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The Effect of Patient Accessible Electronic Health Records on Communication and Involvement in Care - A National Patient Survey in Sweden

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Abstract. During recent years, patient accessible electronic health records (PAEHRs) have been implemented nationally in Sweden, as well as internationally, as a means of supporting patient engagement and shared decision making. Few studies have, however, investigated the long-term effects of PAEHRs on communicaiton with care professionals and involvement in care. The national survey study presented here, answered by 2587 patients in Sweden, focuses on these aspects specifically. The results show that the Swedish PAEHR system *Journalen* has had a positive impact on communication with care overall (84% agree or strongly agree with that communication with medical staff has improved), but only 31% agree or strongly agree with that the content of the PAEHR is discussed with care professionals. *Journalen* also seems to have a positive impact on involvement in care, but the results are mixed when it comes to effects on shared decision making.

Keywords. eHealth, patient accessible electronic health records, communication, patient involvement, national survey

1. Introduction

The communication between clinicians and their patients is a fundamental component of clinical practice and is essential for achieving quality healthcare [1][2]. In recent years, a growing emphasis on patient autonomy, patient-centered care and patient participation has further exemplified the importance of effective doctor-patient communication [1]. Prior research on patient complaints has shown that poor attitudes and poor quality of information provided are the most commonly identified communication errors made by doctors [1]. In Sweden, a new legislation - the Patient Act or Patientlagen - was approved in 2015 with the aim to strengthen the patient's position and rights in healthcare. The patient act covers areas such as accessibility, patient participation, information provided by healthcare professionals and consent. However, studies have reported that the act has had limited impact on healthcare [3]. Patients are still feeling poorly informed regarding their

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test results, treatment options and management and less involved in their own healthcare [3]. These results are worrying as there is a growing recognition that patients can participate more actively in decisions regarding their own care when they are provided with information [4] [5]. Moreover, the WHO in their policy framework for Health 2020 [6] and the Swedish government [7], like other governments worldwide e.g. England [8], advocate and endorse the need for healthcare organizations to support patients being active participants in their own care. Therefore, a lot of effort has been put into the development of new technologies for health (eHealth) with tremendous potential for promoting patient participation, enhancing information-sharing and communication between patients and healthcare professionals and improving health outcomes [9]. An example of this type of a service is to provide patients with easy access to their electronic healthcare record (EHR), so called patient accessible EHR (PAEHR), through secure eHealth services. The overall goal of PAEHR is to improve communication between healthcare professionals and patients, ultimately increasing patients' participation in care and improving the shared decision-making process [10]. Two of the most well-known examples of PAEHR are OpenNotes in USA [5] [11] and MyUHN Patient Portal in Canada [12]. A similar service was launched in 2012 in Sweden, when Region Uppsala gave all citizens over 18 years of age online access to their EHR through the eHealth service *Journalen*. This service was eventually launched as a national system in Sweden, accessible through a national patient portal. However, PAEHR are still accompanied by major concerns from healthcare professionals, who stress that online access might lead to an increased workload, privacy risks and cause patients to worry [13] [14]. Studying and understanding if and how PAEHR affects communication between healthcare professionals and patients is important as communication is essential for the quality of healthcare. Moreover, patients use of and attitudes toward PAEHRs has up until today mostly focused on general attitudes to the prospective introduction of such eHealth services. Hence the aim of this paper is to investigate the effects of *Journalen* on communication with healthcare professionals and the patients' involvement in their own care.

2. Method

A national patient survey was made available through a link on the login page of the Swedish PAEHR system *Journalen*. The survey was ethically approved by the Regional Ethical Review Board in Uppsala (EPN 2016/129). The survey, which was open for all patients accessing *Journalen* during the five months period June-October 2016, included questions on several topics such as attitudes and reactions, access to and use of information, personal health, usage behavior, information literacy and information security. The questionnaire included questions with various response options (5-point Likert scale, multiple choice, and free text form). In total, 2587 patients responded to the survey, giving a response rate of 0.61% (2587/423141). Moll et al. [15] presents the study design in more depth and some overview results from the survey. Even though the results from two of the questions in this study (a and d) are also presented in the overview article (Moll et al. [15]), the contexts in which those results are presented are different - while this paper focuses on communication and involvement the overview article focuses on general usage behaviours and usage patterns. Only completed questionnaires have been analyzed, as the answers were stored in the database only when the respondent chose to submit on the last page. This paper covers two important themes from the survey, and the debate about eHealth systems in general – namely (1) communication with healthcare professionals and (2) involvement in care. SPSS 25 was used for all analyses.

3. Results

When it comes to gender distribution among respondents, the majority (1629/2587 = 63%) of the respondents were women, which corresponds well with official data on usage of the system. The majority of the respondents (61 %) also had an educational background of at least three years in higher education.

3.1. Communication with clinicians

Results related to questions on communication are presented in Table 1. The questions/statements are: (a) *The PAEHR improves communication between medical staff and me*; (b) *To take part of the patient information via Journalen has affected the relationship with health care system positively*; and (c) *I discuss the content of Journalen with medical staff*. As can be seen from the table, the majority of the respondents believe that access to *Journalen* has improved the communication with medical staff and the relationship with healthcare overall. On the other hand, the content of *Journalen* does not seem to be discussed with medical staff to any large extent.

Table 1. Results regarding PAEHR in relation to communication. The highest value for each question is indicated with bold face.

Question	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
a	**1418 (56%)**	705 (28%)	280 (11%)	67 (3%)	55 (2%)
b	**865 (34%)**	781 (31%)	656 (26%)	95 (4%)	118 (5%)
c	255 (10%)	511 (21%)	448 (18%)	329 (13%)	**945 (38%)**

3.2. Involvement in care

Results related to questions on involvement in care are presented in table 2. The questions/statements are: (d) *I use Journalen to become more involved in my care*; (e) *Information in Journalen had a positive impact on the ability to work together with medical staff making decisions about care and treatment*; (f) *Information in Journalen had a positive impact on the ability to follow the prescription of treatment*; and (g) *Information in Journalen had a positive impact on the ability to take own steps to improve health.* As can be seen in the table the majority of the respondents strongly agree or agree with all statements, even though there is a rather high portion of neutral respondents when it comes to shared decision making and self-care.

4. Discussion and Conclusions

The results presented in this paper show how patients experience that their communication with healthcare professionals and their involvement in the care process has been

Table 2. Results regarding PAEHR in relation to involvement in care. The highest value for each question is indicated with bold face.

Question	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
d	**1372 (56%)**	651 (26%)	283 (12%)	57 (2%)	107 (4%)
e	571 (24%)	645 (27%)	**785 (32%)**	186 (8%)	215 (9%)
f	**848 (35%)**	712 (29%)	575 (24%)	117 (5%)	170 (7%)
g	652 (27%)	681 (28%)	**725 (30%)**	139 (6%)	207 (9%)

affected by PAEHR. The results are important for our understanding of the effects of PAEHR for patients, since they are based on the first large follow-up study conducted several years after launch of *Journalen* in Sweden. Earlier studies, like the interview study with cancer patients conducted by Rexhepi et al. [16] one year after launch, rather reflects short-term effects. It is clear that the majority of the respondents believe that access to information from PAEHR allows them to communicate more effectively in conversations with healthcare professionals regarding their own care. One explanation for these results may be that access to test results and information about care plan, treatments etc from PAEHR can, as reported in studies such as [17] and [18], improve the patients' understanding of their medical condition. Hence, it is possible that the patients' understanding of their illness affect their ability to engage in meaningful conversations with the physician. Moreover, as a result of accessing information from the PAEHR, the majority of the patients also report an improved communication and relationship with healthcare professionals.

Furthermore, a significant amount of patients reported that they use *Journalen* to become involved in their own care. However, when it comes to involvement in terms of increased ability to engage in self-care and shared decision making, the results are not as positive. The reasons are difficult to find in a survey, however engaging in e.g., shared decision making is a two-way-process where a clinician and patient jointly participate in making a medical decision [19]. If patients do feel that their opinions are not valued, they may be less inclined to engage in the meaningful conversations needed for effective shared decision making. Hence, provision of information alone from PAEHR will not automatically result in patients engaging in shared decision making. Instead, healthcare professionals must incorporate patients into the decision-making process. Future studies will be needed to look more closely at the association between note reading and shared decision making. Furthermore, despite ethical principles and legal requirements to engage patients in their own care, some patients may not want to be active participants. It is however vital that clinicians assess and understand the role each patient wishes to play in his or her care. Moreover, the majority of the respondents also strongly agree with that *Journalen* makes it easier for them to follow prescriptions, which is in line with earlier studies in the area [20]. The results also show that the contents of the PAEHR is not discussed to any large extent during the patient meeting. This is not surprising considering the resistance shown by the healthcare professionals, especially physicians and their trade union, in Sweden [14]. However, given that patients, over all, perceive PAEHR as positive and important it is of high relevance to study why the contents of PAEHR are not discussed with patients and how they can be integrated into the patient meeting.

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