Impact of patient access to their electronic health record: systematic review

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ABSTRACT

Patient access to their own electronic health records (EHRs) is likely to become an integral part of healthcare systems worldwide. It has the potential to decrease the healthcare provision costs, improve access to healthcare data, self-care, quality of care, and health and patient-centered outcomes. This systematic literature review aims at identifying the impact in terms of benefits and issues that have so far been demonstrated by providing patients access to their own EHRs, via providers’ secure patient portals from primary healthcare centers and hospitals. Searches were conducted in PubMed, MEDLINE, CINHAL, and Google Scholar. Over 2000 papers were screened and were filtered based on duplicates, then by reading the titles and finally based on their abstracts or full text. In total, 74 papers were retained, analyzed, and summarized. Papers were included if providing patient access to their own EHRs was the primary intervention used in the study and its impact or outcome was evaluated. The search technique used to identify relevant literature for this paper involved input from five experts. While findings from 54 of the 74 papers showed positive outcome or benefits of patient access to their EHRs via patient portals, 10 papers have highlighted concerns, 8 papers have highlighted both and 2 have highlighted absence of negative outcomes. The benefits range from re-assurance, reduced anxiety, positive impact on consultations, better doctor–patient relationship, increased awareness and adherence to medication, and improved patient outcomes (e.g., improving blood pressure and glycemic control in a range of study populations). In addition, patient access to their health information was found to improve self-reported levels of engagement or activation related to self-management, enhanced knowledge, and improve recovery scores, and organizational efficiencies in a tertiary level mental health care facility. However, three studies did not find any statistically significant effect of patient portals on health outcomes. The main concerns have been around security, privacy and confidentiality of the health records, and the anxiety it may cause amongst patients. This literature review identified some benefits, concerns, and attitudes demonstrated by providing patients’ access to their own EHRs. This access is often part of government strategies when developing patient-centric self-management elements of a sustainable healthcare system. The findings of this review will give healthcare providers a framework to analyze the benefits offered by promoting patient access to EHRs and decide on the best approach for their own specialties and clinical setup. A robust cost-benefit evaluation of such initiatives along with its impact on major stakeholders within the healthcare system would be essential in

KEYWORDS

Electronic healthcare record; literature review; patient access; benefits; access to EHRs; patient portals

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understanding the overall impact of such initiatives. Implementation of patient access to their EHRs could help governments to appropriately prioritize the development or adoption of national standards, whilst taking care of local variations and fulfilling the healthcare needs of the population, e.g., UK Government is aiming to make full primary care records available online to every patient. Ultimately, increasing transparency and promoting personal responsibility are key elements of a sustainable healthcare system for future generations.

**Introduction**

A significant part of healthcare cost comes from time- and resource-consuming one-to-one interactions with individuals, either at clinic visits or by phone. An electronic health record (EHR) is the systematized collection of patient and population electronically stored health information in a digital format and providing patients with access to EHRs has the potential to decrease these costs, improve self-care, quality of care, and health and patient-centered outcome.

Well-informed patients having access to their health information are generally more engaged in the management of their own health, thus reducing expenditure on healthcare, and prefer self-management. Promoting patients access to their own EHRs helps unlock the general benefits of Information and Communication Technology (ICT) within healthcare. The US Institute of Medicine (IOM) views such access as a bridge between the current and optimal states of healthcare delivery that eventually lead to an improved healthcare system. Winkelman et al. report a strong relation between lack of information about one’s condition/treatment shared by healthcare providers and patient dissatisfaction. The US government’s MyHealthEData initiative has made citizen access to their health records a top priority, as have private companies, like Apple and Google, which can store patients’ records on their phones. The 21st Century Cures Act (signed in Dec. 2016), has important provisions that could significantly impact the availability, usability and patient access of health information. In the UK, primary care EHR providers are giving patients safe and secure access to their health records through tools such as TPP’s SystmOnline, EMIS Patient Access, and InPractice Systems’ Patient Services, which will also be accessible through a recently launched NHS App. Care Information Exchange, MyHealth and MyCareUCLH are some examples of hospital patient portals in the UK.

This systematic literature review examines the existing published evidence of impact arising from providing patients with online access to their electronic health records (EHRs).

**Methods**

The protocol for this systematic review was registered and published in PROSPERO, an international prospective register of systematic reviews. (Available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD4201911742)

**Search strategy**

For this study patient “access” to EHRs was defined as secured “online access” to the patient’s health data via the providers’ patient portal, using a computer by a patient, carer or guardian. A patient portal is a secure online website that gives patients convenient, 24-hour access to personal health information from anywhere with an Internet connection using a secure username and password.

Since the focus of this investigation was the impact of patients having access to their EHRs via patient portals, studies reporting the benefits of EHRs that had no patient access were excluded and
reciprocally the benefits of personal health records (i.e., health data of a patient that is maintained by the patient) that were not created by or shared with health professionals were excluded.

Only papers published in English were considered in this review. The search technique used to identify relevant literature for this paper involved input from five experts from the field of Health Informatics, two of them clinicians and the other health informatics researchers. Searches were conducted in PubMed, MEDLINE, and CINHAL. Google scholar was also used to make sure we did not miss any relevant articles. No date filter was used (Updated till Dec. 2020). Keywords used for the search were electronic health records, electronic medical records, patient portal. MeSH terms used were: electronic health records, patient portals.

PubMed Search Details:
(("patients"[MeSH Terms] OR “patients”[All Fields] OR “patient”[All Fields]) AND online[All Fields] AND access[All Fields] AND ("electronic”[All Fields] AND “health”[All Fields] AND “records”[All Fields]) OR “electronic health records”[All Fields] OR (“electronic”[All Fields] AND “health”[All Fields] AND “record”[All Fields]) OR “electronic health record”[All Fields])) OR (("patients”[MeSH Terms] OR “patients”[All Fields] OR “patient”[All Fields]) AND access[All Fields] AND portal[All Fields]) OR ((“patients”[MeSH Terms] OR “patients”[All Fields] OR “patient”[All Fields]) AND online[All Fields] AND access[All Fields] AND ((“medical”[All Fields] AND “records”[All Fields]) OR “medical records”[All Fields] OR (“medical”[All Fields] AND “record”[All Fields]) OR “medical record”[All Fields]))

The initial searches provided in excess of 2000 papers for consideration. Following the removal of duplicates, the papers were initially screened based on their titles, then on abstract and eventually on full text, as shown on the PRISMA\textsuperscript{15} diagram (Figure 1). The following inclusion and exclusion criteria were applied during the abstract review and full text review of the papers. Seventy-four were eventually retained and reviewed.

**Inclusion criteria**

- An EHR system that closely matched the definition of an EHR given in ISO/TR 20514, 2005,\textsuperscript{16} to classify such systems and was the primary system used in the paper/study.
- Had formally evaluated the impact or outcome in terms of benefits, harms, patient attitudes, and concerns around EHRs after patients were provided access to their records.

**Exclusion criteria**

- Systems accessed solely by healthcare professionals.
- Systems accessed solely by patients.
- Studies considering access to paper/physical records only.

**Handling risk of bias (quality) assessment**

Papers evaluating patient access to their health records which were considered for this review had to contain sufficient detail. Quality assessment was applied during the abstract and full text review. In the methodology, the authors first used the search criteria, along with the inclusion and exclusion criteria and any definitions used by using the PRISMA checklist. The final selection of studies, and any differences or issues in judgment, were resolved by discussions amongst the three independent reviewers who conducted the assessment.

**Data synthesis**

A narrative synthesis was conducted for all the studies reviewed in this paper. Studies whose outcomes were comparable in terms of benefits or concerns were pooled together for a summary. The results
were presented by grouping the results of various studies according to the common outcomes, including the percentage of studies for each outcome and using them to draw conclusions. A meta-analysis was inappropriate due to the variability in patient portals, EHR systems, and patient populations. Three independent reviewers (AT, TP, GD) reviewed the abstracts and any disagreements were resolved by discussions with the other two reviewers (DC, VC).

**Results**

While findings from 54 of the 74 articles (75%) showed benefits of patient access to their EHRs via patient portals, 10 of the articles (14%) highlighted concerns, 8 articles (9.5%) highlighted both and 2 (1.5%) highlighted absence of positive or negative outcomes. The benefits range from re-assurance, reduced anxiety, positive impact on consultations, better doctor–patient relationship, and increased awareness and adherence to medications. Patient access to their EHRs was found to improve patient outcomes in various study populations,\(^{17-20}\) including medication adherence,\(^{21,22}\) achieving control of blood pressure and sugar levels,\(^{17,23-25}\) improving functional status, and reduced high-cost healthcare utilization in patients with chronic conditions,\(^{26}\) enhance timely patient-centered care.\(^{27,28}\) In addition, patient portals were found to improve self-reported levels of engagement, knowledge or

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*Figure 1. PRISMA flow diagram of literature search.*
activation related to self-management, improve engagement in care and caregiver-provider communication, improve recovery scores, and reduce hospital admissions. However, some studies did not find statistical effect of patient portals on health outcomes. Several research papers emphasized the importance of sharing clinical notes with patients via the patient portal. In qualitative interviews, patients reported improved access to information, better insight into their conditions, decreased anxiety, increased appreciation for clinicians, improvements in health behaviors, and more engagement in care. Sharing clinical notes with patients and parents raise also ethical and legal concerns, such as how to document confidential and sensitive information, including issues such as reproductive health, misattributed paternity or provider and parent disagreements.

Patient portals were also found to deliver benefits to maternity patients by providing quick access to their EHRs and support patients in their ability to recall and prepare for appointments. Online refilling of prescriptions was found to increase medication adherence. In a paper analyzing patterns in patient access and utilization of online medical records, the most popular page views were found to be clinical notes, followed by laboratory results and medical imaging reports. A study aimed to examine negative experiences resulting from real-time disclosure of medical information through a patient portal found no significant negative consequences. Here, the authors have discussed in detail the major positive impacts and issues around patient access to their EHRs. (The papers studied are summarized also in a tabular form in the appendix.)

**Impact on consultations/appointments**

Some studies report that patient access to EHRs led to an increase in consultation frequency or its duration. Patients would gain easier and quicker access to their test results as well. The study by Rexhepi et al. confirms that online access can help patients prepare for doctor visits and to understand their medical issues and did not generate substantial anxiety, concerns or increased phone calls to the hospital. Overall, the impact of patient access to their EHRs (including the test results) seems to benefit the patients to be well informed and be better prepared for their consultations.

**Impact on doctor–patient relationship**

Patient access to their own EHRs could help develop the doctor–patient relationship and help patients identify any inaccuracies within their EHR, improve poor data quality that accounts for several medical errors, leading to more “accurate” health information being stored and enhanced patient-provider communication. Level of patients’ trust with their primary physicians influenced the desire to access their online health information and increased health literacy. Overall, the literature shows that the ability of patients to order prescriptions and book appointments online, as well as being able to access their own GP-held records and lab results, will hold benefits for patients and healthcare professionals. There could be significant challenges for clinicians and nurses with ensuring fair access to records to all the patients.

**Minors**

Although far more significant within the USA, on account of differences in laws applicable to various states, promoting EHR access to minors is a challenge. While the patient (minor) might welcome such access, it could raise concerns amongst parents, carers and guardians regarding the level of details visible to the patient.

**Healthcare ownership and medication adherence**

EHR access could improve patients’ knowledge about their clinical condition, leading to an increased ownership and involvement in improving one’s quality of healthcare. While Delpierre et al. 
confirms a positive correlation among EHR access and associated increase in preventive care, the study also reports six studies that did not find any correlation between EHR access and improvement in patients’ health-related outcomes. Relating to medication adherence, studies have shown that statin adherence improved significantly over time among patients who exclusively refilled prescriptions online.22,42,48 Convenient access to portal self-management tools through a mobile device could significantly improve diabetes management.70,71 The findings show an increase in patient adherence to medication schedules and advice provided by clinical staff, once patients have access to their EHRs.39,42,48,72

Use of healthcare resources

Some studies discussed earlier reported an increase in consultation times after patients accessed their own EHRs via patient portals [39,47,48]. An increase in scheduled telephone contacts and decrease in missed appointment rates73 suggests that patients were making use of appropriate healthcare resources. In patients with multiple complex chronic conditions, Reed et al. showed association of portal use with significantly fewer emergency room visits and preventable hospital stays.74 The literature findings overall suggest increased shared decision-making and reduction in the inequality of utilization of healthcare resources by various sectors of the society.

Potential concerns in promoting patients access to their EHRs

Information security has been a major concern for industries such as finance, defense, and health. The fundamental security goals for all these industries, including for EHRs, are confidentiality, integrity, and availability (CIA).75 Promoting patients’ access to their own EHRs could have an impact on activities such as health information disclosures, in job applications or applying for life insurance.76

Confidentiality

ISO EN 13606 defines confidentiality as “a process that ensures that information is accessible only to those authorized to have access to it” (ISO, 2006).77 Inadequate protection around access and level of detail visible to other stakeholders within the healthcare space could negatively impact patients.57,58 Patil et al.78 conducted a pan European survey in which concerns about different levels of access by third parties were expressed by 48.9% to 60.6% of respondents. The findings suggest that ‘confidentiality’ of patient EHRs is a major concern which needs to be protected with appropriate measures.

Security and privacy

Security and privacy were highlighted as two main drawbacks in promoting patient access to their own EHRs.63,76,79–82 Patients were found to be concerned about their EHR security, such as the extent of information sharing, governance and accountability risks, the potential for unauthorized access and prejudice, errors and inaccuracies, as well as use of health data for profit and exploitation.83 However, with reasonable precautions, record access can be made safe and affords many benefits to both patients and clinicians.84

Anxiety

Clinical information like receiving cancer diagnosis online could create anxiety in patients50,52,63,68,74 and longer patient–physician interactions.84 Woods et al. report that seeing previously undisclosed information, derogatory language, or inconsistencies in their notes caused anxiety in some patients.68 However, some studies77,67,85 report access to EHRs helped alleviate patients’ anxiety as they had a better understanding of their condition. Ralston et al. 200486 and Winkelman et al. 20057 believe quicker access to test results via patient portal could in fact help alleviate fear/anxiety amongst patients. Efforts may be needed to improve patient’s understanding when first receiving their radiology results online.87 The literature suggests that patient access to their EHRs may cause anxiety in
serious clinical conditions, but overall the patients are satisfied with access to their EHRs, and patient portal-based access to laboratory test results led to convenience, fewer appointments, and decreased anxiety.  

Adoption of patient portals

Older adults (age 60 and above) are less likely to adopt portals even though they utilize the greater proportion of healthcare resources. Older adults who use one or more patients’ portal, do it in limited ways. Low adoption rates are mainly among older adults who have less access and experience with technology, less education, and who demonstrate low health literacy and numeracy skills. However, most of the older adults are interested in using a patient portal regardless of health literacy level, previous patient portal adoption or experience navigating health information on the Web. Barriers and facilitators to patient portal adoption are described in Zhao et al. and Rosen et al.

Discussion

This systematic review was conducted to have a scope view of the possible impact of patient access to their EHRs. The included studies were conducted at various clinical settings with diverse endpoint measurements. Therefore, study results have provided insights into potential clinical settings, type of medical records and patient cohort that could benefit from promoting patients access to their EHRs.

Patients who are likely to benefit more from accessing their EHRs are those with long-term conditions, who have greater needs to trace their disease trajectories, and patients experiencing recent incident health events that require more information or communication. Hence, patient access to EHRs might work better for instance, in the UK primary care settings where most chronic conditions are managed and greater potentials for continuity of care could be achieved. In universal health coverage systems, access to patient primary care EHR will give both medical professionals and patients comprehensive information about health conditions, treatments and medical management that could be easily missed out during single episodic treatment. The harms posed by information exchange due to EHR accessibility also suggest that the infrastructure of electronic bioinformatic initiative scheme should be aware of and cautious during information dissemination as well as medical professionals should be aware of how to choose the right clinical terms and when to enter major diagnostic information. Interestingly, RCGP reports that such access could potentially reduce litigation charges faced by healthcare providers.

Some patients would prefer to remain uninformed and leave all clinical decisions to the provider/clinician and hence, further feedback/workshops with such patients might help to understand their needs related to access to their records. The healthcare providers should be encouraged to bring patients on-board and consult them when designing and implementing patient portals and the EHR systems. Also, the patients must be assured that the EHRs are accurate, reliable, and auditable.

Critics believe that the goal of patient portal initiatives is to transfer costs and responsibility of healthcare from health providers to patients. However, the authors believe that patient access to their EHRs is becoming recognized as the first step toward greater patient empowerment and shared decision-making. Dickerson et al. report that affluent groups make the most efficient use of healthcare services. Perhaps access to EHRs could help bridge this gap and develop a standardized model for utilization of such healthcare services.

The risk of harm exists across all medical fields but the balance between harm and benefit determines whether to deliver or hold back with access to patient access to records. In fact, the risk of EHR access to patients should be weighed against existing risk of poor information sharing. Provision of patient access to EHRs is challenging and a careful consideration of challenges faced by similar projects such as NPfIT within the healthcare sector, would support an informed decision. It is also essential for policymakers to address issues of equity in terms of adoption and measure usage when deploying patient portals.
Limitations of this study

This literature review has only considered papers published in the English language; however, the authors’ assumption was that most significant publications would be found within this language. Grey literature such as reports from organizations, etc. are not included. Included studies are conducted at various clinical settings with different endpoint measurements and varying populations. The studies are mostly focussed on the impact of patient portal use to the patients and healthcare providers. Perhaps a more holistic view including the impact on other stakeholders including the financiers and IT sector within the healthcare system could be beneficial and form an essential part of future projects.

Conclusion

This literature review identified some benefits and harms involved in promoting patients’ access to their EHRs. Better health outcomes were mostly found to result from patient empowerment through healthcare information exchange to aid self-care, informed decision-making, enhanced medical compliance as well as improved trust between patients and medical professionals. The main issues with patients were around confidentiality, individual distressed response to certain content documented in EHRs and anxiety in serious clinical conditions. This review clearly describes the types of studies, participants, interventions and outcomes, as well as the data sources and search strategy. The focus has been solely on the impact of providing patient access to their EHRs, and not on attitudes to adoption before the provision of EHR access or challenges to its implementation.

Such access to EHRs is often part of government strategies when developing patient-centric self-management elements of a sustainable healthcare system. The findings of this review could help healthcare providers to look at the benefits offered by promoting patient access to EHRs and decide on the best approach for their own specialties and clinical setup. Such initiatives could also help the government address concerns in developing national standards, whilst taking care of local variations and fulfilling the healthcare needs of the population.

Improving health data literacy – educate the public in interpreting their personal health data, should become an essential part of promoting the culture of healthy living among the population. This is aligned with commercial efforts of personal fitness and health device manufacturers (e.g., Garmin, Fitbit, Apple) to promote personal awareness of sensor data measurements. This change in personal responsibility is also reflected in patient’s new ability to review and act upon any inaccuracies in their health data. Transparency of the patient’s record thus subtly changes the dynamic of the patient–provider relationship with data becoming a shared collaborative artifact between them.

In future, patients might be able to download parts of their EHR and fuse this with their own data through apps giving them insights and the opportunity to share combined data with their clinicians for joint decision-making. We will need much more research on collaboration models, and governance models for the sharing of data and decision-making between clinicians and patients, before new best practices could be defined.

Also, a robust cost-benefit evaluation of initiatives around patient access to their EHRs along with its impact on major stakeholders within the healthcare system is essential to understand their impact on healthcare outcomes and health economy. This could form an important part of future work.

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