

Best Practices Used by Pediatric Healthcare Leaders to Decrease Patient Portal Privacy Issues and Increase Patient Data Security

Carla Sandoval and Dr. Bruce Lazar, MBA, DM

Southern Illinois University of Carbondale

Abstract: *The main purpose of this review was to analyze the best practices used by pediatric healthcare leaders to decrease patients' portal privacy issues and increase patient data security. The review provided three major themes which helped answer the research question in a more detailed manner. The three main themes included pediatric patient, patient portal, and patient privacy. Importantly, the review identified privacy issues relating to pediatric patient's data that need to be addressed. Considering the first theme, the research indicated that both healthcare organizations and clinicians who take care of pediatric patients face great challenges in handling sensitive information. However, many clinicians reported to be using notes to store patients' information due to various reasons. Further, the research indicated that the use of patients' portals is associated with various problems such as receiving different views after sharing medical information, varying emotional responses after reading medical information, and balancing the best possible care and granular control. The research indicated that the best way to maintain patient's privacy is by allowing children to control their portal once they are mature enough to make crucial decisions about their health. Another possible way to ensure patient data privacy discussed in the articles is educating healthcare workers on handling sensitive information. Research also indicates that laws and regulations governing how patient's information is shared should be created. The implications of these findings provide healthcare leaders and administrators an opportunity to implement measures aimed at protecting patient's data. For instance, healthcare leaders should offer training to workers to teach them how to handle patient's information and why it is important to do so.*

INTRODUCTION

Although electronic patient portals have several benefits for care delivery, they are affected by a challenge in balancing patient data privacy and patient needs, causing pediatric health leaders to explore opportunities to reduce privacy issues and improve data security. Electric patient portals refer to web-based platforms that patients use to access data from their electronic health records (Powell, 2017). Owing to the increased innovation in healthcare delivery, millions of American patients use electronic patient portals to access a wide range of health information, enhancing their participation in care delivery (Bourgeois et al., 2018). Information that patients can access includes visit summaries or notes and a list of medications. They can also access functions such as secure messaging, educational resources, appointment schedules (Bourgeois et al., 2018). Further, patient portals allow patients and their families to obtain laboratory and radiology results in addition to other healthcare information. The transparency associated with patient portals has been reported to empower patients and their families, increasing their medication adherence and engagement (Bourgeois et al., 2018). It also increases patient satisfaction and trust, improves patient-provider relationships.

These benefits raise the need for increased adoption of electronic patient portals, though many studies report significant barriers to patients' adoption of this innovation. In addition to the lack of awareness and training, privacy and data security concerns are a major hindrance to the use of patient portals. Powell (2017) reports on one study that three out of four focus groups report that privacy concerns are leading barriers to portal use. Niazkhani et al. (2020) also note that the preservation of patient privacy, security of health records, and confidentiality are some of the key concerns associated with electronic patient health records. Precisely, many people are worried about the caregivers' access to their health records and seek better access control. Other people are troubled about the possible inappropriate access by external parties such as strangers, pharmaceutical companies, insurance companies without their consent (Househ et al., 2018). Pediatric health providers face a greater dilemma as both parents and patients have access to the children's patient portal, where sensitive information concerning substance abuse, reproductive health, adoption, and genetic data (Bourgeois et al., 2018). While parents have traditionally had substantial access to their children's health information, patient portals provide it to an unprecedented extent raising ethical issues to pediatric healthcare delivery. As a result, healthcare organizations have been exploring innovative ways to address privacy concerns and improve data security to enhance the adoption of online portals. However, there exists a gap in understanding the best practices for ensuring patient portal privacy. According to Sharko et al. (2018), physicians face a major challenge balancing provision of access to accurate and comprehensive health information with the preservation of the patient's confidentiality. The limited understanding of best practices of addressing patient privacy issues in the use of online portals causes a persistent barrier to the adoption of online portals.

Research Question

What best practices do pediatric healthcare leaders use to decrease patient portal privacy issues and increase patient data security?

Purpose Statement

The purpose of this literature review is to identify some best practices embraced by pediatric healthcare leaders to reduce patient portal privacy concerns and increase patient data security. Relevant and current peer-reviewed articles will be analyzed on the effective approaches embraced by healthcare administrators towards enhancing online portals' security to reduce privacy risk.

This paper will offer a comprehensive guide for pediatric healthcare leaders concerning measures to increase patient portal security and increase the adoption of information sharing technology for better health outcomes.

Population

The population for the study will consist of results from peer-reviewed journal articles from reliable databases. The findings will entail the best practices employed to address privacy and data security concerns associated with patient portals. The analysis will help in identifying the most successful strategies, as the response to the research question.

Key Words

Electronic Patient Portal, Privacy Issues, Data Security Concerns

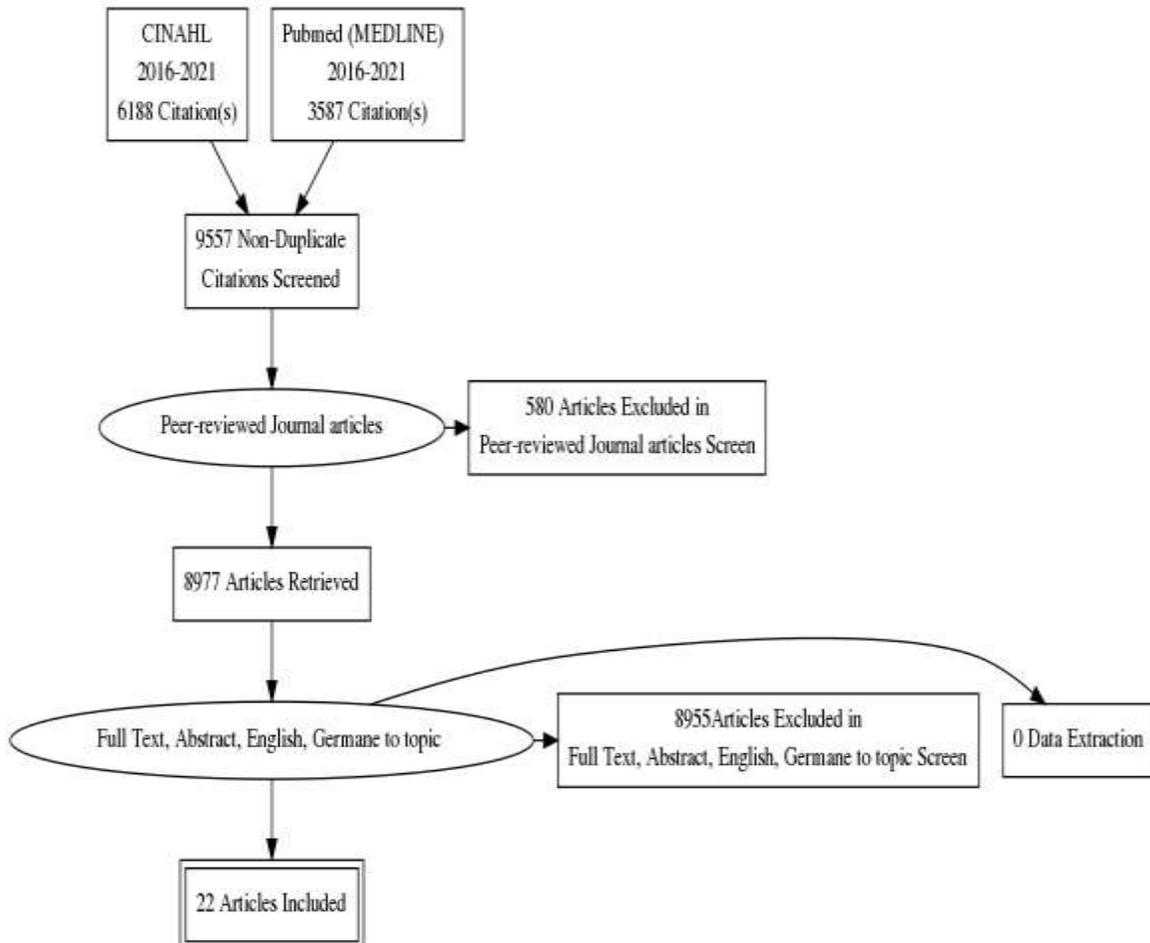
METHODS

The research started by utilizing google scholar to narrow down the research topic, which enabled the researcher to identify articles that were in line with the PICO based research question; What best practices do pediatric healthcare leaders use to decrease patient portal privacy issues and increase patient data security? In search of quality materials to be used in the literature, two academic databases included CINAHL and MEDLINE as per the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA) (Liberati et al., 2009). The phases associated with this method include looking for relevant studies, deciding on inclusion and exclusion criteria, data extraction based on the screening criteria, analyzing the data to determine key themes, and reporting and disseminating findings (Liberati et al., 2009). Also, the search process involved the use of keywords, including **best practices, pediatric patient portal privacy, pediatric patient, and data security**, which provided consistent parameters in deciding the best articles that can answer the research question.

Inclusion and Exclusion Criteria

For articles to be included in the literature, they had to meet certain criteria to ensure their relevance to the topic. They include works published between the years 2016 and 2020, have to be written in English, published peer-reviewed journal articles, full text, and have a major focus on the research question. After the filters mentioned above were put in place, the CINAHL database resulted in 10 articles while the MEDLINE database resulted in 12 sources. Articles that did not meet the inclusion criteria were excluded from the research to ensure only the appropriate and quality sources will be used in the literature.

Figure 1. Search Process with Inclusion and Exclusion Criteria



RESULTS

The key research question explored in this study was, “What best practices do pediatric healthcare leaders use to decrease patient portal privacy issues and increase patient data security?” The intense research inspired by the above-mentioned research question transpired to the use of two academic electronic databases, namely, CINAHL and MEDLINE. A recognized literature search, selection, and data analysis method were used to ensure quality information (Liberati et al, 2009). Out of 9775 articles that were initially identified, only 20 articles were chosen to be used in this literature through inclusion and exclusion criteria. Some of the factors that were considered in the exclusion and inclusion criteria included whether the article was a scholarly journal, its year of publication, had to be written in English, and have a germane to the topic. The availability of these articles led to comparing and analyzing the summary findings of each of the articles, as seen in table one below.

Table 1

Summarized findings of the literature

Title	Findings
2. Four steps to preserving adolescent confidentiality in an electronic health environment	There is guidance issued by professional organizations on how to use patients portal and electronic health records but its implementation vary between systems. It is important to understand the electronic and legal environments as it allows health care workers to advocate, educate, and implement electronic tools in a way that maintains patient privacy.
3. Vulnerable patients’ attitudes towards sharing medical data and granular control in patient portal systems: an interview study.	The research resulted in four themes, benefits of and barriers to portal access, emotional responses from reading medical information, varying views on sharing medical information, and balancing between best possible care and granular control.
4. Variability in adolescent portal privacy features: how the unique privacy needs of the adolescent patient create a complex decision-making process.	Factors in the decision process were: technology capabilities; differing patient population needs; resources; community expectations; balance between information access and privacy; balance between promoting autonomy and promoting family shared decision-making; and tension between teen privacy and parental preferences. Some informants believed that clearer standards would simplify policy-making; others worried that standards could restrict high-quality policies.
5. Ethical Challenges Raised by Open Notes for Pediatric and Adolescent Patients	Healthcare organizations and clinicians caring for adolescent and pediatric patients face confusion on how to document sensitive and confidential information on issues such as misattributed paternity, reproductive health, or disagreements between the provider and the patient.
6. Security and Privacy Risks Associated With Adult Patient Portal Accounts in US Hospitals.	Out of the 102 hospitals that were involved in a cross-sectional study, 68% of them provided proxy accounts to caregivers of adult patients, while 45% of the health care workers agreed to share login credentials. However, 19% of institutions that issued access to proxy accounts allowed patients to reduce the amount of information viewed by their caregivers.
7. Patient portals and young people: addressing the privacy dilemma of providing access to health information	For young people, shared portal access is allowed such that both the patient and the parent/guardian can access the portal. However, as a child grows and their capacity to make health care decision increases, health care workers need to shift to an independent portal. Patient’s views on information disclosure, rights, and their best interest should be considered when making decisions.

8. Meaningful Use of Confidential Adolescent Patient Portal. Adolescents were less likely than parents of younger children to review appointments (73% vs. 85%), laboratory tests (67% vs. 79%), problem lists (40% vs. 78%), or allergies (45% vs. 77%, all *p* values <.001). Parents of younger children more frequently messaged providers (3,297 messages), although adolescents sent 1,397 confidential messages.
9. Preserving privacy for pediatric patients and families: use of confidential note types in pediatric ambulatory care. Out of 402 964 clinical notes that were identified in the research, 2.3% of them were considered confidential. The use of these notes was associated with an increase in patient age and female patient sex. About 83.8% of clinical notes that were reviewed had sensitive information. Reasons for using these notes varied, but the patient's mental health was common.
10. Patient Portals in an Information Demanding Society. With the rising demand for more self-care options, timely delivery of health care, and alternative service delivery, the patient portal has played a major role in filling these gaps. One of the advantages of a patient portal is that it has helped reduce cost by identifying patterns of duplication. Also, it has enabled collaborative health care plans due to the availability of information that can be shared with different health care providers
11. Deriving a Set of Privacy Specific Heuristics for the Assessment of PHRs (Personal Health Records)...ITCH 2017. Numerous violations were in the use of internet-based commercially available vendor-specific PHR applications. Therefore, the newly derived privacy heuristic should be used together with Nielsen's well-established set of heuristics. Privacy-specific heuristics can be used to tell PHR portal system-level privacy.
12. Security and Privacy Risks Associated With Adult Patient Portal Accounts in US Hospitals. Nurses who had a higher education level were more informed about patient's rights regulations and were more concerned about patient's privacy. Healthcare workers who negatively defined gossip cared about patient confidentiality. There was found to be a negative correlation between attitude towards gossiping and the average score on patient confidentiality.
13. Why Most of Your Patients Aren't Using an Online Portal, and What You Can Do About It. Online portal non-users were found out to be on Medicaid, males, have less than a college education, and lack a regular provider. Disparities on who is supposed to use the portal were also noted, with nonwhites reporting having no access. Reasons shared by non-users include privacy issues and the wish to speak directly to the providers.
14. Access and Disclosure of Personal Health Information: A Challenging Privacy Landscape in 2016-2018. Countries are creating regulations, laws, and public policies to try and balance between privacy rights and the unprecedented opportunities to advanced healthcare resulting from the expanded use of health data. Likewise, guidance and regulations are changing but not as fast as the increasing demand and challenges for ensuring access and disclosure of information.
15. Privacy Policy and Technology in Biomedical Data Science. The issue of privacy should be considered when sharing clinical data as it contains sensitive information. Increasing public trust and adequate protection of patient privacy are paramount in biomedical research. Lastly, healthcare workers should think of ethical and social implications caused by inappropriate handling of sensitive information.

16. Protecting patient privacy when sharing patient-level data from clinical trials
There arise concerns on how to appropriately prepare and share clinical trial data with other researchers while maintaining patient confidentiality. A clinical trial database contains detailed patient information, and retention of this data can hinder meaningful scientific research. One of the recommendations suggested in this research is data anonymization and controlled access to data, including data-sharing agreements.
17. Privacy protections to encourage the use of health-relevant digital data in a learning health system.
To maintain a balance between protecting patient's information and making it available for learning purposes, a multi-prolonged approach is recommended. The protection measures should apply to all entities that collect health-relevant data regardless of whether they are under federal health privacy laws. Apart from offering privacy, the approach will also protect victims against harm while governing health-relevant data.
18. The biorepository portal toolkit: an honest brokered, modular service-oriented software toolset for biospecimen-driven translational research.
By using automated de-identification of the specimen and other clinical and genomic data, a future-proofed specimen that can withstand heavy workflow and at the same time use associated information after some time is created. The process facilitates collaborative advanced genomic and tissue research.
19. Beyond Baby Steps: Today's Use of Social Networking Sites and the Nursing Profession.
The use of social networking sites by healthcare providers has raised questions on the compatibility between these sites and the professional values of privacy and confidentiality. Two critical areas were addressed on the issue, they include the regulatory issue and blurring of professional and personal online identities.
20. Patient Portals Facilitating Engagement With Inpatient Electronic Medical Records: A Systematic Review.
The findings indicate that some of the barriers that hinder portal adoption include concerns about its privacy and lack of encouragement from the providers. Also, the varying methods that were used to train the users had varying success among different people. More precisely, the medical condition of the users, sociodemographic characteristics, and the process category were considered to be the major predictors of portal use. When interviewed, some patients wanted personalized health education, unlimited access to their EMRs, non-clinical information and insisted on using portals to communicate to their healthcare providers. Further, patient portals were observed to improve patient engagement and awareness. They were also found to cause anxiety to some patients who valued privacy.
21. Privacy and Confidentiality Practices In Adolescent Family Planning Care At Federally Qualified Health Centers.
Considering the Federal Qualified Health Centers (FQHCs) that reported on the issue of confidentiality, 81% reported providing verbal or written information, and 84% reported to issue limited access to family planning and other medical records. 43% of the centers reported using security blocks on electronic medical records for security purposes. The study indicated how lack of guidelines and confusion result to confidential issues among adolescents.

The data that was retrieved from the 21 articles were placed in different categories based on the occurrence and frequency of various terms such as privacy, pediatric care, interventions, and medical portals. The process led to the identification of three major themes, which include; pediatric patient care, patient portal, and patient privacy.

Table 2*Frequency of occurrence in the literature.*

Benefits	Occurrences	Instances of Attributes (n)	Percentage (%)
Theme 1: Pediatric patient care	5, 9	7	10%
Theme 2 Patient portal	3, 7, 8, 10, 13, 17, 18	7	35%
Theme 3 Patient privacy	11, 2, 4, 6, 12, 14, 15, 16, 19, 20, 21	11	55%

As presented in table two above, 10% out of 20 articles discussed the theme of pediatric patient care, which is evident in articles five and nine. Further, 35% out of 20 articles mentioned theme two, which is the patient portal, as observed in articles 3, 7, 8, 10, 13, 17, and 18. Also, the findings show that 55% out of 20 articles that were analyzed discussed the theme of patient privacy as viewed in articles 11, 2, 4, 6, 12, 14, 15, 16, 19, 20, and 21.

DISCUSSION

The study's main aim was to find the best practices used by pediatric healthcare leaders to minimize patient portal privacy issues and increase data security. To ensure intensive research on the topic, the study used 20 peer-reviewed articles published between the years 2016 to 2020. The research was based on key terms, including best practices, pediatric patient portal privacy, pediatric patient, and data security, which provided consistent parameters in deciding the best articles to answer the research question. As indicated in table two, several themes were identified through a thorough analysis of the articles. The three main themes retrieved from the study include pediatric patient, patient portal, and patient privacy. More precisely, the theme of the pediatric patient was evident in articles 5 and 9. The second theme, patient portal, was evident in articles 3, 7, 8, 10, 13, 17, and 18. Further, the third theme, patient privacy, was identified in articles 11, 2, 4, 6, 12, 14, 15, 16, 19, 20, and 21.

The first theme provided information about pediatric patients and how their data is stored in healthcare facilities. Cases on pediatric patients and how their data is handled were provided by 10% of the articles. Precisely, articles 5 and 9 are the main articles that provided more information on the theme, making it easier for the researcher to understand the issue. In one of the researches conducted, researchers indicated that healthcare clinicians and healthcare organizations that take care of pediatric patients face a great challenge regarding handling and storing sensitive information. On the other hand, a high percentage of clinicians reported being using notes to store confidential patient information due to various reasons. However, the results indicated that 10% of the authors agreed that sensitive pediatrics information should be confidential. Other people cannot access it without the patient's permission.

The patients' portal is the second theme that offers information on privacy issues experience in patient portals and how these issues can be solved. Information on patients' portals is presented by 35% of the articles discussed in the literature review. This information can be found in articles 3, 7, 8, 10, 13, 17, and 18. Based on articles 3 and 13, researchers indicated that the use of patient portals is associated with various barriers such as emotional responses from reading medical information, different views after sharing medical information, and difficulty between balancing granular control and best possible care. These researchers also found out that people without an online portal are on Medicaid, lack regular providers, have less than a college education, and are males. Other researchers in articles 7, 8, 10, 17, and 18 argued that the patient portal has various advantages, including sharing information to ensure quality care and further research. Also, privacy is maintained by ensuring that the child's patient is in control of the portal until the child is mature enough to make decisions independently. However, the majority of the authors argue that the patient portal is critical in ensuring quality care and privacy is achieved by ensuring the authorized personnel are the only people who can access the portal.

The third theme provided information on patient's privacy and how privacy can be promoted. The issue of confidentiality in patients' portals was presented in 55% of the articles used. Based on the results from articles 2, 4, 6, 14, 15, and 21, researchers indicated that health care workers should be educated on the electronic and legal environment and find the right balance when it comes to sharing information. Likewise, laws, regulations, and public policies governing how patient's information is shared among individuals should also be created to ensure privacy. On the contrary, other researchers indicated that information should be easily accessible to facilitate further research that might be of great importance to other people. Also, the researchers argued that information privacy is greatly determined by healthcare worker's education level, which is indicated in articles 11, 12, 16, 19, and 20. However, the majority of the researchers discussed that with the right privacy measures, the patient portal is crucial in ensuring quality care.

Although the research was a success, various limitations were experienced throughout the study. They include time limitation, exclusion of multiple articles based on their year of publication and language, and the search strategies used. Importantly, time was a significant limitation considering that the research was conducted in eight weeks. Also, the exclusion of articles published before 2016 and those not written in English excluded many articles, some of which would have assisted with the research. More so, google scholar was used as the primary search strategy that provided knowledge on the type of articles needed for the research. Further, secondary search strategies, which included CINAHL and MEDLINE, were used to provide peer-reviewed journal articles. Also, keywords were used to search for articles, indicating a higher possibility of missing out on good articles that used different terminologies.

To minimize these limitations, the research aligned with the PRISMA-based systematic review guidelines and protocols. Through the exclusion and inclusion method, information was filtered down from 6188 articles from the CINAHL database and 3587 articles from the MEDLINE database, resulting in 20 articles. Relevancy to the research question was considered to ensure that the articles with the required information were not left out. Likewise, more time was dedicated to completing the research, which helped save the issue of time. Considering that patients' privacy is an ongoing issue, it was possible to get recent articles that discussed the topic in detail, thus gaining more information on the topic within the given period. Despite the challenges of the study, the research identified some of the strategies that should be implemented to ensure patient's information is protected. One of the effective strategies was to educate healthcare practitioners on the importance of protecting patient's information and the legal aspect. This way, health care workers get to understand how they are required to store sensitive information and people who should access it. Laws, regulations, and public policies should also be created to protect patient's information.

Future research can use the results of this literature review to conduct further research that will shed more light on the topic. Researchers should focus on finding the reasons why privacy issues are still an issue despite the great risk it poses to patients and their family members. Recommendations should also be provided on what should be done to ensure patient's sensitive information is protected and can only be accessed by the right people. Future research should use a mixed-method research design to incorporate various data collection methods such as interviews and surveys. Likewise, healthcare leaders should use these findings to create best practices within hospitals to ensure proper and safe documentation of patient information. Policies should also be created stating the people who will be allowed to access sensitive information to avoid confusion among healthcare workers.

CONCLUSION

Despite the various benefits of an electronic patient portal, a major challenge is experienced in balancing patient data privacy and patient needs, which necessitates the need for healthcare leaders to explore opportunities to reduce privacy issues. This systematic literature review aimed to research the best practices used by pediatric healthcare leaders to decrease patient portal privacy issues. The search for this literature transpired using two databases, CINAHL and MEDLINE, according to the Preferred Reporting Items for Systematic and Meta-Analysis guidelines. Importantly, a total of twenty articles were used in the research process to ensure that the correct information was well documented in the literature. More precisely, a screening process that involved constantly comparing information from different articles was used such that the documented information relates directly with the research question. The research question reads, "What best practices do pediatric healthcare leaders use to decrease patient portal privacy issues and increase patient data security?" Based on the research question, the author identified three major themes during the data analyzing process. The themes included pediatric patients covered by 10% of the articles, patient portal covered by 35% of the articles, and patient privacy, constituting 55% of the articles. The findings indicate a need to implement various strategies that can help protect patient's data and improve their portal privacy. The results, however, demonstrated that pediatric healthcare leaders are protecting patient's data by allowing children to control their portal once they are mature enough to make health decisions on their own. Leaders are also focused on training healthcare workers on how to handle sensitive information concerning their patients. Laws and regulations have also been suggested to dictate how patient's information should be handled or shared among healthcare providers. The implications of these findings provide healthcare leaders with an opportunity to implement measures aimed at solving patients' portal issues and ensuring that their data is well protected.

References

- Bourgeois, F. C., DesRoches, C. M., & Bell, S. K. (2018). Ethical challenges raised by OpenNotes for pediatric and adolescent patients. *Pediatrics*, *141*(6). <https://doi.org/10.1542/peds.2017-2745>
- Househ, M., Grainger, R., Petersen, C., Bamidis, P., & Merolli, M. (2018). Balancing between privacy and patient needs for health information in the age of participatory health and social media: a scoping review. *Yearbook of medical informatics*, *27*(1), 29. <https://doi.org/10.1055/s-0038-1641197>.
- Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P., & Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *Journal of clinical epidemiology*, *62*(10), e1-e34.
- Niazkhani, Z., Toni, E., Cheshmekaboodi, M., Georgiou, A., & Pirnejad, H. (2020). Barriers to patient, provider, and caregiver adoption and use of electronic personal health records in chronic care: a systematic review. *BMC Medical Informatics and Decision Making*, *20*(1), 1-36. <https://doi.org/10.1186/s12911-020-01159-1>

- Powell, K. R. (2017). Patient-perceived facilitators of and barriers to electronic portal use: a systematic review. *CIN: Computers, Informatics, Nursing*, 35(11), <https://doi.org/565-573>. 10.1097/CIN.0000000000000377
- Sharko, M., Wilcox, L., Hong, M. K., & Ancker, J. S. (2018). Variability in adolescent portal privacy features: how the unique privacy needs of the adolescent patient create a complex decision-making process. *Journal of the American Medical Informatics Association*, 25(8), 1008-1017. <https://doi.org/10.1093/jamia/ocy042>