Electronic Health Records Are More Than a Work Tool

Conflicting Needs of Direct and Indirect Stakeholders

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ABSTRACT

The involvement of stakeholders is crucial when designing IT in highly complex application domains, such as healthcare. Stakeholder relationships are complex and can include strongly conflicting needs and value tensions. In this case study, we investigate the different perspectives of patients and physicians related to Patient Accessible Electronic Health Records (PAEHR) in Sweden. Generally, the introduction of this service has been heavily criticised by healthcare professionals, but welcomed by patients. The paper presents an innovative study design where themes from interviews with physicians are used as a lens to analyse survey data from patients. The findings highlight the necessity to understand stakeholders' perspectives about other stakeholder groups by contrasting assumptions and expectations of physicians (indirect stakeholders) with experience of use by patients (direct stakeholders), and discusses practical challenges when designing large-scale health information systems.

CCS CONCEPTS

• **Human-centered computing** → **Participatory design**; *Empirical studies in HCI*; **User centered design**; • **Applied computing** → **Health care information systems**;

1 INTRODUCTION

Stakeholder involvement is central to human-centred design and their participation early on, continuously, and throughout the design process is one of its corner stones [32]. However, in practice, stakeholder relationships can prove to be complex and stakeholders have different perspectives and values on both technology and health related issues [8, 55].

Healthcare is a domain facing a paradigm shift related to different stakeholder groups such as a changing doctor-patient relationship, an ageing population, and new technology for patients entering the domain. In this case study we investigated Patient Accessible Electronic Health Records (PAEHR), in particular the launch of PAEHR in Region Uppsala (Sweden). Research has shown that giving patients online access to their Electronic Health Record (EHR) raises strong concerns among physicians [20, 30]. These concerns, however, are often based on a one-sided view of its use and strongly affect acceptance and utilisation of PAEHR. Furthermore, as domain experts in healthcare, physicians are considered an authority, listened to, and represent many user groups when designing eHealth systems. However, less is known about patients' experiences with and use of the system, and patients' perspectives are often not as visible [24].

In this paper we illustrate these complexities within human-centred design, including the tension between different stakeholder groups and discuss them in the context of a large-scale health information system: the launch of PAEHR in Sweden. To investigate these complexities we combined qualitative and quantitative analysis by using themes from interviews with physicians as a lens to analyse survey data from patients. This innovative study design enabled a detailed examination of patient survey data on their use of and experiences with

PAEHR through the lens of physicians and their preconceptions and early assumptions on how patients would use it. Finally, the study provides a novel contribution through contrasting assumptions and expectations of the indirect stakeholder group (here: physicians) with experience of use by the direct stakeholder group (here: patients).

2 RELATED WORK

Healthcare as an application domain has been investigated by several research communities, such as Human-Computer Interaction (HCI) [52], Computer Supported Cooperative Work (CSCW) [24], Value Sensitive Design (VSD) [16], and Participatory Design (PD) [39]. Each research area has their specific focus, for instance, CSCW focuses mainly on healthcare as a workplace in which until recently "patients were invisible apart from being the object of the information and coordination efforts" [24]. Within PD, the primary focus has also developed from healthcare professionals and their work to eHealth that is used in everyday life by patients, relatives, neighbourhoods and citizens in general [39].

Patient Participation through Technology

Today, patients are taking more active roles in their care [17], and decisions should not be made *for* but *with* them in terms of shared decision making [40]. Digitalisation can be a strong enabler of increased participation [46] and there is a trend to implement new technologies in healthcare that aim to increase patient participation and quality in care. There are for example studies reporting on eHealth technologies that can lead to a more collaborative interaction with patients [47], or that enable collaborative interpretation of data by patients and Health Care Professionals (HCP) [3]). Other research has been conducted on the use of self-care technologies by patients and carers, which mainly focus on medical devices and applications to collect data from the patient and then visualise information to patients and HCP [1, 52]. However, other studies have shown that patients do not always want to enclose all health related information to HCPs [45]. Research on self-care technologies reported to enhance the collaborations between clinicians and patients as the collected material can be discussed during the consultations [52]. However, these technologies are often designed to be used in isolation by patients or carers [51]. This has been attributed to the two discourses in the medical domain, that frames care as performed either by patients or by HCPs [51].

One eHealth technology that aims to support patient participation is the Patient Accessible Electronic Health Records (PAEHR). Through PAEHR patients have web-based access to their electronic health records (EHR), which has been launched for example in the US [66], Sweden [20], Denmark [41, 42], Estonia and Australia [50]. PAEHR can be important for patients in various ways; they make use of PAEHR to remember their medical history, to prepare for the next visit, and to better understand their medical condition [6, 34, 56]. PAEHR could also be used to make visible information breakdowns experienced by patients [53], and there has also been studies on the use of EHRs in-clinic care [67] and related to sharing of PAEHR information to relatives and others [71]. A mixed-methods study on patients' experiences in the US found that PAEHR improved their understanding, fostered better relationships, promoted better quality, and improved self-care [22] and another study in the US showed that patients experienced better communication with HCP, enhanced knowledge of their health and improved self-care [68]. Today some countries offer their citizens access to their health data [50] and full access to the EHR raises concerns among HCPs [65]. A study in the US showed strong differences between physicians' and patients' attitudes towards sharing visit notes in that patients expected overall benefits and physicians were far more worried about potential harms [65].

Stakeholders in the Design Process

Within the value sensitive design framework, a distinction is made between two classes of stakeholders, depending on whether they interact directly with the system (direct stakeholders) or are affected by the use even without direct interaction (indirect stakeholders) [26]. Various methods have been developed to support the identification and selection of a robust set of stakeholders [69], to help stakeholders reflect on technical and value aspects of design ideas [70], and to identify value tensions in design [48] (see also the overview of 14 methods in VSD in [25]).

Given that stakeholder refers to a role and not to individual people [16], a stakeholder's group membership (direct vs. indirect) may shift depending on a person's role in a specific context or specific aspects of the technology [15]. Friedman et al. emphasise the importance of involving *all* stakeholder groups in the design process [26], although it is still a challenge how to decide which groups to include and how to balance their competing values [25]. Within PD, it has been acknowledged that conflicts can arise in IT projects [9], however, there seems to be some disagreement on who is responsible to solve such conflicts. Others proposed constructive conflict as a mechanism to enhance learning in stakeholder dialogue [14].

Previous research in healthcare has investigated the different perspectives of patients and HCPs. For example, what patients value as meaningful in everyday life related to health and well-being compared to what people traditionally think [8], or the difficulties of aligning divergent perspectives of patients and HCPs when designing an eHealth service [4]. Other studies investigated the different perspectives of patients and HCPs related to what they value in the in-clinic

communication [55] or regarding security features of implantable cardiac devices [18, 19].

Our study investigates PAEHR which illustrates how the distinction between the previously mentioned two discourses of care (care performed by physicians vs. care performed by patients) can become blurred. Different technologies enable various stakeholder groups access to the same electronic health record and each is likely to be designed for the respective (direct) stakeholder. So even if the particular technology is used in isolation (e.g., the PAEHR system is used by patients; the EHR system is used by HCPs), the data in both technologies is the same.

3   STUDY SETTING AND METHOD

In 2012, Region Uppsala in Sweden launched an eHealth service called *Journalen* that allows patients to access their EHR online and it has become the national PAEHR system. The launch of the PAEHR system was critically debated in the media, and HCPs were strongly sceptical [20, 30, 38]. One reason for their scepticism was the potential negative effect on their work environment. They were also concerned that patients might misinterpret the medical notes, misunderstand the test results, and become anxious or upset about what they read, which, in general, would harm rather than benefit the patient [2, 21, 57, 58].

In the following sections we will briefly describe the methods in the study. For further description see [29].

Interview Study with Physicians. The interview study took place in 2013 and 12 semi-structured interviews were conducted with physicians of different specialities to learn about their expectations and experiences when patients access their EHR. We conducted a thematic analysis [12] on these interviews [30, 31]. We identified four main themes related to how physicians view PAEHR: work tool, workload, process, and control. In short, physicians viewed the electronic health record as their *work tool*, written for communication between HCPs. Most of them were quite pessimistic regarding consequences of PAEHR on their work environment and expected an increased *workload* and negative effects on their work *processes*. They were concerned that it would lead to undue worry or anxiety in patients, given that they expected that patients would not be able to understand the content. Furthermore, some perceived PAEHR as a device for patients to *control* them, which created a feeling of mistrust when patients use it. The themes are described in more detail below to contextualise the patient survey results.

Survey Study with Patients. The design of the questionnaire was informed by previous studies investigating the same system such as [30, 36, 37, 56]. The questionnaire comprised six areas: 1) General questions related to the PAEHR system, 2) Questions targeting experiences from using the content of PAEHR, 3) Information security, 4) General questions about information needs, behaviour, and information-seeking styles, 5) Personal health related questions, and 6) Demographics. The response options for the questions varied between Likert scale (5-point from "strongly agree" to "strongly disagree"), free text form, and multiple choice.

The survey had ethical approval from the regional ethical board (EPN 2016/129). It was made available to patients in Sweden through the national PAEHR system from 16th June to 15th October 2016. The survey was accessible after the patients had logged on to the system Of the 423,141 unique users who logged in during the time-period of the survey, 2,587 initiated the survey (response rate 0.61%). For further descriptions of the survey level, see [49].

In this paper we used interviews from physicians in Region Uppsala and results from respondents who have received care in Region Uppsala. The implementation of the Swedish PAEHR system varies between the different regions and the perspectives of physicians and patients from different regions cannot be well contrasted. In total, 520 of the respondents had received care in Region Uppsala (327 (62.9%) women, 167 (32.1%) men, 1 (0.2%) other, 25 (4.8%) did not disclose their gender). 290 (55.8%) respondents have no professional background in healthcare, 205 (39.4%) stated that they were working or had been working within healthcare, 25 (4.8%) did not answer this question. The percentages in the results section are calculated based on those who answered the particular question.

Mixed Methods Analyses. For this paper we focused on survey questions that were closely related to the four main themes that were of concern for the physicians in the previous interview study [30]: work tool, workload, process, and control (see Figure 1). Related to work tool, workload, and process are the physician's concerns that patients might be harmed by PAEHR due to misunderstandings, incomprehension of the content, and undue anxiety. After the questions for each area of concern were identified, responses to these questions by patients from Region Uppsala were extracted and analysed using descriptive statistics. Given the relatively high ratio of respondents who indicated that they had worked or still work in healthcare further analyses was conducted. To compare the group of respondents who worked or had worked in healthcare to all other respondents, a *Mann-Whitney U* test was used for Likert-scale items after a transformation (Strongly agree = 5; Strongly disagree = 1). For nominal scales the *chi-square test* was used.

4   RESULTS

In the following, we present the results of the survey analysis separated by the four areas of concern identified in the physicians' interviews (heading of columns in Figure 1: work tool,
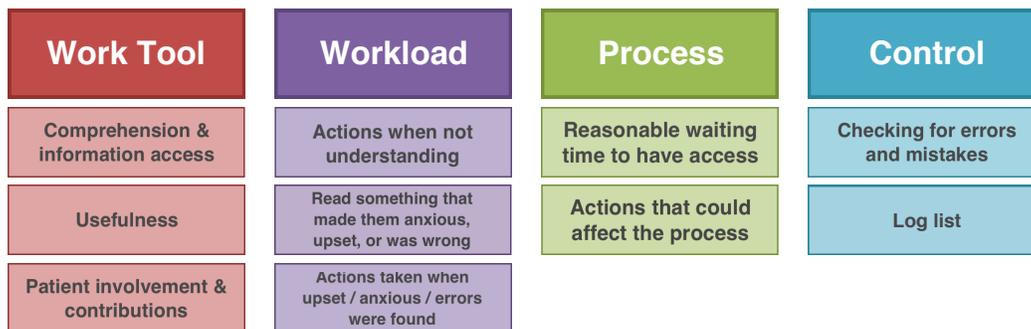
Figure 1: Areas of concern for physicians used as basis to analyse survey data and grouped questions from the patient survey.

workload, process, control). In each section, we first describe the physician's perspective from the interviews and outline the aspects under which we grouped the questions from the patient survey (i.e., the boxes below the heading in Figure 1). For each group, we present the results, which is accompanied by a table detailing the responses to the respective question.

Work Tool

A large majority of the physicians interviewed considered the EHR as their work tool, primarily used for documentation and communication with colleagues. As such, the record entails medical terms and suspected diagnoses which many physicians assumed would create anxiety in patients and / or lead to misunderstandings if not guided or explained by HCPs. The patient's **comprehension** was assumed by many to be little related to the information and test results provided. Also many physicians did not understand why the **information access** would be of much value to patients and assumed that the **usefulness** of PAEHR would be low for patients. However, some physicians considered that PAEHR could potentially contribute to patient **involvement**, as they could make use of it when engaging in self-care and potentially also **contribute** to the electronic health record. A detailed overview of the responses related to the theme *work tool* are presented in Table 1.

Comprehension & information access. It sums up that 96% (469) of the patients strongly agreed or agreed to the statement "I understand most of the information in the medical records". Furthermore, 81% (363) strongly agreed or agreed that they understood most of the test results and 48% (237) disagreed or strongly disagreed with the statement that the records contain too much medical language. However, 32% (155) of respondents strongly agreed or agreed that the language is too technical.

A Mann-Whitney test showed that understanding of the records (U=21442, p<0.001), test results (U=17444, p<0.001), and log list (U=16197, p<0.001) was significantly greater for respondents with a professional background in healthcare. Of respondents with healthcare background, 74.9% (152) strongly agreed, 22.7% (46) agreed that they understand most of the content; whereas of the respondents without healthcare background 49.1% (140) strongly agreed, 45.3% (129) agreed. At the same time, respondents who do not work in healthcare agreed significantly more on the statement that it contains too much medical language (with background: 3.9% (8) strongly agreed, 20.7% (42) agreed; without background: 5.7% (16) strongly agreed, 31.2% (88) agreed; U=34778, p<0.001).

Related to accessing certain information which is completely or partly based on information in PAEHR, 84% (411) strongly agreed that accessing test results is important for them and no difference was found between groups with or without healthcare background.

Usefulness. 90% (477) strongly agreed with the statement that access to PAEHR "is good for me". A Mann-Whitney test showed that respondents who have no professional background in healthcare were significantly more positive (U=31350.5, p=0.012). 63% (316) strongly agreed or agreed that they would consider changing healthcare providers to someone that gave them access to PAEHR. A Mann-Whitney test showed no difference between respondents with or without a professional background in healthcare.

In what way then do patients make use of PAEHR? Taken together, 60% (280) of patients in the survey strongly agreed or agreed to use PAEHR out of "general interest". 75% (369) strongly agreed that they use it to receive an overview of their own medical history and treatment. 89% (436) strongly agreed or agreed that they used it to follow up on what had been said during a clinical visit. 84% (404) strongly agreed or agreed that they use it to become more involved in their care. 60% (291) strongly agreed or agreed that they use it to prepare for their healthcare visit. A Mann-Whitney test indicated that preparation for the next visit was greater for respondents with no healthcare background agreed (U=30529, p=0.049).

Comprehension & Information Access	N	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I understand most of what is in the medical records	491	60% (293)	36% (176)	3% (13)	1% (8)	0% (1)
I understand most of the test results	447 [a]	42% (186)	39% (177)	8% (34)	8% (36)	3% (14)
I think that the medical records contain too much medical language	488	5% (25)	27% (130)	20% (96)	25% (124)	23% (113)
Access to results of tests	492	84% (411)	13% (66)	2% (10)	0% (0)	1% (5)

Usefulness	N	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I believe that access to *Journalen* is good for me	496	90% (447)	8% (39)	1% (6)	0% (1)	1% (3)
I would consider to change healthcare providers to get one that gives me access to *Journalen*	482	43% (208)	20% (98)	25% (118)	4% (18)	8% (40)
Mostly general interest	470	29% (136)	31% (144)	20% (96)	9% (43)	11% (51)
To get an overview of my medical history and treatment	489	75% (369)	18% (87)	4% (18)	1% (6)	2% (9)
To follow up what has been said during a healthcare visit	487	63% (308)	26% (128)	6% (29)	1% (6)	4% (16)
To prepare for my healthcare visit	480	31% (149)	29% (142)	16% (77)	12% (56)	12% (56)
To become more involved in my care	481	56% (271)	28% (133)	10% (46)	3% (16)	3% (15)

Patient Involvement and Contributions	N	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Information in *Journalen*:						
a) has helped me in communication w. medical staff	485	30% (145)	36% (175)	26% (125)	4% (19)	4% (21)
b) had a positive impact on ability to work together with medical staff making decisions about care and treatment	482	29% (138)	26% (127)	32% (156)	7% (35)	6% (26)
c) had a positive impact on ability to follow the prescription of treatment	487	40% (194)	31% (149)	20% (99)	4% (19)	5% (26)
d) had a positive impact on ability to take own steps to improve health	481	29% (142)	29% (139)	31% (148)	5% (22)	6% (30)
Contribute with information on health, for example by providing Health declaration for next visit	483	49% (236)	4% (116)	21% (99)	3% (16)	3% (16)
Ability to write own comments to text in *Journalen*	484	30% (147)	17% (83)	27% (132)	11% (52)	15% (70)
Contribute with information of self-testing or monitoring at home	478	32% (151)	21% (103)	28% (134)	8% (38)	11% (52)

[a] 43 respondents selected "not applicable" option; these are not included in N.

Table 1: Results related to "Work Tool".

Patient involvement & contributions. In sum, 66% (320) of respondents agreed or strongly agreed that information in the PAEHR system helped them in communication with the medical staff. Interestingly, a Mann-Whitney test showed that this effect was significantly greater for respondents who do not / have not worked in healthcare (U=33096.5, p=0.001).

According to the respondents, PAEHR has had a positive impact on the possibility to work together with the medical staff when making decisions as 55% (265) strongly agreed or agreed to this statement. Furthermore, 71% (343) strongly agreed or agreed that they follow the prescription of treatment better; and 58% (281) strongly agreed or agreed that PAEHR has had a positive impact on their possibility to take their own steps to improve health. Here no significant difference was found in the Mann-Whitney test.

Actions when Not Understanding	N	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Ask medical staff at the next visit	487	41% (201)	41% (202)	8% (38)	5% (24)	5% (22)
Contact the current healthcare unit via phone	479	21% (102)	30% (142)	19% (89)	16% (78)	14% (68)
Look for information myself, e.g. via Internet	487	51% (250)	35% (169)	7% (33)	3% (13)	4% (22)
Do nothing	468	3% (12)	8% (35)	22% (105)	12% (57)	55% (259)

Reading something that	N	Yes	No	Do not know		
made you feel anxious	496	27% (135)	73% (361)	-		
made you feel upset	410	11% (44)	89% (366)	-		
was wrong	495	38% (186)	48% (238)	14% (71)		

Actions taken when reading anything that [b]	N	Waited until Visit	Contact HC by Phone	Friend in HC / w Med.BG	Patient Assoc.	Searched Online / Wrote on Soc.Media	Nothing	Other
made you feel anxious	159	24% (62)	19% (51)	10% (27)	1% (3)	29% (75)	10% (25)	7% (19)
made you feel upset	141	18% (33)	18% (32)	8% (15)	7% (13)	4% (7)	31% (57)	14% (26)
was wrong	209	30% (77)	15% (38)	3% (7)	4% (10)	0% (0)	30% (75)	12% (48)

[b] This was a multiple response question. The percentages are calculated based on the answers, not on number of respondents N.

Table 2: Results related to "Workload".

The survey results show that, for most of the respondents, it is not only important to *access* information, but also to *contribute* with information about their own health as 73% (352) strongly agreed or agreed that they want to contribute with information in health. Forty-seven percent (230) of the patients strongly agreed or agreed that they want to write their own comments in the EHR, whereas 26% (122) disagreed or strongly disagreed. In sum, 53% (254) agreed or strongly agreed that they would like to contribute with results from self-testing / monitoring at home, whereas 19% (90) disagreed or strongly disagreed to this. A Mann-Whitney test showed no difference between respondents with or without healthcare background.

Workload

Many physicians mentioned aspects that would increase their workload due to PAEHR. It was assumed that patients may read something that they do not understand and many physicians were concerned about **actions when not understanding** patients contacting healthcare out of a need for clarification which would increase their workload. Another concern was that patients **read something that made them anxious, upset, or that was wrong**. Consequently, certain **actions taken** in these instances could also increase their workload. Certain actions taken by patients were expected to require professionals to immediately respond, for instance when patients call or send them an email. Additionally, they assumed that it would take a great deal of time during the next visit to discuss issues raised by patients reading their EHR. Physicians were also worried that patients

who found errors would call the healthcare unit to demand corrections which would also increase workload for healthcare. In the following, we present the results of the patient survey related to these aspects (see Table 2).

Actions when not understanding. When patients found something they did not understand 82% (403) strongly agreed or agreed that they would ask about this matter at the next visit to the physician. In sum, 51% (244) strongly agreed or agreed that they would contact the healthcare unit by phone, while 30% (146) disagreed or strongly disagreed. Interestingly, 51% (250) strongly agreed and 35% (169) agreed that they would look for information themselves, for example, on the internet. Only 11% of the patients strongly agreed or agreed that they would do nothing when finding things they did not understand, while 67% (316) disagreed or strongly disagreed to do nothing. A Mann-Whitney test showed no difference between respondents with or without healthcare background.

Information that made patients anxious, upset, or was wrong. Of the patients answering our survey, the majority had not read anything that made them feel anxious (73%, 361) or upset (89%, 366). A considerable number of respondents had read something that was wrong (38%, 186), while 48% (238) respondents had never experienced this. A chi-square test on all three questions showed no significant differences between respondents with or without a healthcare background.

Actions taken when upset/ anxious/ errors were found. We asked patients what actions they had taken when they read

Reasonable Waiting Time	N	Same Day	After a Day	2 Weeks	1 Month	Other
How long do you think is reasonable to have to wait after a healthcare visit before you have access to your medical records via *Journalen*?	493	19% (95)	54% (267)	15% (73)	1% (6)	11% (52)

Actions that Could Affect the Process	N	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Ability to contact healthcare electronically and ask questions about medical record	482	46% (224)	28% (134)	14% (70)	6% (27)	6% (27)
Contribute information about expectations for the healthcare visit	480	30% (145)	24% (112)	28% (136)	9% (44)	9% (43)

Table 3: Results related to "Process".

anything that made them feel anxious. The most frequent options chosen were that they tried to find information on the internet (29%, 75), that they waited until the next visit (24%, 62), and that they contacted the healthcare unit by phone (19%, 51). When it comes to actions taken when they became upset, the most frequent response selected were "nothing" (31%, 57), waiting until the next visit (18%, 33), and contacting healthcare by phone (18%, 32). Another concern was that patients might find mistakes or errors and would contact the HCPs to request a correction. Quite many patients (38%, 186) did find something in their EHR that was wrong. However, the three most common response options selected were to wait until the next visit (30%, 77), to do nothing (30%, 75), or to contact healthcare by phone (15%, 38).

Process

The results in this section are related to aspects that affect the physicians' processes of working in care (detailed overview of responses related to *process* are presented in Table 3). Before the PAEHR system was implemented, patients could request paper copies of their health records. This policy was not controversial, and one reason might be that it involved a delay and thus the HCP had the possibility to discuss the content with the patient. With PAEHR in Uppsala, patients have direct access to their record, which means that they can read test results before the physician has seen them. **Reasonable waiting times** for patients to access their records is therefore of interest and whether patients view this in the same way or differently than the professionals. Most interviewed physicians viewed direct access as negative which was related to the assumption that patients would not be able to make sense of the results and thus experience undue anxiety and contact the physician to demand immediate explanations. In other words, physicians were concerned that patients might take **actions that could affect the process** in a negative way. Physicians expected that this situation might then cause interference and interruptions in their daily work process, harm the patient, and also increase their stress due to the felt need to catch up in less time.

Reasonable waiting time to have access. In the survey, we asked how long patients thought was reasonable to have to wait after a healthcare visit before they have access to their records through PAEHR. The options "same day" and "after a day" were accompanied by the information that these notes are probably not signed by the physicians yet (i.e., might contain errors or change later on); whereas "2 weeks" and "1 month" could mean both: notes could be signed or not. 54% (267) of the respondents regarded one day as a reasonable waiting time, whereas 19% (95) wanted to have access the same day, and 15% (73) considered 2 weeks as reasonable. A chi-square test showed no significant difference between respondents with or without a healthcare background.

Actions that could affect the process. The physicians were concerned about the actions taken by patients who have immediate access since they could potentially read things that change later, or before the physicians had read them. As mentioned previously, they expected that patients would call (i.e., interrupt their current processes) when they did not understand the content or become anxious/upset. As outlined in the section *Workload* (Table 2), most respondents in our study felt they understood the information and that if actions were taken, most of them would ask during the next visit. However, 21% (102) strongly agreed and 30% (142) agreed that they would call the current healthcare unit in case they read something they do not understand. Taken together, this is more than half of the respondents of our survey. Although this might not necessarily disrupt the physicians' current work flow, it potentially adds to the nurses' workload. In relation to the importance of certain information, 74% (358) agreed or strongly agreed that it was important to be able to contact the healthcare unit to ask questions about the medical record (see Table 3).

The interviews with the physicians mainly focused on patients *reading* their records through PAEHR. In relation to patient participation there is, however, a trend to involve patients also in terms of electronic information sharing (e.g., providing comments, sharing data from self-monitoring etc.). Currently, the Swedish PAEHR system does support patients

Checking for Errors and Mistakes	N	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Use of *Journalen* because:						
I suspect inaccuracies	473	7% (32)	13% (62)	21% (101)	21% (100)	38% (178)
I am not sure if I got the right care	472	11% (50)	18% (86)	20% (96)	21% (100)	30% (140)
Importance of:						
Ability to point out errors I find in the record	485	60% (292)	18% (88)	16% (78)	3% (12)	3% (15)

Log List	N	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
See which care units and staff groups have been inside *Journalen* (i.e. see log data)	485	56% (274)	20% (95)	14% (69)	3% (13)	7% (34)
I understand most of the log list	411 [c]	49% (202)	31% (127)	15% (61)	4% (15)	1% (6)

[c] 75 respondents selected "not applicable" option; these are not included in N.

Table 4: Results related to "Control".

adding comments to a medical note, although it is emphasised that this is not necessarily read by a professional and in urgent cases the patients should call the healthcare unit. In the survey, patients were asked about the importance of different possible features in the system. 30% (145) strongly agreed and 24% (112) agreed, that it was important for them to contribute information about expectations for the healthcare visit. This also relates to other information shared by patients that may be added to the record (e.g., comments, data from self-monitoring).

Control

In this section we present results related to the physicians' feeling of being monitored by patients reading their EHR and in particular the so-called "log list" which shows all HCPs who have accessed the patient's record. Patients reading their EHR and/ or the log list created or increased a feeling of mistrust, some physicians described. Most of them perceived patients reading their records as unnecessary as physicians have an extensive education, professional experience, and the patient's best interest in mind. In the survey, we wanted to learn whether the patients indeed read out of mistrust and are **checking their record for errors or mistakes** and whether they make use of the **log list** (see Table 4).

Checking for errors and mistakes. Only 7% (32) of the patients strongly agreed and 13% (62) agreed that they have used PAEHR because they suspected inaccuracies. More than half of the respondents (59%, 278) strongly disagreed or disagreed to use it because they suspect inaccuracies. When asked if they had read because they were not sure that they had received the right care, 51% (240) disagreed or strongly disagreed with that statement, while 11% (50) strongly agreed and 18% (86) agreed. In all of these cases, the cross-group

comparison did not show statistically significant differences in their responses. When asked about the importance of the feature "be able to point out errors", 60% (292) strongly agreed that this is an important feature. As mentioned previously, however, most either waited until the next visit or did nothing.

Log list. 56% (274) of the respondents strongly agreed that it is important for them to access the information about which units of staff has been in their EHR (the log list). There was no significant difference between respondents with or without a background in healthcare. Moreover, 49% (202) strongly agreed and 31% (127) agreed that they understood the log list.

5 LIMITATIONS

The implementation of the survey within the system enabled to recruit patients who were *currently* using PAEHR and therefore the results do not reflect the opinions and experiences of those who have not used the system or stopped using it. Other limitations of the survey are the low response rate of 0.61% on the national level and that what people report might not be fully reflected in reality.

The interviews took place shortly after the launch of the PAEHR system which could be interpreted as a limitation given that physicians might have changed their view on patients accessing their record. However, even if that would be the case, this does not change the fact that initially and at a time where they are needed as domain experts in the design process, they had a predominantly negative attitude towards the technology and were strongly convinced about negative consequences for their patients. As technology affects behaviour of people and behaviour of people affects

the working of the technology [44], socio-technical consequences of a design cannot be known before it is actually implemented in practice. The aim of this study was therefore to examine specifically whether the physicians' concerns were valid, how patients actually experience using PAEHR, and how patients assess its usefulness.

6 DISCUSSION AND CONCLUSIONS

In this section we discuss the results related to the four areas of concern and how conflicting perspectives can have consequences for implementations. This is followed by a discussion of the complexities of different stakeholder perspectives in human-centred design projects.

Work Tool. The results from the survey indicate that EHRs are not only a tool for physicians and non-clinical workers e.g., medical secretaries [11], but also for patients. In our study the majority of patients find it useful and important to access their EHR which is also shown in other studies [6, 34, 68] . PAEHR can indeed serve as a tool for patients, not only to access their health information, but also to be more involved in their care and to increase their understanding. In addition to accessing their records to prepare for their next visit, many patients want to *contribute* with information through the system, facts which again emphasise the aspect of the records as a tool for patients.

Workload. PAEHR could have both positive and negative effects on the workload. More informed patients could result in longer consultations, but access to certain information could decrease the workload through fewer questions. Given that a large majority of respondents stated that they understood most of the information, there seems to be no pressing need to change the way of writing or the language used in the record. Even if the comparison of respondents showed a greater understanding for those with a healthcare background, in sum 97.6% (198) with and 94.4% (269) without working experience in healthcare strongly agreed or agreed that they understand most of what is written in the record. Even if patients might struggle to fully understand some of the terms, the results show that many patients read their records to follow up what has been said and to receive an overview of the medical history and treatment. In these cases they might be able to contextualise the content of their record with previous conversations they had with their HCPs. Furthermore, patients seem to find strategies that do not add to the physician's workload (e.g., waiting until the next visit; looking on the Internet for information). This is in line with a recent survey with HCPs from Region Skåne in Sweden, which found that few patients contacted HCPs with questions, found significant errors, or requested changes to the content of the records [54]. As there were still a considerable number of people who did experience anxiety or became upset, this should be investigated in more depth. Did PAEHR as such contribute to this reaction or was the current health situation already anxiety creating or upsetting? As the vast majority strongly agreed that PAEHR is good for them and thus see value in it, this could outweigh negative effects such as becoming anxious.

Process. The possibility of accessing the EHR immediately on demand, whether or not the HCPs have read and approved the content, can be considered as a process change. Previously, patients were informed by professionals or had to request a paper copy of their health record. This is a procedure which usually takes time. Most patients in our survey seem to appreciate timely access to their records and accept the risk that some of the information might change and/or have not been read by professionals yet. The possibility to contact the healthcare unit electronically and ask questions about the EHR was considered important by the majority of respondents. This has the potential to increase the HCPs' workload and would necessitate new processes and practices (e.g., allocating time to answer those questions), but can also support patients' learning process. Patients in our survey were interested in contributing to the EHR with information. Patients adding their expectations and other information to the EHR can affect current processes of professionals in case the HCPs are expected to act on these entries and prepare accordingly for the consultation. Even if this contribution did not result in activities by the HCPs, this feature could still be useful for patients, as long as they are aware of what to expect.

Control. Some patients read their records because they suspect errors and as a way of checking the information they have received. Only a few actually reported to healthcare when they found errors. One interpretation is that it is more about feeling in control, and the possibility to check *information*, than about *checking on* or monitoring their physicians. Previous work has also reported that patients would like to have granular control over their electronic medical records as well as have the ability to share them with different healthcare professionals [13, 59]. For the majority, it was seen as important to see who had accessed their record. Related research from [53] shows that coping strategies are sometimes indeed needed for patients in healthcare to deal with information gaps. PAEHR could be seen as one such coping strategy used both in the hospital setting and otherwise. Another interpretation of why so many think it is important to have the possibility to point out errors but not many took action when they have found them, is that the errors found were not that serious.

Different Implementations Across the Country. Looking at how the problem with conflicting perspectives has been addressed across the different regions in Sweden when PAEHR was launched, it has resulted in different implementations of PAEHR across the country [33]. Some regions and counties have chosen to listen carefully to the HCPs, and many design decisions were based on their perspective *only*. This might result in a low adoption rate, as suggested by Greenhalgh et al., where patients were disappointed with the amount and type of data available [27]. Other regions and counties in Sweden have implemented the system based on the patients' perspective.

Implications for Design and Deployment of eHealth. This study has implications for the design and deployment of eHealth services, especially when adding the perspective of patients and their everyday lives to the traditional clinical perspective, as proposed by Ballegaard et al. [7]. Our research has shown that physicians are concerned that the system will negatively affect their work environment and change the work processes in healthcare. Therefore, they would prefer that test results are accessible only after a period of two weeks, or after having been checked by a physician. The patients, on the other hand, want the results to be available within one or two days. There are indeed numerous such conflicting perspectives involved when designing and implementing PAEHR. Although the domain expertise of HCPs is invaluable in relation to effects on their work environment, they are clearly *not* a good source for understanding patients' needs and values. However, traditionally the design of eHealth tends to focus on the clinical perspective only [7, 23, 52, 62] and in CSCW studies patients have often been invisible invisible until recently [24].

When developing innovative technologies such as PAEHR where consequences are unknown from the start but can be severe, and where there is contradictions and different perspectives, it is *not* enough to just invite people to a human-centred design process. Stakeholders will have to engage with *each other*, communicate and negotiate, in other words, engage in inter-stakeholder dialogue as suggested by [28]. Methods have been developed to help stakeholders reflect on their own values within a co-design process [70], to solve trade-offs concerning values in a dialogue between stakeholders [35], or to use constructive conflict to enhance learning in a stakeholder dialogue [14]. Although these types of methods can help designers and stakeholders in the design process, they may prove difficult to use in practice. For example, these methods imply that a) all stakeholders are willing to engage in a dialogue, and b) that through dialogue conflicts between different stakeholders are solvable. We therefore agree with [10] that we need to look into "the messy activities that occur before, between or after the participatory workshops".

More knowledge is needed on how to negotiate and balance strong and conflicting opinions when little is known about whether the expectations become true and how a new technology will affect the indirect and direct stakeholders. The findings highlight the necessity to understand stakeholders' perspectives about other stakeholder groups by contrasting assumptions and expectations of physicians (indirect stakeholders) with experience of use by patients (direct stakeholders). Our study hence contributes to the value sensitive design literature on direct and indirect stakeholders applicable beyond the health care domain. Specifically, this paper contributes a study design and methods for engaging value tensions between indirect and direct stakeholders.

Another practical challenge is how to recruit both indirect and direct stakeholders and how to keep them engaged long-term. Challenges with commitment have also been reported in so called living labs, which aim to engage key actors in co-design activities over a longer period of time [5]. In our research setting, the indirect stakeholders as represented by the local medical association contested patients' online access to their EHR [20] and were not at all interested in participating in the design process. Ethical considerations relate to using stakeholders' time (here: patients and healthcare professionals) and how to deal with and communicate design decisions that may go against a particular stakeholder group. For example, a particular stakeholder group is invited to participate in the design implying a democratic process, but then other stakeholders and their needs may be prioritised in the actual design. This is exemplified in our study setting where patients in Region Uppsala can access all information immediately, despite demands of medical professionals to have a two-week respite to proofread the entries [20]. This may lead to tensions also between the developers and the stakeholders who then may be less likely to continue their engagement in the project.

Although various methods have been developed within the HCI community on how to identify key stakeholder groups, their needs and values, more knowledge is needed on how to deal with conflicting perspectives of direct and indirect stakeholders of large-scale health information systems in practice. This is particular relevant as the introduction of technology within a complex adaptive healthcare system can tremendously support patients who already perform 'invisible work' [43, 63, 64], but at the same time can have unintended adverse consequences that might endanger patient safety [60, 61].

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