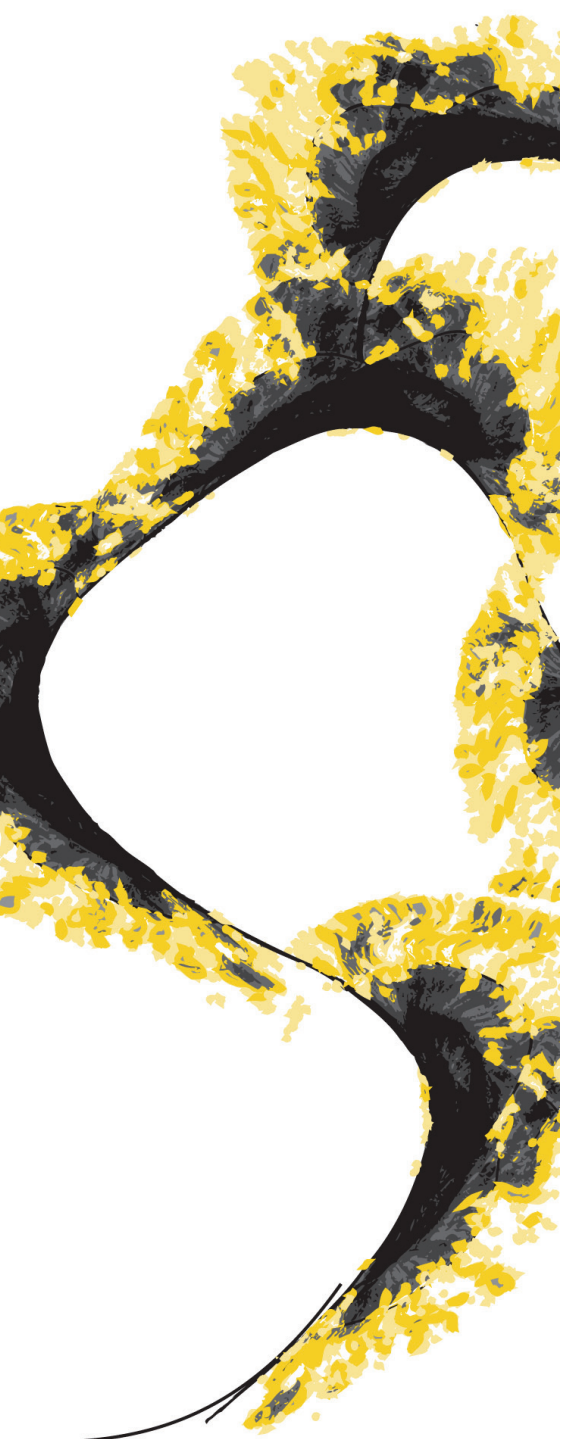


MASTER THESIS

**PERSONAL HEALTH
RECORDS IN DUTCH
HOSPITALS; IS THE HYPE
ALREADY OVER?**

D.F. Dubbink
s0082414



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SCHOOL OF MANAGEMENT AND GOVERNANCE
INDUSTRIAL ENGINEERING AND BUSINESS INFORMATION SYSTEMS

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MANAGEMENT SUMMARY

Personal Health Records, which are electronic, universally available, lifelong resources of health information [87] claim to bridge the gap between obedient patients and informed, involved and percipient patients [13]. They can assist patients as well as healthy people in their health care process and give patients the opportunity to monitor their health. Usage of PHRs can create more awareness about the current health status and can help to achieve a healthier life.

There is a growing interest in PHRs and since the development of a nationwide EHR has been shut down by the Dutch government [20], hope is set on the development of PHRs in order to track an individual's health. In addition, in combination with already established regional EHR's, PHRs claim higher quality of healthcare, more efficiency and greater patient trust in health care [13]. EHRs are already established in the vast majority of the hospitals and therefore, the current presence and development of PHRs is investigated in Dutch hospitals to uncover the status quo.

RESEARCH DESIGN

By means of a thorough literature research, important elements and theoretical benefits of PHRs in hospital setting were retrieved. Thereafter, IT experts and physicians from seven distinct Dutch hospitals were questioned about the current status of presence and development of PHRs in their hospitals.

RESULTS AND CONCLUSIONS

After analysing the outcomes of the questionnaires, seven main conclusions are drawn:

- 1. Patients in Dutch hospitals hardly ask permission to their health records, but would however value access to their data**

On basis of the literature study, most patients would value to have access their personal health records in hospitals [5] [33] [39] [64]. In practise, patient surveys in Dutch hospitals also show that access to health records would be valued and that 12% of the Dutch adults maintain a personal patient record [10]. However, the interviews with physicians and IT managers revealed that patients in Dutch hospitals hardly ask for insights into their records.

- 2. At this time, Dutch hospitals have no PHRs in place; in stead, they focus on patient portals or connect with health platforms**

At present, there are no interconnected PHR systems in place in the hospitals studied. Only two of the hospitals where experts were

questioned offer a patient portal in which patients can get insight into measurements, appointments and the possibility to keep up with a health diary. Other hospitals are connected with a health platform on which patients with certain diseases can exchange knowledge and experiences.

3. The lack of a proven business case hinders PHR adoption in Dutch hospitals

All of the IT managers claim that implementation is no technical problem, but rather a financial and manpower problem that is in accordance with theory [33] [61] [76]. This hinders PHR implementation in Dutch hospitals in the near future.

4. Hospitals are currently not the right place to develop PHRs

The questionnaire revealed that the development of PHRs and future digitalization of personal health records has not started yet in Dutch hospitals. In fact, portals and platforms emerge around syndromes and diseases and are established outside the hospital. This leads to the conclusion that with the current pace of development of (digital) health records in hospitals, hospitals are not the right place to develop PHRs.

5. IT Experts and Physicians from Dutch hospitals are not aware about each others' health record initiatives

Experts from hospitals seem not to inform each other about innovations in health records. While IT experts are somehow aiming at the development of one integrated health record for patients, physicians support the development of disease-specific care platforms. At one hospital, the IT expert did not mention the development of the care platform while the physician did not mention any development in the light of health records.

6. Currently, there are many initiatives around health records in the Netherlands that however solely operate and will end up in isolated islands

There are many initiatives in the Netherlands around health records, personal health records, care platforms and portals [9] [11] [13] [17] [25] [43] [45] [58] but looking at the development of these initiatives, it seems that the patient is offside and is not in the centre of the development. As a matter a fact, all these initiatives end up as data warehouses and isolated islands [76] of information as information exchange between initiatives is certainly not the main focus.

7. In order to create an nationwide integrated PHR, the largest suppliers of EHRs have a great opportunity in developing a large integrated PHR

Looking at the market shares of the EHR suppliers in the Netherlands, there is one large leader which serves 40 hospitals (43% of the Dutch market of EHRs): Chipsoft [22]. Chipsoft offers a specific Personal Health Record module in addition to his EHR and the question arises if these hospital specific PHRs can be linked to each other. While doing so, the supplier creates one large patient record independent of the hospital and fully aimed at the main consumer: the patient. This is suggested to be a good starting point to create interconnected health care records and a 'free flow' of health information, controlled and owned by the patient itself.

IS THE PHR HYPE ALREADY OVER OR HAS IT NEVER STARTED YET?

Looking at the popularity of PHRs in the literature, it can be concluded that the PHR hype is already on the way back. Besides, the withdrawal of Google Health as of January 1st 2012 can also indicate that PHRs arrived at the wrong time.

At the same time, some of the questioned physicians did not know about PHRs and the associated functionality. Next to this, some hospitals still offer paper based copies of health records, indicating that digitalization of health records in Dutch hospitals has a long way to go. However, some hospitals do offer patient portals or connections with health platforms indicating a possible first step towards PHR development. Perhaps, the development of these (disease specific) platforms can accelerate PHR development for the average patient in a hospital, despite the fact that hospitals do not need to develop PHRs themselves. Budgetary problems seem to hinder PHR development or adoption by hospitals. It is therefore likely that PHRs need to be developed outside the hospital but directed and demanded by patients. Hospital-patients then have to claim access to their health records because hospitals are not likely to offer them to patients in advance. Hospitals in turn need to connect to these common PHR systems upon patient demand. In the current situation in the Netherlands, this seems to be the only possibility for PHR development to succeed.

Looking at these development of portals and platforms in the surroundings of hospitals in the Netherlands, the PHR hype thus is yet to come.

LIMITATIONS AND FUTURE RESEARCH

Limitations of this research reside in the fact that patients are not questioned about their opinions and wishes. In addition, also future plans from IT suppliers as well as board of directors of hospitals are lacking. This can be taken into account in future research. Next to this, the impact of PHRs can also be researched. For example, the effect of PHRs on the quantity and quality of the patient's visits, on specific health outcomes and the effect of a patient's health literacy and the use of a PHR. Also, the legal and ethical aspects of PHRs can be researched more thoroughly. At last, the ownership of a patient's health record and the effects on the data currency and accuracy can be investigated supplemental to this research.

PREFACE

Through a large detour hereby I am finalising my master study Industrial Engineering and Management. While the start of my research began a few years ago, I have been mainly working on assignments in the last couple of years. First in my own consultancy company, later on until now in a larger management consultancy company. The main similarity with my thesis is however health. We have a lot of health clients nowadays and I am undiminished curious about the state of affairs in these large organisations.

The start of my research began with reading the book of Thomas Goetz:

Goetz, T. (2010). The Decision Tree: Taking Control of Your Health in the New Era of Personalized Medicine.

He describes a new area of health, where the care system is no longer a top-down, doctor-driven system but in stead, individuals are put at the centre of the equation by means of cutting-edge technology that can impact each of our lives. The examples in his book are illustrative and got me to wonder: what if hospitals, where the largest number of patients go in and (hopefully) out every day, offer tools to patients that enable them to track their own health?

This also was the starting point of an extensive literature research on personal health records. However, several work assignments and interesting opportunities came across and I decided not to let them slip away. Until January of this year. In the last months, I updated the literature research and spoke with experts from hospitals to put the theory into practise and to finalize this thesis.

I would like to thank dr. Ton Spil for his endless patience and good advice in how finishing this research. I would definitely remember his subtile recommendation to 'stop searching in literature and talk to experts', which meant the reversal in my research progress.

D.F. Dubbink
November 2013

TERMS AND ABBREVIATIONS

The following terms and abbreviations are often used in this research study and are therefore mentioned and explained in advance.

Acronym	Explanation
PHR	Abbreviation for Personal Health Record. The personal health record (PHR) is an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider. [87]
EHR	Abbreviation for Electronic Health Record. The EHR is a patient record that resides in a computer system specifically designed to support care providers by providing accessibility to complete and accurate patient data, medical alerts, reminders, clinical decision support systems, links to medical knowledge and other aids. [20]
HL7	Abbreviation for Health Level 7. Computer language developed with the intention to avoid double data communication between care providers and health instances.

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1

INTRODUCTION

Imagine a situation in which patients in hospitals are put in the centre of the healthcare process, where they are the point of integration and when they are given tools to help them make better decisions. The entire health care system in hospitals becomes simpler, more scalable, more robust, and more useful. Patients are more involved in their health care, understand more about their health, have a better recovery and fewer follow-ups. But how to reach such a situation? Will hospitals offer the tools and functionality to patients or do patients claim them from the hospitals? And last but not least, what is the current situation in hospitals regarding the implementation of such functionality?

1.1 PERSONAL HEALTH RECORDS

Personal Health Records, which are electronic, universally available, lifelong resources of health information [87] claim to bridge the gap between obedient patients and informed, involved and percipient patients [13]. They can assist patients as well as healthy people in their health care process and give patients the opportunity to monitor their health. Usage of PHRs can create more awareness about the current health status and can help to achieve a healthier life.

Currently, there is a growing interest in PHRs, a so called 'hype'. Some hospitals are experimenting with offering such systems to patients and experts are claiming added value of the use of PHRs in combination with already established Electronic Health Records (EHR's). These systems are intended to provide accessibility to patient data for care providers. However, these systems are commonly built around care pathways and healthcare professionals in stead of putting the patient in the centre.

1.2 PRESENCE AND DEVELOPMENT OF HEALTH RECORDS

Presence and development of Personal Health Records are therefore the main topics of this research. These topics gained my attention because of two reasons. At first, the implementation of Health Records is about giving access to personal data that is somewhere available in the organisation but not always accessible to the end user which can be frustrating. Secondly, it's about health. I consider health to be of major importance because a good health enables one to enjoy a productive and rewarding life of working, recreation, spirituality, family and friend relations, and an overall achievement attitude.

1.3 CURRENT STATE OF THE NATIONWIDE EHR

In July 2010, the Dutch Senate voted to make major changes to the national programme of launching a nationwide EHR. This system is intended to support care providers by providing accessibility to complete and accurate patient data and other relevant medical information [20]. The EHR programme will no longer be mandatory until the EHR legislation is approved. When too many amendments were introduced, the proposed EHR legislation fell into disgrace. Senators believed that the wrong technological model had been adopted. The rollout of the two core services (online medication list and a patient medical summary for general practitioners) will now continue on a voluntary basis without financial incentives from the government. In addition, no new functionality will be allowed to add to the present EHR rollout. Many questions arose since then and the continuation of the rollout is not likely to happen soon. [69]

WILL THE ROLLOUT OF THE EHR FAIL AND IF SO, WHAT WILL HAPPEN NEXT?

What about the future? Will the current rollout of the nationwide EHR continue or will it fail due to unfair competition with regional systems, use of the widely discussed third version of the HL7 standard, growing dissatisfaction under general practitioners and other care providers and the growing citizens that opted to stay out of the nationwide EHR? [63]

Perhaps there is another possibility: the introduction of PHR systems. The growing interest in the PHR cannot be neglected and in combination with already established regional EHR's, PHRs claim higher quality of healthcare, more efficiency and greater patient trust in health care [13]. If so, can PHRs be the future of healthcare in the Netherlands and are hospitals offering them to patients? Or do patients need to claim these functionalities from hospitals? What factors determine the presence of PHR functionalities in hospitals? The considerations above are the subject of this research.

2

RESEARCH DESIGN

As stated in the introduction, the future of the implementation of the nationwide EHR is uncertain and in the meanwhile, the rise of the PHR cannot be neglected. In combination with existing EHR's, the PHR can be of added value as stated by several experts in the field [11][13][17]. Examples of proven concepts in America at the Cleveland Clinic [11] but also in the Netherlands at MijneFlevoziekenhuis [17], show that PHRs can assist patients as well as healthy people in order to create awareness about their health and to achieve a healthier life. According to one study, patients who participated in decisions about their care, had a better recovery, better emotional health and required half as many follow-up tests and doctors visits. In addition, another study found that when patients are given tools to help them make better decisions, they understand more, have better health care and they opt for fewer surgeries. [27]

2.1 FOCUS ON HOSPITALS

Hospitals are currently implementing EHR systems due to the possible upcoming legislation. Because of the large number of users hospital systems normally have, the implementation of such systems can take a lot of time and effort and requires collaboration and acceptance among the users. But to what extent do EHR systems satisfy patients needs? And what about improving the patient's health? Is the patient better off with an hospital using a EHR?

Next to this questioning about the EHR, the popularity and hype of PHR systems cannot be neglected. Therefore, the question arises: Can the presence of an PHRs result in added value for both patients and the hospital? Theoretical benefits of PHRs are efficient communication, so-called disease management and a better competitive position [13].

And if PHRs are proven to add value to the health of patients, what do those systems look like, are they already in place in hospitals or are they planned to be implemented? And also important, will hospitals offer those systems or do patients need to claim them?

2.2 RESEARCH OBJECTIVE: STATE OF PERSONAL HEALTH RECORDS DEVELOPMENT IN DUTCH HOSPITALS

The objective of this research assignment is to investigate the questions above and is defined as follows: *What is the current state of the development of PHRs in Dutch hospitals?*

RESEARCH MODEL FOR DETERMINING THE CURRENT STATE OF THE DEVELOPMENT OF PHRS IN DUTCH HOSPITALS.

To gain insight into the different steps to fulfil the research objective, a research model is displayed below and is explained afterwards. Thereafter, research questions are deduced from this research model.

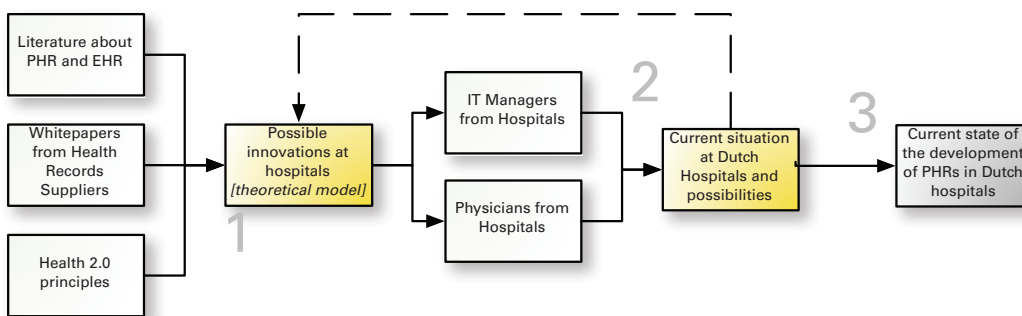


FIGURE 1
Research model Graduation Assignment

By means of a literature study on EHR and PHR systems, white papers from suppliers and health 2.0 principles, possible innovative solutions for hospitals are discovered (1). Thereafter, IT managers and physicians from hospitals are consulted to gain insights in the current situation at hospitals on health records and possibilities in the future (2). The comparison and analysis of the current and desired situation leads to conclusions about the current state of the development of PHRs in Dutch hospitals (3).

2.3 RESEARCH QUESTIONS

Next to the research model, the following questions are aimed at reaching the objective to get an answer to the question 'What is the current state of development of PHRs in Dutch hospitals? '.

Question 1: Which elements are important to take into consideration in view of development of personal health records in hospitals?

This question is answered in the fourth chapter: Important elements and theoretical benefits of PHRs in hospital setting.

Question 2: What is the current situation at Dutch hospitals regarding the presence and use of personal health records?

This question is answered in the fifth chapter: Current situation of PHR presence in Dutch hospitals.

Question 3: What is the current state of PHR development in Dutch hospitals?

This question is answered in the sixth chapter: Analysis and discussion: the current state of PHR development in Dutch hospitals.

Finally, in chapter 7, the main conclusions from this research are drawn and limitations and future research opportunities are described.

2.4 CONTRIBUTIONS TO THEORY AND PRACTICE

At first, this research aims at improved practices at Dutch hospitals. Hospitals are implementing EHR systems as a consequence of the Dutch law. Next to this, patients are willing to get more involved in the health care processes and demand insights into their health records. This research contributes to bridge the gap between the current situation and the desired situation in personal health records at Dutch hospitals.

In addition, this research also contributes to theory by defining the factors that explain the current pace of PHR development. While a short literature review reveals that a lot has been written about strategies to implement EHR systems as well as about the benefits of the use of PHRs, factors that explain the current state and pace of PHR functionality are lacking.

2.5 RESEARCH METHODOLOGY

In order to gain sufficient knowledge about the topic of health records, a literature review will be executed. This literature review will be described in detail and the results will be described thoroughly. Outcomes of the literature review are used to construct questionnaires and to execute a case study among IT managers and physicians. Experts are asked about their opinion by means of qualitative one-to-one interviews. All this effort is done to gain insight into the current and desired situation of the functionality of health records in Dutch hospitals. The following sections describe the research methods in detail.

LITERATURE REVIEW

By means of a literature review among the top 25 information systems journals [67], relevant articles on health records are selected to be included in a literature synthesis to eventually conduct a theoretical model which will be questioned to experts from hospitals and

suppliers. The literature review will include a specification of used key-words, used search engines, in- and exclusion criteria and prioritization criteria.

INTERVIEWS WITH IT MANAGERS AND PHYSICIANS FROM HOSPITALS

Qualitative one-to-one interviews are executed with IT managers and physicians from hospitals to gain insight in the current situation of health records in the hospital and the added value these records have for patients. In addition, these experts from hospitals are asked about their opinion what their hospital is going to offer to patients in the future in the case of personal health records.

To select relevant hospitals, the following criteria are taken into consideration:

- Bed capacity of a single hospital (low, medium, large)
- Type of hospital (Academic, Top clinical, Categorical, General hospitals)
- Geographical location

The table below specifies the seven selected hospitals to conduct the interviews:

TABLE 1
Six selected hospitals for interviews graduation assignment

	Hospital	Location	EHR Supplier	Bed Capacity	Type of Hospital	Additional Information
1	Ropcke -Zweers	Hardenberg	Chipsoft	172	General	
2	Isala	Zwolle	IC2IT	949	Top clinical	New hospital building in 2013
3	Maasziekenhuis	Boxmeer	Chipsoft	250	General	
4	Antonius	Sneek	iSoft	304	General	
5	UMCG	Groningen	iSoft + own EPD	1339	Academic	
6	Martini Ziekenhuis	Groningen	Chipsoft	580	Top clinical	
7	NKI-AVL	Amsterdam	Chipsoft	180	Categorical hospital	

3

STRUCTURED LITERATURE REVIEW

In this section, a literature review is conducted on health records from patients perspective. In the end, the goal of the literature review is to find high quality research on health records from patient perspective, that cover the whole spectrum about these health records. This literature review is done in a structured manor in order to maximize the reliability of this study and to reflect the scope of the literature study. The outcome of this structured literature review is a description of all relevant aspects of health records from patient perspective which will be used in the interviews experts from hospitals and suppliers.

3.1 KEYWORDS AND SYNONYMS

Primary keywords have been identified, including synonyms and related aspects to be used in the review of high quality research and eventually for answering the research questions and establishing a theoretical model. The used keywords are displayed in the table below:

TABLE 2

Keywords, synonyms and related aspects

Primary Keywords + Synonyms	Related aspects
PHR (Personal Health Record)	EHR (Electronic Health Record)
PCHR (Personally Controlled Health Record)	Interoperability
	Integration (-strategy)

These keywords, synonyms and related aspects are combined to be used as search strings in search indexes. The table below indicates all possible combinations.

TABLE 3

Search strings used in search indexes

Search Strings	
+ PHR (Personal Health Record)	+ PCHR (Personal Controlled Health Record)
+ PHR + EHR	+ PCHR + EHR
+ PHR + EHR	+ PCHR + EHR + Interoperability
+ PHR + EHR + Integration	+ PCHR + EHR + Integration
+ PHR + EHR + Integration strategy	+ PCHR + EHR + Integration strategy

3.2 USED INDEXES AND SEARCH ENGINES

Determining the indexes to use in a research is the starting point of a literature review [67]. Choosing indexes that have the best coverage of high quality journals is key to be able to conduct a valuable research. Schwartz & Russo [67] indicated the indexes that have the best coverage of the top 25 IS journals, a list originally ranked by Mylonopoulos and Theoharikis [50] according to world and geographic preference. As Health Records are electronic information systems,

indexes according to the Swartz & Russo [67] research are used in this research. Outcomes of the work of Schwartz & Russo [67] are indicated below:

Rank	Index	Coverage of top 25 IS Journals	Full-text search coverage
1	Ingenta	24	0
2	INSPEC	21	0
	Web of Science	21	0
4	EBSCO Business Source Premier	19	11
5	ACM Guide	16	4
6	ABI / Inform	14	2
7	Ei Compendex	10	0

The research of Schwartz & Russo [67] have a few limitations. At first, the research did not mention the length of which a certain journal is covered by a certain index. Furthermore, it is not clear for some indexes how long it takes until a new paper is available. And also important, the research of Schwartz & Russo [67] is conducted in the year 2004, six years ago. The possibility exist that the significance of IS journals is changed in the meanwhile, just as the coverage of the indexes may be changed.

Nevertheless, since a repetition of the Schwarz & Russo [67] study is not in line with this research, recommendations of their study are followed in selecting proper indexes for this research with the observance of the limitations mentioned above. The authors suggest either a combination of Ingenta and ACM Guide, or a combination of INSPEC, ACM Guide and one of the following three: ABI / Inform, EBSCO Business Source Premier or Web of Science. To concede to the limitations of the Schwarz & Russo [67] study, the top five indexes from their study is used in this research, as well as the Scopus database for searching articles. This combination of indexes covers the top 25 IS journals and includes 14 journals that support full text search. The total list of applied indexes in this research are thus: Ingenta, INSPEC, Web of Science, EBSCO Business Source Premier, ACM Guide and Scopus.

3.3 INCLUSION AND EXCLUSION CRITERIA

Personal Health Records are a relatively new subject in health care and therefore, only articles from the year 2000 and on are included in this research. When a search resulted in more than 50 hits, the

TABLE 4
Indexes that cover most of the top 25 IS Journals [67]

results were sorted out on the number of times a specific article is cited. However, when less than five articles were found by a specific combination of keywords and used search index, abbreviations were written out word by word to yield more results. Hereafter, articles have been selected to be included in the research on basis of the relevance of their title, abstract and keywords.

TABLE 5

Selected articles that met inclusion criteria

3.4 SELECTED ARTICLES

Table 5 shows the selected articles and the way they are found, by means of the used search string and search index. The total amount of unique articles is 47. Note that there is some overlap in the articles found by using different search strings and search indexes.

Search Strings	Search Index	Hits	# Selected	References
+ PHR (Personal Health Record)	Ingenta	7	3	[16], [82], [83]
	INSPEC	95	6	[14], [37], [61], [74], [82], [83]
	EBSCO	54	4	[37], [41], [55], [62]
	ACM	48	6	[18], [54], [59], [65], [68], [74]
	Web Of Science	252	4	[5], [33], [76], [90]
	Scopus	141	5	[7], [8], [34], [38], [76]
+ PHR + EHR	Ingenta	1	1	[83]
	INSPEC	15	2	[3], [36]
	EBSCO	15	4	[53], [55], [68], [77]
	ACM	12	3	[6], [12], [18]
	Web Of Science	37	3	[76], [84], [85]
	Scopus	49	3	[71], [83], [88]
+ PHR + EHR + Interoperability	Ingenta	2	0	
	INSPEC	26	5	[16], [26], [37], [79], [83]
	EBSCO	57	2	[68], [79]
	ACM	6	1	[6]
	Web Of Science	26	1	[66]
	Scopus	7	1	[42]
+ PHR + EHR + In-tegration	Ingenta	1	0	
	INSPEC	82	4	[16], [37], [79], [83]
	EBSCO	14	1	[3]
	ACM	7	0	
	Web Of Science	35	1	[29]
	Scopus	9	2	[42], [60]

+ PHR + EHR + Integration + Strategy	Ingenta	1	0	
	INSPEC	105	4	[16], [37], [79], [83]
	EBSCO	18	1	[83]
	ACM	8	0	
	Web Of Science	5	1	[60]
	Scopus	5	1	[60]
+ PCHR (Per- sonal Controlled health Record)	Ingenta	12	0	
	INSPEC	14	3	[30], [80], [81]
	EBSCO	8	2	[40], [75]
	ACM	1	0	
	Web Of Science	59	3	[38], [80], [81]
	Scopus	75	2	[38]
+ PCHR + EHR + PCHR + EHR	Ingenta	4	1	[83]
	INSPEC	47	4	[14], [16], [37], [83]
	EBSCO	37	6	[3], [16], [37], [79], [82], [83]
	ACM	44	2	[23], [32]
	Web Of Science	6	0	
	Scopus	6	0	
+ PCHR + EHR + Interoperability	Ingenta	1	0	
	INSPEC	23	5	[16], [26], [37], [79], [83]
	EBSCO	53	2	[68], [79]
	ACM	6	0	
	Web Of Science	2	1	[66]
	Scopus	2	0	
+ PCHR + EHR + Integration	Ingenta	1	0	
	INSPEC	33	4	[16], [37], [79], [83]
	EBSCO	3	2	[40], [53]
	ACM	20	0	
	Web Of Science	47	2	[29], [38]
	Scopus	4	1	[38]
+ PCHR + EHR + Integration + Strategy	Ingenta	1	0	
	INSPEC	34	4	[16], [37], [79], [83]
	EBSCO	21	4	[3], [40], [53], [83]
	ACM	9	0	
	Web Of Science	2	0	
	Scopus	2	0	

3.5 BACKWARD RESEARCH

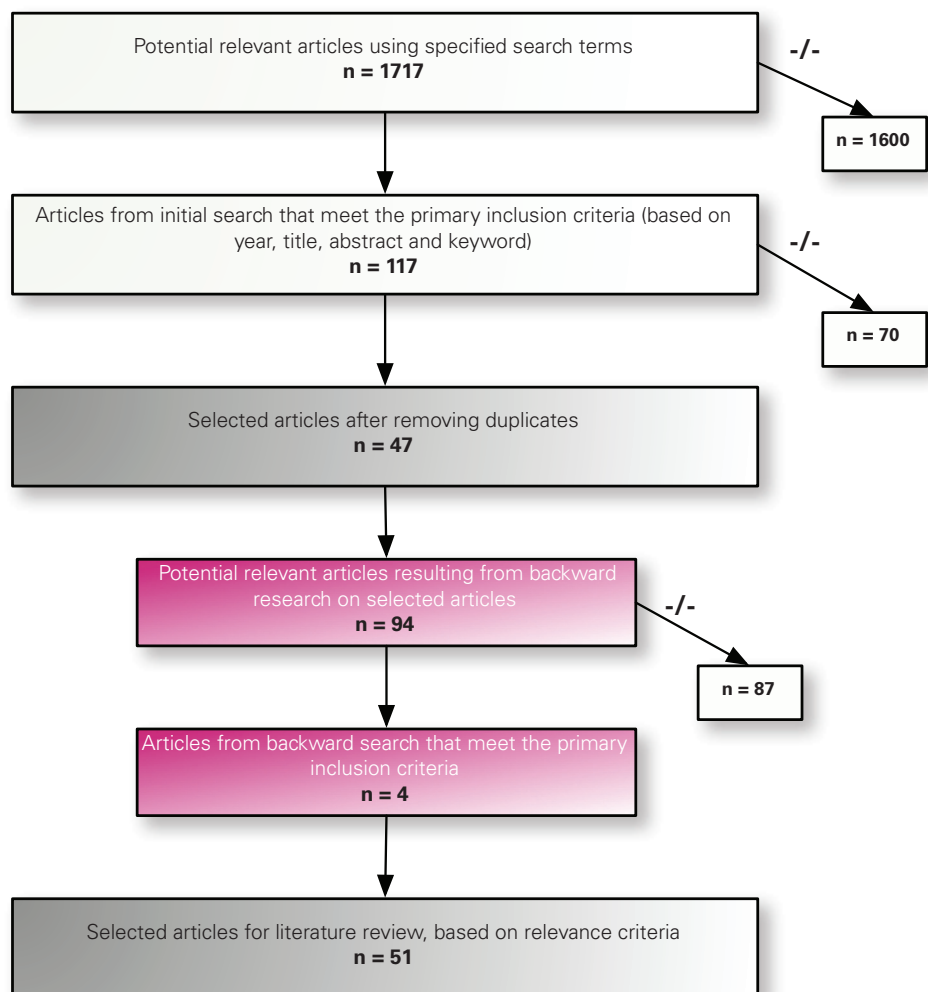
The 47 selected articles were thoroughly analysed and references from those articles were scanned on title, year and journal to see whether a reference article was also found to be relevant in this research. 94 potential articles were discovered during this analysis. After removing duplicate articles, seven unique articles were selected for further analysis. Finally, four articles met the inclusion criteria and were selected next to the other 47 articles that were initially selected. In total, 51 articles are selected for this research.

3.6 EXPLICIT SEARCH METHODOLOGY

The initial search strategy and backward search are summarized in the figure below. The number of articles found in every step of the search methodology are specified in this figure.

FIGURE 2

Explicit search methodology



3.7 SHORT ANALYSIS OF PAPERS

The search methodologies yielded 51 articles. Altogether, these articles were cited 1036 times (as of the 6th of June, 2012) and four of them were published in one of the top 25 IS Journals (according to Schwarz & Russo [67]). 98 percent of the selected articles have been published in the years of 2005 till now, indicating that the Personal Health Record is a relatively new topic in science, since the years from 2000 till 2004 only produced one paper that has been selected in this research. Table 6 displays the number of articles selected in each year and the corresponding percentage of the total number of 51 selected articles.

Year	Articles	Percentage
2012	1	2,0 %
2011	4	7,8 %
2010	5	9,8 %
2009	12	23,5 %
2008	8	15,7 %
2007	8	15,7 %
2006	5	9,8 %
2005	7	13,7 %
2004	0	0,0 %
2003	0	0,0 %
2002	1	2,0 %
2001	0	0,0 %
2000	0	0,0 %
Total	51	100 %

TABLE 6

Year of publishing of selected articles

3.8 PHR CATEGORIZATION

The selected articles are categorized according to the work of Kaelber, Jha, Johnston, Middleton and Bates [33], named 'A Research Agenda for Personal Health Records', who identified seven categories in relation to Personal Health Records. The authors reviewed existing PHR specific literature (100 articles), found by the PubMed index and divided the articles into six distinctive categories and one category 'other'. A limitation of this study is that it only used the PubMed search index and selected articles from a large span of years (1950 till 2007). In contrast, this research used six search indexes (as stated in the paragraphs above) and selected only articles from the most recent years (more than 98 percent from the past seven years).

When applying the six distinct categories to the 51 papers, it turns out that the most is written about 'position statement' of PHRs and secondly about 'adoption and attitudes' of PHRs. Table 7 displays an overview of the references in each category. In addition, the fourth column displays the percentage of the number of references compared to the total number of articles. The fifth column displays the percentage of the number of references compared to the total number of references in each of the categories.

Category	References	Total # of Refs	%	Normalized %
Adoption and Attitudes	[5], [6], [14], [29], [33], [39], [53], [54], [56], [61], [64], [65], [68], [71], [75], [76], [77], [80], [81], [82], [83], [84]	22	43,1 %	21,8 %
Architecture	[5], [12], [18], [23], [26], [30], [33], [38], [39], [42], [53], [56], [60], [76], [90]	15	29,4 %	14,9 %
Function Description	[5], [29], [33], [37], [39], [40], [70], [74], [76], [80], [90]	11	21,6 %	10,9 %
Function Evaluation	[5], [6], [14], [23], [33], [34], [39], [54], [56], [61], [65], [74], [88]	13	25,5 %	12,9 %
Position Statement	[3], [5], [6], [7], [8], [16], [21], [26], [33], [36], [39], [40], [41], [42], [55], [59], [61], [62], [66], [75], [77], [79], [81], [83], [85]	25	49,0 %	24,8 %
Privacy and Security	[5], [18], [23], [30], [32], [33], [38], [39], [42], [56], [61], [65], [80], [83], [90]	15	29,4 %	14,9 %
Total		101	198 %	100%

The categorization will be used in the next chapter where the literature will be discussed.

TABLE 7

Categorization of the selected articles

4

IMPORTANT ELEMENTS AND THEORETICAL BENEFITS OF PHR'S IN HOSPITAL SETTING

In this chapter the selected literature is summarized using the categories of Kaelber, Jha, Johnston, Middleton and Bates [33], who divided PHR literature into six distinct topics. This is done in order to have a basic understanding of relevant aspects of PHRs and to be able to discover innovative PHR solutions in hospital settings.

Eventually this chapter gives an answer to the first research question how the usage of PHRs in hospitals can contribute to a more efficient and effective healthcare process. The conclusion will be used in developing questionnaires.

The literature summary is preceded by a general introduction into PHRs and PHR definitions and is ended by discussing the business case for PHRs.

4.1 GENERAL INTRODUCTION

The field of healthcare is changing. Individuals demand that responsibilities related to one's personal health shift from healthcare professionals to the individuals themselves [36] [40] [61]. Healthcare professionals face problems in coping with the information submitted by individuals and seem not to be ready for this new and valuable information source [36]. However, the rise of empowered individuals who come well prepared to the appointment with information about different elements of their personal health cannot be overlooked. Individuals have become more knowledgeable about their personal health (or about the health of their relatives) and about healthcare in general, and they also desire to know more. New information management practices are therefore needed to exploit the challenges that individuals as well as healthcare professionals face [6].

Next to these trends, the scope of healthcare has broadened [36]. Health is nowadays an issue about a comprehensive well-being covering mental, physical and social dimensions. And with the ever-growing availability of so-called quantified-self tools, one can measure almost every aspect of health that can be quantified in numbers. As a result of these developments, there is a demand for personal health information management (PHIM), as storing information on paper is no longer sufficient [59]. Applications and tools that can keep track of one's health are requested and that is where Personal Health Records (PHRs) can come in.

PHRs have the possibilities to support individuals in the desire to

“As the Automatic Teller Machine (ATM) has once transformed the banking business, PHR will be used to build new relationships and structures to support consumers in healthcare”

- BALL AND GOLD [7]

know more and capture more. PHRs assist individuals in health self management and make medical records and other relevant information accessible to patients [5] [40] [61].

4.2 PHR DEFINITIONS

Since there is no universally accepted definition of a PHR [85], most of the authors from the selected papers use one of three common used definitions to characterize a PHR. The Connecting for Health Personal Health Working Group, sponsored by the Markle Foundation, defines a PHR as follows:

“The Personal Health Record (PHR) is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it. PHRs offer an integrated and comprehensive view of health information, including information people generate themselves such as symptoms and medication use, information from doctors such as diagnoses and test results, and information from their pharmacies and insurance companies.” [39]

The American Health Information Management Association (AHIMA) uses a somewhat similar definition as the one above, but put emphasis on the fact that it is not simply a patient view on EHR data:

“The Personal Health Record (PHR) is an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider.” [1]

And thirdly, the often cited work of Tang et al. [76] define a PHR in a broad manor:

“A PHR is an electronic application through which individuals can access, manage, and share their health information and that of others for whom they are authorized, in a private, secure and confidential environment.” [76]

Note that all the definitions use terms like ‘persons’ or ‘individuals’ rather than ‘patients’ to stress that the PHR is a tool that can be useful in maintaining health and wellness in a broad way as well as a

tool to help with illness, where the term 'patient' implies [76]. In this research the term 'individuals' will be used and a PHR will be viewed in the broadest scope by analogy with the definition of Tang et al. [76].

4.3 ADOPTION AND ATTITUDES

Several studies have indicated that most 'patients' would value to have access to their health records [5] [33] [39] [64]. Patients and individuals with chronic conditions and disabilities, people caring for elderly parents and frequent users of healthcare services however show to have the most interest in PHRs [5]. The greatest benefit can be expected from these users, since they need to track their illness and treatment the most [56].

On the contrast, physicians remain more sceptical about individuals having access to their health records and are more sensitive to the potential risks [56]. They foresee problems from patient PHR use and expect that this would generate more uncompensated work [4] [35]. Physicians are however receptive to patient access to most laboratory and other EMR information, if access to physician notes is limited [4]. Archer et al. [5] therefore conclude that education of physicians therefore is needed on how PHRs can also support patient empowerment, disease prevention and disease control, and health self-management.

As a general rule, increasing individuals' abilities to access their medical records will result in better preparation and motivation, reductions in treatments and medication errors, and improved health [56] [80]. However, widespread adoption and use of medical records like the PHR will not occur unless these records provide added value to the individuals [33] [76]. This implies perceptible value, easy to learn and easy to use systems, and justified efforts associated with PHRs [76]. Archer et al. [5] suggest the use of the well-known DeLone and McLean model of information success [19] to be applied in PHR research to uncover inter-related measures of success.

In addition, to realise their full potential, health records need to be integrated within care processes [56]. This requires huge efforts to develop policies and change attitudes and expectations in the doctor-patient relationship.

**“Patients as co-pilots in their care”
“A continuous healing relationship is a two-way interaction (whether
electronic or face-to-face) between patients and their provider.”**

- TANG AND LANSKY [75]

BARRIERS TO ADOPTION AND USE

Archer et al. [5] investigated the barriers to adoption and use of PHRs and came up with eight technical and nontechnical barriers and 24 related issues. Privacy and confidence turned out to be an important barrier, even as the availability of technical standards for system interoperability. Furthermore, poor computer and internet skills and fear of technology [5] as well as low health literacy counteract PHR adoption [36]. As mentioned before, the willingness of practitioners and institutions is also a prevalent issue in PHR adoption. [5]

ACCEPTANCE AND MOTIVATION

Sensmeier [68] argues that healthcare providers can encourage patients to achieve personal goals by the next visit and use PHRs to keep track of their maintenance. Nurses play a key role in this situation in helping patients understand and navigate these tools. However, nurses therefore need to develop necessary information competencies to act on new personal health information management (PHIM) demands [59]. When these competencies are successfully embedded, it will also enable patients to achieve their personal health goals [68].

4.4 ARCHITECTURE

In general, health information technology, like PHRs, consist out of three primary components; Data, infrastructure and applications [33]. The following table specifies these components. The data component is described in appendix C, Infrastructure and Applications are described in this paragraph.

Component	Description
Data	The types and elements of information that are exchanged, analysed and stored by different information technologies (such as healthcare claims, laboratory results and medication history)
Infrastructure	The computing platforms, software packages, functions or websites that exchange and process healthcare data
Applications	The capabilities and outputs of health information systems, that are enables through data and infrastructure.

TABLE 8
Components of a PHR or health information technology in general [33]

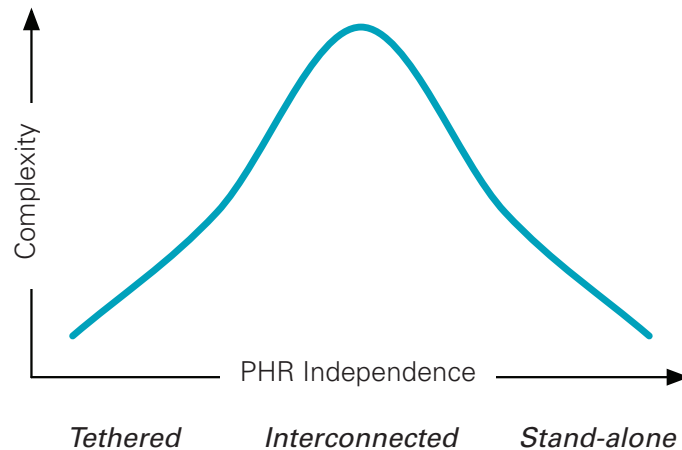
INFRASTRUCTURE, INTEROPERABILITY AND STANDARDS

There are different approaches in creating a functional PHR [76]. Complexity ranges from simple to very complex and the independ-

ence of a PHR ranges from tethered to stand-alone. The figure below shows the several possible approaches.

FIGURE 3

Range of complexity in different approaches to PHR's [75] [76]



The most simple approach is the [stand-alone](#) version of the PHR. In this situation, individuals may create a PHR using stand-alone systems (for example USB-sticks with a PHR application [37]) or commercially available web-based applications to enter and access their health data [74]. These systems do not connect with any other system and become 'isolated islands' [76], because they cannot exchange information with other systems. Tang et al. [76] therefore suggest that a PHR at minimum should have the ability to import and export data with other healthcare systems like the EMR and EHR in a standard way.

At the other end of the spectrum is the [tethered](#) version of a PHR. This is where PHR functionality is provided by allowing patients or individuals to view their own health information that is stored in a EHR or EMR of healthcare providers [76]. There are several examples of healthcare providers that offer tethered PHRs with additional functionality, such as allowing individuals to request appointments and prescription renewals [9] [75] [76]. The tethered PHRs are often called 'patient portals' and enable patients to view (and not always change or update) patient data, clinical summaries and test results [28]. A major downside of these portals is the fact that they are tethered to a single healthcare provider and that different healthcare groups have their own patient portal, leaving the data of one patient diffused [28].

The last approach is the [interconnected](#) version of a PHR. Whereas a tethered PHR is integrated with a single healthcare provider, a interconnected PHR is connected to various healthcare data sources to

“In 2004, President Bush set the goal that most Americans have their medical info maintained in EHR systems in the next 10 years.”

-TANG AND LANSKY [75]

acquire and transmit data [76]. This makes this type of PHR much more complex, but overcomes the limitations of being connected to only one healthcare provider. Several authors are convinced that this type of PHR provide much greater benefits than stand-alone PHRs [5] [76]. In addition, Kaelber et al. [33] mention a PHR paradigm that is in line with this interconnected approach. Their so called ‘hub and spoke’ concept (see figure 4) consist of a personal controlled PHR as a hub at the centre, connected with different stakeholders as spokes who exchanges data and interact with the individual who controls the PHR [33]. The PHR becomes more valuable when the hub grows in functionality, when the hub is more connected to other sources of health information, and when the health information sources are more complete [33].

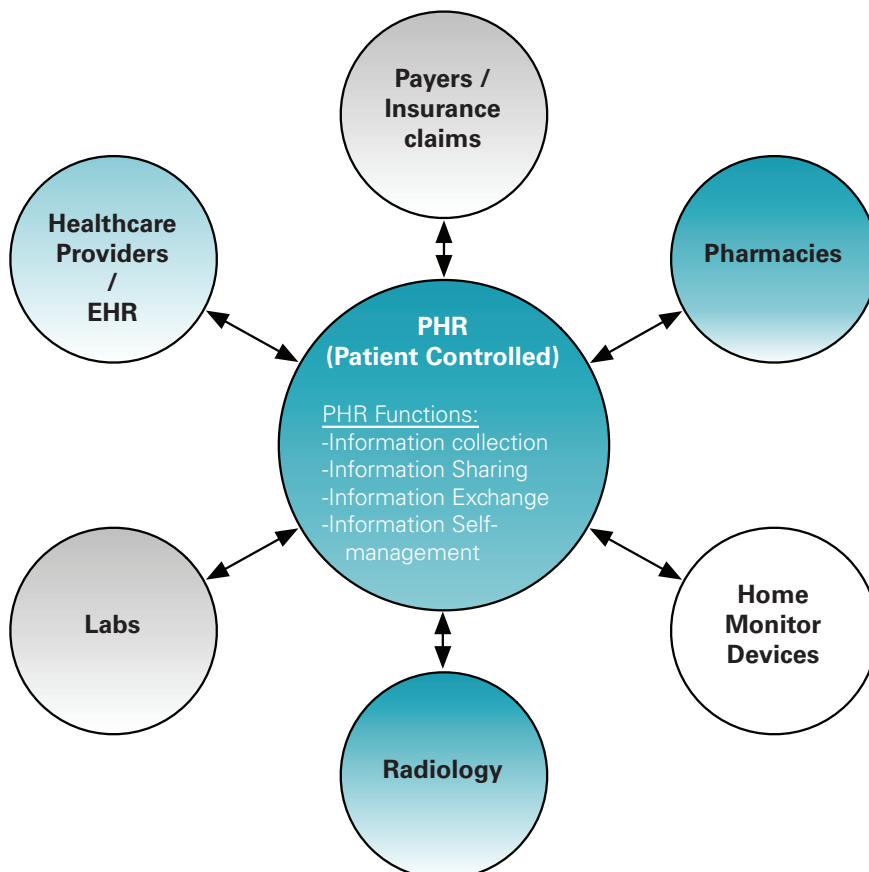


FIGURE 4

Idealized hub and spoke concept of a PHR system [33]

Most authors agree on the fact that interoperability is a key component of a PHR architecture in order to be an effective tool that provides real value to individuals [5] [7] [33] [76]. Interoperability is defined by the IEEE Glossary as:

“The ability of two or more systems or components to exchange information and to use the information that has been exchanged.” [31]

This definition is also in accordance with the hub and spoke concept of Kaelber et al. [33] which is shown in figure 6. PHRs become useful when connected and integrated with a larger healthcare system [75]. However, representation of PHRs need to be adapted to the user of the PHRs information since not all personal health data entered by individuals is clinically relevant to healthcare professionals and caregivers. It can help consumers modify their behaviours though, and therefore need to be included in a PHR [75].

In order to define, view and describe an PHR, it must be considered in contrast to other electronic records that are used in the medical community, such as the Electronic Health Record (EHR) and the Electronic Medical Record (EMR) [83]. As a matter a fact, these records are important sources of data for the PHR and the definitions are therefore denoted in the table below:

TABLE 9

Definitions of EMR, EHR and PHR

Type	Definition
EMR	"A computerised platform for managing detailed medical information collected during a hospital stay or in a doctor's office." [1] Data is owned by the providing organisation, although some organisations let individuals view their lab results or appointments [83].
EHR	"A collection of health information that has been gathered and managed by an enterprise - typically a doctor's office, a hospital or an integrated system." [75] Data is owned by the providing organisation, although some organisations provide interactive patient access and the ability for patient data entry [83].
PHR	"A PHR is an electronic application through which individuals can access, manage, and share their health information and that of others for whom they are authorized, in a private, secure and confidential environment." [76] Data is owned by the patient or individual [83].

Interoperability between health systems and health records require standards and standard based frameworks. In appendix C, some standards are mentioned and described.

APPLICATIONS

There are several applications available that support the maintenance of an individual's health status. However, these applications differ in functionality and use. The independent Dutch research organisation TNO made a list [9] of the most relevant applications that are available in the Netherlands and the most important foreign applications [9]. It is noticeable that none of the national initiatives that are aimed at multiple diseases have an interconnected structure that enables interoperability. Of the foreign applications that TNO have listed, the following four applications have an [interconnected](#) structure:

- Google Health (As of January 1st 2012, Google Health is no longer available)
- Microsoft HealthVault
- ICW LifeSensor (As of May 31st 2012, ICW LifeSensor is no longer available)
- Sundhed Denemarken

Remarkably, two of the four [interconnected](#) systems are no longer available. Some articles state that Google Health failed because of the tough healthcare market, absence of reimbursements, lack of focus on development, low interest of individuals to fill a digital cabinet, lack of physician involvement, low number of users, and individual's trust in digital health records [15] [40] [86].

The same sources indicate that Healthvault on the contrary may survive due to the affiliation of large nonprofit healthcare providers, and that it is positioning its system as a means for businesses and organisations to hook up with new customers and members [15] [40] [86].

Initiatives from national hospitals are mainly focused on support of appointments and visit preparations [9] and do not offer interconnected applications but have a [tethered](#) architecture. These applications are well suited to support the patients of these hospitals, but offer no or limited possibilities to manage someone's health status.

At last, there are some [stand-alone](#) applications on the Dutch market that offer PHR functionalities like Medlook [43], Patient1 [57] and MijngEZondheidplatform.info [45] whereas patients can log in and fill in their medical data. These applications are however not automatically connected with EHRs from hospitals ([not interconnected nor tethered](#)).

4.5 FUNCTION DESCRIPTION

PHR functionality in its broadest sense can be classified as [5] [33]:

- Information collection
- Information sharing and exchange
- Information self-management.

PHR functionality comprise sending and receiving (thus: two sided communication of) electronic messages to and from physician's offices; completing prescription renewal forms, appointments, and referral authorizations; viewing lists of current medications and allergies; and accessing health and practice information [5] [33]. In addition, decision support can also assist individuals and patients in managing chronic illnesses, based on the data in the PHR [29] [33]. Kaelber, Jha, Johnston, Middleton and Bates [33] also argue that the nature of the patient's illness affects the preference for functionality. A patient with diabetes for example may prefer other functionalities than kidney patients.

Whetstone and Randeree [83] define PHR functionality in a more specific sense, according to the HL7 Functionality model, and is elaborated on in appendix C. This standard is largely in line with the specification of the required data to be included in a PHR, mentioned before.

4.6 FUNCTION EVALUATION

Many authors link function evaluation with the definition of PHRs and with the function description (see previous paragraph) in order to evaluate the functions of a PHR [5] [9] [34] [40] [56] [74]. Table C4 in appendix C summarizes the criteria used in several studies on function evaluation. For example, Marshall [40] reviews PHRs on basis of effectiveness and states that an PHR should have the following common qualities to be effective: accessible, secure, portable, interoperable, actionable and usable. However, Sunyaev, Chorny, Mauro and Krcmar [74] did a more extensive literature research on specific evaluation criteria for PHR functionality. These criteria are used as a basis in the table C4 of PHR function evaluation criteria and is complemented by other authors.

4.7 POSITION STATEMENT

PHRs have the aim and potential to change and improve the patient-provider relationship, create patient collaboration, enhance shared decision making, and enable the healthcare system to evolve toward a more personalized model [5] [8] [90].

PHRs are emerging internationally as a new way of supporting individuals to access and manage their personal electronic health data. Individuals increasingly ask for flexible access to health information and services in order to be better informed about health and to be actively engaged in their healthcare [7] [8] [56] [76] [90]. The availability of medical information on the web and the widespread use of the internet have created awareness among individuals about symptoms, diagnostic tests, diseases and treatments [5] [79]. Usage of PHR systems have increased recently [1] [90], and high levels of satisfaction with existing systems are reported [5] [90]. Furthermore, individuals show strong interest to PHR capabilities [1] [6] [33] [90], and PHR adoption is likely to increase as functionality of these systems is expanding and benefits are becoming clear [33] [55]. Most PHRs are enabled by health insurance plans, health care providers, employers, or independent titles [1] [83].

However, growth of PHRs evolves often with the adoption of electronic medical records (EMR's) by primary care physicians [5] [6] [55]. EMR's are often used as a source of data for PHRs and primary care physicians therefore play an important role in advising and supporting individuals in education and health self management [5] [6]. A PHR in this situation is more or less tethered to the EMR, but there are more possibilities. Page [55] makes a distinction between 'portal PHRs' and 'true PHRs'. The first type is integrated with the hospital's EMR, the latter is a stand alone solution and can be updated by care teams as well as by individuals [55].

Next to use of PHRs in healthcare settings, Sachinopoulou et al. [66] consider PHRs as an important enabler for making small changes in a person's lifestyle by being more informed and involved concerning someone's own health. At the end, the society can benefit from more informed and involved individuals due to reduced healthcare expenses [66].

To conclude this paragraph, envisioned benefits of PHRs include [8] [76] [83] [85]:

- Empowered and informed consumers who can better manage their own healthcare
- Improved patient-provider relationships and communication
- Timely and accessible medical data sharing
- Immediate access to automated clinical information, diagnostic tests and treatment results
- Reduced repetition of examinations and testing
- Reduced costs

-
- Improved standardisation
 - Increased care efficiency
 - Death prevention
 - Improved quality of care

4.8 PRIVACY AND SECURITY

Approximately two-third of PHR users and non-users are concerned about the privacy of their personal medical records [5] [39] [90]. Some individuals fear that PHR use will increase risk for identity theft or unauthorized access to information by marketers, health insurers or employers [5] [39]. However, chronically and acutely ill and frequent users are likely to be less concerned about privacy than are health professionals [5].

Issues regarding security are complex in the design of PHRs, because on the one hand, such systems incorporate data from multiple sources while on the other hand, the data is accessed from multiple digital devices [90]. Security mechanisms need to provide some level of protection but must not become so tight that PHRs become unusable [5] [85]. Some authors discuss the use of access control and authentication methods as a solution for security issues of PHRs [38] [65] [66].

4.9 BUSINESS CASE FOR PHRS

Tang et al. [76] argue that the lack of a proven business case for widespread deployments hinders PHR adoption. In addition, Raisinghani and Young [61] claim that the determination of who should pay for PHRs is key to consumer adoption. Next to this, patients, providers, payers, pharmacies, labs, etc. must have sufficient incentives in order to be willing to participate by direct use of through data exchange [33].

In order for an organization to survive and succeed, the business case needs to fit with the business model and moreover, needs to be aligned with the business strategy and the business processes of the organization [2]. According to Al-Debei et al [2], the business model is "an abstract representation of an organization, be it conceptual, textual, and/or graphical, of all core interrelated architectural, co-operational, and financial arrangements designed and developed by an organization presently and in the future, as well as all core products and/or services the organization offers, or will offer, based on these arrangements that are needed to achieve its strategic goals

and objectives". The business model should be reviewed continually to ensure its fit with the complex and rapidly changing external environment [2].

4.10 MAIN FINDINGS

To conclude the literature research, table 10 below summarizes the main findings concerning PHRs in care processes in hospitals. The main findings are used to construct questionnaires for IT managers as well as physicians as can be read in the next chapter.

TABLE 10

Main findings of the literature research

Category	Main findings concerning integration of PHR's in hospitals
Adoption and Attitudes	<ul style="list-style-type: none"> • Most 'patients' would value to have access to their health records • Physicians remain more sceptical about individuals access to health records • Education of physicians is needed on how PHR's can contribute to the care process • PHR's should be integrated within care processes to realize their full potential • Nurses play a key role in encouraging patients to use PHR's to keep track of their progression
Architecture	<ul style="list-style-type: none"> • There are three approaches in creating a functional PHR: <ol style="list-style-type: none"> 1. Tethered 2. Interconnected 3. Stand-alone • The EMR and EHR are important sources of data for the PHR • There are several applications available that support the maintenance of an individual's health status. None of the national initiatives is aimed at an interconnected structure that enables interoperability.
Function Description	PHR functionality in its broadest sense can be classified as [5] [33]: <ul style="list-style-type: none"> • Information collection • Information sharing and exchange • Information self-management.
Function Evaluation	<ul style="list-style-type: none"> • A PHR should accessible, secure, portable, interoperable, actionable and usable to be effective. • Table 13 indicates 32 PHR function evaluation criteria that can be used to evaluate the functions of a PHR.
Position Statement	<ul style="list-style-type: none"> • PHR's have the aim and potential to change and improve the patient-provider relationship, create patient collaboration, enhance shared decision making, and enable the healthcare system to evolve toward a more personalized model • Growth of PHR's evolves with the adoption of electronic medical records or electronic health records

Privacy and Security	<ul style="list-style-type: none">• Two-third of PHR users and nonusers are concerned about the privacy of their personal medical records• Security mechanisms need to provide some level of protection but must not become so tight that PHR's become unusable
Business Case	<ul style="list-style-type: none">• The lack of proven business cases hinder PHR adoption• The business case of a PHR needs to fit within the business model of an organization and needs to be alignment with the business strategy and business processes of an organization.

5

CURRENT PHR PRESENCE IN DUTCH HOSPITALS

In this chapter, the current situation at Dutch hospitals is investigated by describing the outcomes of one-to-one interviews with experts from several Dutch hospitals. The results are described twofold: at first from IT manager perspective, secondly from physicians perspective. Next to this, PHR applications and portals used in other Dutch hospitals are described. Eventually, this chapter contains an answer to the second research question how PHRs are currently offered to patients in Dutch hospitals.

5.1 RESEARCH METHOD

To investigate the current presence and development of PHRs in Dutch hospitals, data is collected from ten one-to-one qualitative interviews with IT-managers and physicians from several Dutch hospitals. Qualitative studies can generate insights that can explain the effects of healthcare specific characteristics [72]. The questionnaires are based upon the main findings from the literature research and the work of Stoop and Berg [72], who recommend to evaluate Patient Care Information Systems (PCIS's) along six distinct domains and to distinguish three phases of implementation. In this research, the technical, professional, organisational and economic domain are evaluated, leaving the ethical and legal domain unquestioned, due to the fact that the literature research did not focus on these areas. The phase of a PHR implementation [72] in certain hospitals could not always be discovered beforehand, however, it turned out that none of the hospitals was implementing a PHR at the time, meaning that the phase of implementation is categorized as 'pre-implementation' [72].

The outcomes of the interviews are described as two distinct perspectives, thereby interpreting the outcomes of the interviews with IT managers as the one perspective and consequently the outcomes of the interviews with physicians as the second perspective. Thereby, two distinct stakeholders are evaluated. Note that this research focuses on these two stakeholders and that other stakeholders in the hospital (patients, PHR suppliers, board of directors, insurance companies) are not questioned in this research.

The basic questionnaire is included in appendix A. Completed questionnaires can be found in appendix B. In total, four IT managers (of which one project leader) from different hospitals are questioned as well as six physicians from five different hospitals and departments, ranging from Gynaecology and Paediatrics to the Emergency department. In total, the interviewees work in seven different hospitals in the Netherlands with bed capacities ranging from 172 to 1339. Three hospitals are classified as 'general', two as 'top clinical', one as 'aca-

“Physicians are ‘shivery’ to use PHR’s but this will be only temporary. Patient data is becoming public and physicians have to conform.”

- IT MANAGER FROM A DUTCH HOSPITAL

demic’ and one as ‘categorical’. The hospitals altogether have three different EHR suppliers. The hospitals, their characteristics and the number of questioned experts are noted down in the next table.

TABLE 11

List of hospitals and interviewed experts

	Hospital	Location	EHR Supplier	Bed Capacity	Type of Hospital	IT Manager	Physician
1	Röpcke-Zweers	Hardenberg	Chipsoft	172	General	1	1
2	Isala	Zwolle	IC2IT	949	Top clinical	1	1
3	Maasziekenhuis	Boxmeer	Chipsoft	250	General	1	
4	Antonius	Sneek	iSoft	304	General		1
5	UMCG	Groningen	iSoft + own EPD	1339	Academic		2
6	Martini Ziekenhuis	Groningen	Chipsoft	580	Top clinical		1
7	NKI-AVL	Amsterdam	Chipsoft	180	Categorical	1	

In the next two paragraphs, the outcomes from the questionnaires are described. When referring to a specific interview, the interview-number is indicated between brackets “(#Bx)” and corresponds with the elaborations in appendix B.

5.2 FIRST PERSPECTIVE - IT-MANAGERS

ADOPTION AND ATTITUDES

In general, IT managers have the perception that patients are not asking permission to their own personal health record nowadays. One IT manager (#B1) recalled a sudden ‘hype’ in a call for access to medical data but that hype dropped to zero in a short time. Another IT manager (#B2) said to have no insight into the call for medical data by patients.

On the contrary, from a survey held at one hospital (#B4), patients valued the presence of a patient portal whereas patients could view appointments and lab results.

All of the interviewees but one believe that physicians are not in favour of sharing medical information and notes directly with patients. One IT manager (#B3) calls physicians ‘shivery’ but indicates that this will be only temporary. “Patient data is becoming public and physicians have to conform”. Another IT manager (#B2) mentions the personal notes from physicians; they have difficulty to share such notes with patients.

ARCHITECTURE

All of the hospitals have the ability to implement a PHR relatively easily and on a short notice. However, a proven business case is lacking in most situations and hinders actual implementation. In fact, none of the respondents believes that a PHR will be implemented within the next couple of years.

Most of the hospitals offer abstracts of medical records by means of hard copies and print screens in stead of digital access.

All of the hospitals have distinct exchange tools for certain specialisms to share data with other hospitals or instances but not with patients.

Two of the hospitals (*#B3*) (*#B4*) have a patient portal in place where appointments and measurements are shared with patients. In addition, patients can log their daily achievements and can watch instructional video's. These portals are offered as an additional feature to patients. In one hospital, the portal is not a part of the long term strategy of the hospital. This hospital is said to be reasoning mainly from care-proces perspective and not from patient perspective. At the other hospital, the portal is offered knowingly because of the added value it can offer to patients.

FUNCTION DESCRIPTION

From the interviews can be concluded that none of the hospitals has a full PHR implemented within their care processes. Only one of the hospitals (*#B3*) is large enough and has budget to buy a tool that offers some insights to patients into lab tests and appointments. One of the other hospitals (*#B4*) offers portal functionalities to patients in line with their strategy .

The IT managers all think that chronic patients benefit most from a PHR, despite the fact that there is currently no demand for access to medical data. One of the managers (*#B1*) concludes that this is because of the fact that the care is organized around the employee and not around the patient.

FUNCTION EVALUATION

Despite of the intentions and strategy of the hospitals, none of the hospitals has the true believe that a PHR is absolutely necessary in the near future. Only one IT expert (*#B2*) believes that a PHR can add

“Hospitals are indeed the most logical place to offer PHR functionalities.”

- IT MANAGER FROM A DUTCH HOSPITAL

value to the healthcare process and that a PHR ensures patient empowerment. However, that hospital has no budget in the near future to deploy an PHR.

POSITION STATEMENT

All of the IT managers are convinced of the link between the patient's illness and the intention to use a PHR. Also, they believe in the additional value of a PHR. However, other IT problems hinder the focus on offering tools to patients. One of the managers (#B1) stated that his department has no hours or budget available to develop such tools to patients.

One of the managers (#B2) argues that the patient need to be in the centre of the healthcare. His hospital participates in a local care project where different local care providers are connected to. In this perspective, the hospital is also talking with Microsoft in order to explore the possibilities with Microsoft Healthvault and the integration with the used EHR.

PRIVACY AND SECURITY

All of the hospitals are sceptical about the privacy and security issues that are connected with the implementation of a PHR. Minimum requirement for access is the 'digi-d' security protocol, according to one of the managers (#B1). However, the interconnected aspect of a PHR definitely leads to security issues.

BUSINESS CASE

One of the hospitals (#B2) is totally depending on the EHR supplier's intention to deploy a PHR system. This hospital has no budget in place to fund the purchase of such a tool. Another hospital (#B4) has no plans at all to implement a PHR system.

One of the IT managers (#B2) believes that the health insurances companies have to finance PHRs in order to keep up with the fact that patients are willing to live longer, in stead of being healthy alone.

Another IT manager (#B1) argues that hospitals are indeed the most logical place to offer PHR functionalities.

To summarize the interviews, IT managers believe that chronic patients will benefit the most from PHRs despite the fact that patients in general do not demand access to their medical data. Physicians indeed are said to be sceptical about the use of personal health records and do not encourage the use of PHRs.

“It is no problem to give patients access to their personal records.”

- PHYSICIAN FROM A DUTCH HOSPITAL

Suppliers of EHR have PHR modules in place that can be integrated into the EHR. However, none of the hospitals has already such a module installed because of the high costs associated with the implementation and maintenance. There are no large technical barriers that hinder PHR implementation at a hospital. The main reason for the absence of PHR systems is the lack of a proven business case and the shortage of available budget.

5.3 SECOND PERSPECTIVE - PHYSICIANS

Next to IT managers, six physicians from different hospitals are questioned in order to determine the presence and actual usage of PHRs in dutch hospitals. In the subparagraphs below, the results from the interviews are discussed.

ADOPTION AND ATTITUDES

Most physicians argue that patients hardly ask for access to their medical data. However, patients do ask for their labresults or radiographs sometimes. In addition, when something goes wrong in the medical process or a patient is not satisfied with his or her treatment, then it is more plausible that a patient will ask for access to personal health records.

Most physicians indicate that it is no problem for them to give patients access to their personal records. After all, it is a right for patients to view their own medical records. However, physicians do not offer access to medical records in advance. One of the physicians (*#B6*) believes that physicians are unconsciously reluctant to patients in giving access to their personal medical records.

One physician (*#B10*) argues that it is in favour of the patient not to have access to his or her personal record because this can harm the progress of the treatment. Next to this, the physician (*#B10*) argues that a medical record is full of medial terms which are not know to the patient and therefor not directly useful.

ARCHITECTURE

None of the physicians mentioned the integration with an already installed EHR or other technical elements. Most of them answered in terms of activities that need to be carried out as a result of the introduction of a PHR.

Two of the physicians (*#B5*) (*#B8*) did not know about the possibilities of a personal health record. Most of the physicians, including the

“I was not aware of the possibilities of a PHR, nor of the existence of such systems.”

- PHYSICIAN FROM A DUTCH HOSPITAL

two previous mentioned physicians, were not fond of the idea that patients own their medical data in a record.

In one hospital (#B10), a pilot will be executed in order to give patients access to their medical records and the ability to add extra data.

Several physicians believe that personal health records will result in extra activities and workload, because they believe that physicians will have to explain the records in detail to the patients.

One physician (#B7) mentioned the ideal situation in which a physician is able to view patient information from different sources, including other hospitals. On the contrary, the same physician (#B7) is afraid that patients are able to select and include only the data and records they prefer, leading to incomplete data and possibly wrong treatments.

The majority of the physicians indicate that in the current situation, medical records are printed or copied upon patient request. Some of physicians give personal explanation to patients when requested.

FUNCTION DESCRIPTION

Two physicians (#B5) (#B7) mentioned that select patients groups will definitely benefit from PHRs, such as diabetic patients, patients with chronic diseases, patients with loads of medication or patients with a large medical history. In such situations, there is one person who keeps the medical data together and other care providers will benefit from the complete set of medical history.

Two other physicians (#B6) (#B9) claim that only the patient-physician relationship determines the fact whether a patient will request access to personal records or not.

FUNCTION EVALUATION

None of the hospitals has a true PHRs in use. One of the hospitals has an extensive EHR system (#B6) but patient insight is not a standard feature. Most of the physicians state that there are no other PHR functionalities offered to patients.

POSITION STATEMENT

Most of the physicians are not acquainted with future plans with patient records. Only one physician (#B10) mentions the upcoming pilot with patient access to medical records.

“In my opinion, the actual end-user has to pay for the development of such a system. If this is the patient, than the patient needs to provide the funds.”

- PHYSICIAN FROM A DUTCH HOSPITAL

PRIVACY AND SECURITY

All of the physicians indicate the security measures that are in place when accessing the diverse health systems. One physician (#B6) mentions the importance of access control to medical data and stresses the risk of privacy violation and abuse of data.

BUSINESS CASE

One of the physicians (#B9) argues that it has to be investigated whether or not patients demand for access to their own medical data. Further more, two physicians (#B6) (#B9) state that if legislation requires PHRs, the government has to finance the implementation of PHRs. Otherwise, if only the hospital benefits, then the hospital itself has to finance the implementation and maintenance of a PHR.

To summarize the interviews, most physicians also believe that patients with chronic diseases benefit most from PHRs. Two physicians claim that the patient-physician relation determines actual PHR usage. All of the physicians indicate that patients do not often demand for access to their health records. Most physicians give insights into medical records upon request with ease. However, a few physicians are shivery about the patient as the owner of the medical data. None of the physicians mentioned a supplier of PHRs or possibilities, other than a pilot about health record access at one of the hospitals next year. In addition, none of the physicians mentioned technical barriers of PHR implementation. Physicians argue that the government or the hospital itself has to finance PHR implementation depending on the legislation.

5.4 APPLICATIONS AND PORTALS USED IN OTHER HOSPITALS

No PHR is in place in the investigated hospitals. Two of the hospitals however do use a sort of patient portal, whereas patients can view their appointments, lab results and prepare a visitation. The question rises what the situation is at other Dutch hospitals. This paragraph describes some of the initiatives that are currently in place in other hospitals. An extensive overview of PHR initiative in the Netherlands is described by Barelds et. al [9].

E-VITA: A CARE PLATFORM FOR SPECIFIC CHRONIC DISEASES

Three of the academic hospitals have a care platform (sort of patient portal) in place, called e-Vita [25], for specific chronic diseases

(diabetic, chronic heart failure and COPD). This is an interactive care platform whereas patients with chronic diseases are actively involved with their disease in order to have a more pleasant life [25]. This platform is aimed at increasing the knowledge about a certain disease, improving someone's health and giving an overview of a patient's health status. It connects patients with the same disease and caregivers which enables the exchange of knowledge. The platform enables health self-management. [25]

However, patients do have to fill their own profile on this platform and the platform is not interconnected with other hospital EHR's or EMR's. This platform can be characterized as a stand-alone PHR since it does not connect with other health systems [76].

PAZIO: AN E-HEALTH PLATFORM

One of the academic hospitals launched an e-health platform called Pazio [58]. With Pazio, health insurances, hospitals and 'eerste-lijns' care providers like general practitioners and physiotherapists offer patients an integrated portal whereas they can get an online consult, online recipes, online appointments, and where they can find knowledge about how to work on prevention [58]. This is an initiative which tends to an interconnected architecture because it aims at connecting other parties than the hospital itself, but in its current form is a tethered portal of the hospital with links to other care providers [76].

MIJNGEZONDHEIDSPATFORM.INFO: A HEALTH PLATFORM

Mijngezondheidsplatform [45] supports self-management in health care, where people work on their health, with or without the guidance of a practitioner. The platform facilitates coaching at one or more chronic conditions and guidance on lifestyle improvement.

The platform can be used on an individual basis and is offered by the health insurance or employer. In addition, when it is used to support treatments, it is offered by the doctor, nurse or therapist. [45]

The platform is aimed at self support and self control in case of chronic diseases or lifestyle changes. It can be characterized as a stand-alone portal, since it is not affiliated with hospital EHR's or other health records. [76]

MEDLOOK: ONLINE MEDICAL RECORD

Medlook offers an online medical record whereas patients can ar-

chive their medical health status. It is aimed at collecting medical data and users can add data to their files themselves. A doctor, pharmacist or other healthcare professional may itself add data to the file and a patient can ask them to confirm his or her medical status. [43]

Medlook can be characterized as a stand-alone PHR and is controlled and owned by a patient itself. [76]

5.5 CONCLUSION: ACTUAL PRESENCE OF PHRS IN DUTCH HOSPITALS

In none of the evaluated hospitals is a PHR in use which can (automatically) connect with other (systems from) care providers. Only two hospitals offer some portal functionality to patients. The questioned IT managers as well as physicians indicate that patients hardly ask permission to access their personal medical records. Despite the fact that physicians do want to give insights into medical records, they are sceptical at PHRs where patients are the owner of their medical records.

Most suppliers of the EHR systems in the hospitals also offer a kind of PHR tool. However, the lack of a proven business case and actual budgets hinder PHR implementation. Technical barriers are not an issue in any of the investigated hospitals.

Other hospitals, where no experts were questioned, have patient portals in place or support a health platform initiative, mainly aimed at patients with chronic diseases. None of these initiatives or portals has an integrated structure, but are developed stand alone or upon an existing health system (tethered architecture). The platforms however differ in functionality with portals; platforms support patient self-management and offer more functionality than portals, which are mainly about appointments and test-results.

6

ANALYSIS AND DISCUSSION: CURRENT STATE OF PHR DEVELOPMENT IN DUTCH HOSPITALS

In this chapter, the current state of PHRs in Dutch hospitals is analysed on basis of the literature study and the outcomes of the interviews with experts from the hospitals. The highlighted sentences refer to one of the conclusions in the next chapter.

6.1 CURRENT STATE OF PHR DEVELOPMENT IN DUTCH HOSPITALS IN COMPARISON WITH THEORY

At present, there are no interconnected PHR systems in place in the hospitals studied. Only two of the hospitals where experts were questioned offer a patient portal in which patients can get insight into measurements, appointments and the possibility to keep up with a health diary. Other hospitals are connected with a health platform on which patients with certain diseases can exchange knowledge and experiences. However, these platforms are mainly focused on and arranged around specific diseases and are not suitable for the average patient who wants to maintain it's own health and that wants to exchange data with several care providers. Despite the numerous advantages of PHRs from theory [8] [76] [83] [85], actual usage of PHRs in Dutch hospitals is approaching zero. Notwithstanding the fact that PHRs have the aim and potential to change and improve the patient-provider relationship, create patient collaboration, enhance shared decision-making and enable the healthcare system to evolve toward a more personalized model [5] [8] [90], the current situation shows no actual usages of such systems in dutch hospitals. It can be concluded that there exists an enormous gap between theory and practise in this case.

Physicians remain indeed more sceptical about individuals access to personal health records [56], other than explaining the record face to face. Physicians foresee more (uncompensated) work [4][35] with the introduction of PHRs in hospitals and can be educated [5] on how PHRs can contribute to care processes to understand the added value.

On basis of the literature study, most patients would value to have access their personal health records in hospitals [5] [33] [39] [64]. In practise, patient surveys in Dutch hospitals also show that access to health records would be valued and that 12% of the Dutch adults maintain a personal patient record [10]. However, the interviews with physicians and IT managers revealed that patients in Dutch hospitals hardly ask for insights into their records.

Surprisingly, none of the hospitals included in this research experiences technical barriers that hinders PHR implementation, despite the fact that none of these hospitals actually has a PHR in place. All of the IT managers claim that **implementation is no technical problem, but rather a financial and manpower problem** that is in accordance with theory [33] [61] [76]. **This hinders PHR implementation in Dutch hospitals in the near future.**

Both IT managers and most of the physicians argue that the nature of a patient's illness affects the preference of PHR functionality [33]. Only two physicians claim that the patient-physician relation determines actual PHR usage, in stead of the patient's illness.

Physicians as well as IT managers are concerned about privacy and security of PHRs (which is in line with theory [5] [39] [90]) and argue that adequate security measures must be in place before offering patient access to medical records.

Notwithstanding the fact that one of the IT managers claimed that the hospital is the right place to develop a PHR, practise shows that this development has not started yet. In fact, portals and platforms emerge around syndromes and diseases and are established outside the hospital. Hospitals as well as patients in general would however benefit from these portals and platforms if these can be integrated in the hospital care processes or if medical data from the hospital could be loaded into these portals or platforms. This however is certainly not possible at the moment, since most of the questioned hospital still exchange medical records on paper with the patient in stead of digital exchange. **This leads to the conclusion that with the current pace of development of (digital) health records in hospitals, hospitals are not the right place to develop PHRs.**

6.2 OBSERVATIONS ON BASIS OF THE OUTCOMES OF THE INTERVIEWS

Experts from hospitals seem not to inform each other about innovations in health records. While IT experts are somehow aiming at the development of one integrated health record for patients, physicians support the development of disease-specific care platforms. At one hospital (#B3 and #B6), the IT expert only mentioned the developments of a small portal while the physician did not mention any development in the light of health records. As a matter a fact, this hospital seems to support the development of a disease-specific care platform, not mentioned by the IT expert nor the physician.

There are many initiatives in the Netherlands around health records, personal health records, care platforms and portals [9] [11] [13] [17] [25] [43] [45] [58] but looking at the development of these initiatives, it seems that the patient is offside and is not in the centre of the development. While it is claimed that health records bridge the gap between obedient patients and informed, involved and percipient patients [13], the development of the mentioned initiatives is mainly driven by 1) the institution, 2) the disease or 3) the supplier which all have their own goal with the health record or platform. Unfortunately, the patient is not put in the centre of this goal, but so is the strategy of the institution, the disease itself or the profit of the organization. *As a matter of fact, all these initiatives end up as data warehouses and isolated islands [76] of information as information exchange between initiatives is certainly not the main focus.*

Looking at the market shares of the EHR suppliers in the Netherlands, there is one large leader which serves 40 hospitals (43% of the Dutch market of EHRs): Chipsoft [22]. Chipsoft offers a specific Personal Health Record module in addition to his EHR and the question arises if these hospital specific PHRs can be linked to each other. While doing so, the supplier creates one large patient record independent of the hospital and fully aimed at the main consumer: the patient. *This is suggested to be a good starting point to create interconnected health care records and a 'free flow' of health information, controlled and owned by the patient itself.*

7

CONCLUSIONS

This chapter contains the main conclusions from the research. Next to this, the main question whether the hype of PHRs in hospitals is already over is answered in this chapter. In addition, it concludes with the limitations of this research and further research opportunities.

7.1 MAIN CONCLUSIONS

On basis of the outcomes of the questionnaires described in chapter 5 and the analysis in the previous chapter, the following conclusions are drawn looking at the current presence and development of PHRs in Dutch hospitals. The elaborations of these conclusions have been highlighted in the text in the previous chapter.

1. Patients in Dutch hospitals hardly ask permission to their health records, but would however value access to their data
2. At this time, Dutch hospitals have no PHRs in place; in stead, they focus on patient portals or connect with health platforms
3. The lack of a proven business case hinders PHR adoption in Dutch hospitals
4. Hospitals are currently not the right place to develop PHRs
5. IT Experts and Physicians from Dutch hospitals are not aware about each others' health record initiatives
6. Currently, there are many initiatives around health records in the Netherlands that however solely operate and will end up in isolated islands
7. In order to create an nationwide integrated PHR, the largest suppliers of EHRs have a great opportunity in developing a large integrated PHR

7.2 PHRS IN DUTCH HOSPITALS; IS THE HYPE ALREADY OVER?

Looking at the literature study and the selected papers in this research, it can be concluded that from the years of 2002 and further, PHRs became more popular in research. In addition, after the years 2008-2009, less had been written about personal health records and thereby indicating the way back of the hype.

Besides, the withdrawal of Google Health as of January 1st 2012 can also indicate that PHRs arrived at the wrong time. Perhaps the current situation in care centres including hospitals is not ready for patients who access their medical records, let alone the ownership of medical records.

OR IS THE PHR HYPE NEVER STARTED IN DUTCH HOSPITALS?

Some of the questioned physicians did not know about PHRs and the associated functionality. Next to this, some hospitals still offer paper based copies of health records, indicating that digitalization of health records in Dutch hospitals has a long way to go. However, some hospitals do offer patient portals or connections with health platforms indicating a possible first step towards PHR development. Perhaps, the development of these (disease specific) platforms can accelerate PHR development for the average patient in a hospital, despite the fact that hospitals do not need to develop PHRs themselves. Budgetary problems seem to hinder PHR development or adoption by hospitals. It is therefore likely that PHRs need to be developed outside the hospital but directed and demanded by patients. Hospital-patients then have to claim access to their health records because hospitals are not likely to offer them to patients in advance. Hospitals in turn need to connect to these common PHR systems upon patient demand. In the current situation in the Netherlands, this seems to be the only possibility for PHR development to succeed.

Looking at these development of portals and platforms in the surroundings of hospitals in the Netherlands, the PHR hype thus is yet to come!

7.3 LIMITATIONS OF THIS RESEARCH

Limitations of this research reside in the fact that patients are not questioned about their opinions and wishes. It can be a good addition to have significant insights from patient's perspective. In addition, also future plans from IT suppliers as well as board of directors of hospitals are lacking. Despite the fact that a lot of suppliers were summoned, none of the suppliers responded on the questionnaires.

7.4 FURTHER RESEARCH

As stated in the previous paragraph, it is interesting to complement this research with insights from suppliers as well as patients. Next to this, the effect of PHRs can be researched. For example, the effect of PHRs on the quantity and quality of the patient's visits, on specific health outcomes and the effect of a patient's health literacy and

the use of a PHR. Also, the legal and ethical aspects of PHRs can be researched more thoroughly. At last, the ownership of a patient's health record and the effects on the data currency and accuracy can be investigated supplemental to this research.

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QUESTIONNAIRE (DUTCH)

ADOPTION AND ATTITUDES

- In hoeverre vragen patiënten om toegang tot zorginhoudelijke gegevens?
- Wat is de rol en houding van zorgprofessionals ten opzichte van het verlenen van toegang tot zorginhoudelijke gegevens?
- Hoe kunnen PHR's geïmplementeerd worden binnen het huidige zorgproces?

ARCHITECTURE

- Op welke wijze wordt er inzage gegeven in zorginhoudelijke gegevens?
- Zijn er plannen om aan te sluiten bij internationale initiatieven zoals Microsoft HealthVault?

FUNCTION DESCRIPTION

- Welke functionaliteiten worden reeds aangeboden aan patiënten? En welke staan gepland voor de toekomst?
- In hoeverre is de aard van de ziekte en/of aandoening leidend in de vraag naar inzage in zorginhoudelijke gegevens?

FUNCTION EVALUATION

- Hoe effectief functioneren de diverse functionaliteiten? Hoeveel gebruik maken patiënten hiervan?

POSITION STATEMENT

- Wat zijn de plannen met betrekking tot de uitrol van EPD's binnen uw ziekenhuis? In hoeverre wordt patiënt inzage daarin meegenomen?

PRIVACY AND SECURITY

- Welke beveiligingsmaatregelen zijn er momenteel in gebruik ten aanzien van het verkrijgen van toegang tot zorginhoudelijke patiëntgegevens?

BUSINESS CASE

- Wat zou volgens jou de business case moeten zijn voor PHR's in ziekenhuizen? Past de business case binnen de strategie van het ziekenhuis?

COMPLETED QUESTIONNAIRES (DUTCH)

#	Expert	Date
B1	ICT Manager	6-6-2013
B2	Hoofd ICT	6-5-2013
B3	IT manager beleid en strategie	8-5-2013
B4	Projectleider patientenportal	11-9-2013
B5	Arts (UMCG)	21-8-2013
B6	Arts (Isala)	19-8-2013
B7	Arts (Ropcke-Zweers Ziekenhuis)	18-8-2013
B8	Arts (Martini Ziekenhuis)	19-8-2013
B9	Arts (UMCG)	19-8-2013
B10	Arts (Antonius Ziekenhuis)	18-8-2013

#B1 - INTERVIEW EEN ICT MANAGER OP 6 JUNI 2013

ADOPTION AND ATTITUDES

De vraag vanuit de patiënt naar inzage zorginhoudelijke gegevens is in het begin heel groot, daarna zakt het naar nul. In het begin is er veel interesse, 'ik wil mijn data hebben'.

Technisch gezien kan een chipsoft module erg eenvoudig ingevoerd worden binnen een paar maanden tijd. De doorlooptijd hangt af van de mogelijkheden van de leverancier. Intern is dat geen probleem (patientenportaal van chipsoft).

ARCHITECTURE

Wanneer er nu om inzicht gevraagd wordt naar medisch inhoudelijke gegevens, dan wordt er een printje gemaakt van het systeem welke per post naar de patiënt gestuurd wordt, niet per mail (volgens NEN7510).

Het ligt in de planning om in 2015 toch te zijn aangesloten bij het chipsoft alternatief, echter, het is maar de vraag of er dan prioriteit aangegeven wordt.

In Nederland heerst een poldermodel; het is versnipperd. Iedereen probeert het zelf te regelen en ik heb de indruk dat dat alleen maar meer wordt. In België bijvoorbeeld of in Estland, daar is er een healthcard.

De oncologie en de orthopedie wisselen gegevens uit met andere zorgaanbieders via een VPN lijntje en door middel van videoconferenties.

FUNCTION DESCRIPTION

Chronische patiënten zullen er meer vraag naar hebben. Vanuit het ziekenhuis komt echter geen vraag naar inzage. Dat komt ook omdat de zorg rondom de medewerker is georganiseerd en niet om de patiënt. Dat kan veel beter, maar door de inrichting komt de vraag vanuit de patiënt niet. Privacy en security issues zijn er echter volop.

FUNCTION EVALUATION

Er wordt momenteel geen inzage geboden, slechts via printjes van het systeem die per post verstuurd worden. Voor 2015 staat meer gepland, echter, dit zijn geen harde plannen.

POSITION STATEMENT

In het EPD zitten bijna alle medische dossiers en verpleegkundige dossiers. Intern is hieromtrent in ieder geval alles geregeld, naar extern toe totaal nog niet. In 2013 moet 5% van de ziekenhuizen aangesloten zijn. Kartrekkers hierbij zijn de apotheken en huisartsen. Vraag is of de noodzaak er is, ook in verband met de privacy. Met de implementatie van het EVS zijn we nog bezig. 1-1-2014 moet dat klaar zijn.

Men wil zo veel maar dat is niet realistisch. Het beleid van ICT is eigenlijk dat de ICT vooral moet werken. Daarna gaan we kijken hoe mee te gaan met Business-IT alignment? Hoe kunnen we de zorgprocessen beter ondersteunen? Nu hebben we 32 medewerkers (27 FTE) op ICT gebied inclusief functioneel applicatiebeheer. IT doet het er allemaal bij; eigenlijk hebben we 0 uren over voor projecten als PHR of EPD.

PRIVACY AND SECURITY

Er is altijd een risico met betrekking tot het delen van gegevens. Het gaat hier om de schuldvraag.

BUSINESS CASE

In het ziekenhuis speelt nog niets omtrent PHR's. Chipsoft biedt een 'patientenportaal' aan, gebaseerd op een soort sharepoint. Daarnaast is er een koppeling met MS healthvault waarbij er zelf data geëxporteerd kan worden van een EPD naar Healthvault. Het ziekenhuis gaat die ontwikkeling van Chipsoft volgen voornamelijk.

Hoe ga je dat terugverdienen? Je moet goede zorg verlenen, dan is er geen 5 ton over voor een PHR module. Het ziekenhuis geeft hier dan ook zeker geen prioriteit aan. In het geval van de zorgcentra/thuiszorg leverde NEDAP de tool (CAREN). Dat was aantrekkelijk en NEDAP wilde het als een soort pilot inzetten.

ICT is eigenlijk ondersteunend en totaal niet leidend. ICT zou geen kartrekker zijn van een dergelijk initiatief. Als je kijkt naar Daan Dohmen van FocusCura, dat is puur subsidiegedreven. Verder zijn er initiatieven als van Lucien van Engelen (FaceTalk), maar dat blijft momenteel meer bij hip zijn dan bij daadwerkelijke bijdrages.

#B2 - INTERVIEW ICT HOOFD OP 6 MEI 2013

ADOPTION AND ATTITUDES

Patienten vragen zo nu en dan om dossiers; ik heb echter geen zicht op de frequentie. Momenteel bieden we op een geknutselde manier inzage, via printscreens en PDF-prints.

Artsen hebben moeite met de gelijkwaardigheid; die is er totaal niet. Artsen maken een verslag dat meegestuurd wordt met de patiënt naar de huisarts. Persoonlijke aantekeningen; daar hebben artsen moeite mee dat die gedeeld worden.

ARCHITECTURE

Momenteel maken we voor enkele specialismen gebruik van EVOCS. Huisartsen maken gebruik van EDI-fact formaat (EDI berichten) om informatie uit te wisselen met het ziekenhuis. Het delen van documenten staat echter nog in de kinderschoenen.

Aan de ene kant willen we meedoen met het LSP en de landelijke ontwikkeling, we geloven echter ook in de regie naar de burger en die daar ook neer te leggen.

FUNCTION DESCRIPTION

Er wordt momenteel nauwelijks inzage gegeven in gegevens. Wel meer voorkomend bij bijvoorbeeld cardiologie en chronische aandoeningen.

FUNCTION EVALUATION

Weinig functionaliteiten momenteel aangeboden aan de patiënten.

POSITION STATEMENT

De burger moet in de regie komen. Visie is onderdeel van Vitaal Vechtdal, een overkoepelend zorgproject in de regio. Daarin zijn we bezig om alle partijen aan te schakelen.

In dat kader zijn er ook gesprekken geweest met Piso van Microsoft Healthvault. Als MS dat kan aanbieden binnen ons ziekenhuis, dan willen wij daarop aansluiten. Er is een pilot geweest in NL met het westfries gasthuis. Chipsoft heeft een koppeling op de plank liggen voor PHR (chipsoft -> healthvault). Daar willen wij bij aansluiten.

PRIVACY AND SECURITY

EPD: eigenaarschap ligt niet bij de patiënt. Wel uitwisseling, alleen

kunnen zien wie toegang heeft gehad. Bij koppeling met andere systemen ontstaan veel risico's, dat is een maatschappelijke zorg.

Ten aanzien van de beveiliging: daar zijn protocollen voor in werking.

BUSINESS CASE

Volgens mij zou de zorgverzekeraar moeten financieren. Nu draait het om zo fijn mogelijk te leven. In de toekomst gaat het om zo lang mogelijk leven. Daar past een PHR bij.

Ook een mogelijkheid is om de werkgever te laten betalen.

Microsoft Healthvault krijgt het in NL nog niet gefinancierd. Ze roepen al een paar jaar dat ze het op de NL markt gaan brengen maar momenteel zie ik er nog te weinig van. Misschien moeten we wel kijken naar alternatieven. Voordeel is echter wel dat healthvault een soort platform functie heeft. Het is een connector van alle gegevens en daarom ook interessant voor ons.

#B3 - INTERVIEW MANAGER BELEID EN STRATEGIE ICT. 8 MEI 2013

ADOPTION AND ATTITUDES

Een groot aantal doctoren is huiverig. Dit is tijdelijk: de strijd is allang gestreden, patiëntgegevens worden openbaar en doctoren moeten zich conformeren. De directie dicteert hierbij!

Beleid is: de patiënt heeft inzage, tenzij. Ruwe meetwaarden worden gewoon opgeslagen en inzichtelijk gemaakt in het patiëntenportaal, zonder interpretatie. Het lab is hierin nog wel huiverig om informatie te delen.

Er zijn veel uitwisseltools (evocs). LSP is niet geschikt voor uitwisseling van gegevens. Je kunt via het LSP alleen opvragen; het is een soort verwijsregister. Cardiologie werkt met EVOCS, EDIFACT (huisartsen).

De differentiatie neemt toe. Focus ligt daarom op uitwisseling van gegevens tussen EPD's.

ARCHITECTURE

Het ziekenhuis heeft een patiënten portaal. 2 jaar geleden ingericht bij een pilot met 1 van de poli's. In augustus 2013 gaat het patiëntenportaal live bij alle poli's. Dit hebben we laten bouwen door vital-health. Dus niet zelf ontwikkeld. Destijds was het een initiatief van een longarts, in samenwerking met Achmea. In het Catherina Wilhelmina ziekenhuis draait eenzelfde portal.

Daarnaast worden afspraken zichtbaar in ultragen (pink roccade). Dit is een zelfbouw systeem en dus ook eindig. Dit is zo gegroeid door de fusie. Beide ziekenhuizen hadden zelfbouw systemen, gebaseerd op MS technologie. Het EPD heet ERIDANOS. Eerst was de focus op de integratie tussen de ziekenhuizen en andere systemen. Daarna werd de 'kijkdoos' belangrijk: een schil om alle data. Een derde stap betrof de stap naar clove HL7. Nu echter aan de grens van zelf ontwikkelen en dus ook aan het kijken naar andere aanbieders. Daarvan zijn er 3 grote partijen: chipsoft, epic, siemens/SAP (en MC-Kesson). Het ziekenhuis heeft geen links met healthvault.

Ons ziekenhuis denkt nog niet direct vanuit de patiënt maar het zorgproces is leidend.

FUNCTION DESCRIPTION

Chronische zieken hebben veel belang bij uitwisseling; dit is de markt voor het patientenportaal.

FUNCTION EVALUATION

Afspraken maken door patienten. Brieven inzien, instructiefilmpjes en voorlichting. Labuitslagen.

Ook kan de patient een dagboekje bijhouden met een agenda, pre-opname, 1 plek voor alle informatie. Dit wordt rechtstreeks in het EPD ingeladen. De perceptie is dat dit van het ziekenhuis komt en dus een toegevoegde waarde levert.

POSITION STATEMENT

Ons ziekenhuis heeft geen plannen voor het ontwikkelen van een PHR. Wel willen ze het eigen systeem doorontwikkelen en patient zelf laten invullen. Daarbij is er geen BC en die is mijns inziens ook niet te maken. Het gaat om de kwaliteit van zorg en de toegevoegde waarde die de patient ervan kan ervaren.

PRIVACY AND SECURITY

Patient moet zich aanmelden met een formulier per specialisme of zorgpad, beveiliging via Digi-D. Barriers voor interconnected is de beveiliging. Het is niet voor niets dat google zich terugtrekt. Beveiliging is een belangrijk aspect. Dat moet gewoon goed ingeregeld zijn, desalniettemin wel heel belangrijk.

BUSINESS CASE

In ons ziekenhuis draait het patiënten portaal puur om patiëntenbinding. Het patientenportaal is echter direct belegd onder verantwoording van de RvB en de operationeel directeuren.

Bij het Catherina Wilhelminaziekenhuis draait alles om de patient. Ons ziekenhuis wil het beste ziekenhuis van NL worden in de komende 5 jaar (open en transparant, professioneel handelen en met hart en ziel). De beleving is daarbij belangrijk! Dit moet de toegevoegde waarde zijn met de focus op menselijk en dus niet ICT. Belang is echter dat de informatie opnieuw kan worden gelezen, bijvoorbeeld in slechtnieuws gesprekken.

Ziekenhuizen zijn de meest logische plek om patientenportalen in te richten.

#B4 - INTERVIEW EEN PROJECTLEIDER PORTAL OP 11 SEPTEMBER 2013

ADOPTION AND ATTITUDES

Vanuit behoefte pijningen is opgemerkt dat patienten de aanwezigheid van een patientenportaal enorm zouden waarderen. De patient is dan ook nauw betrokken bij de ontwikkeling van het patiëntenportaal.

Medisch specialisten staan overwegend positief tegenover de introductie van het patientenportaal.

ARCHITECTURE

Er zijn momenteel twee bewegingen in huis (e-care to move en voorlichting op maat) die uiteindelijk als doel hebben om een interactief patiënten portaal in te richten. De focus ligt nu op het verder uitrollen van het patientenportaal om daarmee de kwaliteit van leven iets te verbeteren.

FUNCTION DESCRIPTION

In dit patientenportal staan vragenlijsten om de stages of cancer te bevragen, antwoorden op basis van deze stages en labuitslagen. Deze vragenlijsten worden direct in het EPD van Chipsoft geladen en toegankelijk gemaakt voor specialisten.

FUNCTION EVALUATION

Het portal is vooral geen PHR. Daarvoor ontbreken teveel functies, hoewel ik daar wel graag naar toe zou willen.

POSITION STATEMENT

Portalen zullen voornamelijk gebruikt worden door chronisch zieken. Als je 1x je been breekt heb je geen portaal nodig. Wanneer je regelmatig terugkomt destemeer.

PRIVACY AND SECURITY

Eén van de eerste onderwerpen bij de ontwikkeling van het portaal was beveiliging, welke plaats gaat vinden via Digi-D en SMS.

BUSINESS CASE

Ik denk dat ziekenhuizen zelf de ontwikkeling van dergelijke tools zouden moeten betalen. Dit gaat de patiënt niet (direct) doen.

#B5 - INTERVIEW ARTS (UMCG). 21 AUGUSTUS 2013

ADOPTION AND ATTITUDES

Patienten vragen soms om een rontgenfoto te kunnen zien. Er wordt vrij weinig om echt inzicht in het hele dossier gevraagd. Eenmalig lag een advocaat opgenomen en die heeft inzage in zijn dossier gevraagd.

Open houding. Eigenlijk wordt er niet moeilijk over gedaan als er om inzicht wordt gevraagd aangezien het een verslaglegging is van de bevindingen.

ARCHITECTURE

Ik zou hier niet goed een antwoord op weten. Dit gaat buiten mijn kennis en interesse.

Er worden vaak prints gemaakt van de verzochte documenten. Ik print of zelf een brief of een kopie van een röntgenfoto of vraag het aan een secretaresse. Ik heb nog nooit een volledig dossier hoeven te geven.

FUNCTION DESCRIPTION

Mensen met psychiatrische aandoeningen vragen eerder om inzicht. Advocaten vragen tevens eerder om inzicht.

FUNCTION EVALUATION

Ik ben niet op de hoogte van functionaliteiten die worden aangeboden. Mijns inziens nauwelijks sprake van.

POSITION STATEMENT

Wij werken met Chipsoft maar de ontwikkelen bij en van deze leverancier ken ik niet. Bij inzage worden er prints gemaakt neem ik aan.

PRIVACY AND SECURITY

Je moet inloggen in de computer en apart inloggen voor het patientendossier. Je moet om de zoveel tijd verplicht je password wijzigen naar iets wat je nog niet eerder hebt gebruikt.

BUSINESS CASE

Hier heb ik geen kijk op; ik weet niet wie er zou moeten sponsoren of betalen.

#B6 - INTERVIEW ARTS (ISALA ZIEKENHUIS). 19 AUGUSTUS 2013

ADOPTION AND ATTITUDES

Patiënten vragen niet of nauwelijks toegang tot hun zorginhoudelijke gegevens, mits er niks verkeerd is gegaan. Op het moment dat de behandeling of behandelingsovereenkomst niet naar behoren is gegaan, en er mogelijk een klacht wordt ingediend dan vragen patiënten of diens vertegenwoordigers wel degelijk toegang tot hun zorginhoudelijke gegevens. Daarnaast kan er natuurlijk door de patiënt altijd een second opinion worden aangevraagd in een ander ziekenhuis, waarbij de zorginhoudelijke gegevens ook opgevraagd kunnen worden door de patiënt.

In principe is er geen bezwaar tegen het verlenen van toegang tot zorginhoudelijke gegevens, de patiënt heeft altijd het recht om zijn of haar gegevens in te zien en de arts mag dit niet weigeren. Wel is het zo dat het niet wordt "aangeboden". Patiënten moeten hier zelf om vragen, en veelal is het de patiënt misschien niet eens duidelijk dat dit mogelijk is. Naar mijn mening is de zorgprofessional hier dus onbewust terughoudend in.

ARCHITECTURE

Door patiënten zelf online (mogelijk via een speciale website van het ziekenhuis) hun medische dossier in kunnen zien en hier dan ook aanvullende informatie (bijvoorbeeld bijwerkingen van medicijnen) in kunnen noteren. Wellicht is het mogelijk om dit bijvoorbeeld door middel van een medische app te koppelen aan het PHR? Momenteel echter nog geen sprake van.

Voorheen was het mogelijk dat de patiënt een kopie van zijn/haar status kon opvragen bij het secretariaat. Sinds de digitalisering van de papieren dossiers bestaat er nog steeds de mogelijkheid om een kopie te krijgen van het betreffende dossier, nu echter op cd-rom. Ik denk echter dat veel patiënten hier niet van op de hoogte zijn en niet weten dat zij het recht hebben op inzage in hun eigen dossier. Zoals eerder vermeld wordt de patiënt vaak mondig en eisend wanneer de dingen niet lopen zoals behoort.

FUNCTION DESCRIPTION

In bepaalde gevallen zal dit zeker een rol spelen in de vraag naar inzage in zorginhoudelijke gegevens. Denk bijvoorbeeld aan een second opinion bij een andere specialist en ziekenhuis. In de meerderheid van de gevallen gaat het dan om moeilijk te behandelen diagnoses

met een slechte prognose (bijvoorbeeld erfelijke aandoeningen of oncologische problemen). De patiënt kan dan zelf zijn/haar gegevens opvragen, maar de zorgprofessional kan dit ook doorsturen. Verder is er dan ook nog de vraag in hoeverre de ziekte of aandoening goed te behandelen valt. Wanneer er hier fouten zijn gemaakt en er bijvoorbeeld een verkeerde behandeling is gegeven dan zal dit zeker een rol spelen in de vraag naar inzage in zorginhoudelijke gegevens al dan niet door de patiënt en diens vertegenwoordigers of inspectie van de gezondheidszorg.

FUNCTION EVALUATION

Een echt persoonlijke gezondheidsdossier wordt nog niet aangeboden. Wel wordt er gewerkt met een elektronisch patiëntendossier. In principe wordt er voor iedere patiënt een EPD aangemaakt. Hierin staan alle gegevens zoals verwijsbrieven, laboratoriumuitslagen en andere onderzoeken, maar wordt dit niet "aangeboden" aan de patiënt. Bij vraag kan de patiënt hier echter wel een kopie van krijgen.

POSITION STATEMENT

Nee, ik weet niet precies wat er nog veranderd en of verbeterd gaat worden de komende tijd. Ik kan me voorstellen dat er bepaalde functies worden toegevoegd; zoals het automatisch aanmaken van een brief bij het typen van een consult zodat dicteren overbodig wordt, of dat ook opnames met bijbehorende visites in het ziekenhuis duidelijk onder een kopje zichtbaar zijn in het EPD. Voor zover ik weet wordt hierin de patiëntinzage niet duidelijk meegenomen.

PRIVACY AND SECURITY

Ik denk dat het belangrijk is dat niet iedere willekeurige zorgprofessional toegang heeft tot elk EPD. Bij het specialisme waarbij de patiënt onder controle is dient wel toegang te zijn tot het EPD, maar de ICT of andere ondersteunende functies hoeven naar mijn idee geen officiële toegang te hebben tot het EPD. Verder is er het gevaar van misbruik en schending van privacy door onbevoegden zoals bedrijfsartsen, werkgevers en (zorg)verzekeringsmaatschappijen of hypotheekverstrekkers. Daarnaast vind ik het belangrijk dat de toegang op computers hiertoe wordt beperkt. Vaak kan nu ook op de thuiscomputer worden ingelogd op de werkplek, naar mijn idee moet dit beperkt toegankelijk zijn. In dienstsituaties e.d. is dit uiteraard prima, maar er moet voorkomen worden dat willekeurige personen in een EPD van een patiënt kunnen kijken. Verder is er het gevaar van misbruik en schending van privacy bij inbraak in het systeem door hackers. Bij inbraak komt medische informatie over mensen naar buiten. Dergelijke informatie is zeer privacygevoelig en kan de slachtoffers

grote schade berokkenen.

BUSINESS CASE

Voor het financieren van de persoonlijk gezondheidsdossiers is in mijn ogen "de Overheid" mede verantwoordelijk. Uiteraard zal het ziekenhuis "als bedrijf" ook zelf de kosten moeten dragen door inkomsten en gezondheidsverzekeringen (zorgverleners), maar heeft daarbij ook de steun nodig van de Overheid door bijvoorbeeld subsidies en toelagen (Nationaal ICT Instituut in de Zorg).

#B7 - INTERVIEW ARTS (ROPCKE ZWEERS ZIEKENHUIS). 18 AUGUSTUS 2013

ADOPTION AND ATTITUDES

Ik heb nog nooit gehad dat patiënten toegang vragen voor zorginhoudelijke gegevens. Op dit moment in de psychiatrie is het echter wel het geval dat enkele ouders/patiënten eerst zelf de informatie willen lezen en willen goedkeuren, voordat het gestuurd wordt naar huisarts of andere externen/verwijzers.

Zorgprofessionals moeten toegang geven aan de patiënt als het wordt gevraagd. In principe moeten ze er open voor staan, maar ik weet niet in hoeverre dat ook echt altijd zo is. Ik vermoed dat ze er wel open voor staan. Uit ervaring weet ik wel dat bepaalde termen soms hierdoor worden vermeden. Zo wordt bij een vermoeden van kindermishandeling dit niet letterlijk er neer gezet maar met Engelse termen of andere woorden er neer gezet. De professionals weten wat er aan de hand is, maar mogelijk de ouders niet direct.

ARCHITECTURE

Ik denk voor bepaalde groepen zoals diabetes patiënten, patiënten met chronische ziekte, vele medicatie of uitgebreide voorgeschiedenis het handig is. Er is dan 1 iemand (persoon zelf) die alles bij elkaar houdt. Ze komen bij vele dokters en dan is er 1 duidelijk dossier waarin alles staat. Ook patiënten die in meerdere ziekenhuizen komen (Bv door specialistische zorg in grote steden en reguliere controles in de buurt) zo'n PHR handig, zodat ze zelf alles goed kunnen bijhouden en alle ziekenhuizen ook.

Er wordt alleen inzage gegeven als de patiënt er om vraagt en ik denk gewoon via papier.

FUNCTION DESCRIPTION

Voor bepaalde personen is het ideaal. In de psychiatrie wordt het denk ik ook vaak gebruikt omdat ze daar juist vaak niet eens zijn met diagnose.

FUNCTION EVALUATION

Bij ons worden eigenlijk alle verslagen opgestuurd en moeten ouders en kinderen > 12 jaar de behandelplannen ondertekenen. Hiermee geven ze aan akkoord te zijn met wat er op papier staat en ondertekenen ze dat ze het eens zijn met de behandeling. Dus er is in principe al veel inzage in het dossier.

Verder heb ik alleen bij de diabetes mensen gezien dat ze de bloedsuikers online invullen, zodat de arts ze ook kan zien.

BUSINESS CASE

Wie moet het betalen: als het in heel Nederland is: de overheid / ziekenkosten (als het vele voordelen heeft voor de zorg). Is het voor het ziekenhuis handig, dan het ziekenhuis. Ligt dus aan de exacte reden waarom het wordt geïmplementeerd.

#B8 - INTERVIEW ARTS (MARTINI ZIEKENHUIS). 19 AUGUSTUS 2013

ADOPTION AND ATTITUDES

Ik heb tot nu toe alleen meegemaakt dat patiënten om inzicht in hun dossier vragen op het moment dat zij niet tevreden zijn over de geleverde zorg. Zij willen het dossier dan met name gebruiken om te laten zien dat er dingen in de 'levering van zorg' fout zijn gegaan.

Over het algemeen doen zorgverleners niet moeilijk over inzage in het dossier. Het is immers een recht van de patiënt en plicht van arts om deze informatie te verstrekken. Meestal gaat dit ook via een klachtencommissie aangezien het meestal is op basis van een klacht. Een andere situatie is wanneer een patiënt over gaat naar een andere zorgverlener; die situatie heb ik zelf nog niet meegemaakt, dus ik weet niet goed hoe de zorgverleners daarop reageren. Als het mij zou overkomen zou ik ook dan niet moeilijk doen over informatieverschaffen/dossierinzage.

ARCHITECTURE

Ik denk eigenlijk dat een PHR niet de beste oplossing is. Ik snap dat openheid van zaken/transparantie belangrijk is voor goede zorg, maar zodra je een patiënt manager gaat maken van zijn/haar eigen dossier, zal dat de dossiervoering niet ten goede komen. Veel notities die artsen (en verpleegkundigen) maken zijn indrukken van hoe zij de patiënt ervaren, met name medisch gezien. Ik kan mij zo voorstellen dat veel notities die in een dossier komen door een patiënt heel anders en fout begrepen kunnen worden. Het zou gek zijn als je visite loopt en je bevindingen opschrijft, om de volgende dag van de patiënt te horen dat hij/zij het niet eens is met je bevindingen. Ik denk dat veel medici op dat moment ook anders hun 'status voeren', om zichzelf veel meer in te dekken.

Ik denk dat we niet zo'n kant op moeten, de VS achterna, waarbij je om het minst of geringste al aangeklaagd kan worden. Ik zou het niet prettig vinden als een patiënt zonder moeite alles in kan zien wat ik heb opgeschreven.

Het zou wel ideaal zijn om vanuit meerdere ziekenhuizen medische gegevens in te kunnen zien, echter soms willen patiënten dat ook helemaal niet, dat je als arts info vanuit ander ziekenhuis ziet. Daardoor loop je gelijk het risico dat een patiënt selecteert welke informatie je wel en niet mag zien, waardoor je een incompleet of fout beeld van een patiënt krijgt.

Zodra een patiënt zijn/haar dossier opvraagt, wordt hiervan een uitdraai aan patiënt gegeven. Dus niet via een digitaal systeem of iets dergelijks.

FUNCTION DESCRIPTION

De aard van de aandoening maakt niet uit. De tevredenheid van de patiënt en de kwaliteit van de arts-patiënt relatie is met name van invloed op of patiënten hun dossier opvragen.

Ik was niet op de hoogte van het bestaan van een PHR. In het ziekenhuis waar ik werk wordt dit nog niet toegepast.

FUNCTION EVALUATION

Ik werk op twee afdelingen; op de een werken we al lang met een elektronisch dossier, op de andere afdeling zijn we sinds kort over op een elektronisch dossier. Ik weet dat men steeds meer dossiervoering digitaal toepast, ik weet alleen niet in hoeverre de ontwikkelingen staan met een landelijk EPD.

POSITION STATEMENT

Bij ons wordt de patiëntinzage niet zozeer meegenomen, in ieder geval nu geen PHR functionaliteiten. Als patiënten dit dossier willen inzien, moeten ze hun dossier opvragen.

PRIVACY AND SECURITY

Voor het inloggen op elke computer moet je je eigen inloggegevens gebruiken, om in de patiëntendossier te komen moet je nogmaals inloggen. (wij gebruiken twee verschillende programma's waarvoor je beiden los moet inloggen; Chipsoft EZIS, Mosos)

Vanuit huis kan je ook dossiers inzien, met een 'remote control', icm wachtwoord. Ook dan geldt dat je voor de dossiers nogmaals moet inloggen in het programma.

BUSINESS CASE

Ik denk dat een PHR niet de beste oplossing is. Mocht er toch zoiets ingevoerd moeten worden denk ik dat de kosten neerkomen op de ziekenhuizen en zorgverzekeraars. Het ligt eraan wie het meeste belang heeft bij zo'n nieuw systeem; diegene mag er van mij dan ook voor betalen. Mogelijk is dat dan zelfs de patiënt..

Ik heb echter het idee dat dit met name een manier is om de zorgkosten nog meer omhoog te drijven, terwijl er weinig profijt van is.

#B9 - INTERVIEW ARTS (UMCG). 19 AUGUSTUS 2013

ADOPTION AND ATTITUDES

Sinds ik in dit ziekenhuis werkzaam ben is het nog niet voorgekomen dat patiënt vroeg om dossiergegevens. Wel krijgen patiënten altijd een behandelplan (maar ook nog niet voorgekomen dat een patiënt daar zelf naar vroeg). Wel tijdens stage een keer gehad dat patiënt zijn dossier wilde inzien.

Wanneer een patiënt vraagt naar dossiergegevens zijn we verplicht deze aan te dragen; het aanbod komt naar mijn idee niet vaak vanuit de hulpverlener zelf; houding zal bij veel patiënten meespelen in de mate waarin een patiënt hier om zal (durven) vragen. Ik vermoed dat veel zorgprofessionals een afwijzende houding zullen hebben, dat ze het gedoe zullen vinden.

ARCHITECTURE

Het zal er oa op neer komen dat patiënt op de hoogte gebracht moet worden van de mogelijkheid, dat je als arts (mede) moet bepalen welke info ter inzage wordt gesteld (bij ons onderverdeling van aantekeningen en "officiële" dossiergegevens), dat informatie bij verkeerde hulpverleners terecht komt of hulpverleners inzage (onbewust e.d.) wordt geweigerd en dat je als arts het dossier in de gaten moet houden - ofwel, extra werk.

Wanneer patiënt hier om vraagt worden dossiergegevens afgedrukt en bij voorkeur in bijzijn van een hulpverlener doorgenomen.

FUNCTION DESCRIPTION

Ik kan me binnen de psychiatrie voorstellen dat aard van ziekte leidend kan zijn in de zin dat bv een patiënt met paranoïde psychose zijn of haar dossier eerder in zou willen zien dan iemand met een depressie bijvoorbeeld.

PRIVACY AND SECURITY

Voor hulpverleners in het UMCG wat betreft digitale gegevens: Deel van onze gegevens is alleen in te zien door hulpverleners uit eigen specialisme of met bepaalde autorisatie; wanneer een patiënt niet tot je patiëntenpopulatie behoort wordt een melding gemaakt van de inzage door hulpverlener en bv als coassistent kun je niet alle gegevens inzien of wijzigen. Digitale gegevens over het algemeen alleen ingezien worden door medewerkers van het ziekenhuis, ivm inloggen e.d. Papieren dossiers worden op onze afdeling bewaard in het secretariaat, dat gesloten is wanneer het niet bemand is.

BUSINESS CASE

In afweging nemen of patiënten hier wel daadwerkelijk behoefte aan hebben en hoeveel tijd het wie gaat kosten.

#B10 - INTERVIEW ARTS (ANTONIUS ZIEKENHUIS). 18 AUGUSTUS 2013

ADOPTION AND ATTITUDES

Geregeld vragen mijn patiënten om inzage van hun dossier, dit is vaak vanwege achterdocht naar de behandelaar toe of wanneer ze het niet eens zijn met hun diagnose. Een schatting is lastig, maar ik vermoed ongeveer 30%. Soms willen ze enkele dingen bekijken, maar vaak willen ze van alles kopieën hebben.

Uiteraard hebben patiënten het recht op inzage. Echter gaan mijn patiënten vaak aan de haal met de gegevens die hun dossiers vermeld staan. (ik behandel momenteel patiënten met psychose (al dan niet in het kader van schizofrenie), zij hebben vaak achterdocht als klacht en hebben meestal geen ziekte-besef/inzicht). Daarom ben ik altijd terughoudend met het verstrekken van (gehele) dossiers, omdat dit hun behandeling en vooruitgang in de weg kan staan. Daarnaast staat het vol medisch jargon en moet ik er een hele tijd vooruit trekken om er naast de gaan zitten en het uit te leggen (wat ik overigens wel doe).

ARCHITECTURE

Laatst hoorde ik over een trial dat volgend jaar bij ons wordt opgestart. Dat pt's online in hun dossier kunnen kijken en tevens kunnen aanvullen waar nodig. Zodoende naast de sessies (met behandelaars), ook thuis aan hun herstel kunnen werken. Het nadeel hiervan vind ik dat wanneer de patiënt het op alle fronten niet eens is met jouw observaties, dat die er niet in komen te staan. Wanneer een pt dan later weer een keer komt bovendrijven, dan kan de volgende behandelaar niet in zien wat zijn/haar collega er van vond. (maar goed, pt's hebben nu ook het recht op hun dossier te laten vernietigen, heb je helemaal niets!)

Een andere oplossing is misschien het aanstellen van 'coaches' (met medische kennis) die dossiers met pt's doornemen en verstrekken.

Soms worden de digitale dossiers met pt's achter de computer doorgenomen en soms wordt alles gekopieerd en zo verstrekt.

POSITION STATEMENT

Ik ben momenteel niet op de hoogte van andere IT projecten.

PRIVACY AND SECURITY

Toegang is gelimiteerd middels dubbele wachtwoorden.

BUSINESS CASE

In hoeverre je wel een goede observatie als professional kunt beschrijven, zonder dat de patiënt hier teveel in kan veranderen zodat er voor de toekomst een goede overdracht gepleegd kan worden.

ADDITIONAL RESULTS FROM LITERATURE RESEARCH

This chapter contains additional results from the literature research that were not directly relevant but worth mentioning in the light of the topic of PHRs.

C.1 ARCHITECTURE

DATA AND DATA SOURCES

Several authors describe what kind of data should be included in a PHR [5] [33] [37] [61] [76] [83]. Although there are no standards or guidelines on what information to be included in a PHR [5] [76], the suggestions by the mentioned authors correspond reasonably and are summarized in the table below. Note that certain chronic illnesses may require additional information and data types.

TABLE C1

Summary of data to be included in PHR's [5] [7] [37] [61] [76] [83]

Data type	Data sources						Mentioned by
	Patient	Caregiver	PCP	Other Physicians	EMR	Insurance claims	
Personal information	X	X					[5], [7]
Problem lists	X	X			X		[5], [7], [37], [61], [76], [83]
Procedures, hospitalization	X			X	X	X	[5], [7], [37], [61], [76], [83]
Major illnesses	X	X	X	X	X	X	[5], [7], [61], [76], [83]
Provider list, potentially linked to problems	X		X	X	X		[5], [7], [37], [61], [76]
Allergies and adverse drug reactions	X				X		[5], [7], [37], [61], [76], [83]
Home monitor data (eg. BP, glucose)	X	X					[5], [61], [76]
Family history	X				X		[5], [7], [61], [76], [83]
Social history, lifestyle	X				X		[5], [61], [76], [83]
Preventive health recommendations			X	X			[5], [7], [83]
Immunizations	X				X		[5], [7], [37], [61], [76], [83]
Examinations, diagnoses			X	X	X		[5], [7], [83]
Medications	X				X	X	[5], [7], [37], [61], [76], [83]
Laboratory tests, appointments	X				X	X	[5], [7], [37], [61], [76], [83]
Living wills and advance directives	X						[7], [83]
Eye and dental records	X	X				X	[7], [83]
Organ donor authorisation	X						[7], [83]
Notes	X	X	X	X	X		[5]

Next to personal information, a PHR can store other data that is relevant to the health status of an individual as social history, family history and eye and dental records [61]. The main source of information is usually the physician supplemented by individual input and other sources of information like test results, insurance claims, etcetera [18]. Information sourced by practitioners should use easy-to-understand medical language for laypersons [64] in order for individuals to act upon the information. This can be challenging because of varying health literacy levels [36]. The quality of the information entered by individuals is presumably lower than the data exchanged between healthcare providers [88].

INTEROPERABILITY STANDARDS

Standard	Description
ISO/IEEE 11073	This standard describes the communication and information exchange between medical devices and external computer systems [42].
HL7	Health Level 7 is an international standard for electronic exchange of medical, financial and administrative information between care providers. The standard is being defined by the organisation with the same name, HL7 [42].
ISO/EN 13606	Archetype for describing interoperable domain models and data structures [42].
CDA	Abbreviation for Clinical Document Architecture, a standard developed by the Health Level 7 (HL7) organisation [60].
CCR	Abbreviation for Continuity of Care Record, an architecture standard developed by the American Society for Testing and Materials (ASTM) [60].
CCD	Abbreviation for Continuity of Care Document, an architecture standard that harmonizes the CDA standard of the HL7 and the CCR standard of the ASTM [60].

TABLE C2

Interoperability standards for PHR purposes

C.2 FUNCTION DESCRIPTION

Whetstone and Randeree [83] define PHR functionality in a more specific sense, according to the HL7 Functionality model, and is displayed on the next page. This standard is largely in line with the specification of the required data to be included in a PHR, mentioned in chapter 4 before.

TABLE C3

HL7 Functionality Model according to Whetstone and Randeree [83]

Category	#	Functionality
Personal Health	PH.1	Account Holder profile
	PH.2	Manage Historical Clinical Data and Current State Data
	PH.3	Wellness, Preventive Medicine, and Self Care
	PH.4	Manage Health Education
	PH.5	Account Holder Decision Support
	PH.6	Manage Encounters with Providers
Supportive	S.1	Provider Management
	S.2	Financial Management
	S.3	Administrative Management
	S.4	Other Resource Management
Information Infrastructure	IN.1	Health Record Information Management
	IN.1	Standards Based Interoperability
	IN.3	Security
	IN.4	Auditable Records

Note that the functions are categorized and listed hierarchically and that each function as an ID, name, statement, description, examples and conformance criteria. The description of PHR functionality by Pagliari [56] is also in line with the HL7 functionality model.

C.3 FUNCTION EVALUATION

Many authors link function evaluation with the definition of PHRs and with the function description (see previous paragraph) in order to evaluate the functions of a PHR [5] [9] [34] [40] [56] [74]. Table C4 summarizes the criteria used in several studies on function evaluation. For example, Marshall [40] reviews PHRs on basis of effectiveness and states that an PHR should have the following common qualities to be effective: accessible, secure, portable, interoperable, actionable and usable. However, Sunyaev, Chorny, Mauro and Krcmar [74] did a more extensive literature research on specific evaluation criteria for PHR functionality. These criteria are used as a basis in the table C4 of PHR function evaluation criteria and is complemented by other authors.

TABLE C4

PHR function evaluation criteria according to [5] [9] [34] [40] [56] [74]

Patient Information	
1.	Access and view medical records through a PHR system [5] [9] [34] [40] [74]
2.	Information in a PHR should be up to date [74]

3.	Medical information should be presented in a cognitively accessible way [34] [40] [74]
4.	Users should be able to edit their medical records, annotate them or in the least request the responsible medical professionals to make corrections for them [5] [9] [34] [56] [74]
5.	PHR should be technically accessible [5] [9] [40] [74]
6.	It should be possible to set-up and maintain a live-long health record [9] [40]
Personal control	
7.	Each individual is owner of the PHR [9]
8.	Each individual should control access to their PHR [5] [9] [40] [74]
9.	Each individual should get or give access to health information from service providers [5] [9] [40] [74]
10.	A possibility for an emergency access should exist [40] [74]
11.	An individual should know who accessed their account and what actions were performed [40] [74]
12.	A PHR should ensure redundancy in case of system failure [40] [74]
Communication	
13.	Communication with care providers [5] [9] [34] [40] [56] [74]
14.	Communication with family and peers [5] [9] [40] [56] [74]
15.	Possible support with administration tasks [9] [40] [74]
Additional services	
16.	Capturing cost information [40] [74]
17.	Document printing [56] [74]
18.	Secure messaging [5] [56] [74]
19.	Prescription refills [5] [56] [74]
20.	Appointment scheduling [5] [56] [74]
21.	Reminders [74]
22.	Notifications [5] [74]
23.	Educational information [5] [34] [40] [56] [74]
24.	Support groups [40] [56] [74]
25.	Device integration [5] [34] [40] [56] [74]
26.	Decision support [5] [9] [34] [40] [56] [74]
27.	Filing referral requests [56] [74]
28.	Medicine information [5] [34] [56] [74]
29.	Address book [74]
30.	Quality comparisons [40] [74]
31.	Localization [74]
32.	Searching [74]
