

## Patient Access to Health Records: A Case for Healthcare Improvement

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### Abstract

**Background:** In recent decades, there has been a worldwide shift from the traditional system of health records towards electronically managed health records. It is due to the increasing evidence of the potential of electronic health records to improve health outcomes and population health by disease prevention and better care. It necessitated the study of patients' behavior towards online portals and their health records. Although accessible health records and online portals are intuitively appealing to improve health outcomes and enhance communication between patient and provider, little is known about the difference in patients' preferences when they are asked to think about the relative importance of different features of health records or various functions of a hypothetical portal. It is known that ethnic minorities are less likely to adopt health information technology initiatives as compared to their majority counterparts. Knowing the behavior and preferences of all groups of society will be useful while designing an online portal. Health Information Technology tools that cater to the needs of all members of the society irrespective of race, gender, socioeconomic condition, and educational background is necessary for a just and equitable healthcare system. Such knowledge is crucial for an action-guiding anticipatory understanding of current behaviors in the adoption of online health records and the level of motivation required bringing about a behavior change.

**Methods:** A literature review is carried out to summarize the information on electronic health records, patient portals, and personally controlled health records. It will also shed light on International as well as the consumer's perspective. It will briefly emphasize the impact of EHR's on patients and their perceived barriers and facilitators of online health records adoption. Furthermore, it will also shed light on the cognitive mismatch between patient and health information technology, existing proposed theoretical frameworks on patient access to health records, their potential impact on health outcomes, barriers and facilitators in the use of health information technologies, and analysis of eHealth interventions as if they are overcoming or creating health disparities due to an unequal adoption and use. This knowledge is useful for the designs for potential e-portals to optimize the full potential of an "empowerment agenda" that would otherwise be undermined due to the "lack of engagement" of patients. Moreover, it will help ensure a just and equal healthcare system for all, including vulnerable and marginalized populations, thus, mitigating their risk of further marginalization.

**Conclusion:** The review will discuss the potential of eHealth initiatives to transform healthcare along with the unintended consequence of widening disparities due to unequal adoption and use. It has implications for future patient portal designs and it gives suggestions for potential portal designs to ensure engagement of all patient groups.

**Keywords:** Electronic health records; Electronic medical records; Personal health records; Patient access/Use; Healthcare provision; Health improvement; Improved health outcomes

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**Citation:** Afzal N (2021) Patient Access to Health Records: A Case for Healthcare Improvement. J Health Commun Vol. 6: No. 2:3.

**Received:** January 05, 2021; **Accepted:** January 19, 2021; **Published:** January 26, 2021

## Introduction

The traditional paper-based system of health records was frustrating for most of the patients worldwide as they were not often well informed of their underlying illness, available options, and the prognosis of their disease. Patients had only a single copy of the health record available. The records were maintained in discrete sections in separate folders based on the type of note. Even the well informed subjects find it exasperating to deal with the intricacies of the system as they are required to tell their disease histories repetitively in the case of hospitals losing their records. Therefore, it is widely believed that technology can offer great convenience and greater control in transforming healthcare as it did in other aspects of life. It will enable the patients to share their records across organizational boundaries in the interest of their care.

Both nationally and internationally, governments, healthcare providers, and medical insurers are promoting the uptake of Personal Health Records (PHRs), with broadly the same message of engaging the patients in their healthcare to secure better health outcomes and incur low costs, but most of the electronic portals are generally designed on the assumptions of healthcare providers (doctors, nurses, etc.) so they do not meet the expectations of patients, resulting in either their abandonment, low or non-sustainable uptake by the patients. Another reason for low uptake is found to be "cultural apathy". People generally do not care about their health until they are diseased and do not consider their health as their 'personal responsibility'.

This cultural apathy and a cognitive mismatch between patients and health information technologies are perceived to be the main barriers in the uptake of PHR, so an increased uptake will require a behavioral and mind set change to involve and inform patients as equal partners in their care. It will require a massive cultural shift in dealing with their apathy to Personal Health Records. Chronic conditions are more likely to benefit from electronic health records. Supporting patient self-management by the use of e-portals will have a positive impact on the health outcome by increasing patient activation in the management of their health. Moreover, such portals enable information sharing between patients and Health Care Providers (HCPs) and support communication with HCP. While designing eHealth interventions, the needs and expectations of the user group must be kept in mind and addressed increased patients adoption and utilization of EHRs' greater potential.

## Literature Review

### Shift from traditional health record to electronic health record

A traditional paper-based record was just a doctor record of patient-encounter related information. It does not solve the needs of modern healthcare, so it continues to evolve to keep pace with modern healthcare requirements. This traditional health record emerged around the early 19th century lacking any formal structure. It was a highly personalized lab notebook, which physicians use to record important details about the

patient which they use to review as the patient came to visit next time [1].

The design was based on the assumptions of physicians and it was not meant to be shared with patients so they do not allow active patient involvement in their care. With the growth and proliferation of health technologies and their numerous benefits on humans, there is an increase in the momentum to involve patients in all aspects of their health and healthcare. Patients can now interact with the HCP outside the clinical setting. Patient active involvement and engagement in their healthcare by self-managing their health conditions could potentially transform the overall level of healthcare.

### EHRs, online portals, and the consumer-centered context

**Electronic health records:** A record of patient managed health information is an Electronic health record (EHR) and is defined as "An electronic application 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 [2]." So, it is perceived that EHRs have a significant potential to transform healthcare.

Current EHRs offers a variety of features ranging from administrative (appointment bookings, prescription ordering, managing transactions) to clinical features (reviewing information, communication with the GP, summary care records, etc. therefore now, electronic health record systems are not just static repositories for patient data rather they combine data, knowledge, and software tools, which help patients to become active participants in their care. Chronic diseases can be better managed by patient engagement in their care. [3] So a plethora of web-based health sites that support chronic disease self-management [4] is seen that compare the quality of physicians, hospitals, and health plans [4,5]. Information sources that support patient and consumers active participation in healthcare are widely expanded and patients have the option to select care based on quality [6].

**Personally Controlled Health Records (PCHRS) and patient portals:** PCHRs are portable, patient-controlled records that provide lifelong access to health information and are capable of aggregating data from multiple sources. [7]. Some features of PCHRs are specific to healthcare institutions or providers such as the ability to manage appointments or to request referrals or prescription refills. Healthcare quality and safety can be greatly improved by more activated and involved patients in their health [8-10].

If the patient and doctor communicate outside face to face interaction through PCHRs and patient portals, this two-way communication and access to potentially important information outside of office visits or hospitalizations could potentially benefit patients. Examples include more timely communication between patient and provider regarding rapidly deteriorating conditions such as heart failure; more timely medication adjustments, especially for newly prescribed drugs, quicker follow up, post-discharge communications and interventions,

pre-visit communication of questions and concerns, and potential for e-visits to substitute for office visits. Therefore, Healthcare institutions, employers, commercial entities, and insurance companies are increasingly offering personally controlled health records to allow patients access to their health information.

Traditional portals allow patients certain administrative functions and communication. These tethered applications allow patients access, but not control of, certain healthcare information, such as secure messaging, appointment management, and prescription refill requests, facilitating care at a specific healthcare facility. These secure internet-based communication portals (portals) are used to facilitate asynchronous communications with patients outside of face to face interactions [11,12].

There is a variation in the features and functionality of available patient portals and PCHRs. Most tethered patient portals allow patient access to select health information from a single institution, and enable them to perform certain administrative tasks, such as appointment management and prescription refills. [8,13]. Data are controlled by the portal provider, and patients can only access the site as long as they have an active relationship with the institution supplying the portal. There are three PCHR platform providers currently.

- Indivo (used by Dossia consortium, which includes Walmart, Intel, AT&T, and five other companies)
- Microsoft and Google [14].

### Impact of EHRs and internet-based patient communications portal

**Impact on patients:** The need for Electronic Health Record (EHR) is strongly recognized in literature and it has been emphasized that EHRs may be associated with improved health outcomes [11,15,16], by improving patients safety, quality, and access to health care as well as saving healthcare staff time and money [17,18], therefore, EHRs are regarded as a positive advancement in healthcare.

Generally, EHRs allows patients to securely retrieve test results, make appointments, refill medications, and email providers [1]. They can empower patients by allowing them access to their health information and by exerting better control over their health records. Patients' communication with the HCPs by the use of EHRs makes them more satisfied and engaged in their care [1,10]. Patient safety can be improved by a significant reduction in medical errors by electronic storage and transmission of patient information. For example, quick access to critical health data could be a matter of life or death especially during emergencies (e.g. allergy or medicines interactions).

**Impact on conditions (Chronic vs. acute):** Chronic medical conditions are likely to benefit more from the use of PHRs [19]. It is because PHRs designed for chronic disease management allow for self-monitoring via the feedback loop (which is the section of PHR that adjusts itself according to the differences between the actual and desired/optimal output) and therefore support the management of chronic conditions by behavior change.

**Impact on health outcomes:** Patients activation in their health management and engagement in preventive behavior can be increased by supporting patients' self-management. It will not only impact patients' use of traditionally provided health services but also positively impact health outcomes [3]. Activated patients follow healthcare recommendations and practice a healthy lifestyle because they are knowledgeable, skilled, and confident in the management of their condition [20,21]. Patients can self-manage their conditions by being active participants in their care by the use of an electronic patient portal [22,23]. It can be done with patient communication with healthcare professionals and efficient information sharing between a patient and the health care provider [24-26].

Typical Patient portals only allow patients to access their medical records documented and managed by a health care institution [24,25]. Other common patient portal functionalities are secured electronic messaging with a health care professional, medication refills, and access to medical information [27]. In addition to the potential positive effect on patient activation (knowledge about the disease, etc.), a patient portal may also relieve the need for health services offered through traditional channels, such as phone calls and face-to-face office visits [11].

### Impact of EHRs and internet-based patient communications portal

Cognitive skills are a prerequisite for the efficient utilization of health information. Not all individuals possess such skills. In a situation where patients are increasingly expected to use complex health care information to make informed decisions, it is unclear how many have the skills to do so. Hibbard argued that the empowerment agenda requires cognitive skills that not all individuals possess. This is one of the reasons that participants with low health literacy in a study showed a lack of interest in their health by responding that they do not want a "health space account" [21].

Sir Derek Wanless also warned that the "lack of engagement" agenda could potentially undermine the success of numerous public health initiatives in the UK. The introduction of electronic health records was supported by the assumed empowerment agenda but a group of patients sees their summary care records as a good thing because it reduces personal responsibility for health. This finding is against the assumed empowerment agenda of the introduction of summary care records and health space [28].

### International perspective on EHR adoption

The potential of EHR's to improve population health leads to the growth of an international trend of adopting legislation to give patients access to their personal health records. The US Health Insurance Portability and Accountability Act [29], ensured that patients will have access to their health records. The Data Protection Act, UK has also given the right to all the patients to access their personal health information. Similarly, the EU digital Agenda has also highlighted that an essential factor for eHealth technologies to be successful is to give the individuals, the right to access safely stored personal health information.

## Current practices of EHR adoption

Despite all the legislation, patient access to their health records is limited. This is attributed to patients' perception of health records access to be a cumbersome process and a lack of awareness of this option [30]. Studies have also argued that a person's decision to have (or not to have) an electronic health record is both an individual and complex process [31]. Personal priorities and context must be addressed while designing EHRs for diverse user groups. The benefits of electronic health records (especially the availability of medical information in an emergency) must be weighed against its drawbacks (such as the risk of security breaches, human error, the potential stigma of disclosure) before designing online health records for various user groups.

## Patient perspectives on EHR

EHRs ease of use was perceived as being both a barrier and facilitator to EHR implementation among user groups and was closely associated with the design and technical issues [32]. Where systems were reported as user-friendly, participants tended to perceive EHRs as easy to use and a valuable tool to facilitate work processes. However, when systems were not adapted to the needs or abilities of the users, studies reported participants as perceiving the EHR system as being difficult to use. Other issues were related to the lack of understanding of EHR features [33], or confusing screens, options, and navigational aids [34].

**Existing proposed theoretical frameworks on patient access to EHRs:** Most of the proposed theoretical frameworks originated from the USA where the EHRs represent an entirely different business model and the context in which patient's access and use it. For example, the following theoretical frameworks have been proposed targeting various patient populations and for various health conditions.

A study conducted by Winkelman using the grounded theory approach identified four themes in patients living with chronic Inflammatory Bowel Disease (IBD) promotion of a sense of illness ownership, patient-driven communication, personalized support, and mutual trust [35]. The identified themes can serve as focal points for the evaluation of information technology designed for a patient living with chronic IBD use, and allow technology developers to adapt existing EHR systems by utilizing a patient-centered framework to improve health care quality and health outcomes. The only study was undertaken by Greenhalgh on patients' attitude to summary care record (SCR, a centrally stored medical record drawn from the GP record) and health space (a personal health organizer accessible through the internet from which people can view their SCR) [36]. The limitation of this study is that it is particularly targeted towards those with low health literacy, potentially stigmatizing conditions, or difficulties accessing healthcare. Various themes and tensions associated with the use of Health space were identified and recommended that the benefits (especially the availability of medical information in an emergency) must be weighed against its drawbacks (security breaches, human error) in a way that addresses personal priorities and context. Another important finding of the study is that most

people were not aware of SCR and health space and did not even recall receiving any information about it. It followed another case study of Health space by Greenhalgh on the adoption, non-adoption, and abandonment of personal electronic health records [34]. It evaluated the policymaking process, an implementation by NHS organizations, and patient and carer's experiences of efforts to introduce health space in a public sector healthcare system. The main outcome measures of the study were national statistics in invitations sent, Health space accounts created, and interviews, and ethnographic observation of patients and carers. Data analysis was informed by a socio-technical approach that considered macro and micro influences on both adoption and non-adoption of innovations. Few (0.13%) of the anticipated population opened an advanced account and overall, patients perceived Health space as neither useful nor easy to use and its functionality aligned poorly with their expectations.

Policymakers hope that deploying Health space would lead to empowered patients, personalized care, lower NHS costs, better data quality, and improved health literacy. The study concluded that unless PHRs align closely with people's attitudes, self-management practices, identified information needs, and wider care packages including organizational routines and incentive structures for clinicians, there is a substantial risk of non-adoption or abandonment. If these records will be conceptualized as a dynamic entity (as components of a socio-technical network) rather than a static one (as containers for data) and user-centered design techniques will be employed, the chances of their adoption and use will be enhanced.

## Health interventions-overcoming or widening disparities?

The potential of PHRs to improve care delivery and the patient-centeredness of medical care is widely recognized in the literature. While it is believed that eHealth applications and the possible contributions of this field has the potential to overcome disparities in health and health care [37,38], but an unintended consequence of these tools identified in the literature is the widening of disparities due to unequal access and use [39-41]. An unequal adoption and utilization of various forms of health information technologies could give rise to health disparities. Digital health disparities arise when a population (racial/ethnic minority) cannot adopt digital technologies due to the digital divide (a term used to describe disparities in access to technology and is the population level gap in the internet and computer access). In this scenario, the adoption of health IT could actually increase or exacerbate existing healthcare disparities or even create a new one [42,43].

While designing eHealth interventions, the needs and expectations of the user group must be kept in mind and addressed as if the cause of the digital divide is barriers in access to technology or longstanding disparities in health-seeking behavior. A recent study of Kaiser Permanente enrollees found significant racial and ethnic disparities among enrollees who registered to use the PHR available to all Kaiser Members. Among African American members, 30.1% registered, compared with 41.7% of whites. Those with baseline internet access were more likely to register,

and a significant educational gradient was also observed (with registration more likely among those of higher educational levels). Interestingly, differences in education, income, and internet access did not account for the disparities in PHR registration by race. However, the factors moderating this difference remain unexplained [44]. Patients with multiple comorbidities (diabetes, hypertension, Asthma) are likely to benefit more from EHR due to deeper engagement in the process of managing their health and healthcare [45], but the digital divide in such patients will prevent them from adopting and using EHRs and further marginalize their care. Raghavan also identified in their study that frequent internet users, higher literacy rates, younger people are more likely to adopt EHRs while per capita patient days (a proxy for healthcare need intensity within a state) are negatively correlated with EHR adoption rate [46,47].

Human interaction with devices in challenging environments is the province of human factors engineering. These interactions are related to the people, tasks, environments, and technologies involved in the care process, which are often different for racial and ethnic minority patients. Patients of different ethnicities might have varying perspectives of interaction with technology that need to be understood because such perceived barriers, issues, or problems could impact health IT adoption, utilization, and ultimately outcome [47]. The need to study cultural issues related to trust, privacy, economic status, and literacy that may sustain the PHR adoption gap [48-50]. Moreover, he also indicated that healthcare disparities can be overcome via interventions and methodologies that support the social and cultural realities in which people work and live. To overcome health disparities, issues of guaranteeing internet access for every individual may prove to be less important than attempting to address health disparities via interventions and methodologies that lack cultural relevance. Problems could impact health IT adoption, utilization, and ultimately outcome. There is evidence to suggest that applications that are tailored to the individual, participatory, personally relevant, and contextually situated will be more likely to promote behavior change [51,52].

### **Barriers in the use of health information technology tools among vulnerable populations**

Numerous barriers to the adoption of health information technologies have been reported among underserved patients. One major barrier for patients is the lack of perceived benefit of health IT. If patients do not perceive a benefit to be gained from using a given system, they are unlikely to use it, especially when there is a significant degree of inconvenience in the data entry, if the patient is already doing well, or when there are only a small number of other users [52]. Another barrier is a perception of health IT creating more work for patients, or patients finding it difficult to fit the health IT into their busy everyday lives [52-54]. Lack of trust in the device, technical problems, confusing educational or instructional materials and/or technology content, limited access to computers or hardware, technology fears/anxiety, and cognitive and physical disabilities have all been shown to be barriers to health IT utilization and adoption among vulnerable populations [15,44,55-59]. The competing

responsibility of taking care of a family has been identified as a barrier for some minority patients. The poor computer knowledge, literacy, and skills are also barriers among minority populations [49]. Lack of cultural relevance as well as privacy and trust concerns all have been reported as barriers to the use of CHI (Consumer Health Informatics) tools and applications [60-64].

## **Discussion**

With the advent of modern computer technology, the foundation for the development of the Electronic Health Record (EHR) was laid. It has made patients' medical information easier to read and access from almost any location in the world and has substantially empowered patients. They have contributed to considerably reduced medical errors and incomplete, self-reported, contraindicated data.

Despite the huge benefits of electronic health records, PCHRs, and patient portals, patients are not found to be engaged in their care due to a lack of health records access. Institute of Medicine in its report crossing the Quality Chasm identified this lack of access as a "Missing element of patient engagement and recommended that "patients should have unfettered access to their medical information" [64-67].

While it is believed that eHealth applications and the possible contributions of this field has the potential to overcome disparities in health and health care but an unintended consequence of these tools identified in the literature is the widening of disparities due to unequal access and use. Until the needs of a diverse group of patients are addressed before the design process and the user group should be continuously involved in the design process, it is unlikely that patients will adopt them. This knowledge must be kept in mind while designing e-portals/electronic health records systems to prevent the marginalization of the vulnerable population due to their disengagement [68-73].

## **Conclusion and Recommendations for Future Research**

This review has implications for future e-Portal/electronic health records design. The needs and expectations of all user groups (patients and healthcare providers) must be researched and addressed for the effective utilization of health records and improvement of population health. While qualitative studies cannot be generalized to a wide user group due to their interpretative nature, yet they serve to explain patient perspective on technology. EHR features vary and terms like PHR, EHR, EMR, PAEHRs are constantly used in literature interchangeably and various studies identified patients' expectations from those EHRs. Health outcomes can be influenced by promoting Patients' behavioral changes by the use of EHR's. The finding from one study cannot be generalized to another due to differing structures of EHRs as well as the target populations. It necessitates the need for further studies in other populations to enhance the generalizability of the emergent theories. Therefore the theoretical frameworks proposed in the literature in one study cannot be applied and used to design an EHR based on the

assumptions of participants of other studies.

Healthcare provider's perspectives must also be taken into consideration while designing the EHR system. Further research is needed to understand what is causing clinicians to rely on paper alternatives of EHR, and how can healthcare providers exert better control over EHRs to fit in their schedule and practice. Many healthcare providers reported feeling frustrated due to the complex data search interface of existing EHRs. Effective integration of EHRs at patient encounters also need to be studied.

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