

Attitudes and acceptance of patients undergoing visceral surgery towards an open access electronic medical record – a Swiss-German single-centre study

Bindschädler Patrick^{a*}, Frei Lina^{a*}, Raptis Dimitri A.^b, Tschuor Christoph^{a†}, Breitenstein Stefan^{a†}

^a Department of Surgery, Cantonal Hospital Winterthur, Switzerland

^b Department of Surgery, Royal Free Hospital London, United Kingdom

Summary

INTRODUCTION: With the digitalisation of patient medical records, providing patients with free access to their electronic medical record (EMR) has become an important topic of debate in many countries. Recent studies show that the quality of treatment in healthcare may be improved by encouraging patients to take an active part in their care. Providing patients with access to their EMR may also improve the patient-doctor relationship, adherence to treatment and patient satisfaction. In June 2015, the Swiss government passed a law to set the framework for a nationally coordinated EMR system. A major stipulation to this legislation is that patients and doctors must consent to having an open access EMR (oEMR). The aim of this study was to assess patients' attitudes towards an oEMR.

METHODS: Consecutive patients attending the outpatient clinic of our department within two months were included in this study. Patients were asked to complete a questionnaire consisting of 43 items, including amongst others disease characteristics, their expectations regarding an oEMR and its implementation. This study was approved by the ethics committee of the Canton Zurich (BASEC-Nr. Req-2016-00383).

RESULTS: 149 patients were included with a mean age of 52 (standard deviation 17) years. 42% suffered from abdominal diseases (benign or malignant), 26% from hernias, and 17% from anorectal disorders. 76% of the responding patients fully supported an oEMR. Among all items, a higher educational degree (odds ratio [OR] 55, 95% confidence interval [CI] 39–70), patients with general or half-private insurance (OR 10, 95% CI 0.99–100) and patients with suspected cancer (OR 6, 95% CI 0.93–42) were independent predictors for a positive attitude regarding an oEMR on multivariate analysis.

CONCLUSION: To our knowledge, this is the first study conducted in a hospital in the German-speaking part of Switzerland evaluating patients' opinions regarding an

oEMR. Overall a large majority of the patients support an oEMR. Patients with cancer, a higher educational degree and general or half-private insured patients were more likely to support an oEMR. An important next step would be to conduct studies investigating opinions of medical professionals during the implementation of an oEMR.

Keywords: open access electronic medical record, oEMR, Swiss Electronic Patient Record, EPR, patient data, Swiss healthcare, Swiss Federal Law on Electronic Health Records, EPDG

Introduction

The systematic digital documentation of patient data is an important consequence of the advancing global digitalisation taking place in recent years. Subsequently, the question of whether patients should have electronic access to their data has become one of the key topics under discussion in many countries. Studies from the United States showed that the quality of treatment in healthcare may be improved by encouraging patients to take an active part in their care. Providing patients with access to their own medical records facilitates the patient's own involvement. Furthermore, it may improve the patient-doctor relationship, adherence to treatment, and patients' understanding of their condition while also enhancing safety and patient satisfaction [1–5].

In June 2015 the Swiss government passed a law to set the framework for a nationally coordinated electronic medical record system called “elektronisches Patientendossier” [Electronic Medical Record (EMR)] [6]. The EMR is a virtual record encompassing data on the patient's medical history, data relevant to further treatment or data captured by the patient themselves. The data will be accessible online on demand [6]. Implementing the EMR is thought to (i) strengthen the quality of medical treatment, (ii) enhance the process of the treatment, (iii) increase patient's security, (iv) avoid duplicity and (v) increase the efficiency of the healthcare system. Furthermore, it is intended to encourage and improve the patients' own health expertise [6].

* Shared first authorship

† Shared last authorship

Correspondence:
Prof. Stefan Breitenstein,
MD, Department of
Surgery, Cantonal Hospital
Winterthur, Brauerstrasse
15, CH-8401 Winterthur,
stefan.breiten-
stein[at]ksw.ch

The corresponding federal law took effect in April 2017 [6]. The legally defined time frame for the implementation of the EMR is 3 years for hospitals and 5 years for retirement homes from the entry into force of the law. Pharmacies are asked to participate as well, however, compliance is not on a mandatory basis. Patients willing to participate in the EMR, need to provide written consent. On 19 February 2020, the Federal Office of Public Health announced that the EMR will not be available until summer 2020. This is due to a delay in the certification of the core communities, the future providers of the EMR. On the planned introduction date in April 2020, at least one of the eight core communities should have completed certification and be able to start operations in summer 2020. The other core communities should follow in autumn 2020.

Against this political backdrop, our goal was to assess the attitude of our patients towards the implementation of the EMR. In March 2016 the annual report on eHealth called Swiss eHealth Barometer [7] showed support of the EMR at 55% among the Swiss public. The number was stable over the previous years, with 55% in 2014 and 54% in 2015.

This study specifically examined a sample of patients who received ongoing medical treatment in our surgical outpatient clinic and compared their support of EMR to that of the Swiss public. To our knowledge this is the first study examining the support of an EMR in a hospital setting in the German-speaking part of Switzerland. The results of this study are of practical relevance for planning future studies regarding the implementation of the EMR.

Methods

Eligibility criteria

The study included consecutive patients visiting the Clinic for Visceral and Thoracic Surgery of the Cantonal Hospital Winterthur (Kantonsspital Winterthur), Switzerland, within a two-month period (July and August 2016). Questionnaires were given to patients in the waiting rooms of the outpatient clinic. The answers were collected anonymously and transferred to an electronic database by a research assistant. The Ethics Committee of the Canton of Zurich approved the protocol type and the questionnaire of this study (BASEC-Nr. Req-2016-00383).

Questionnaire

The questionnaire included demographic items, questions about current patient-doctor communication, questions relating to the patients' internet usage, as well as questions assessing potential benefits and concerns of an oEMR (appendix 1). Some of the questions had been used before in other trials for patient-accessible medical records [8, 9]. Patients were also asked to specify their insurance status. In Switzerland, everyone has a mandatory basic health insurance. It is also possible to receive optional private insurance, which offers additional benefits (e.g., free choice of doctor, coverage of alternative medicine, single hospital room) in exchange for higher insurance premiums. For those people who want some of the benefits of private insurance, but are looking for a more affordable premium, there is half-private insurance, which covers more than basic health insurance but not as much as private insurance.

At the end of the questionnaire patients were asked if they supported an oEMR, as well as how the medical history should be accessible and which information should be viewable.

oEMR score

A scoring system was developed based on nine questions regarding potential benefits of an oEMR and five questions regarding potential concerns about the oEMR. For each question, a choice of five answers was provided ($-2 =$ disagree; $-1 =$ weakly disagree; $0 =$ neutral; $1 =$ weakly agree; $2 =$ agree). The oEMR score (positive) was calculated by adding the values of each answer (range -18 to 18). The same applied to the oEMR score (negative) regarding potential concerns (range -10 to 10). The oEMR score (overall) resulted of adding the oEMR score (positive) and the oEMR score (negative) (range -28 to 28). Patients with a high oEMR score (overall) expect benefits and have less concerns about an oEMR. Therefore, patients with a high oEMR score (overall) are more likely to support an oEMR than patients with a low or negative oEMR score (overall).

Sample size

The sample size calculation was performed using the Raosoft[®] software [10] typically used for surveys. With an 8% margin of error, 95% confidence intervals, a 70,000-estimated population of the region, and a 50% estimated response distribution, 150 patients were required to power this study.

Statistical analysis

Data were collected using an online platform in a password protected and encrypted database, as previously described [11]. Data are presented as mean (standard deviation, SD), median (interquartile range, IQR) and odds ratio (OR) with 95% confidence intervals (CI). Statistical analysis was performed using R version 3.3.2 (R Core Team, GNU GPL v2 License), R Studio version 1.0.44 (RStudio, Inc. GNU Affero General Public License v3, Boston, MA, 2016) with the graphical user interface rBiostatistics.com alpha version (rBiostatistics.com, London, UK, 2017) and SPSS version 21 for Mac (SPSS, Inc., Chicago, IL). Continuous variables were compared with the Student *t* and the Mann-Whitney U tests, where appropriate. Differences among proportions derived from categorical data were compared using the Fisher exact and the Pearson χ^2 tests, where appropriate. Internal consistency (also known as reliability) was assessed using the Cronbach's alpha test. All p-values derived from univariate analyses were two-sided and considered statistically significant if $p < 0.050$. Stepwise backward logistic regression analysis was performed to identify independent predicting factors of acceptance of an oEMR. Covariates with $p < 0.100$ were included in the final step and considered statistically significant.

Results

Participation rate

In July and August 2016, 150 consecutive patients in the outpatient clinic of the Clinic for Visceral and Thoracic Surgery were asked to participate in the survey. 149 patients completed the questionnaire. The participation rate, monitored over two weeks, was 35%. Main reasons not to

participate in the survey were lack of interest (44%) or insufficient knowledge of the German language (32%).

Demographics of the patients

Of all participants, 54 were female (36%) and the mean age was 52 (SD 17) years. Most of the patients suffered from abdominal diseases (benign or malignant) (42%), from hernias (26%) or from anorectal disorders (17%). There were more patients with a higher educational degree (72% tertiary education, 21% university degree) than patients with just compulsory education (7%). The study included 120 patients with general insurance (80%), 19 with half-private insurance (13%) and 10 with private insurance (7%). This matches the overall distribution of the patients' insurance status at our department (data not shown). Most of the patients (72%) had frequent consultations (>3/year) with a doctor. Only few patients (7%) did not use the internet at all, whereas the majority of patients (82%) used the internet on a daily basis (table 1).

Support of an oEMR

Overall, 76% of the responding patients supported an oEMR. There was no significant difference in supporting an oEMR between men and women (72 vs 83%, OR 0.50, 95% CI 0.22–1.17; $p = 0.116$). Furthermore, there was no significant difference in supporting an oEMR between the different age groups: younger patients (under 30 years of age) did not support an oEMR significantly less than patients over 30 years of age (64 vs 78%, OR 0.50, 95% CI 0.20–1.24; $p = 0.134$) and nor did older patients (over 60 years of age) support an oEMR differently from patients under 60 years of age (75 vs 76%, OR 0.97, 95% CI 0.42–2.27; $p = 1.00$). However, there was a significant difference in support for an oEMR according to the type of medical insurance they held. Patients with basic and half-private health care were more likely to support an oEMR compared to patients with full private insurance (78 vs 40%, OR 5.45, 95% CI 1.44–20.57; $p = 0.013$). Patients with more medical consultations (>3/year) were not more likely to support an oEMR than patients with less than three medical consultations per year (76 vs 76%, OR 1.02, 95% CI 0.44–2.35 $p = 1.000$). Patients with high internet

Table 1: Patient characteristics.

	All patients (n = 149)
Demographics	
– Male	95 (63.8%)
– Female	45 (36.2%)
Age (y)	52 ± 17
Disease region	
– Intraabdominal	58 (42.6%)
– Thoracic	12 (8.8%)
– Thyroideal	7 (5.1%)
– Hernia	36 (26.5%)
– Proctological	23 (16.9%)
Disease type	
– Cancer	31 (22.5%)
– No Cancer	107 (77.5%)
Complexity of surgery	
– Minor	15 (13.4%)
– Intermediate	37 (33.0%)
– Major	60 (53.6%)
Highest education	
– Compulsory education	10 (6.9%)
– Tertiary education (level B)	104 (71.7%)
– Higher education (university)	31 (21.4%)
Insurance	
– General	120 (80.5%)
– Half-private	19 (12.8%)
– Private	10 (6.7%)
Physician visits per year	
– More than three	108 (72.5%)
– Less than three	41 (27.5%)
Internet access	
– At home or work	142 (95.3%)
– No internet access	7 (4.7%)
Internet usage	
– Once a day	122 (81.9%)
– Once a week	17 (11.4%)
– Never	10 (6.7%)
E-health apps	
– Regular use	26 (17.4%)
– No use	123 (82.6%)

Values are mean ± standard deviation or number (percentage).

usage did not support an oEMR more often than patients with low internet usage (70% of patients with no internet usage, 77% of patients with internet usage once a week and 76% of patients with daily internet usage supported an oEMR). Patients with regular use of e-health apps supported an oEMR (92 vs 72%, OR 4.58, 95% CI 1.03–20.46 $p = 0.041$). Moreover, patients who were interested in communicating with their doctor by email were also significantly more likely to support an oEMR than patients who were not (89 vs 60%, OR 5.27, 95% CI 2.26–12.28; $p < 0.001$) (table 2 and fig. 1).

Multivariate analysis

A multivariate analysis revealed four independent predictors supporting an oEMR: Patients with cancer (OR 6.25,

95% CI 0.93–41.67; $p = 0.060$), general and half-privately insured patients (OR 9.80, 95% CI 0.99–100; $p = 0.051$), patients with a higher educational degree (tertiary education or university) (OR 54.60, 95% CI 3.07–969.69; $p = 0.006$) and patients with an oEMR score (overall) above 20 (OR 16.95, 95% CI 2.98–100; $p = 0.001$) (fig. 2).

Access format and type of content

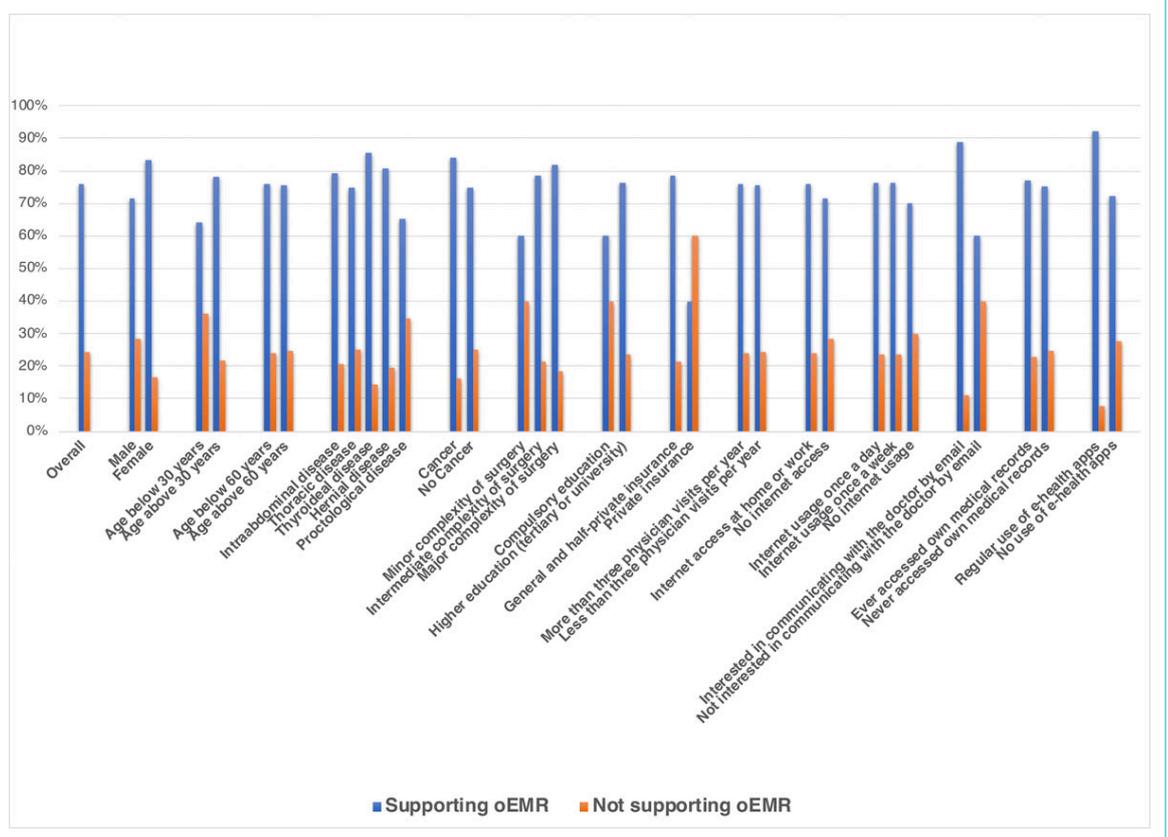
When asked what format an oEMR should have, the patients that supported an oEMR ($n = 113$) answered mostly with (i) secure online portal (87 patients, 77%) and (ii) downloadable portable document format (PDF) files (50 patients, 44%). Fewer ($n = 21$, 19%) patients desired access on a mobile app. A majority ($n = 92$, 81%) of the patients that supported an oEMR thought that all informa-

Table 2: Patients who support an oEMR.

		Supporting oEMR	Odds ratio	p-value
Overall		113 (75.8%)		
Gender	Male vs Female	68 (71.6%) vs 45 (83.3%)	0.50 (0.22–1.17)	0.116
Age	Below vs above 30 years	16 (64.0%) vs 97 (78.2%)	0.50 (0.20–1.24)	0.134
	Above vs below 60 years	43 (75.4%) vs 70 (76.1%)	0.97 (0.42–2.27)	1.000
Disease type	Cancer vs no cancer	26 (83.9%) vs 80 (74.8%)	1.76 (0.61–5.02)	0.343
Highest education	Compulsory vs higher education (tertiary or university)	6 (60.0%) vs 103 (76.3%)	0.47 (0.12–1.76)	0.265
Insurance	General and half-private	109 (78.4%) vs 4 (40%)	5.45 (1.44–20.57)	0.013
Physician visits per year	More vs less than three	82 (75.9%) vs 31 (75.6%)	1.02 (0.44–2.35)	1.000
Internet access	At home or work vs no internet access	108 (76.1%) vs 5 (71.4%)	1.27 (0.24–6.85)	0.676
Communicating with the doctor by email	Interested vs not interested	72 (88.9%) vs 41 (60.3%)	5.27 (2.26–12.28)	<0.001
Own medical records	Ever vs never accessed	37 (77.1%) vs 76 (75.2%)	1.11 (0.49–2.49)	0.841
E-health apps	Regular use vs no use	24 (92.3%) vs 89 (72.4%)	4.58 (1.03–20.46)	0.041

Values are odds ratio (95% confidence interval) or number (percentage).

Figure 1: Overall and subdivided support of an open access electronic medical record.



tion (even serious diagnostic reports) should be accessible. Fewer ($n = 21$, 19%) of these patients thought that only selective information (determined by the physician) should be accessible.

Reasons not to support an oEMR

The main reasons given by patients that do not to support an oEMR ($n = 36$) were privacy and security concerns (23 patients, 64%) as well as concerns about increasing dependency on electronic tasks (14 patients, 39%). These patients also mentioned concerns about their own benefits (10 patients, 28%) and about complexity and usability (5 patients, 14%).

Internal consistency of the questionnaire

The survey consisted of 14 questions about potential benefits and concerns for an oEMR. Using the calculated oEMR scores, we determined the internal consistency (also known as reliability) using the Cronbach's alpha test. The oEMR scores resulted in a Cronbach's alpha of 0.8, which indicates good internal consistency.

Discussion

With 76% overall acceptance rate of an oEMR in our study, the result was considerably higher compared to the result of a study conducted in the United States between 2003-2004, where only 56% of all patients thought it was "a good idea for patients to be able to review their outpatient medical records using the Internet" [8]. Due to the current controversial discussion about data privacy and data security in the Swiss media, our expectation towards the overall acceptance was clearly lower. As expected, the main reason not to support an oEMR were privacy and security concerns. Thus, the government should focus on these items when addressing to the public to ensure a higher acceptance rate.

Compared to about half of the Swiss public supporting an oEMR in the 2016 "Swiss eHealth Barometer" [7], the overall acceptance rate in our study was over two-thirds, and thus considerably higher. We attributed this difference to the fact that our study sample consisted of patients with an ongoing treatment. An online survey on patient use and experience with online access to electronic health records by the Norwegian center for eHealth Research [12] supported the theory that patients with complex, long-term or chronic conditions seem to benefit the most. In Norway,

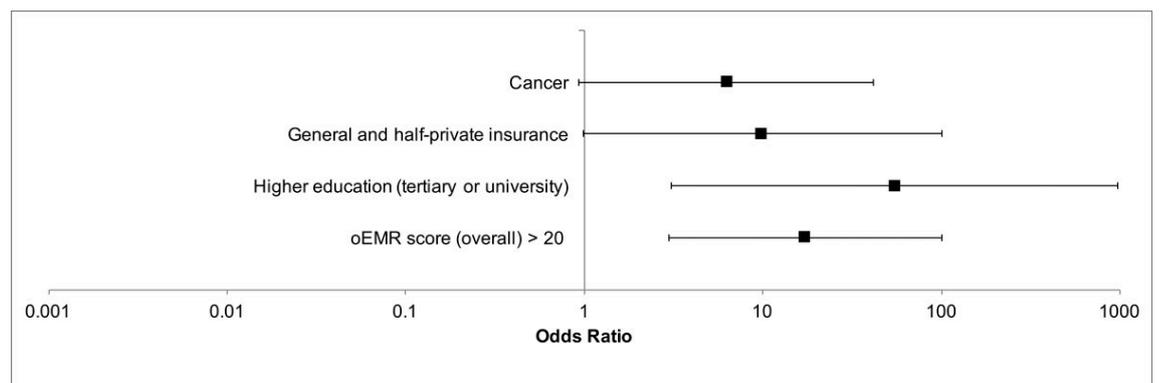
electronic health records are established in all hospitals and patient access is available to citizens over the age of 16. Since 2016 the rate of people supporting EMR in the Swiss Public has risen continuously with 56% in 2017 and 69% in 2018. The "Swiss eHealth Barometer 2019" [13] revealed a considerably higher rate (78%) of of the Swiss public supporting an oEMR.

As shown in our multivariate analysis, cancer patients were more likely to support an oEMR with an odds ratio of 6.25. This is reflected in the results of various studies that have shown that oEMR users have a higher morbidity than the average population [14]. One explanation may be the complexity of their disease, which entails numerous examinations (e.g. CT-scans, laboratory tests) and the involvement of various doctors and other health professionals. Another possible motivation was shown in a study by Fisher et al 1993 [15]. He conducted a study with 32 cancer patients who were allowed to review their medical records in the doctor's waiting room. 19 of the 20 patients who made use of the offer, declared their motivation as verifying facts in case doctors were hiding important information. A recent study by Shaverdian et al 2019 [16] evaluating the impact of open access to physician notes on radiation oncology patients showed that all patients who accessed the notes found them to be useful. After accessing the notes, approximately 96% of patients reported an improved understanding of their diagnosis, 94% of patients an improved understanding of treatment side effects, and 96% of patients feeling more reassured about their treatment, respectively.

We think the fact that younger patients did not necessarily support an oEMR more than older patients was due to a higher awareness for data security, as younger patients tend to be more active in the digital world. Furthermore, it shows that older patients do not automatically oppose digitalisation. As a result, no difference in supporting an oEMR was shown between age groups.

What we had not expected when designing this study was to find a significant difference in the support of an oEMR between patient groups of different insurance status. There is some support in the literature for this result [17]. One reason may be that privately insured patients attach greater value to their privacy and data security. This was shown in a study by Ralston et al. in 2008 (UK). They showed that patients with commercial insurance (= private insurance) were more likely to communicate with their doctor by secure messaging compared to patients with Medicaid

Figure 2: Odds ratios to support an open access electronic medical record and 95% confidence intervals of the multivariate analysis.



insurance (= national insurance), who often used less secure messaging [18]. Therefore, for privately insured patients, the benefits of an oEMR may not outweigh the privacy concerns.

As shown in various studies [17, 19], we also found that patients with a higher educational degree were more likely to support an oEMR. This may not only be explained by enhanced self-motivation but also by the fact that they more often come in contact with digital media during their education and at their jobs. As a consequence, they are used to digitalisation reaching into all economic sectors and thus might consider it a logical step to be established in health care.

The fact that a high oEMR score (overall) is associated with a high acceptance of an oEMR was expected and it shows that the questions of our questionnaire were relevant. Patients with a high overall oEMR score (overall) expect many advantages of an oEMR and do not fear possible disadvantages.

The most prominent reasons the patients stated for not supporting an oEMR were privacy and security concerns. This was not surprising. 64% of the patients who did not support oEMR patients in this study mentioned privacy concerns, which is higher compared to the results of an US study by Vodicka et al. that was published in 2003, where 33% reported concerns about privacy [20]. This rate of privacy concern is also higher compared to a study from Pai et al. that was published in 2013, where 77% of the patients “felt their privacy and confidentiality were preserved” by using a secure Webbased personal health record [21]. However, since in our study only asked patients who did not oEMR about their concerns, the privacy and security concerns in the whole study group is very likely to be lower and maybe at a comparable level to these two studies. Nevertheless, security concerns must be taken very seriously and data security must be given the highest priority in the implementation of an oEMR with respect to applicability and easy access. Masys et al. showed in their PCASSO-project that patients were more likely to accept a complicated login system providing a high level of security compared to physicians. 88% of the patients rated the login process very reasonable or reasonable whereas only 60% of physicians did so [19]. Developing a procedure for accessing a secure online portal is certainly one of the most difficult tasks for the implementation of an oEMR. In our study very few patients were interested in accessing the oEMR via a mobile app, which could be for data security reasons.

The majority (81%) of the patients supporting oEMR in this study think that all information, even serious diagnostic reports, should be accessible, which corresponds to the results of a study that was published 2011 by Patel et al. In that study most of the patients indicated that they would like their personal health records to include a wide variety of information such as immunisation records (89%), list of providers visited (88%), lab test results (87%), history of prior medical visits and surgeries (87%), and medication history information (87%) [22].

This survey has some limitations. First, the second most frequent reason not to participate the survey was insufficient knowledge of the German language, which could mean that not all patients of our clinic may be perfectly represented. Second, uneven group numbers of patients

with private insurance and patients without private insurance make the results potentially susceptible to bias. Third, regarding the education of the patients the risk of bias cannot be excluded due to uneven group numbers of patients.

Conclusion

In conclusion, the overall acceptance of an oEMR was very high and patients with a higher educational degree, general and half-privately insured patients and patients with cancer were more likely to support an oEMR. To our knowledge, this is the first study conducted in a hospital in the German-speaking part of Switzerland evaluating patients' opinions of an oEMR. Because of the encouraging results of this study, the next step would be to develop a study including medical professionals. Moreover, a pilot project with patients of higher educational degree and patients with suspected cancer should be conducted. In addition, it would be necessary, to perform a comparative study to evaluate and quantify benefits and risks of an open access database during the implementation of the oEMR in the whole population. For better implementation and higher acceptance with the associated higher user rate, patients who do not support oEMR can be specifically targeted, their reasons for rejection analysed and ideally eliminated with suitable measures, so that as many patients as possible will use the oEMR.

Disclosure statement

No financial support and no potential conflict of interest relevant to this study was reported.

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Appendices 1 and 2: Questionnaire (German version and English translation)

The appendices are available in separate files at <https://smw.ch/article/doi/smw.2020.20328>.