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A critical view on the computer-based medical reports and the involvement of patients in health portals

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Symbol Index

AHRQ	- Agency of Healthcare Research and Quality
CG	- Control Group
HER	- Electronic Health Record
EMR	- Electronic Medical Record
ICD 10	- International Classification of Diseases
IG	- Intervention Group
MPC	- Medicine Plus Connect
PHR	- Personal Health Record
PSPS	- Preventive Service Reminder System
EKG	- Electrocardiography

1. Introduction

Patients' ability of sharing and recording medical conditions at all day and night times with their physicians and hospitals is the achievement of empowering patients to be in control of their own medical data. Nowadays patient charts are mostly digitalizes at some point (Sakar et al., 2010:184). That saves time to diagnose and treat patients correctly to their medical history (Ball et al., 2007: 2). But constructing portals for patients is a relatively new field to explore. Portals and webpages individualized for certain patients start to be available on the market and has been in use by hospitals for few years now.

This paper provides the reader with an overview about the possibilities patients have to get involved in their medical state in our digitalized society. The medical data can be uploaded on patient portals as well as used, stored and renewed all the time by each patient- from medication they need to previous taken X-rays. That promotes new possibilities, for patients and doctors (Emont, 2011: 3). There is no need any longer to acquire human resources to provide certain information about a patient. Everything can be stored in one device. But is that the truth? There are critiques and high risks in digitalizing every patient's information, thinking about security lacks in the digital data or incorrectly written medical conditions by the patient or the portal itself (Greenhalgh et al., 2009). Besides that who is able to use that device referring to the medical condition, internet access and different skill levels? Patients who suffer from chronical diseases might be less able to fill in the portal forms than people in good health.

During that examination I analyze two different kinds of portals that advertise with helping patients to keep track with their own medical history and stay in contact with their hospitals or doctors. That for, the paper opens with a brief overview about digital health reporting and continues with presenting "My Wellness Portal" and "The PatientSite" successively by focusing on the medical and wellness features each of them offers in their portals and analyze differences and implications on two important sides, patients and physicians, leaving insurance companies and other providers for further research. Before concluding and referring to the questions raised above, additional developments of digitalizing patient records in Europe and security concerns will be presented briefly. Thereby the paper hopes to give an insight on the impact EHR and especially portals have, on both patients and providers and on possible implications that are linked to that.

2. Patient Portal- The Digitalization of patient records

The medical health care seeks for better safety, effectiveness, efficiency, equity, timeliness and mostly considered in this paper a more integrated patient by providing and using Electronic Health Records (EHR) (Ball et al., 2007, p. 77; Greenhalgh et al., 2009, p. 730). Such database collects systematically health data electronically from a population or only one patient and seems to outdate paper based patient records at first glance. That digital device can be shared within its health network (e.g. institutions like hospitals, physicians, insurance companies) for faster and more organized medical information transfer that includes data such as demographics, medication, personal information like age and weight, test results, radiological images and medical history or insurance data. The EHR communicates Electronic Medical Records (EMR), managed and provided by individual hospitals, with e.g. physicians or laboratories and pharmacies. (Kierkegaard, 2011, p. 503-504). That definition has been changing over time as the development of EHR continues more and more to include further functions over the past years and new sub-movements can be discovered. (Greenhalgh et al., 2009, p. 731).

But it is not even close running correctly without additional notes and intervention of physicians as well as the need of being careful with the completeness of contents of a patient record. Koppel et al. (2010) revealed by analyzing various EHR different kinds of problems, from misleading information of allergies data to not correctly transferred personal data within the system. Consequences are various, from wrong medical treatment to the question of responsibility for various kinds of failures, while the service provider of the EHR is contract-backed to have no obligations. (Koppel et al, 2010, p. 9-10).

Furthermore this form of digitalization of patient data is still very disease-centered and mostly provided through medical doctors and hospitals as mentioned above and does not include the equality of patient and doctor in being responsible for patients' health. As Aarts and Nøhr 2010 discussed, the role of self-care and compliance has been growing for more than forty years. People want to empower themselves to be aware and responsible of their own life and therefore provide themselves with knowledge, skills and self-awareness to achieve that goal. New technologies as the internet and other digital devices can provide various and large communities about certain topics on a global scale, for instance in the medical sector through certain online forums where patients, suffering from the same illness, are able to exchange knowledge or gain knowledge from medical doctors, providing their services online (Aarts et al., 2010, p. 141-142). That this peer-to-peer connectedness helps people to cope with various illness has been

researched by Susannah Fox in 2011. The author's findings were extraordinary in how people experience comfort through building internet relationships in social networks but at the same time how they need physical contact with their families, friends and medical doctors in regard to feel safe and get information about their condition (Fox 2011). The same kind of physical experience can be discovered while asking physicians about their attitude towards paper based and electronic based patient records. Most of them appreciate the work with paper records in terms of having something 'real' in their hands (Varga 2011: 3).

All these electronic services, including, without limitation, EHR and information seeking through the internet by patients, come together in one fashionable term, called "e-health", which combines telecommunication and information technology within healthcare and is sometimes called the counterpart of e-commerce (Della Mea 2001). This trend of patients' wanting to access detailed information about their medical state together with being able to control their own medical records leads to the core subject of this paper- the electronic health care record controlled by patients and providers at the same time. Patient Portals can be defined as "a secure Web site through which patients can access a PHR and often certain information from an EHR. Portals typically enable users to complete forms online, communicate with their providers, request prescription refills, pay bills, review lab results, or schedule medical appointments." (Emont, 2011, p. 2). That means that compared to the EHR which is only conducted by physicians and hospitals, these portals can enable patients to become active within their own healthcare.

Research has been made upon those portals in regard to analyze the utility of these portals to both health care providers and patients, both before implementation and during use. Those studies include among others patient portals developed for patients with chronical diseases like diabetes (Sakar et al. 2010). In the next chapter I present two different portals that can be accessed by patients with highly diverse medical conditions.

3. Electronic Patient Portals

This section gives an understanding on how patients become truly involved in their own healthcare by typing their medical state into their home computer and what characteristics patient portals offer. Therefore two different portals are presented next.

3.1 The preventive care Portal: The “My Wellness Portal”

My Wellness Portal advertises with addressing patients’ need for preventive health care with their slogan “Take Control of Your Health” on their web page and provides therefore a portal to access personalized information to enhance one’s medical condition in English and Spanish. That means the portal is designed to be a patient oriented as well as preventive oriented and an internet based EHR. Beforehand the potential user is able to inform himself about the development and introduction of the portal via short web-clips available on the internet source of Agency of Healthcare Research and Quality (AHRQ). AHRQ has been funding the Portal from the start. Furthermore, patients already using the portal are presented to show the process as well as the success of the portal (My Wellness Portal 2013: online).

My Wellness Portal has been developed under the patronage of Dr. Zsolt Nagykaldi by the University of Oklahoma Health Science Center Department of Family and Preventive Medicine and offers access to care practices and wellness institutions throughout Oklahoma. That means that the portal can only be accessed locally and not on a big scale by using the information system “Preventive Service Reminder System” (PSRS) provided by Oklahoma Physicians Resource/Research Network (AHRQ: online).

As the Portal is patient oriented it consists of various items to keep track with one’s own health record. Patients are able to access and add their own medical history, can set their own risk factors and preferences for care services, vital signs and symptoms. Additional to that, the patient portal is open to arrange appointments and includes patient information material. A Wellness Plan, provided over three years, and recommendations for preventive services are also a part of the EHR. Those tools have to be accessed not only by the patient but furthermore by physicians. Needed information is digitally transferred to the clinical information system of Oklahoma Physicians Resource/Research Network, called Preventive Service Reminder System. Receiving medical data about a patient before the actual meeting, the physician is able to prepare better on behalf of their patients’ questions and concerns (Mold et al. 2010).

The presented portal went on operation with its services described above after a pilot study and a cluster randomized controlled trial. The main aims to that study were first to develop the portal, second to receive knowledge about the impact on the perceived patient-centeredness through patients’ and providers’ experience by observing their behavior and about the impact on individualization of recommendations through personalized risk factors. The third aim was to create a textbook example how a patient’s visit to a practice could look like that uses the Wellness Portal and disseminates them. The pilot study includes two practices to survey the

portal's acceptance rate and feasibility over a six-month period. As the findings show, most participants seem to be satisfied with the portal. Users also suggested additional features like lab results or symptom diaries and further changing options, like to shorten the drop down menus (Mold et al. 2010).

The study that followed comprises eight clinicians in six different practices split in one intervention and one control group with each having four participants. The intervention group (IG), given access to the Wellness Portal, were educated about the use of the Portal while the Control Group (CG) neither had access to the Portal nor got any training about it. This study took place in a 12-month interval, adding new features every week to offer incentives to continue. The participants included 560 patients, among them 116 children. All were picked and divided in groups randomly. The findings reveal mostly positive responses. The patients in the IG perceived themselves to be more included in their health care than the CG, the visits to their physicians lessened and the recommended health care services were used more often by the participants of the IG. The physicians perceived the utility of the portal very differently. Most reported only slight improvements on the prevention care in their practices, but agreed on the helpfulness for their patients without concerning to use it on their own or for relatives. Besides that only a small number of patient's each practice belonged to the study, which states a problem to remember who is participating. Patients who dropped out of the study, IG and CG, are slightly older on average than the participators (Mold et al. 2010).

Furthermore, addressing to the real participation in the IG during the whole study another perspective should be discussed even when the researchers did not mention it to be considerable. Only 73 percent of all participants in the IG signed into the portal and accomplished one task that is worth considering. Only 12 percent continued and used not more than two features. In the end only five percent of all participants got involved in the portal frequently. That implicates, even if 384 of 538 participants (71 %) completed the survey, that the expressed need to involve patients into their own medical care and enabling them to become active is either not well enough communicated or the patients, randomly or not, do not yearn that trend. Nevertheless what stands out in the key findings is that patients' children being the IG received almost all recommended vaccinations (Mold et al. 2010). That indicates that the Portal seems to be a good information source for immunization recommendations.

As this portal is highly operating on their wellness factor and preventive care it is necessary to dig deeper into the risk characteristic feature the portal offers. A tool called "Health Risk Appraisal" offers patients to receive a personalized list of recommendation to help them

managing their preventive care. The information that the system includes is provided by the National Center of Health Statistics. General probabilities, death causes and demographics regarding to life expectancy are used to generate an estimated life expectancy for each individual, based on a separate algorithm. That shows the probability of death for each person and includes risk factors, like smoking and excessive drinking (Nagykaldi et al. 2013: 77).

Obviously there seems to be no further progress to the Portal in the last years on a big scale, at least nothing that can be discovered without using the portal as a patient. However, the portal seems to be successful as it is still on the market. It might be necessary to repeat that study in order to gain more recent data and to understand the implications of the My Wellness Portal on preventive patient centered care on full operation.

3.2 The "health journey" Portal: "The PatientSite"

"Manage your healthcare online, anytime" (BIDMC 2014: online) is the header of "The PatientSite" Portal's introduction page. The provider advertises the portal as one of the first portals went on operation with an aim of constant improvement. It can be accessed through several electronic devices- laptop, tablet or smartphone (BIDMC 2014). The portal operates for patients having a Beth Israel Deaconess primary physician since 2000. The "PatientSite" patients get access if they are enrolled in a practice using the portal on their own web page. Patients is sent a link to the portal via e-mail, the portal itself is password secured and the provider needs a secure password as well to see the data. (Weingart et al. 2006: 92-93).

Each patient is able to use the portal to inspect his/her lab results, X-rays or EKGs as well as currently taken medication. Allergies or upcoming/received vaccinations can be noted and appointments can be arranged. E-mail connection with providers, prescription requests, cancel or request an appointment with a reminder option as well as changes in demographical data is also possible. Furthermore, the portal connects with medical care information by hyperlink their EHR with "MedicinePlus Connect" (MPC), an internet source provided by the U.S. National Library of Medicine. The knowledge the patients receive throughout that page reaches from individual relevant topic about diseases and medical treatments about understandably written drug information to information concerning personal lab results. For that the Portal and MPC

resort automatically to medical codes and standards, like the ICD 10[1] for showing symptoms, which are already in the system of the portal (Medicine Plus 2014: online).

In 2013 the Portal introduced a new tool to its page, called "OpenNotes". OpenNotes, a program appreciated by 19 clinical facilities, makes it possible for "patients and clinicians [to be] on the same page" (OpenNotes 2014: online) by providing the possibility for patients to read the visit notes made by their physicians after the appointment at home or in advance to the next meeting. That improves the knowledge of patients about what their providers think about their medical condition, helps them remembering every important detail and reconstruct these visits. For physicians the report leads them to be more careful in writing about the patient's condition and appreciating the grown knowledge of their patients (OpenNotes 2014: online).

However, the implementation of the "OpenNotes" raises also negative statements and limitations. Some physicians noted to gain no positive or no outcome of writing these reports. Regarding to patients who are not influenced positively, the detailed notes even frightened them or made them even more anxious about their diseases. That for limitation are given regarding to patients suffering from domestic violence or mental disorders. Suffering from domestic violence, patients might need special treatment and security in regard to their notes. Reading them only under supervision of their providers might secure them from possible revelation/exposure at home (My OpenNotes 2014: What people are saying: online; BBC 2014: online).

To get more information about how the "PatientSite" Portal affects the participating patients and providers a study is presented next. It was outlined by the Boston teaching hospital in 2006. The purpose is to reveal who is using the portal and who does it really help to change from a passive to a more active patient. Thereby Weingart et al. analyzed two primary care practices, where they selected 200 among 30000 adult patients with 2296 enrolled ones. Enrollees needed to be signed in the portal must have used it at least once. Characteristics like age, gender, ethnical background and insurance conditions are analyzed together with other clinical information like health problems or lists of medication as well as patients' utilization out of using the portal, measured by office visits and admission to the portal. Referring to the researchers' documentation, lab results or radiology reports were most frequently used. Patients enrolled to the portal at most during their first two months of enrollment. The added case control study revealed critical differences between users and nonusers demographically,

[1] IDC 10- "International Classification of Diseases and related health problems" classifies diagnostic codes published by the WHO (The free dictionary by Farlex 2014: online)

socioeconomically and due to their health condition. Non enrolled patients are older in average, take more prescribed medicine, suffer from more medical problems and few of them own a health insurance compared to enrolled patients who were younger, mostly white and better socioeconomically situated (Weingart et al. 2006).

That result by Weingart et al. raises questions about the effectiveness and availability of such a portal to every kind of patient without limitations due to ethnical or wealth situation. The next paragraph brings both portals and EHR in general together in regard to their benefits, impacts and limitations. In addition to that various views on the implementation of digital patient records will be given.

3.3 Impacts and Limitations of EHRs

The following paragraph brings both portals together and tries to focus on beneficial indicators of patient portals but at the same time stresses limitations, both on portals and on EHRs in general. Therefore the upcoming text refers to previous given data.

One advantage both share is that the portal is free of charge and accessible on every digital format. Privacy conditions for "The PatientSite" are carefully outlined for the patient and it shows the exact documentation procedure during practice visits and given data, e.g. handing it over to third parties (BIDMC 2014). The "My Wellness Portal" secures itself from misleading information and treatment their portal might provoke, but offers no statement how patient's data is used, at least not before a person signs in and so could not be observed in regard to this research (My Wellness Portal 2013).

Furthermore, both patient portals show mostly positive reactions by patients and physicians who signed in and worked with them. It seems to help them with their relationship to one another and patients strengthen their involvement and knowledge about medication, immunization of their children, lab results or their general health and wellness condition. Recommendations are served to patients differently, one uses risk factors measured through patients' medical condition that lead to health suggestions, the other draws its recommendation in terms of individualized information provided by an external source from patients stated data (as shown in 3.1 and 3.2). That seems to benefit patients in both cases as they reported to be more informed about their health but raises at the same time another question, as it implicates that the portal is not able to reach everybody. That problem should be addressed and researched more in terms of preventing the exclusion and to understand the reasons behind it. It might be

possible that there are integrated lectures on how the portal is used. Free access to the portal in hospitals is also a good option to use the portal without personal access to the internet at home. Both ways to access the portal were integrated in My Wellness Portal pilot study (Mold et al. 2010). At the same time, as noted earlier the amount of people that used the Wellness Portal appears to be really small which is contrary to the observation that people want to get engaged in their own health care (see 2.) as well as to the option to use the portal in hospital or be trained on it and provokes questioning the communication methods of the portal or lack of interest. Patients also vary in their knowledge of medical terms or computer based skills. That problem in particular was not explicit mentioned in the cases above but was discovered during other research programs that studied portals for diabetes patients. Findings about difficulties in navigation or accessibility aroused. The latter problem shows that not every patient might know about the existence of these portals nor be capable to use them due to the lack of computer or other digital devices that would give the person access (Sarkar et al. 2010: 190-192). Additional, the PatientSite study provided slightly similar information about the question (see 3.2) by asking who is really able to use the portal and concluded that fewer people coming from poor background signed in the portal than people that were younger and well situated. That reveals possible obstacles for patients who are older, less wealthy and suffer from a bad health situation (Weingart et al. 2006).

In both cases the best care wants to be given. They advertise to be patient-oriented and the "My Wellness Portal" even included its patient into the development and implementation phase as shown above. But thinking about the EMR/EHR maintained by hospitals and might be used by several portals leads to a question about who should be included in the development of these information systems in general and to whom might it be best by now. Is it the best for hospitals or practices to lower their costs and labor hours by abandoning paper based medical records or for the advantage patients gain to access their health care in every situation they like? Nowadays EHR are provided through different available medical information system co-operations. Researchers observed, that the amount and specification of detailed features which these systems offer come from a strategic, top-down management layer, deciding on behalf of standardization and control rather than on the feasibility it should have. That implicates a need in changing perspectives on who should be integrated in the progress of patient recording systems in favor of physicians, patients and the care system in general. (Eason et al. 2014: 196). That for, parallel can be drawn to the "PatientSite Portal" findings, as they reported a need of a stronger patient centered health care in general and a better acceptance by physicians on both, EHR and patient portals (Weingart et al. 2006: 94). There is evidence that physicians are not

ready to implement these information systems in daily work as they are not convinced about the use of EHR and still prefer paper based patient records, even if they tried the digital version (Varga 2011: 3). Medical Practices also reject the use of EHR caused by fear of high investment costs, training time and the lack of knowledge about succeeding or failing (Emont 2011: 3).

The next paragraph allows to give a broader view on the development of medical records in the digital environment. Therefore security concerns as well as the European point of view are outlined.

3.4 Site effects and the late entrance of Europe in the digital world of EHRs

The more medical information is stored and can be accessed by several entities by using one data source the more questions on data retention and data breach arises. Both are not considered by the portals above but is essential to register and being aware of that danger.

Since the EHR can be used, saved and changed the concerns about how to store and protect them in a safe manner arises. There are no explicit rules on how long patient data is allowed to be stored as long as there is always a reason on keeping them (Kierkegart 2011: 513). Security concerns are caused by the same in fact positive feature of portals- mass data stored in one place, open to all involved entities. Breaches caused by computer viruses or hacker attacks are able to erase all patient data and is therefore one of the biggest negative side effects the digitalization of patient data has to face and to cope with (Kierkegart 2011: 512).

Security and data safety need to be improved constantly which is one of the reasons why Europe has only been starting with these portals for a couple of years now. Both described portals are located in the United States and therefore only allow a narrow perspective in terms of general validity. That is due to the popularity of these portals as well as their experience with it and the reason they are analyzed in this paper. Contrary to the USA, Europe is still in a development phase of providing national and a cross-border EHR to its patients, physicians and other third parties. Thereby the EU faces several national and transnational problems in terms of protecting personal rights established in EU law and national legal text. Personal data, such as ethnical background, age and gender or other medical confidential information, is allowed to be published or transferred to third party e.g. in Germany under strictly secured paths and needs to be protected and considered while developing such records (Kierkegaard 2011: 504-507). There are maintain portals in terms of providing an EHR for patients and other entities like them. The “PatientsSite” model or the “My Wellness Portal” has only had its early stages of

development for a few years. Last but not least cultural differences need to be considered as well. The way patients interact with their medical care as well as their physicians might differ in Europe from the one in the United States where this program seems to find echo by its audience, the patient.

Conclusively it can be said that, wanting to integrate digital patient portals step by step in daily medical care makes it necessary to balance the negative sides and keep them in control by developing medical information systems that outweigh the benefits over the negative side effects digital data unavoidably has, as it is written above.

4. Conclusion and further Research

This paper wants to give an overview on the digital world of medical care with the focus on patient-centered portals available to patients to manage their own health care and to stay in contact with their physicians online. At first, information about EHRs were given showing the current stage of development. EMRs enable physicians to access patient data within seconds on every ward but still limit their user to technical failure. At the same time the medical sector seems to concentrate on getting patients involved in their own health care. Therefore the paper outlined two US patient portals, the "PatientSite" Portal and "My Wellness Portal". It can be stated, that the reaction to the portal is mainly positive by patients who are using it and are informed about the possibilities those portals offer. Limits can be seen for example in the accessibility, the usage in the long run, the physician`s partly negative attitude to the portals' utility or in the danger to provide too much medical information to patients who easily get hypochondriac about their condition. Older patients or patients less educated or less wealthy showed less interest or less inclination to continue using the portal once signed in. A considerable part of physicians stated to prefer relying on paper based protocols.

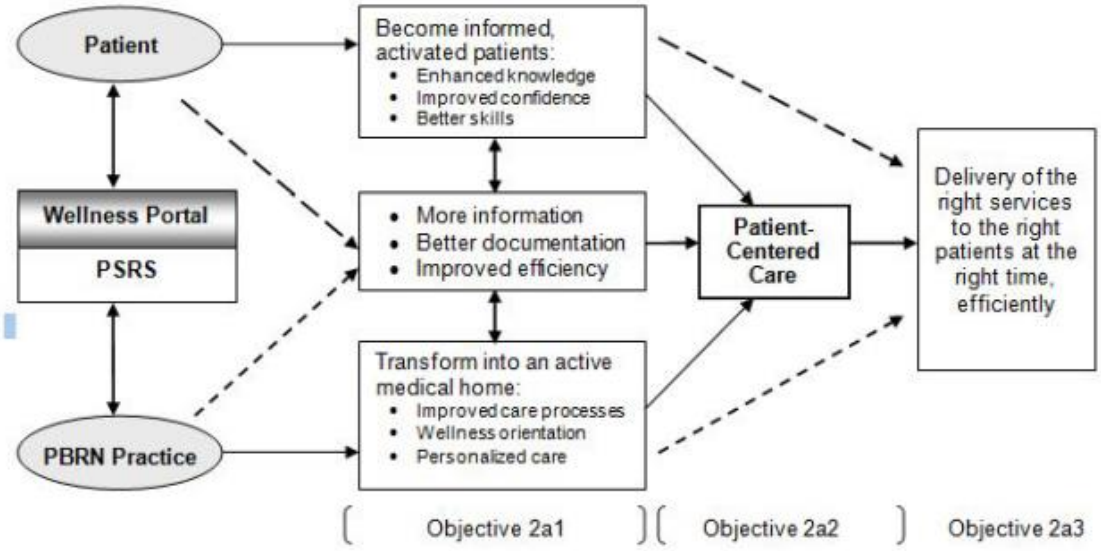
Furthermore, portals and EHRs in general provide sensitive data. That is why the paper points out rising security problems by digitalizing patient records. As this topic is only mentioned briefly it is required to go further in analyzing security issues also in regards to the amount of institutes that access these information.[2]

[2] Insurance company for instance might receive high amounts of information on a patient's health condition. That might decrease insurance options in cases of bad health conditions and the insurance company's access beforehand and requires in my opinion research as well.

The facts mentioned above about portals advertise the patients' active role to their own medical concerns, but at the same time they provide them with given data on medical information and easy tools to stay in contact with providers and other entities. This procedure raises questions about patients' 'real' active role in the process of medical care and needs further research as well. "OpenNotes" as one of the recent approaches (see 3.2) helps patients to 'remember' hospital visits in detail as shown above but it raises questions whether it better activates patients' efforts or gives him/her more the reason to become passive again. As the answer to that as well as to those matters mentioned above are open and therefore free to discuss, it is still our duty, being a patient or a physician, to answer in favor to really achieve the goal. "My Wellness Portal" already advertises with: a "delivery of the right services to the right patient at the right time, efficiently." (Nagykaldi et al. 2012: 159) - even if it makes hospitals go back and use paper based protocols again.

Appendix

Figure 1. Conceptual model of the impact of the wellness portal on patient centered, individualized care



(Nagykaldi et al. 2012: 159)

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