

From eHealth to ePatient: The Role of Patient Portals in Fostering Patient Empowerment

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Abstract

Background: Health IT adoption is high in Austria, but health IT targeted at the patient is still rare.

Objectives: To analyse the shift from eHealth to ePatient and the role that patient portals may have in this shift, from an Austrian perspective.

Methods: Analysis of the situation in Austria regarding the use of eHealth and patient portals.

Results: While eHealth applications are broadly used in Austria, only few applications address the patient as user and aim at facilitating patient empowerment. Patient portals are one approach to foster patient empowerment. In Austria, a national patient portal is introduced at the moment, but only with limited functionalities. Systematic

reviews show that the evidence on the impact of patient portals on patient empowerment is still unclear, which may explain low adoption rates. It seems to be still a long way to support a new generation of ePatients who are equipped, enabled, empowered and engaged in their health and health care decisions.

Conclusion: Patient portals and other eHealth interventions aiming at fostering patient empowerment can only show impact when health care professionals are willing to engage in a true partnership with the patient, and when patients are willing to take over responsibility for their own health management.

Keywords

Medical informatics; Evaluation studies; Telemedicine; Patient participation; Patient portals

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EJBI 2018; 14(2):20-23

Received: February 24, 2018

Accepted: March 13, 2018

Published: April 30, 2018

1 Introduction

As in many other countries, health care in Austria is not possible any more without the use of information and communication technologies (health IT). The usage of health IT has strongly increased in the last decades due to demographic change, rising costs of health care, medical progress, and technological achievements.

In the 1990th and 2000th, both private and public hospitals started to introduce health IT such as administrative systems, physician and nursing documentation systems, order entry systems, patient data management systems, or picture and archiving systems [1]. Today, many hospitals have introduced mobile tools (such as tablets or laptops) to support information access and clinical documentation at the patients' bedside.

In 2005, the Austrian government started to establish a national electronic health record system (Elektronische Gesundheitsakte, ELGA) [2]. ELGA connects hospitals,

nursing homes and physicians, and allows them to exchange patient-related information such as discharge letters, lab findings, radiology findings, and information on prescribed and dispensed medication [3].

In 2015, the ELGA patient portal went live. This patient portal allows patients to access all patient-related information stored within ELGA. It also allows patients to grant access rights to specific health care providers or to relatives. Patients may also decide to fully opt-out of ELGA. In 2014, less than 12% of Austrian citizens planned to opt-out. In 2018, less than 4% of all citizens had really opted out [4].

The ELGA patient portal does not present much information at the moment, as health care providers are just starting to make information available via ELGA. Currently it is unclear whether the ELGA patient portal will contribute to a more patient-centered care in Austria, and whether it will empower the Austrian patients to take over a more active role in their health care.

The objective of this presentation is to discuss the change from eHealth to ePatient from an Austrian perspective, and to analyse the role of patient portals may have in this shift.

2 From eHealth to ePatient

The term eHealth emerged around 20 years ago. eHealth can be defined as the “use of emerging information and communication technology, especially the Internet, to improve or enable health and healthcare” [5]. eHealth allows health care providers to exchange patient-related information. That way it supports patient-centered, integrated care.

Austria is a country with a high eHealth penetration. High IT adoption rates especially in hospitals, but also in physicians’ offices as well as introduction of the national electronic health record ELGA clearly illustrate this [6].

But eHealth is not only about communication between health care providers and health care institutions. eHealth is also about communication between health care providers and the patient. And here, Austria seems not so strong at the moment. Typical patient-centered applications such as appointment scheduling, secure messaging, electronic ordering for medication refills, telemonitoring or eVisits are seldom available to patients. Only telemonitoring applications show a higher penetration in Austria [6]. For example, in Tyrol, telemonitoring is routinely offered to patient with heart failure since 2017 [7].

As health care providers show some reluctance to offer eHealth applications for their patients, patients themselves have started to use eHealth applications on their own. Social networks of patient support groups proliferate, personal health records are used in various forms especially by chronic patients, and mobile health and quantified health applications show increasing usage rates [6].

But eHealth is not only about IT-supported communication. Rather, eHealth is “also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care” [8]. And this new perspective also includes “a new relationship between the patient and health professional, towards a true partnership, where decisions are made in a shared manner” [8]. This new relationship is based on patient encouragement and patient empowerment. And here, Austria seems to be only at the beginning. But let’s look a bit closer on the concept of patient empowerment first.

Patient empowerment is based on a philosophy which views humans as having the right and ability to choose by and for themselves. Patients are responsible for their choices and the consequences of their choices. Patient empowerment means that patients are able to make autonomous, informed decisions within a true partnership between patient and health care professional [9, 10].

The evolving role of the patient in the last 50 years can be described in five steps [11], as summarized in Figure 1:

The patronized patient, where the physician was the only one to decide on the next steps of care.

The informed patient, where the patient has at least to give his informed consent to a treatment decision.

The mature patient, where the patient was involved in decision making before the final treatment decision was made.

The autonomous patient, where the patient was considered as equal partner and where a shared decision marking between physician and patient took place.

The empowered patient, where the patient is put in the center of any decision making.

What comes next? Probably we will see the ePatient, willing to be empowered and to use health information technologies to support his well-being and his medical care. To be more specific, the term ePatients describes individuals who are “equipped, enabled, empowered and engaged” in their health and health care decisions [12].

Technologies supporting patient empowerment of ePatients are, among others, internet-based information resources, social networks, internet-based patient support groups, personal health records, mobile health tools, and patient portals. Evidence shows that patients want to be empowered and that empowered patients show better clinical outcome [10].

Now let’s have a closer look at patient portals and how they may support patient empowerment.

3 Patient Portals and Patient Empowerment

A patient portal can be defined as provider-tethered applications that allow patients to electronically access his health information that is documented and managed by a health care institution [13]. A simplified categorization may describe three levels:

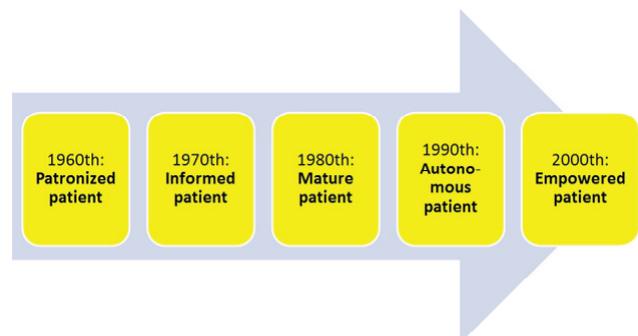


Figure 1. The development of patient empowerment [11].



Figure 2. Jana Zvarova at the eHealth 2016 conference in Vienna, May 25th, 2016, talking about international cooperation with Klaus-Peter Adlassnig.

- Level 1: Patient portal allows patient access to clinical data from electronic patient records from one or more health care institutions (e.g. discharge letters, lab values, medication information).
- Level 2: Patient portal supports communication between the patient and a healthcare provider (e.g. appointment scheduling, secure messaging, ordering of medication refills, eVisits).
- Level 3: Patient portal offers disease-specific functionalities as part of a systematic disease management (e.g. personal reminders, clinical guidelines, educational material, self-documentation, feedback).

In the United States, Meaningful Use criteria have accelerated patient portal adoption in the last years, a recent survey showing that 57% of health care providers offer a patient portal [14].

In Austria, health care institutions are not obliged to offer patient portals, and thus very few have started projects in this direction. For example, Steiermärkische Krankenanstalten, a network of 12 hospitals in Styria, offers a patient portal that contains discharge letters and radiology findings [15], being equivalent to the portal level 1 described above. In this portal, appointment scheduling for patients is planned, but not yet realized.

Since 2015, the national electronic health record ELGA is made available. ELGA includes a patient portal for all citizens in Austria. However, ELGA only offers level 1 functionality at the moment. Thus, patients can access discharge letters, lab and radiology findings, and (starting in 2018) information on prescribed and dispensed medication. Further functionalities for patient empowerment, such as functionalities supporting communication with providers or disease-specific functionalities, are not planned yet.

So, summarizing, patient portal adoption in Austria is quite at an early stage. Several reasons can be assumed for this low adoption: Health care professionals may be concerned in giving too much clinical information to their patients; health care professionals or patients may be concerned about possible data security issues; the impact of patient portals may be unclear; or the costs for patient portal development may outweigh the expected benefits. At the moment, no systematic assessment of these barriers has been conducted from an Austrian perspective. An earlier study, however, found skepticism among Austrian physicians with regard to electronic health records in general [16].

Whether patient portals really can have a positive impact on patient empowerment or not seems to be quite unclear at the moment. First systematic review showed a low number of studies and insufficient evidence [13, 17]. This is an unsatisfying situation giving the premise of Evidence-Based Health Informatics to provide the best evidence to support decisions related to health IT introduction and usage [18].

Therefore, at the moment, a Cochrane review was started by our group to systematically evaluate the most recent evidence on the impact of patient portals on patient empowerment [19]. A still running systematic literature search identified only 12 randomized studies, most of them from the United States. Data analysis is just underway.

4 Discussion

We can assume that success of patient portals will not come from specific functionality, but from “successfully communicating the idea that patients can effectively manage their own illness” [12]. Or, to be more specific: Patient portals and other eHealth interventions aimed at improving patient empowerment will only show impact:

- When health care professionals are willing to engage in a true partnership with the patient and to give up power; and
- When patients are willing to take over responsibility for their own health management.

Both requirements may be considered questionable at the moment. What can medical informatics contribute here? In my opinion, we must understand that information systems have to be considered from a socio-technical perspective [20]. This means that health IT is not about technology, but about how technology can help to transform healthcare. eHealth is about changing roles, about people, and about changing power relationships.

Or as Sherry Turkle from MIT put it: „The key question we must ask is not what technology will be like in the future, but rather what we will be like” [12].

5 Conclusion

The challenges of electronic health records and patient portals can only be understood and addressed from an international point of view. While countries may show differences in healthcare organization, the challenges are identical for all countries: How can we provide affordable health care for all citizens? And how can eHealth contribute to this objective?

Jana Zvarova whom we are commemorating in this special issue was always a strong supporter of international communication and collaboration in medical informatics, both in research as well as in education. Already in the 1980th, she organized meetings and conferences with colleagues from abroad and was ever-welcomed partner in international projects. She was also an active and creative member of IMIA and EFMI.

When we decided to develop the Austrian annual eHealth conference into an international conference in 2016, Jana Zvarova was one of the first to accept the invitation to serve in the International Scientific Programme Committee of this Austrian eHealth conference. In this role, she helped to promote the conference especially in the eastern part of Europe. She also gave us the honor to participate in person to the first international edition of the Austrian eHealth2016 conference in Vienna in May 2016 (Figure 2), showing her strong commitment and full support for international cooperation.

We will remember her as a friendly, supporting, and creative scientist with strong international vision, and as a friend!

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