings. However, the overarching theme of the study, was that future research is needed to ensure that PHRs are designed and used in a patient safety context with human factors and usability considerations.

Keywords. Personal health record, patient safety, patient portal, health informatics

1. Introduction

Personal Health Records (PHRs) have gained market prominence as healthcare technologies, poised to improve patient safety. PHRs are electronic applications that enable authorized citizens to access, share, and manage health information in secure and confidential environments [2]. To understand their true value, PHRs must be contextualized as dynamic heterogeneous tools. Currently PHRs lack nomenclative consistency, functionality and design standardization. They have range from web-based applications, stand-alone systems, to programs tethered to a patient electronic health record (EHR) or electronic medical record (EMR) [2]. Consequently, limited longitudinal and empirical data is available to assess PHRs from broad perspectives and thus evidence of their impact on patient safety has remained unclear. The objectives of this scoping review were to: 1) establish the extent of the evidence that PHRs improved patient safety, 2) determine where PHR research has been done per International Medical

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Informatics Association (IMIA) Represented Region [1], 3) to identify the PHR naming convention(s) used per IMIA Region [2].

2. Methods

We conducted a scoping review following the Arksey and O'Malley framework [3] using the PubMed® database, with the search terms "Personal Health Record" and "Patient Safety." PubMed® was utilized as it provided a robust sample of currently available published literature. To support interpretive consistency, prior to screening the articles, the researchers defined the terms PHR and patient safety. For the purposes of this study, we defined PHRs as the variety of electronic applications that enabled authorized citizens to access, share and manage health information in secure and confidential environments [2]. Thus, various terms and technologies that enabled citizens to modify and access their health information were categorized under the PHR umbrella. We defined patient safety as the opportunity to detect errors or risks in the healthcare system and remedy them to provide optimal patient outcomes [4]. Following this, two researchers conducted a first screen of the search results by title and abstract in Covidence®, then applied the following inclusion criteria: English articles (with abstracts) published between 2011-2021; PHR articles with a relationship to patient safety; PHRs tethered to EHRs or EMRs; PHRs with a different naming convention in which the data was maintained or modifiable by the patient or authorized delegate; electronic PHRs; PHR prototypes tested with patient populations. Articles that did not satisfy the inclusion criteria were excluded from the study. Once the final article sample was established, the authors completed a full text review of all remaining articles and tabulated the findings in a data extraction table (Table 1) for thematic analysis. The articles were iteratively assessed by two researchers based on the inclusion criteria and conflicts were resolved through discussion and consensus. A perceived limitation of the study, was the inclusion of electronically available English articles only and therefore other relevant articles may have been omitted based on this criteria. Additionally, as the intent of a scoping review is to provide a holistic assessment of the current state of the literature, all articles that satisfied the inclusion criteria were included, regardless of study design and methodological quality [3,5]. An ethics review was not required, as this was an assessment of publicly available literature.

3. Results

The search yielded 402 articles, with no duplicates and thus, all 402 articles were included in the first screen and assessed by title and abstract. From this, 336 articles were excluded as they did not meet the inclusion criteria and a full text review of the remaining 66 articles was done. After the 66 articles were read in full, another 44 articles were excluded and resulted in a final inclusion of 22 articles[2]. Of those 22 articles, 13 showed evidence that PHRs facilitated patient safety. We extracted the data (Table 1) using the following categories: PHR naming convention, IMIA Region [1], description of safety impact, thematic category. The four thematic categories identified in the literature were:

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[2] For a complete reference list of all included articles, please contact the corresponding author.

1) shared decision making, 2) communication challenges, 3) medication safety, 4) usability and design challenges. Lastly, to facilitate comparative analysis, study specific acronyms were created for the PHR naming conventions, thematic categories and the IMIA Region [1] acronyms were utilized (Table 1).

Table 1. Data extraction

Naming convention	IMIA Region [1]	Description of safety impact	Thematic category	Reference
PHR, PP, EPR	APAMI, EFMI, MENAHI, NAMI	Health information systems have helped citizens improve their health status and manage their care with health professionals.	SDM	[6]
PHR	NAMI	PHR improved medication reconciliation self-management with patients and providers.	MS	[7]
PWP	NAMI	Portal communication was safe and effective, but unread message notifications posed risks.	CC	[8]
PP	N/A	Patient portals enabled discovery of medical errors and improved medication adherence.	MS	[9]
EPP	EFMI	42% of participants identified inaccuracies in clinical documents.	SDM	[10]
PP	EFMI	Patients had difficulties interpreting and understanding laboratory test results.	CC	[11]
PP	NAMI*	Patients and families identified errors and recognized quality problems in their records.	SDM	[12]
ACP	NAMI	Participants found medical terms and acronyms in clinical notes hard to understand.	CC	[13]
IP	NAMI	The portal facilitated recognition of medication errors.	MS	[14]
PP	NAMI	Participants reported errors online and 93% found that reporting mistakes improved safety.	MS	[15]
OPHR	NAMI	The PHR tool improved safety and decreased patient-reported medication errors.	MS	[16]
PMR	N/A	Patients were able to correct mistakes and discrepancies in their medical file themselves.	SDM	[17]
PHR	NAMI	Interception of medication dosing errors was achieved by patients accessing their data.	MS	[18]

*Assumption: authors are affiliated with NAMI Region institutions.
Naming convention(s):Personal health record (PHR), patient portal (PP), electronic patient record (EPR), patient web portal (PWP), electronic patient portal (EPP), acute care portal (ACP), inpatient portal (IP), online PHR (OPHR), personal medical record (PMR). Region: Asia Pacific (APAMI), European (EFMI), Middle East and North African (MENAHIA), North America (NAMI). Thematic categories: Shared decision making (SDM), communication challenges (CC), medication safety (MS), usability and design challenges (UDC).

The results of the thematic analysis indicated that 9 of the 22 of the articles represented medication safety issues and how PHR interventions impacted medication administration (e.g., reconciliation, error detection, dosage). Whereas 6 articles described communication challenges between providers and citizens with PHR use. Shared decision making in which citizen and provider collaboration was established through frequent communication and open medical record access, was present in 5 articles. Lastly, 2 articles described usability and design challenges which prevented citizens from using PHRs safely, effectively and enjoyably [19]. The findings (Table 1) revealed that heterogeneity existed in: PHR naming convention(s), where PHR research has been done, how PHRs impacted safety, thematic category. There was evidence that PHRs facilitated patient safety in 13 articles, however, 9 articles failed to provide clear evidence that PHR use improved patient safety (Figure 1).
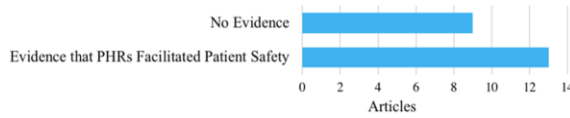
Figure 1. Evidence of patient safety in the literature

The findings revealed that there is much to learn about the relationship between PHRs and patient safety. Additionally, it was discovered that future work is required to establish safety parameters in PHR design and evaluation. The PHR nomenclature varied (Figure 2) and with 5 articles, the patient portal was the most prominent naming convention. Additionally, the IMIA Region [1] representation was diverse (Figure 3), 9 articles described the NAMI region as the most prominent region for PHR research.
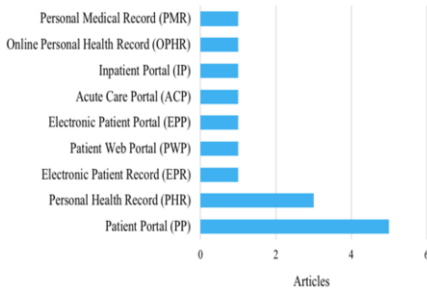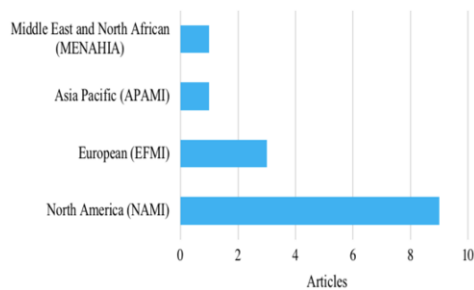
Figure 2. Varied naming conventions   **Figure 3.** PHR research per IMIA Region [2]

4. Discussion and Conclusion

This scoping review presented a range of PHR naming conventions, research representation by IMIA Region [1]. As evidenced by the findings, the relationship between PHRs and patient safety has only been partially established. Therefore, the integration of usability, human factors and human cognitive processing abilities [20] into PHR design and concept planning, could result in safer systems. Moreover, utilizing patient journey mapping activities [21] in PHR design and implementation planning could improve patient outcomes. Such activities could illustrate the varied clinically related intersections that exist between citizens and providers that could compromise patient safety. A broader analysis is required to further explore the current state of PHRs in the global marketplace. There is a need for a generalizable framework to evaluate PHRs from stratified perspectives (e.g., micro, meso, macro, multi [22]) to improve design, safety, functionality and adoption.

References

[1]   IMIA Represented Regions [Internet]. IMIA. [cited 2022 Jan 19]. Available from: https://imia-medinfo.org/wp/regional-members/.

[2] Chumbler NR, Haggstrom D, Saleem JJ. Implementation of health information technology in Veterans Health Administration to support transformational change: telehealth and personal health records. Med Care. 2011 Dec;49 Suppl:S36-42.

[3] Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol.2005;8(1):19-32.

[4] General Patient Safety [Internet]. Canadian Patient Safety Institute.[cited 2022 Jan 19]. Available from: https://www.patientsafetyinstitute.ca/en/Topic/Pages/General-Patient-Safety.aspx.

[5] Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, Moher D, Peters MDJ, Horsley T, Weeks L, Hempel S, Akl EA, Chang C, McGowan J, Stewart L, Hartling L, Aldcroft A, Wilson MG, Garritty C, Lewin S, Godfrey CM, Macdonald MT, Langlois EV, Soares-Weiser K, Moriarty J, Clifford T, Tunçalp Ö, Straus SE. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med. 2018 Oct 2;169(7):467-473.

[6] Borycki EM, Househ MS, Kushniruk AW, Nohr C, Takeda H. Empowering Patients: Making Health Information and Systems Safer for Patients and the Public. Contribution of the IMIA Health Informatics for Patient Safety Working Group. Yearb Med Inform. 2012;7:56-64.

[7] Chrischilles EA, Hourcade JP, Doucette W, Eichmann D, Gryzlak B, Lorentzen R, Wright K, Letuchy E, Mueller M, Farris K, Levy B. Personal health records: a randomized trial of effects on elder medication safety. J Am Med Inform Assoc. 2014 Jul-Aug;21(4):679-86.

[8] Crotty BH, Mostaghimi A, O'Brien J, Bajracharya A, Safran C, Landon BE. Prevalence and Risk Profile Of Unread Messages To Patients In A Patient Web Portal. Appl Clin Inform. 2015 Jun 12;6(2):375-82.

[9] Dendere R, Slade C, Burton-Jones A, Sullivan C, Staib A, Janda M. Patient Portals Facilitating Engagement With Inpatient Electronic Medical Records: A Systematic Review. J Med Internet Res. 2019 Apr 11;21(4):e12779.

[10] Fitzsimons M, Power K, McCrea Z, Kiersey R, White M, Dunleavy B, O'Donoghue S, Lambert V, Delanty N, Doherty CP. Democratizing epilepsy care: Utility and usability of an electronic patient portal. Epilepsy Behav. 2021 Sep;122:108197.

[11] Fraccaro P, Vigo M, Balatsoukas P, van der Veer SN, Hassan L, Williams R, Wood G, Sinha S, Buchan I, Peek N. Presentation of laboratory test results in patient portals: influence of interface design on risk interpretation and visual search behaviour. BMC Med Inform Decis Mak. 2018 Feb 12;18(1):11.

[12] Gerard M, Fossa A, Folcarelli PH, Walker J, Bell SK. What Patients Value About Reading Visit Notes: A Qualitative Inquiry of Patient Experiences With Their Health Information. J Med Internet Res. 2017 Jul 14;19(7):e237.

[13] Grossman LV, Creber RM, Restaino S, Vawdrey DK. Sharing Clinical Notes with Hospitalized Patients via an Acute Care Portal. AMIA Annu Symp Proc. 2018 Apr 16;2017:800-809.

[14] Kelly MM, Hoonakker PL, Dean SM. Using an inpatient portal to engage families in pediatric hospital care. J Am Med Inform Assoc. 2017 Jan;24(1):153-161.

[15] Lam BD, Bourgeois F, Dong ZJ, Bell SK. Speaking up about patient-perceived serious visit note errors: Patient and family experiences and recommendations. J Am Med Inform Assoc. 2021 Mar 18;28(4):685-694.

[16] Schnipper JL, Gandhi TK, Wald JS, Grant RW, Poon EG, Volk LA, Businger A, Williams DH, Siteman E, Buckel L, Middleton B. Effects of an online personal health record on medication accuracy and safety: a cluster-randomized trial. J Am Med Inform Assoc. 2012 Sep-Oct;19(5):728-34.

[17] Vermeir P, Degroote S, Vandijck D, Van Tiggelen H, Peleman R, Verhaeghe R, Mariman A, Vogelaers D. The patient perspective on the effects of medical record accessibility: a systematic review. Acta Clin Belg. 2017 Jun;72(3):186-194.

[18] Woollen J, Prey J, Wilcox L, Sackeim A, Restaino S, Raza ST, Bakken S, Feiner S, Hripcsak G, Vawdrey D. Patient Experiences Using an Inpatient Personal Health Record. Appl Clin Inform. 2016 Jun 1;7(2):446-60.

[19] Kushniruk AW, Patel VL. Cognitive and usability engineering methods for the evaluation of clinical information systems. Journal of Biomedical Informatics. 2004;37(1):56-76.

[20] Joseph AL, Borycki EM, Kushniruk AW. Alert fatigue and errors caused by technology: A scoping review and introduction to the flow of cognitive processing model. Knowledge management & e-learning. 2021;13(4):500-521.

[21] Joseph AL, Kushniruk AW, Borycki EM. Patient journey mapping: Current practices, challenges and future opportunities in healthcare. Knowledge management & e-learning. 2020;12(4):387-404.

[22] Joseph AL, Stringer E, Borycki EM, Kushniruk AW. Evaluative Frameworks and Models for Health Information Systems (HIS) and Health Information Technologies (HIT). Studies in health technology and informatics. 2022; 289: 280 - 285.