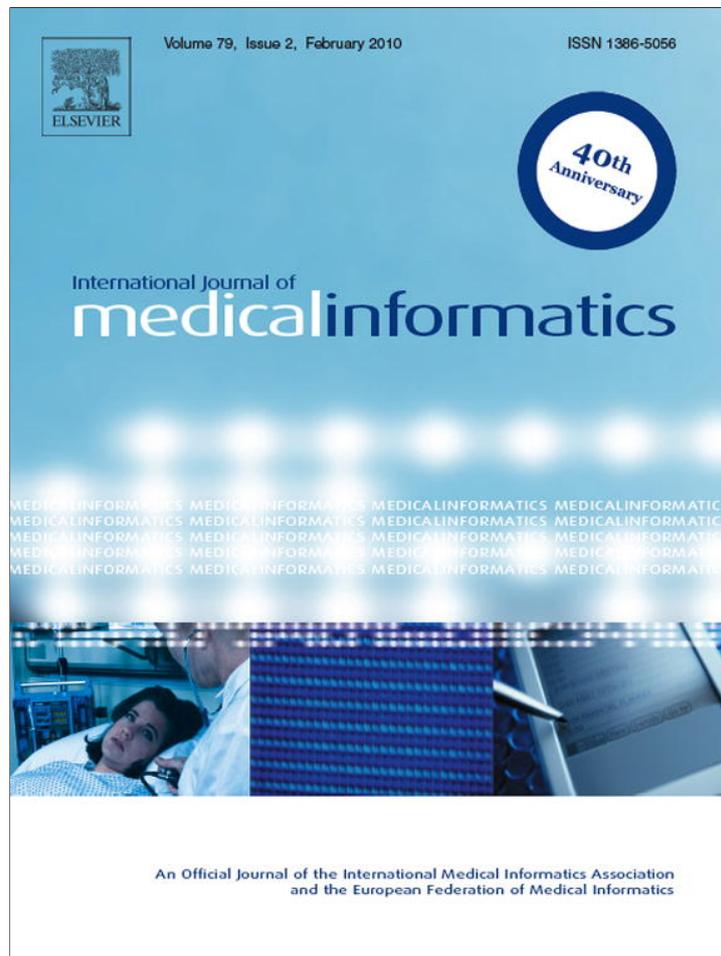


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Attitudes and behaviors related to the introduction of electronic health records among Austrian and German citizens

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ABSTRACT

Background: Acceptance by citizens seems to be crucial for the future success of an electronic health record (EHR) in Germany and Austria. We analyzed citizens' knowledge and expectations about the concept and contents of an EHR. We also addressed possible fears and barriers, and we investigated desired EHR functionalities relevant to citizens in the Austrian and German population.

Methods: Standardized interviews of a convenience sample of 203 Austrian and 293 German citizens recruited in two metropolises.

Results: Up to three-quarter of the interviewed citizens already collect and store medical documents at home, mostly in paper-based form. No respondents had already used an Internet-based personal health record. Between 80% and 90% of respondents were supportive of the idea of an electronic exchange of health-related data between health care providers as core functionality of an EHR. However, many respondents formulated concerns with regard to data protection and data security within an EHR. The EHR functionalities most supported by respondents included the electronic vaccination record, online information on doctors and hospitals, and the administration of appointments and reminders.

Conclusion: The results indicate a generally positive attitude towards the EHR. However, the study shows that data protection is an issue for many citizens, and that despite strong media discussion, there are information deficits with regard to the national EHR initiatives.

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1. Background

Ongoing medical progress leads to an increase in medical knowledge. This rising amount and complexity of medical knowledge leads to an increase in specialization of health

professionals, and to a strong need to exchange information between healthcare providers [1].

The concept of an electronic health record (EHR) sets out to close the gap between institution-specific patient data and a comprehensive, probably lifelong, collection of patient's health and healthcare data [2] that supports information

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exchange between healthcare providers. For this paper, we want to understand the term EHR as a trans-institutional, digital repository of information regarding the health status of a subject of care [3].

Within the concept of the EHR, the patient is understood as an active partner who is accessing, adding and managing health-related data. The active integration of the patient is said to support the quality of care as well as the compliance of the patient [4,5]. An EHR that allows the patient to actively manage his/her data is also called a personal health record (PHR). Waegemann distinguishes five types of PHRs, such as off-line personal health records, that are often paper-based and comprise copies of clinical documents; web-based personal health records; and provider-based personal health records where hospitals and other providers make some of the patient's health information available for the patient [6]. For this paper, we want to understand the term PHR as that part of the EHR that is accessible to the patient.

The patient thus takes a prominent position for the success of the future implementation of an EHR. Therefore, it seems important that, apart from institutional requirements and health professional related requirements, the patients' needs are also taken into account, both as an EHR user and receiver of EHR-based patient care. As the acceptance by patients and citizens is crucial for the future success of the EHR, it is mandatory to address those issues early enough to identify expectations and barriers that can then be dealt with during future EHR implementations.

Both in Austria and Germany, initiatives are under way to implement nationwide EHRs. In both countries, patients are expected to be a relevant future user group. However, at the moment it is unclear as to how well patients (or more generally, citizens) are informed of the concept of an EHR, how they judge the basic idea of the EHR, which fears and barriers may currently exist, and which functionality citizens see as important. While those questions have partly been addressed for other countries [7–9], a comprehensive investigation from Germany and Austria is missing.

Our study takes place in two large cities in Austria and Germany, which are countries with a comparable life standard and health care structures, but that have different roadmaps and concepts with regard to a nationwide EHR.

The objective of the present paper is, on the basis of a survey of citizens in both countries, to analyze citizens' knowledge about the concept of an EHR, to address the possible fears and barriers with regard to the EHR, and to investigate the desired EHR functionality.

2. Status of the electronic health record in Austria and Germany

The following remarks provide a brief overview of the current situation with regard to the implementation efforts of the electronic health record in the two countries of the present study.

2.1. The EHR in Austria

Every citizen in Austria already possesses a smart card issued by insurance companies. This e-card contains basic admin-

istrative information and is used for patient identification and for check of insurance coverage both in inpatient and outpatient areas. In 2005, the health reformation law (*Gesundheitsreformgesetz*) [10] provided the initial basis for the introduction of an electronic health record in Austria. The law explicitly defined the goal of EHR introduction but a specific timeframe for the introduction is not defined in the law. EHR is here understood as health-related information that is shared on demand between healthcare institutions, using a central EHR directory service to locate and access clinical documents. In the public media, the term ELGA (*Elektronische Gesundheitsakte*, electronic health record) is used to name this Austrian EHR concept. For the patient-related view, the name "patient portal" is in use.

A feasibility study was commissioned to develop the first concepts for an EHR implementation [11]. The first results of the study were presented at the end of 2006, in turn describing the present legal, scientific, organizational, and functional situation as well as the directions for a basic EHR architecture and functionality. In mid-2007, a master plan for an Austrian EHR was developed [12]. This master plan describes the creation of a central document meta-index which helps to search and retrieve medical documents of all participating institutions. Based on this document registry, the master plan describes the following EHR core functions: exchange of lab reports, radiology reports, discharge letters, and medication information between institutions. Later, a patient portal should support the citizen to access his/her clinical documents, and also to add health-related information.

At the end of 2007, the detailed planning of all the components commenced. At the moment, all the results are being discussed by the commission for state health (*Bundesgesundheitskommission*). No final decision had been taken regarding the actual implementation of an EHR in Austria, and no detailed plans or prototypes for the patient portal are available yet.

Apart from the efforts taken by the state, there are several concrete initiatives establishing prototypes of an EHR in Austria, such as H.ELGA [13] or health@net [14]. These projects closely cooperate with public initiatives, but share a more scientific view on the EHR.

The opinions of health professionals with regard to the Austrian EHR initiatives are mixed—major organizations of health professionals such as physicians and pharmacists are quite critical, fearing increased transparency, cost pressure, and reduced confidentiality of patient data [15,16]. Whereas hospital operators or public bodies definitely have a positive attitude towards the introduction of an EHR as they expect mid-term a positive impact on costs and quality of patient treatment. In the public media, however, the EHR initiative has not yet been in the center of larger critical discussions.

2.2. The EHR in Germany

In Germany, the development of an EHR is currently not a national initiative but a free market. However, as a first step towards an EHR and as part of Germany's strategic e-health intentions, the German law (Book V of the German Social Welfare Code) claimed the introduction of an electronic health card for all German citizens by 2006. This card should, as a

start, be able to carry not only administrative information, by this replacing the electronic health insurance cards that have been in use for many years, but also electronic prescriptions. Medical emergency data are expected to be added a certain time after introduction. Also a network infrastructure and central document repositories shall be established which – in combination with the card – supports the secure exchange of electronic findings and discharge letters between health institutions. The patient shall be able to access the information on his/her card and to use the services provided by health card and underlying infrastructure by using a so called 'eKiosk' (which bears resemblance to automatic teller machines). In the media, the EHR concept is often referred to as "electronic health card".

Specifications of the German health card and the underlying infrastructure are developed by Gematik, an organization which has the mission to introduce, maintain and enhance the electronic health card. The Gematik was founded by the head organizations of the German public health sector [17].

At the moment, the German health card is still under development, and the introduction of a national EHR is a long term objective. Card and infrastructure are currently tested in pilot settings, and regular operation is planned for 2010, starting with basic functions such as access to administrative information. With approximately 70 million citizens that have to be equipped with electronic health cards and several hundred thousand health care institutions that need the technical equipment to process health card data, the German Health Card project is regarded as one of the largest IT-projects worldwide.

Besides this national project, several local EHR initiatives exist. For example, at the Federal State level the State of North Rhine-Westphalia is attempting to develop specifications for interoperable electronic health records [18]. Apart from that example, several commercial vendors offer own electronic health records, which are either maintained by the patients or managed by physicians.

The overall progress of the EHR project in Germany has been delayed several times, due to the technical complexity and strong resistance of health professional organizations. Those problems have been intensively discussed also in the public media, and there seems to be an increasing public awareness that this project is running into problems and may even completely fail.

3. Methods

3.1. Study questions

The overall study questions were as follows:

1. Do citizens show an overall interest to receive, manage and use personal clinical data? This question is addressed by asking whether they have any copies of clinical data at home, and for which purpose they use it. This question should help to elaborate whether the idea of patients as active EHR users is realistic.
2. Do citizens already use any kind of computer-based PHR? If yes, which one? If not, why not?

3. Are they familiar to the term EHR, and if yes, how do they understand this term?
4. After being given a short definition by the interviewer: do the citizens support the general idea of an EHR, which is exchange of health-related documents between providers?
5. What functionality within an EHR would they see as relevant for themselves?
6. Which concerns or fears exist with regard to introducing and using an EHR?

3.2. Data collection

To find answers to our study questions, fully standardized interviews with citizens were conducted in Austria in the city of Innsbruck in Tyrol in December 2007 as well as in Germany in the city of Heidelberg in May 2008. The interviews comprised 6 open and 18 closed questions, which were based on previously designed and tested interview guidelines.

The interview guidelines were thematically grouped in four areas of interest:

- Questions about demographic data (such as sex and age) and the use of IT (5 questions).
- Questions about the private collection of medical documents including the type of storage, type of documents, and reasons for storing (7 questions).
- Questions concerning the concept of EHR and desired functionalities (12 questions).

The interviews were carried out by groups of two people. In total about 24 groups (11 in Germany and 13 in Austria) were conducting the interviews. To assure uniform interview conditions, guidelines for the interviewers were developed and tested, describing the rules as to how to pose the questions and how to document the answers. Furthermore, all interviewers were trained together in pretest interviews to reduce inter-coder variability. The interviews were carried out in public areas such as shopping centers, pedestrian zones, train stations, and universities. Pedestrians were addressed and asked whether they would be willing to participate in a 10-min interview on the topic of EHR. Selection of pedestrians was done based on their age, to get a sample that is representative to the age distribution of the population. The age of an interviewee was estimated by the interviewers before each interview. People of a certain age were invited to participate in the interviews as long as the planned number for each age-group was not reached. The Tyrolean population was stratified according to the age distribution published by Statistic Austria in their demographic yearbook of 2006 [19]. The German population was stratified according to the age distribution of the urban district of Heidelberg published by the Statistical Office of Baden-Württemberg [20].

The full interview guidelines as well as the guidelines for the interviewers are available upon request from the corresponding author. The questioning took approximately 10 min per interviewee. In total, 495 people were questioned, 203 in Austria and 292 in Germany. The number of cases or the reasons for rejection to participate in the interviews was not documented.

Table 1 – Age distribution of interviewees. Austria: n = 203; Germany: n = 292.

	<26		26–45		46–65		>65		Total	
	n	%	n	%	n	%	n	%	n	%
Innsbruck	40	20	92	45	65	32	6	3	203	100
Heidelberg	68	23	99	34	90	31	35	12	292	100
Total	107	22	191	39	156	32	41	8	495	100

3.3. Data analysis

The analysis of the collected data was carried out using descriptive statistics methods via SPSS Statistics Version 17 and Microsoft Excel 2003. Answers to the open questions were grouped according to the techniques of the content analysis as described by Mayring [21]. This qualitative analysis was supervised by CDK and AH. To assure the comparability of results, the grouping was performed by two independent coders, in which it was subsequently controlled and adjusted if deemed necessary.

4. Results

The following section addresses the results from the current two studies from Germany and Austria and compares them. The data is presented according to the structure of the interview guidelines.

4.1. Demographic data

In the course of the Austrian study, 203 interviews were carried out (female: $n=101$, male: $n=102$). The German sample comprised 292 interviews (female: $n=160$, male: $n=132$). The age distribution of the interviewees is shown in Table 1 below.

The majority of people questioned (85% in Innsbruck, 73% in Heidelberg) were from the same city or from the region nearby.

4.2. Private collection of medical documents

Table 2 shows that 75% resp. 47% collect and store medical documents at home. Those who answered “no” were asked to give reasons for not collecting such data. Participants that gave an answer here stated that they never obtained any data from their caregivers (A: 18%, $n=9$, D: 16%, $n=22$) or that there

Table 2 – “Do you collect and store medical documents such as medical reports or images at home?”

	Austria		Germany	
	n	%	n	%
Yes	151	74.8%	137	46.9%
No	51	25.2%	155	53.1%
Total	202	100%	292	100%

is no need, as all the relevant data is already stored by the caregivers themselves (A: 12%, $n=6$; D: 5%, $n=7$).

The data that is most frequently stored at home are medical findings, medical images, invoices, and doctors' letters (see Table 3 for details).

Major reasons for the collection of medical data at home are shown below in Table 4.

The interviewees were also questioned about the way they store medical data at home. The majority of people use traditional paper-based tools to store their data (for example copies in a folder). Only 11% store their data using at least partially electronically (for example images additionally stored on a CD). Nearly none of the interviewees stored their data solely electronically. See Table 5 for details.

The major reasons for collecting documents either in paper-based or in electronic form mentioned by the respondents were that they were already provided in the respective form by the health care providers. Further reasons for collecting documents in paper-based form were that paper is easier to use, habit, too little computer knowledge, and privacy concerns.

4.3. The electronic health record

The respondents were questioned about their specific knowledge regarding the electronic health record (see Table 6). Detailed analysis revealed that very young people and older

Table 3 – Types of medical data collected at home. Percentage is calculated on the basis of those interviewees that indicated that they collect data at home; A: n = 151; D: n = 137. Multiple answers are possible.

	Austria		Germany	
	%	n (nominations)	%	n (nominations)
Medical images	84%	127	72%	99
Medical reports	77%	117	51%	70
Invoices	59%	89	57%	78
Doctors' letters	44%	67	47%	65
Others	21%	32	n.a.	n.a.
Total (interviewees)	–	151	–	137

Table 4 – Reasons for the collection of medical data at home, and the rank in each country. Percentage is calculated on the basis of those interviewees that indicated that they collect data at home; A: n = 151; D: n = 137. Multiple answers are possible. Answers were grouped by content analysis of free-text answers.

	Austria			Germany		
	Rank	% (interviewees)	n	Rank	% (interviewees)	n
For insurance issues	1	36.4%	55	3	16.8%	23
My Doctor always hands out images and other documents	2	29.8%	45	2	19.7%	27
I want to judge progression of my disease	3	27.8%	42	5	11.7%	16
I want to understand the treatment	4	25.2%	38	1	23.4%	32
To remind me (for example on appointments, vaccinations)	5	23.1%	35	9	2.9%	4
I changed the Doctor	6	18.5%	28	4	14.6%	20
Just for curiosity	7	16.6%	25	6	11.7%	16
I want to obtain a second-opinion	8	13.2%	20	8	5.8%	8
I want to increase my own level of medical knowledge	9	9.3%	14	7	8.8%	12
Others (for example, "because I may need them")	-	42.4%	64	-	14.2%	22
Total n	-		151	-		137

Table 5 – Way of collecting medical data at home. Percentage is calculated on the basis of those interviewees that indicated that they collect data at home; A: n = 151; D: n = 136.

	Austria		Germany	
	n	%	n	%
Only paper-based	133	89%	120	88.2%
Mix of paper- and computer-based	17	11%	16	11.8%
Total (interviewees)	151	100	136	100

people were found to be less familiar with the term electronic health record.

The respondents who felt familiar with the EHR concept were then asked to actually describe the concept of an electronic health record with their own words. Approximately 50% (n = 31) of the Austrian respondents and 56% (n = 53) of the German respondents who previously answered 'Yes' were able to do so (for example by referring to a computer-based collection of medical documents). 21% (n = 13) of the Austrian respondents and 37% (n = 35) of the German respondents wrongly associated the concept of an EHR solely with the national administrative health insurance card.

After explaining that an EHR supports the storage and exchange of health-related data, allows providers to access that data with patient consent, and that the patient may access and manage the information shown in the EHR, the respondents were asked if they would allow selected physicians have access to their clinical data in the EHR (Table 7). 94% vs. 81% found it a good or even excellent idea. Without being explicitly asked, participants gave 55 further comments on this issue, 32 of them were related to data privacy con-

Table 6 – "Are you familiar with the term EHR?"

	Austria		Germany	
	n	%	n	%
Yes	62	30.5%	95	32.5%
No	141	69.5%	197	67.5%
Total	203	100	292	100%

Table 7 – "Would you allow selected physicians to access parts of your electronic health record?"

	Austria		Germany	
	n	%	n	%
Excellent idea	82	40.4%	76	26.0%
Good idea	109	53.7%	162	55.5%
Not so good idea	5	2.5%	29	9.9%
Absolutely not	3	1.5%	17	5.8%
No comment	4	2%	8	2.7%
Total	203	100	292	100%

cerns (for example, "only with my consent", "if data privacy is guaranteed"). Those who disagreed all issued data privacy concerns.

4.4. Functionality of EHRs

To determine the potentially useful functionalities of an EHR for citizens, the respondents were asked to judge seven predefined functionalities on a four-point Likert scale, with electronic vaccination records attaining the largest consent (for details, see Table 8). Respondents were also given the possibility to name additional desired functions that would be favorable for an EHR. In Austria, 10% of all respondents named additional functions, mostly stating "list of allergies and intolerances" and "anamnesis". In Germany, 22% of all respondents suggested additional functions, such as "accounting and fee information", "function to rate physicians", or "diet counseling and planning".

5. Discussion

5.1. Do citizens show an overall interest to receive, manage and use personal clinical data?

Between half and three-quarter of the interviewed citizens already collect and store medical documents at home (see Table 2), mostly medical images and medical reports. Around one-third of those just do it because "my doctor always hands them out to me". The other two-third give several reasons for collecting, many of them related to the active manage-

Table 8 – Judgment of proposed EHR functionalities. The consent was determined by aggregating the answers ‘Excellent idea’ and ‘Good idea’. The scale, furthermore, comprises the elements ‘Not such a good idea’, ‘In no case’, and ‘Not applicable’. For each function, the most often mentioned pros and cons (open answers) are indicated.

Functionality	Consent in %	
	Austria	Germany
Electronic vaccination record Pro: Helps to remind Con: Data protection	90% (n = 183)	88% (n = 257)
Online information on doctors and hospitals Pro: Find information more quickly Con: Already available	90% (n = 182)	76% (n = 223)
Administration of appointments and reminders Pro: Helps to remind Con: Don't need this	83% (n = 168)	82% (n = 240)
Electronic medication list (provided by the physician) Pro: Helpful for elderly or chronic patients Con: Don't need this	77% (n = 156)	78% (n = 229)
Electronic access to findings and medical images Pro: Everything easily available Con: Don't understand terminology	71% (n = 144)	76% (n = 223)
Online appointment booking Pro: Saves time Con: Prefer personal/phone contact	69% (n = 138)	55% (n = 162)
Online consultation of a GP or specialist Pro: Saves time Con: Prefer personal contact	68% (n = 111)	49% (n = 144)
Total	n = 203	n = 292

ment of the own health status (such as “judge progression of disease”, or “understand the treatment”). We see this as an indicator that citizens are willing to get actively involved in health management. This is in line with ongoing research on empowerment of citizens (for an overview, see [22]), and with a recent survey among 8000 German citizens that showed that 71% of participants want to actively add data to an EHR [26].

5.2. Do citizens already use any kind of computer-based PHR? If yes, which one? If not, why not?

Citizens mostly use a paper-based form of document collection; no one explicitly stated to use a web-based personal health record (see Table 5). Reasons for dominance of paper were that the providers still mostly provide information on paper, or personal preference for paper. It seems that information is stored in electronic form only when providers provide this already in this form (for example, a CD with medical images was mentioned). At the moment, there seems to be no benefit in scanning paper-based documents to build up an electronic personal health record.

Another smaller study confirmed those results: in a survey of 40 patients visiting an outpatient unit of a large university hospital in Tyrol, 26 respondents collected paper-based documents at home, 4 had both paper-based and electronic data, and 10 did not collect any documents at all. None were found to use a personal health record (PHR) [23].

Other studies have found a higher percentage of PHR usage. For example, a survey of 1285 German Internet users [24] found that 4.5% manage personal health-related information via the Internet, in which more than 80% of those by a personal homepage. 4.1% of the Internet users state that they use a web-based access to personal disease information managed by a medical institution (practice or hospital). The reasons for not doing so

included “no interest” followed by “data safety”, and “security concerns” [24]. In this study, however, only Internet users were included, that may have an increased IT knowledge and a preference for computer-based documentation, while our survey included a sample of the overall population, including older people and people without computer knowledge.

Higher numbers of PHR use can also be found in the U.S. Here, a recent investigation estimated – based on a survey of 8714 adults – that approximately 7.3 million U.S. adults already used online PHR systems in 2008, which would only be approximately 2.5% of the overall population [25]. These numbers are, at least at the moment, much higher than in Austria and Europe. A reason may be that many hospitals and other healthcare organizations have established provider-based PHRs, allowing their patients to access selected medical data via the Internet [6]. This is, at least at the moment, not routinely available from Austrian and German healthcare institutions.

5.3. Are respondents familiar to the term EHR, and if yes, how do they understand this term?

Only approximately one-third of all respondents in our study felt familiar with the term EHR (see Table 6), and only half of those possessed a mostly correct understanding of the term. This finding is supported by another larger survey of 8000 German citizens that also noted that the knowledge on existence and possibilities of an electronic health record is very limited [26]. In both countries, the local terms for “EHR” are often used in the press and are thus known at least to a part of the population. However, in both countries, the term “EHR” was often confounded with the e-card (the national health insurance card). Objective information on the aims and benefits of a national EHR seems have to be sufficiently communicated.

5.4. Do the citizens support the general idea of an EHR, which is document exchange between providers?

To get an idea whether citizens support the general idea of information exchange, we directly asked whether they personally would allow their physicians to access parts of their electronic health record. In both countries, at least 80% found this to be a good or excellent idea, with Austria showing higher support. This indicates very high support in both countries. Despite the published critical discussion especially by healthcare providers in both countries, citizens seem still to be very supportive of the general idea of information exchange. This result is also supported by a representative German survey of 2000 citizens that came to the conclusion that 70% have a positive attitude towards the introduction of the EHR in Germany [27].

5.5. What functionality would they see as relevant for themselves?

We offered the respondents a list of typical functionalities that may be of benefit for the citizens when accessing information located in an EHR. All proposed functionalities gained the support of at least half of the respondents. The highest acceptance was reached by the electronic vaccination record, online information on doctors and hospitals, and the administration of appointments and reminders. The electronic vaccination record was also mentioned by others, for example by [28] as a central functionality of an electronic health record. The already mentioned survey among 8000 German citizens found comparable high support for the vaccination record (69%) and little support for online consultation (34%). While the other two items (online information and appointment administration) are not typical EHR functions, they would clearly provide the citizens with additional benefits in an integrated health system.

5.6. Which concerns or fears exist with regard to introducing and using an EHR?

A number of unsolicited remarks were made in different parts of the interviews such as: "It is only a question of time until criminals try to make profit of the EHR, for example by searching for all the patients with cancer and then contacting them to offer placebos.", "Health-related data of a politician or other famous people will be systematically searched in the EHR to create a scandal.", "I am strictly against this; data collection should only be done by the GP.", "This will lead to the 'transparent citizen'." In fact, in many interviews, concerns with regard to data privacy were issued. While we did not quantify those concerns, it seems sensible that citizens are aware of the potential risks that shared EHRs may have. This fear may be increased by reports of accidental loss or theft of sensitive clinical data that were reported in recent years [29,30], and by the generally critical discussion on the EHR by health professional organizations in both countries. This concern is also supported by the aforementioned German study [27], where 73% of respondents stated their data protection concerns, as well as by [26] that also noted data security concerns in German citizens. Further data protection concerns are

also reported from other populations, for example by a Danish study [8] or a study conducted in New Zealand [35]. Both in Austria and Germany, information initiatives to reduce such concerns are foreseen or under way. In addition, at least in Austria an opt-out possibility is discussed, allowing citizens to decide that their health-related data should not be shared between institutions and health care professionals.

5.7. Comparison between Austria and Germany

Austria and Germany are comparable with regard to health data. For example, they are comparable with regard to life expectancy (D: 79 years vs. A: 79.5 years), total health expenditure (10.7% vs. 10.5% of GDP), hospitals beds (6.4 vs. 6.1 per 1000 inhabitants), and rate of practicing physicians (3.8 vs. 3.5 per 1000 inhabitants) [31]. Only the length of stay is different, with 8.6 in Germany and 5.9 days in Austria [31].

In both Austria and Germany, initiatives are currently under way to implement EHRs. Austria is seeking to introduce a complete, nationwide EHR, whereas Germany is commencing with an e-card as a first step towards a comprehensive EHR infrastructure.

Three-fourth of the Austrian sample, but only half of the German sample, said to collect medical data at home (Table 2). Reasons for this difference can only be guessed. Table 4 shows that in Austria, professionals seem to more frequently hand over documents to their patients. In addition, in Austria, insurance reasons as well as second-opinion are mentioned much more often than in Germany, what may lead to a higher percentage of citizens storing clinical documents. In both countries, though, documents are typically handed-over and stored in paper-based form (Table 5).

The general IT knowledge in the populations is also comparable. In Austria, in 2008, 76% of the private households had a computer, and 69% had Internet access [32]. In Germany, the corresponding numbers (for 2007) were 73% and 65% [33]. The e-readiness index, defined as "the state of a country's information and communications technology (ICT) infrastructure and the ability of its consumers, businesses and governments to use ICT to their benefit" is 8.4 for Austria and 8.0 for Germany [34].

In both Austria and Germany, the term EHR is known to around one-third of respondents (Table 6), and 90% resp. 80% would allow their physicians to access clinical documents from other providers (Table 7). Nevertheless, in both countries, critical discussion on benefits and costs of the IT investment is going on in the media, increased among others by a very critical opinion of the official physicians' organizations. However, only in Germany, the overall project is years behind its original time schedule which gives rise to further public critic. This may explain why in the German sample, only one-fourth found document exchange an excellent idea, while in Austria, it were 40% (Table 7). The judgment of specific EHR functionality was mostly comparable in both countries.

5.8. Study limitations

The study has several limitations: first, while we interviewed approximately 500 people from both countries and used an age-based stratification, this sample is not representative

Summary points

“What was already known before our study”

- The acceptance of an electronic health record (EHR) by the citizens and health professionals is crucial for its success.
- Missing information about the preferences and fears of citizens as well as health professionals can lead to major problems in the acceptance of possible EHR/PHR (personal health record) concepts and solutions.
- The preferences of Austrian and German citizens have so far not been investigated in depth with regard to an electronic health record.

“What this study has added?”

- In general, Austrian and German citizens have a positive attitude towards the introduction of an EHR, but share certain concerns, e.g., with regard to data protection.
- Citizens wish to actively participate in their medical treatment; they have good notion which EHR functionalities would be of advantage for them.
- There are information deficits with regard to the concept, potential advantages and dangers of national EHR projects.

for the overall population. The interviews were conducted in city areas where several universities and companies are located working in the EHR area. This may have influenced the results, even when none of the respondents already used a PHR. Then, interviews were conducted by different interviewers. Even after designing an interview guideline and intensive training, it may be possible that the interviews were not executed in an entirely identical way. Finally, we collected some quite open answers and analyzed them by structured qualitative methods. However, as we did not use a tape-recorder, only keywords could be collected during the interview, that may have limited the quality of the collected data.

6. Conclusion

The results of the survey indicate that citizens are interested to manage their health data, but that PHRs are not in use at the moment. With regard to an EHR, a strong majority supports the idea of document exchange between health care providers. However, data protection concerns were often mentioned, and the citizens were often not aware on the correct meaning and functionality of their national EHRs. In addition, the results provide important evidence about the desired functionalities by citizens, which is an important basis for the prioritization of the planned EHR functionalities.

To fully prove the results gathered by the two studies and to achieve representative results for the two countries, further comprehensive studies are necessary. Nevertheless, the

studies should act as an important first indicator for the great interest of citizens in EHRs and provide a basis for additional studies.

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REFERENCES

- [1] E. Berner, J. Moss, Informatics challenges for the impending patient information explosion, *J. Am. Med. Inform. Assoc.* 12 (6) (2005) 614–617.
- [2] F. Burns, *Information for Health: An Information Strategy for the Modern NHS 1998–2005. A National Strategy for Local Implementation*, 2006, Available from: <http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH.4002944> [cited March 2009].
- [3] ISO TC 215. ISO Technical Committee 215-WG1. *Health Informatics – Electronic Health Record – Definition, Scope and Context*, 2005.
- [4] D.F. Sittig, Personal health records on the internet: a snapshot of the pioneers at the end of the 20th century, *Int. J. Med. Inform.* 65 (1) (2002) 1–6.
- [5] D. Detmer, M. Bloomrosen, B. Raymond, P. Tang, Integrated personal health records: transformative tools for consumer-centric care, *BMC Med. Inform. Decision Making* 8 (2008) 45.
- [6] C. Waegemann, *Testimony Regarding Personal Health Records*, National Committee on Vital and Health Statistics, Chicago, IL, 2002, <http://www.ncvhs.hhs.gov/020724p6.htm>, July 24, 2002.
- [7] A. Westin, Public attitudes toward electronic health records, *AHIP Cover* 46 (4) (2005) 22–25.
- [8] L. Zurita, C. Nohr, Patient opinion—EHR assessment from the users perspective, *Stud. Health Technol. Inform.* 107 (Pt 2) (2004) 1333–1336.
- [9] A. Honeyman, B. Cox, B. Fisher, Potential impacts of patient access to their electronic care records, *Inform. Primary Care* 13 (1) (2005) 55–60.
- [10] *Gesundheitsreformgesetz, Gesundheitsreformgesetz 2005*, BGBl. I Nr. 179/2004, 2005.
- [11] IBM, *Machbarkeitsstudie betreffend Einführung der elektronischen Gesundheitsakte (ELGA) im österreichischen Gesundheitswesen [Feasibility study for implementing the electronic health record (ELGA) in the Austrian health system]*, 2006, Available from: http://www.arge-elga.at/fileadmin/user_upload/uploads/download.Papers/Arge_Papers/Machbarkeitsstudie_ELGA_Endbericht.21112006.pdf, English summary at http://www.arge-elga.at/fileadmin/user_upload/uploads/download.Papers/Arge_Papers/Endbericht.Folgeauftrag.en.pdf [cited March 2009].

- [12] IBM, ELGA Systemkomponenten und Masterplan [EHR system components and master plan], 2007, Available from: <http://www.bmgfj.gv.at/cms/site/attachments/7/2/0/CH0709/CMS1169796766007/ergaenzungsstudie.pdf> [cited March 2009].
- [13] A. Kollmann, D. Hayn, J. Garcia, J.D. Trigo, P. Kastner, B. Rotman, et al., Feasibility of a telemedicine framework for collaborative pacemaker follow-up, *J. Telemed. Telecare* 13 (7) (2007) 341–347.
- [14] T. Schabetsberger, E. Ammenwerth, R. Breu, A. Hoerbst, G. Goebel, R. Penz, et al., E-health approach to link-up actors in the health care system of Austria, *Stud. Health Technol. Inform.* 124 (2006) 415–420.
- [15] W. Hackl, Die Elektronische Gesundheitsakte in Österreich: Ängste, Befürchtungen und Widerstände aus ärztlicher Sicht, UMIT, Institute for Health Information Systems, 2008, http://iig.umit.at/dokumente/msc_hackl.pdf.
- [16] M. Krassnitzer, E-Health: Verdrängte Gefahr. *Ärztemagazin* 2006; 48/2006. <http://www.medical-tribune.at/dynasite.cfm?dssid=4169&dsmid=76984&dspaid=597946#dsa597949>.
- [17] Gematik, Gematik—Wer wir sind, 2009, Available from: <http://www.gematik.de> [cited March 2009].
- [18] S. Kühn, EPA.nrw, ein Projekt der Landesregierung NRW mit Partnern aus Industrie und Selbstverwaltung, *Telemedizinführer Deutschland*, 2008, Available from: http://www.telemedizinfuhrer.de/index.php?option=com_content&task=view&id=107&Itemid=62 [cited March 2009].
- [19] Statistik Austria, Demographisches Jahrbuch 2006, Bundesanstalt Statistik Austria, Wien, 2007.
- [20] Struktur- und Regionaldatenbank, Statistical Office of Baden, Württemberg, 2008, Available from: <http://www.statistik.baden-wuerttemberg.de/SRDB/home.asp?H=BevoelkGebiet&U=06&R=GE221000> [cited March 2009].
- [21] M. Mayring, Einführung in die qualitative Sozialforschung, *Psychologie-Verlag-Union*, Weinheim, 1993.
- [22] A. Coulter, Patients' views of the good doctor, *BMJ* 325 (2002) 668–669.
- [23] K. Freina, Einsicht in die Krankenakte. Studie über Akzeptanz, Nutzung und Nützlichkeit aus Sicht des Patienten, Private Universität für Medizinische Informatik und Technik Tirol, Hall in Tirol, 2006.
- [24] C. Birkmann, R.C. Dumitru, H.-U. Prokosch, Evaluation of health-related Internet use in Germany, *Methods Inform. Med.* 45 (4) (2006) 367–376.
- [25] The Advisory Board Company, How Many U.S. Adults Use or Are Interested in Using Online PHRs? The Advisory Board Company, 2009, Available from: <http://www.ihealthbeat.org/Data-Points/2009/How-Many-US-Adults-Use-Online-Personal-Health-Records-or-Are-Interested-in-Using-Online-PHRs.aspx> [cited March 2009].
- [26] H. Kirchner, H.U. Prokosch, J. Dudeck, K.-H. Jöckel, W. Lehmacher, Gesenhues S. Querschnittsbefragung von 8.000 BARMER-Versicherten zu Erwartungen und Einsatz einer elektronischen Gesundheitsakte [Survey on expectations and implementation of an electronic health record, in German], in: *Proceedings of the Annual Meeting of the GMDS*, Essen, September 7–10, 2009.
- [27] H.E. Krüger-Brand, Versichertenbefragung zur Gesundheitskarte: Kritische Befürworter in der Mehrzahl *Dtsch. Arztebl.* 105 (33) (2008) 1723–1724.
- [28] M.I. Kim, K.B. Johnson, Personal health records: evaluation of functionality and utility, *J. Am. Med. Inform. Assoc.* 9 (2) (2002) 171–180.
- [29] NHS Lothian Communications Office, NHS Lothian Staff Member Loses Patient Data, 2008, Available from: http://www.nhslothian.scot.nhs.uk/news/mediaroom/news_release/08.07.03.patient.data.loss.asp [cited March 2009].
- [30] Department of Veterans Affairs Office of Inspector General, Review of Issues Related to the Loss of VA Information Involving the Identity of Millions of Veterans, 2006, Available from: <http://www.va.gov/oig/51/FY2006rpts/VAOIG-06-02238-163.pdf> [cited March 2009].
- [31] OECD, Organisation for Economic Co-operation and Development: Health at a Glance 2007—OECD Health Indicators, 2007, Available from: <http://www.oecd.org/health/healthatagance>.
- [32] Statistik Austria, Statistik Informationsgesellschaft, 2008, http://www.statistik.at/web_de/statistiken/informationsgesellschaft/index.html.
- [33] Federal Statistical Office of Germany, Private Haushalte in der Informationsgesellschaft (IKT) Fachserie 15 Reihe 4-2008., Federal Statistical Office of Germany, Wiesbaden, 2009, <https://www-ec.destatis.de/csp/shop/sfg/bpm.html.cms.cBroker.cls?cmspath=struktur,vollanzeige.csp&ID=1023448>.
- [34] Economist Intelligence Unit, The 2007 e-Readiness Rankings, Economist Intelligence Unit, 2007, http://www.eiu.com/site_info.asp?info_name=eiu_2007_e_readiness_rankings&rf=0.
- [35] P. Chhanabhai, A. Holt, Consumers are ready to accept the transition to online and electronic records if they can be assured of the security measures, *Medscape Gen. Med.* 9 (1) (2007) 8.