

# The patients' active role in managing a personal electronic health record: a qualitative analysis

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## Abstract

**Purpose** The complexity of illness and cross-sectoral health care pose challenges for patients with colorectal cancer and their families. Within a patient-centered care paradigm, it is vital to give patients the opportunity to play an active role. Prospective users' attitudes regarding the patients' role in the context of a patient-controlled electronic health record (PEPA) were explored.

**Methods** A qualitative study across regional health care settings and health professions was conducted. Overall, 10 focus groups were performed collecting views of 3 user groups: patients with colorectal cancer ( $n=12$ ) and representatives from patient support groups ( $n=2$ ), physicians ( $n=17$ ), and other health care professionals (HCPs) ( $n=16$ ). Data were audio- and videotaped, transcribed verbatim and thematically analyzed using qualitative content analysis.

**Results** The patients' responsibility as a gatekeeper and access manager was at the center of the focus group discussions, although HCPs addressed aspects that would limit patients

taking an active role (e.g., illness related issues). Despite expressed concerns, PEPAs possibility to enhance personal responsibility was seen in all user groups.

**Conclusions** Giving patients an active role in managing a personal electronic health record is an innovative patient-centered approach, although existing restraints have to be recognized. To enhance user adoption and advance PEPAs potential, key user needs have to be addressed.

**Keywords** Patient empowerment · Personal electronic health record · Colorectal cancer · Chronic care

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## Introduction

With improvements in treatment and ongoing survivorship, cancer is increasingly regarded as a chronic illness [1, 2]. Patients with cancer often have complex health care histories and needs in dealing with their illness [3, 4]. For patients with cancer, in particular patients with colorectal cancer [5], cross-sectoral health care involving a variety of health care professionals (HCPs) from multiple healthcare settings at different stages of the patients' care pathway is required. Consequently, the course of treatment is characterized by high complexity and may result in gaps of care. For patients and their families, these aspects can pose a major challenge [6–8].

For several years, efforts have made to strengthen patient-centered care for patients with chronic conditions [9, 10]. Empowering patients to take responsibility for their own health condition and to participate in managing their health care gives them the opportunity to take a more active role in health [11]. In addition, promoting self-management can improve health status and reducing health care costs in patients with chronic diseases [12, 13]. However, a shift from a paternalistic, acute care focused paradigm towards a more patient-

centered paradigm in health care of chronic illness is a complex undertaking that is still in development [14–16].

In reshaping the way health care is understood and delivered, the integration of new information and communication technologies (ICTs) is becoming increasingly important [17]. Significant potential for patient empowerment is seen in ICT-concepts aiming to give patients access to their own health and treatment related data [18–20], where in particular, personal health records (PHRs) are discussed [21]. PHR-systems as often used in the U.S., allow patients to access primary data from a HCP-managed electronic health record (EHR) through a patient portal (tethered PHRs) [22]. However, PHRs adoption and use in the context of cancer is not yet widespread [23]. The development and research regarding PHRs has focused on chronic conditions such as diabetes, HIV, or hypertension [24].

With PHRs, patients' opportunities to manage and to share their health information in cross-sectoral care are nevertheless restricted. In order to promote a more active patient role, it is important to give patients the chance to take more responsibility and participate actively in their health care. This may include controversial aspects such as allowing patients to decide which physician or other HCP gets access to their personal health information (PHI) in the course of treatment. To date, patients have limited possibilities to control cross-sectoral information exchange.

In contrast to this, a "personal electronic health record", called PEPA, is under development within our research project. This personal electronic health record will be controlled by the patient and therefore offers the possibility to empower patients in taking more responsibility regarding their health care. As a subset of PHRs, the web-based PEPA would enable patients to access, maintain, and manage (including access management) a secure copy of their PHI integrated from various HCPs' primary systems (e.g., electronic medical record in hospital, electronic health record in general practice). Within the PEPA concept, patients are understood as active partners who manage their PHI across settings as one prerequisite for a more active role in their health care.

Nevertheless, the question whether this concept could be usefully integrated into daily practice and cross-sectoral health care structures is not answered yet. Particularly, evidence about perceived possibilities and concerns regarding a more active role of patients in management their PHI remains scarce. Therefore, the aim of this study was to explore attitudes of prospective users regarding the patients' role in managing a PEPA.

## Methods

### Study design

A pilot project called "Information technology for patient-centered health care" (INFOPAT), funded by the German

Federal Ministry of Education and Research (2012–16), has been initiated in the Rhine-Neckar region (population: 2.3 million) in Baden-Wuerttemberg, Germany aiming to improve cross-sectoral health care especially for patients with colorectal cancer. Within this project, a "personal electronic health record" (PEPA) is being developed and implemented regionally.

In the first phase of this INFOPAT project, a qualitative, exploratory study design using focus groups was chosen, to allow intensive exploration of attitudes and needs of selected user groups. The following general research question was explored within this analysis:

- "What are the perceptions of prospective users regarding patient management of data and access with the PEPA?"

Ethical approval was given by the Ethics Committee of the University Hospital Heidelberg (S-497-2012). All participants gave their written informed consent. The participants' anonymity and confidentiality was ensured throughout the study.

### Study sample

In a regional (Rhine-Neckar region), cross-sectoral health care setting, prospective user groups of a PEPA were identified. The first user group comprised patients with colorectal cancer as well as representatives (staff) from patient support groups. The second group was made up of physicians, and the third group comprised other non-medical HCPs.

Patients were recruited through the National Center for Tumor Diseases (NCT) in Heidelberg, Germany, where they were receiving their cancer treatment. Additionally, patients were recruited via an umbrella organization for patient support groups in Heidelberg, called "Heidelberger Selbsthilfebüro". Clinicians (oncological specialists) and other non-medical HCPs (nurses, stoma therapist, social workers, physiotherapists, and nutritionists) were also recruited at the NCT. GPs, registered medical specialists (e.g., oncologists) and health care assistants from GP practices were recruited by the Department of General Practice and Health Services Research (University Hospital Heidelberg).

### Data collection

The decision to use focus groups was based on the explorative character of the research topic. A focus group is a kind of group interview with participants, who are involved in the research field of interest, to generate data. The idea of focus groups is that group processes can help participants to explore and clarify their views, attitudes, and opinions that would be less easily accessible in a one-to-one interview [25].

The basis for conducting focus groups was a semi-structured, pilot-tested interview guide (appendix 1). Themes and

questions of this interview guide are based on theoretical considerations, expert discussions and an extensive literature review. This approach is in accordance with the principle of qualitative research to be theory-driven. The principle of openness is taken into account by asking questions that allow participants a broad discussion.

At the beginning of each focus group, the PEPA principles (web-based, access management by patients, copies of treatment documents) were shortly explained based on a figure (appendix 2). Each focus group lasted until no more new aspects were addressed (on average 120 min) and took place at the University Hospital Heidelberg. For each user group (patients, physicians, HCPs) it was planned to conduct at least three focus groups.

The focus groups were conducted by an experienced researcher (the moderator), which was supported by a co-moderator. A third researcher wrote a protocol, which was integrated into the data analysis phase of this study. All focus groups were audio- and videotaped and transcribed verbatim.

### Data analysis

The approach for qualitative content analysis used in this study [26, 27] dealt with the transcribed texts of conducted focus groups as material, in which all data were included. To perform a qualitative content analysis, data were taken from the texts, edited, and analyzed. This was done by using a search grid (category system) which was based on theoretical considerations of patient-centered care and a literature review regarding personal health records. On the other hand, the category system was adapted during the process of analysis if the data showed additional and new information that did not fit into the previous category system.

Therefore, the performed qualitative content analysis included inductive development of categories and a deductive application of categories. In a first step, a preliminary search grid (category system) was developed by the researcher team. Afterwards, three transcripts were reviewed independently by the first author (IB), a co-author (MK), and the last author (DO) and additional key issues were identified. Following that, the findings were discussed within the researcher group to break with the individual preconceptions. After

summarizing and labeling all key issues as codes, the codes were sorted into main and subcategories. The codes were clearly defined and linked with representative examples from the original texts. The categories were discussed and further modified within our interprofessional researcher team until a consensus on the final category system was achieved. Qualitative content analysis of the data was performed using the software ATLAS.ti (version 7.0.80).

### Presentation of results

In order to facilitate a better readability, the key findings are presented as categories, subcategories, and aspects. Tables that present the categories enable differentiation between the user groups' perspective with respective aspects mentioned. The quotations in the text are examples for some of the identified key findings. Additionally, to these quotations in the result section, an online appendix with quotations supporting every identified key thematic category is given (appendix 3). Following translation from German into English, the quotations cited in this article were cross-checked by an English native speaker working at the Department of General Practice and Health Services Research.

## Results

From March until October 2013, ten focus groups with a total of 47 participants were conducted. Three focus groups with patients ( $n=12$ ) and representatives from patient support groups ( $n=2$ ), four focus groups with physicians ( $n=17$ ), and three focus groups with other HCPs ( $n=16$ ) were performed. For all user groups, separate focus groups were performed (Table 1).

The characteristics of the focus group participants are presented below (Table 2). One third of the participating patients ( $n=4$ ) were living with their diagnosis for less than 1 year, four patients between 1 and 2 years, and four patients for at least 6 years. The average duration since the diagnosis of participating patients was 1.7 (0.8; 6.7) years.

**Table 1** Description of focus groups ( $n=10$ )

User group	Number		Description
	Focus groups	Participants (total)	
Patients	3	14	Patients with colorectal cancer, representatives from patient support groups
Physicians	4	17	Oncological specialists, GP's, registered specialists
Other HCPs	3	16	Nurses, social workers, physiotherapists, nutritionists, health care assistants
Total	10	47	

**Table 2** Sample characteristics

	Patients	Representatives*	HCPs	Physicians
<i>n</i>	12	2	16	17
Sex (male)	83.3 %	50.0 %	18.8 %	58.8 %
Age (years) <sup>a</sup>	61.5 (58.0; 67.2)	(44; 62) <sup>c</sup>	38.0 (28.5; 50.0)	43.0 (35; 56.5)
Living in rural area <sup>b</sup>	58.3 %	NA	NA	NA
Living with a partner	91.7 %	NA	NA	NA
Education ≥12 years	50.0 %	100.0 %	43.7 %	NA
Professional experience (years) <sup>a</sup>	NA	(10; 38) <sup>c</sup>	20 (5.0; 26.0)	15 (5.0; 26.5)
Health care setting	NCT <sup>c</sup>	NA	75 %	29.4 %
	Outpatient care <sup>d</sup>	NA	25 %	70.6 %

<sup>a</sup> *Md (IQR)* median with interquartile range

<sup>b</sup> Less than 15,000 inhabitants

<sup>c</sup> NCT National Center for Tumor Diseases

<sup>d</sup> General practitioners; registered specialists

<sup>e</sup> Minimum; maximum

\*Representatives = staff from patient support groups

The active role given to patients with colorectal cancer within the PEPA concept, i.e., managing access and having oversight of all personal health information, was a controversial topic for all focus group participants. Participants, in particular HCPs, tended to be critical in this respect and expressed concerns rather than highlighting potential advantages.

#### Expressed concerns regarding the patients' active role

The focus group participants expressed several concerns regarding the patients' active role and discussed the patients' role as a gatekeeper of health-related information, the subjective behavior, possible limitations of an active role as well as

expected consequences for patients through reading their own health-related information (Table 3).

#### *Patients as gatekeepers to the PEPA*

In the context of the patients' active role, the focus group participants' main concerns in all three user groups were directed towards the access management and control by patients. Most physicians had strong concerns about the patients' role as an access manager. The idea of giving patients the chance to decide whether a treating physician gets access to patient's health information or not caused serious concern on the physician's side.

**Table 3** Expressed concerns regarding the patients' active role

Subcategory	Aspects	User group*
Patients as gatekeepers to the PEPA	Physicians' strong concerns about the patients' role as an access manager	b
	Doubts about the patients' ability to manage and control access	a/c
	Challenges for patients in assessing medical information and its relevance	a/b/c
	Withholding of information by patients	b/c
Subjective health behavior	Active participation is not every patients' wish	a/b
	Individual variance in the quantity of information required on personal health issues	a/b/c
Limitations of the active role	Illness related issues	a/b/c
	Age or generation related issues	b/c
	Challenges in accessibility	b/c
Expected consequences for patients through reading PEPA's health information	Creating anxiety in patients	a/b
	Uncertainty in terms of professional documentation	b/c
	Increased need for dialogue with professionals	b/c

*a* patients, *b* physicians, *c* other HCPs, e.g., nurses

\*Represents from which user group the aspect was presented

“[...] and actually I have a problem with the fact that the patients decide what we can see and what we can't see [...]” (Ph4-F04).

Likewise, patients and other HCPs expressed concerns. Both groups had doubts about the patients' ability to manage and control access appropriately. Both groups emphasized the challenges for the patient to assess medical information and its relevance to their health care journey. Concerns expressed included patients' problems in understanding medical terms and, specifically, the assumed difficulty in assessing the relevance of health information for the complex treatment of an illness like colorectal cancer, in the present and the future. The HCPs feared that patients could withhold relevant information for their treatment and the whole health care journey. They described various clinical scenarios, e.g., in terms of consequences for chemotherapy because of patient withheld information on their diabetes in order to illustrate their concerns.

“Does he think, for example, [...] I've had high blood sugar levels for 20 years now, [...] my oncologist doesn't need to know about that. And then we give him cortisone and his blood sugar level rises and we didn't even know anything about it, to exaggerate slightly.” (Ph3-F04).

#### *Subjective health behavior*

Another aspect that was mentioned by all three user groups referred to the health behavior in the care of each individual patient. Especially among patients and physicians, it was discussed that not every patient with colorectal cancer, who could use a PEPA, has the wish to be actively involved in their health care. Individual preferences were described as ranging from passive to an active role. It was assumed that a PEPA would not be appropriate for every patient, given that self-motivation and personal responsibility had been highlighted as prerequisites. In all three user groups, it was considered that individual needs would play a role in terms of the quantity of information required on personal health issues.

“That's one of the most important questions, to know what I definitely want to read about myself. [...] Where is the limit between knowing what I really want to know and what I don't want to know [...]” (P3-F01).

Some physicians even went so far as to say that patients also had the right of “not knowing” certain information about their medical care. Meaning that some patients emphasized the need to clarify and if necessary to limit how much detailed health information they receive, according to what they could cope with. The patient is the one who has to draw this line.

#### *Limitations of the active role*

Illness-related issues as a limitation were raised, in particular, by both professional groups.

“I think you have to let go of the idea that the patient is in control of the process, so he can always control the process 100 % in all situations – he can't.” [...] (PR1-F02).

They argued that patients with colorectal cancer were strained and burdened by their disease and the effects of their tumor-associated therapy. They pointed out that patients may become unable to manage access and a PEPA itself in the course of their illness. Both physicians and non-medical HCPs also described limitations to do with age and generation. They highlighted that most patients with colorectal cancer are over 60 years old. Typically, this generation has less familiarity with and use of the internet. Furthermore, challenges in the accessibility of a PEPA were discussed including: patients without a computer or access to the internet or sufficient skills for use. Furthermore, patients with a migration background and language barriers were mentioned as limitations.

#### *Expected consequences for patients through reading PEPA's health information*

Patient focus group participants mentioned that having a lot of information about them is not always positive. It could also create uncertainty or anxiety in patients. Non-medical HCPs raised the issue that patients could be concerned by the jargon in professional documentation. They expected that the more information a patient could read at home, the more questions could arise. However, patients' need for dialogue with professionals to improve understanding could add challenges to already busy workloads.

“The more the patient is able to read about what's wrong with him, the more questions he will have and the more often he will visit his GP and the GP can't cope with this, and that could also be a problem, I think.” (HCP3-F06).

#### *Perceived possibilities regarding the patients' active role*

The focus group participants discussed mainly two perceived possibilities regarding the patients' active role like possibilities to enhance the personal responsibility and prerequisites for the patients' active role (Table 4).

**Table 4** Perceived possibilities regarding the patients' active role

	Subcategory	Aspects	User group*
<i>a</i> patients, <i>b</i> physicians, <i>c</i> other HCPs, e.g., nurses *Represents from which user group the aspect was presented	Possibilities to enhance personal responsibility	Data ownership as a patients' right	a/b/c
		Strengthen the patients' active role through information	a/b/c
		Control professionals' actions with increased transparency	a/b/c
	Prerequisites for the patients' active role	Participation requires personal responsibility	a/b
		Patient education and motivation	a/b/c
		Change in professionals understanding of their role	b/c

### *Possibilities to enhance personal responsibility*

All three user groups considered that the patients' active role in managing a PEPA could strengthen personal responsibility. Some patients explicitly welcomed the opportunity of taking more responsibility that a PEPA offered to them and were aware of their data ownership. From the users' perspective, dealing with a PEPA and its health information could enhance the patients' responsibility, if they were willing to accept data ownership as a patient's right.

"I do think it's interesting, because of course you pass the responsibility on to the patient and the patient then takes on personal responsibility for his own illness, takes himself more seriously, I think that's obvious." (GP1-F09).

Participants from all three user groups mentioned that being more informed through an enhanced information access could strengthen the patients' active role in their health care journey. Patients anticipated being better informed about their illness and treatment as well, thus having the chance to ask better questions and communicate on a higher level with their doctors. Moreover, it was pointed out that the use of a PEPA and access to all health information could lead to higher level of transparency in the health care process for patients. Patients could get the opportunity to have more influence and involvement in the health services they received from professionals.

### *Prerequisites for the patients' active role*

From the patient groups' perspective, patient participation in their health care process always requires personal responsibility.

"[...] to be able to bring things together from all the different areas, being the only person who actually knows where they have been, this makes the patient the hub and pivot of the matter." (Ph1-F04).

HCPs emphasized patient education and self-motivation as crucial enablers allowing patients to take an active role in

managing their own PEPA. Furthermore, the need for changing professionals' understanding of their role as a prerequisite for active patient participation was discussed.

## Discussion

The aim of this study was to explore prospective users' attitudes regarding the patients' role in the context of a personal electronic health record (PEPA) under patients' control. Our study allowed an intensive and critical examination from the users' perspective. Overall, the patients' responsibility as a gatekeeper and access manager was at the center of the PEPA concept discussions. In particular, physicians had strong concerns regarding the idea that patients can decide whether a treating physician gets access to the patients' health information or not. Potentially limiting issues in patients' performing this active role, e.g., in case of change in health condition, were mentioned. Moreover, both patients and HCPs highlighted that not every patient wants to be actively involved in his or her health care.

However, all three user groups mentioned that enhanced information access and dealing with a PEPA may strengthen personal responsibility and the patients' active role in their health care journey. In this context, the need for changing professionals' understanding of their role as a prerequisite of active patient participation was discussed.

### Expressed concerns regarding the patients' active role

From professionals' perspective, reservations about the patients' role as an access manager were revealed. The idea that patients can decide whether a treating physician gets access to patient's health information or not caused serious concerns on the physician's side. Yet, there is little known from literature about these issues and the identified users concerns have to be recognized. However, experiences from other projects (e.g., Open Notes) showed that physicians likewise expressed concerns regarding the patients' access to doctor's notes. But these expressed concerns were diminished after patients had access to their personal doctor's notes [28, 29].

Moreover, our study results indicate that not all patients are willing to be actively involved as well as to take more responsibility in their health care. These findings are in line with previous findings in the literature [30]. Both, patients and HCPs mentioned that having a lot of PHI is not always positive for patients. Uncertainty or anxiety could be created as result. These concerns have been raised by HCPs in other studies before [28, 31].

On the other hand, it is known that the more ill patients are, the more likely they are to use a PHR [18, 19]. However, our professional participants pointed out several limitations for patients to perform this active role. Patients may become unable to manage access and a PEPA itself in the course of their illness due to decreasing health status. In this context, access for non-professional persons like informal caregivers could be a relevant user need [32].

Furthermore, HCPs mentioned concerns regarding the PEPAs accessibility, e.g., for patients without sufficient computer and internet skills or hardware. Thus, they feared excluding people from this technical innovation in health care who are not well educated and have lower health literacy, or are social disadvantaged, old or have language barriers. Problems with accessibility regarding ICTs and the need for overcoming accessibility barriers are often mentioned in literature [22, 33, 34].

#### Possibilities regarding the patients' active role

Participants from all three user groups mentioned that being more informed through enhanced information access could strengthen the patients' active role in their health care journey. In the literature, patients' good experiences and perceived usefulness with accessing medical information has been reported before [35, 36]. Potential benefits associated with the access to clinically relevant PHI are themes found in several studies [37–39]. A central assumption was that widespread PHR use could contribute to patient-centered health care by empowering patients to manage their own health care studies on experiences with PHR use support these findings.

Our participants expected that dealing with a PEPA and its health information could enhance the patients' responsibility if they were willing to accept data ownership as a patient's right. Other studies on patient access to medical information showed that patients felt stronger involvement in their care process [40, 41], and being able to take a more active role, take more responsibility for their health issues, and have more control. Gaining insight into the illness and care process supported them in learning about their own illness as well as in decision-making [18]. The expected facilitated that tracking of the course of illness and care processes is supported in literature [35, 40].

Despite the sense of enhanced patient empowerment, identified as a facilitator in PHR adoption [36], study results on the

effect of PHR use on patient empowerment [42, 43] or patient activation [44] remain insufficient. Finally, the need for changing professionals' understanding of their role was identified to be a prerequisite for active patient participation in health care and managing their health information. In making the shift towards patient-centered health care, professionals' resistance towards sharing responsibility with patients' needs to be overcome [45]. In regard to PHR adoption and use, change in attitudes and levels of trust between patients and their HCPs are needed [37].

#### Strengths and limitations

As user acceptance has a significant impact on widespread implementation and use of a PEPA in health care, it is essential to involve users early in the technical development and evaluation processes in order to develop a patient- (user-) centered tool that addresses the users' needs. Consequently, exploring attitudes regarding the PEPA concept from the users' perspective was an important first step in development and implementation of an innovative ICT fit into existing health care structures. The study was conducted by an interprofessional team of researchers (nursing, physiotherapy, medicine, philosophy) enabling a broad perspective during design and analysis stages. Some limitations in recruitment of participants must be declared. Most patients willing to participate in the study were men, and the average level of education was relatively high. It can be assumed that the innovative and technical character of this approach was attracting potential early adopters of ICT [22], therefore, the findings must be interpreted with caution.

#### Conclusions

PEPA may offer patients with colorectal cancer a more active role according to manage their complex chronic illness. Giving patients an active role in managing a personal electronic health record is an innovative patient-centered approach, although existing restraints have to be recognized. To enhance user adoption and advance the possibilities of PEPAs, key user needs must be addressed.

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