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# **FROM CHAOS TO CLARITY - DESIGNING EHEALTH TO SUPPORT SELF- MANAGEMENT IN STROKE CARE**

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# FROM CHAOS TO CLARITY-DESIGNING EHEALTH TO SUPPORT SELF-MANAGEMENT IN STROKE CARE

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**To my little sister**

Whom I shouldn't have taken for granted

I love you and I miss you a little more every day



# ABSTRACT

**Introduction:** Currently healthcare is shifting from a paternalistic model to a more patient-centered model in which patients' involvement and self-management play a crucial role. Information and communication technology has the potential to shift the balance of power and responsibility from healthcare professionals to patients and citizens. To provide patients with health information systems and eHealth services which meet their needs and support them throughout their care and rehabilitation processes, there is a need of involving them not only in their care processes but also in the design and evaluation of eHealth.

**Aim:** The overall aim of this research was to explore how a health information system or eHealth service (in this context an electronic care and rehabilitation planning tool) used by post-discharge stroke patients can be designed to improve patient self-management and collaboration between patients, their next-of-kin and different care professionals.

**Methods:** A design research strategy was employed in this thesis project where an online care and rehabilitation planning was designed and evaluated to contribute to the knowledge base on patient involvement in both design of eHealth and in their care through use of eHealth. In study I, the current care and rehabilitation processes of post-discharge stroke patients in Stockholm County Council were explored using a qualitative case study. Data were collected through interviews and observations. Study II explored the stroke patients' information needs and potential eHealth services were suggested by the researchers and discussed with the patients. An interactive prototype 'My care plan' was designed and improved based on the participants' input. Data for this study were collected through focus groups and usability tests. Study III was mainly a document study where the authors explored the Swedish current infrastructure for health information exchange. In study IV, the prototype was evaluated from both care professionals' and aphasia patients' perspective.

**Results:** Based on the patients' risk factors and disabilities, post-discharge stroke patients' involvement throughout the care and rehabilitation processes varied significantly. The analysis of patients' information needs resulted in design of an interactive care and rehabilitation planning tool 'My care plan' which consisted mainly of a rehabilitation plan and necessary health and administrative information. The results from the evaluation of the care and rehabilitation planning tool showed that despite some challenges and limitations with using the tool, both care professionals and stroke patients were positive towards using it. The Swedish national health information exchange platform provides opportunities for information exchange, however needs to be further evaluated from a patient perspective to determine how it can support and impact on patient empowerment and collaboration in care.

**Conclusions:** The main contribution of this thesis is involvement of chronically ill patients

suffering from several cognitive and physical disabilities in the design and evaluation of eHealth services. Despite several challenges throughout this research project, a deep understanding about this patient group's needs throughout their care and rehabilitation processes was gained. The thesis also provides an early exploration of the Swedish national health information exchange platform. As this is an area rapidly evolving and of high priority in Sweden today, the results presented in this thesis will provide important input to future research, development and policy in this field.



## LIST OF SCIENTIFIC PAPERS

- I. **Davoody N**, Koch S, Krakau I, Hägglund M. Collaborative interaction points in post-discharge stroke care. *International Journal of Integrated Care*. 2014; 14(4)
- II. **Davoody N**, Koch S, Krakau I, Hägglund M. Post-discharge stroke patients' information needs as input to proposing patient-centred eHealth services. *BMC Medical Informatics and Decision Making*. 2016; 16(66)
- III. **Davoody N**, Koch S, Krakau I, Hägglund M. Accessing and sharing health information for post-discharge stroke care through a national Health Information Exchange platform- a case study. *Manuscript*
- IV. **Davoody N**, Eghdam A, Koch S, Hägglund M. A usability study of an electronic care and rehabilitation plan with stroke patients suffering from aphasia. *Manuscript*

### Other relevant publications

Lundberg N, Koch S, Hägglund M, Bolin P, **Davoody N**, Eltes J, Jarlman O, Perlich A, Vimarlund V, Winsnes C. My care pathways-creating open innovation in healthcare. *Studies in Health Technology and Informatics*. 2013;192:687-91

**Davoody N**, Woldemariam Y, Hägglund M. Stroke patients' post-discharge information needs and actual information provision. *Studies in Health Technology and Informatics*. 2016

**Davoody N**, Hägglund M. Care professionals' perceived usefulness of eHealth for post-discharge stroke patients. *Studies in Health Technology and Informatics*. 2015;216:992

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## LIST OF ABBREVIATIONS

API	Application Programming Interface
EHR	Electronic Health Record
HIE	Health Information Exchange
HIS	Health Information System
ICF	International Classification of Functioning, Disability and Health
ICT	Information and Communication Technology
ISO	International Organization for Standardization
GAS	Goal Attainment Scale
SMART	Specific, Measurable, Achievable, Relevant, and Time-bound
PCC	Patient-Centered Care
UCD	User-Centered Design
UTAUT	Unified Theory of Acceptance and Use of Technology

# 1 INTRODUCTION

The research presented in this thesis explores how a health information system (HIS) or eHealth service can be designed to improve self-management and rehabilitation of post-discharge stroke patients. The focus was mainly on involving this group of patients in the design and evaluation processes. A user-centered design (UCD) approach was therefore used throughout the study to design an electronic care and rehabilitation planning tool aiming to support post-discharge stroke patients during their journey. The tool also aimed to provide patients with necessary administrative and health information and improve the collaboration between patients, their next-of-kin, and care professionals. Before presenting the results, an introduction to the research field and important concepts is given.

## 1.1 Changing role of patients

### 1.1.1 Patient-Centered Care

Modern healthcare systems are shifting from paternalistic care to patient-centered care (PCC) and partnerships. Patient centeredness has become an essential part in today's healthcare and patients desire a PCC. Good communication, partnership and health promotion have been key messages about PCC by Little et al. [1]. In today's healthcare, most care professionals are aware that providing appropriate PCC requires involvement of patients as well as their next-of-kin and seeing their patients as their interactive partners [2]. A recent review study has explored the core elements of PCC in health policy, medicine and nursing. The core themes describing the concept have been: patient participation, the relationship between the patient and the healthcare professional, and the context where care is delivered [3]. In order to provide PCC, the patients need to be well informed. Stewart defines patient centeredness as "taking into account the patient's desire for information and for sharing decision making and responding appropriately" [4]. In addition, studies show that patients' preferences in PCC have e.g. been patient involvement in decisions, time for care, availability/ accessibility, information and communication [5-7].

In 2001, the Institute of Medicine Crossing the Quality Chasm defined the concept PCC as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" [8]. Barry et al. believe that the core factor of PCC is "the active engagement of patients when fateful healthcare decisions must be made- when an individual patient arrives at a crossroads of medical options, where the diverging paths have different and important consequences with lasting implications" [9]. According to Pelzang's literature review from 2010 [10] PCC is understanding the patient as a person and it is mainly about considering the patient's point of view in the decision-making process, focusing on patients' needs and preferences, interaction and information-giving, and engagement (doctor-patient relationship).

Weston [11] sees the shared decision-making as a core factor in a PCC and discusses the physicians' paternalistic role before and the importance of patient involvement in today's

healthcare system. Patients are no longer passive receivers of care. They are more involved in the decision making process throughout their care and rehabilitation journey. Physicians are experts in disease and medicine, but patients are experts in the way they experience their disease and in their preferences [12]. Merging the knowledge of both parties may lead to a better choice of treatment.

Charles et al. suggest some key characteristics of shared decision-making in a medical encounter between a clinician and the patient: both parties share information, the clinicians describe the risks and benefits with different possible treatment options, and the patient expresses his/her preferences and values, and an agreement is reached on the treatment [13]. Robinson et al. in a review study in 2008 [14] also showed that PCC leads to improved health outcomes and its fundamental characteristics are patient involvement and individualization of patient care. Despite some differences in definition, all studies mentioned in this section highlight the importance of PCC and its impact on health outcomes. Patient involvement has been a core characteristic in PCC in almost all the studies and communication and shared decision making have been mentioned as crucial factors in an effective PCC practice in these studies. Involving patients in the decision-making process and providing them with necessary information are considered crucial factors in empowering patients through expanding their role throughout their healthcare processes.

### **1.1.2 Patient involvement & patient empowerment**

Patient involvement and patient empowerment are two essential concepts in today's healthcare and have been the focus of many studies for a long period of time. Studies have shown that increased patient involvement leads to improved health outcomes [15, 16]. Doctor- patient interaction, good communication, and being clearly informed are considered important aspects of patient involvement [17]. Studies have shown that patients, especially chronically ill patients are positive towards being involved in their care and rehabilitation processes [17]. The focus of patient involvement is mainly on the relationship between patients and healthcare. It is about involving patients in communication with different care professionals while patient empowerment is focusing more on the patients' ability to have control over their disease and have an active role throughout their healthcare processes.

There is no clear definition of patient empowerment; however, Gibson defines empowerment as “a process of helping people to assert control over the factors which affect their lives. This process encompasses both the individual responsibility in healthcare and the broader institutional, organizational or social responsibilities in enabling people to assume responsibility for their own health” [18]. The term empowerment is also used in other contexts, but the definitions can be helpful to understand patient empowerment. According to Bank Institute in 2007 empowerment means to “enhance the capacity of an individual or group to make purposive choices and to transform those choices into desired actions and outcomes” [19]. Applied to patient empowerment, this connects to e.g. informed and knowledgeable patients engaged in shared decision making and self-care activities to improve their health outcomes. These aspects are also clearly reflected in the review by Bravo et al.

which also stresses that empowerment can exist on a scale from low to high empowerment, suggesting that different outcome measures or indicators could be identified to be able to measure e.g. an intervention's effect on patient empowerment [20].

Despite the benefits described in the literature, in today's healthcare, there is still a need of working towards the culture of sharing responsibility and power between patients and healthcare professionals. Such cultural changes are notoriously difficult, and will take time. Yet, patients' involvement and empowering patients are acknowledged as crucial parts of a PCC process. Patient empowerment and patient involvement are of great importance particularly for chronically ill patients who suffer from a disease during a long time and usually require care from several care providers. For these patients, self-management and self-care are also essential activities to achieve good quality of life.

## **1.2 Self-management and chronic care**

### **1.2.1 Self-management**

Improving self-management of chronically ill patients has been in focus for a long time and healthcare professionals are aware of the importance of self- management of chronic illness. Many authors distinguish 'self-care' from 'self-management' of chronically ill patients. In a review by Clark et al. [21] 'self-care' has been interpreted as a preventive strategy in contrast to 'self-management' which is the tasks that an individual needs to undertake to manage or reduce the impact of the disease. Some suggestions about a successful self-management have been made in the review by Clark et al. namely having sufficient knowledge about the disease and its treatment, performing relevant activities and having necessary skills to maintain adequate psychosocial functioning. Barlow et al. [22] have defined self-management as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition". According to Barlow et al. an effective self-management involves the "ability to monitor one's condition and to effect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life." As a result, the self-management is more than treatment of the disease; it also involves the social and psychological management.

Richard & Shea [23] performed a literature review in which similarities and differences among five concepts (self-care, self-management, self-monitoring, symptom management, and self-efficacy) were identified. Based on the results of this study, self-care was the most encompassing concept compared to other concepts. Self-care is a broad concept and according to Wilkinson and Whitehead [24] self-management may be a subset of self-care as it is understood as "people being responsible for their own health and well-being through staying fit and healthy, physically, mentally and where desired, spiritually". In recent years self-management has, however, been described as "the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatment, lifestyle changes and psychosocial, cultural, and spiritual consequences and inherent lifestyle changes required for living with a long-term chronic disease" [24].

In this thesis, the term self-management is used to signify patients' search for coping strategies to handle their disease and to become active participants in their care and rehabilitation processes. They require necessary health information as well as administrative information to be able to understand their disease and to participate in the goal setting and decision making about their treatment and the management of their disease from medical, social, and emotional perspectives.

Self-management has a great importance for chronically ill patients and their next-of-kin as their lives change deeply due to the illness. Corbin and Strauss identified three tasks of self-management for living with a chronic illness including medication management e.g. taking medication; behavioral management e.g. adapting lifestyle; and emotional management e.g. processing emotions [25].

To improve self-management for chronically ill patients, there is a need for appropriate interventions. Several self-management components including "providing information, drug management, symptom management, dealing with psychosocial consequences, life style (including exercise) communication and other self-management strategies such as career planning, goal setting and accessing support services" have been identified in the review study by Barlow et al. [22]. The review also showed that several non-ICT based approaches in form of booklets, lectures and goal setting have been developed for some chronic diseases such as asthma and diabetes. These studies suggested that self-management interventions have a positive impact on the well-being of patients in the short-term.

Care and rehabilitation planning is a potential tool to involve and improve self-management of chronically ill patients throughout the care and rehabilitation processes.

### **1.2.2 Care and rehabilitation planning as a tool for self-management**

There are several definitions of what a care plan is. According to the Medical Dictionary for Health Professions and Nursing 2012, a care plan is "a carefully prepared outline of nursing care showing all of the patient's needs and the ways of meeting them; a dynamic document initiated at admission and subject to continuous reassessment and change by the nursing staff caring for the patient; typically includes nursing diagnoses, nursing interventions, and outcomes; ensures consistency of care; may be standardized or pre-printed" [26]. The National Board of Health and Welfare in Sweden defines a care plan as "a health and social care plan that outlines healthcare for an individual patient" [27]. According to the Swedish national care handbook a "care plan includes the diagnosis (problems, risks) and goals that have been determined with and for a patient, followed by actions/activities and prescriptions" [28].

A care plan can be interdisciplinary which means that all professionals involved in the patient's care processes are responsible for their parts in the joint care plan and should work towards the same goals and carry out the activities that have been decided together with the patient. A care plan may include individualized care and is based on the individual's specific needs. Some care plans are meant to improve the continuity of care as they are means of



communication between different actors who are involved in the care and rehabilitation processes of the patient.

There are different types of care plans in Swedish healthcare. Standardized care plan is a term used for describing recommended healthcare efforts for patients with similar health problems or patients with the same type of treatment. The plan can be complemented with an individual care plan if it doesn't provide sufficient flexibility for individuality. Coordinated care planning is a term used for a structured cooperation between municipality and county council for managing the information exchange and care planning for a patient who is discharged from inpatient care to outpatient care and social services. Rehabilitation plan is a care plan that describes the rehabilitation needs of an individual.

Despite several descriptions of care plans for different patient groups, all care plans include some main parts, namely: goals, activities, and follow up efforts. In addition, all care plans should be established together with the patients and possibly their next-of-kin. Depending on the type of care plan, some planned activities aim to support self-management. This applies particularly to rehabilitation planning which is often relying on patient self-training. Rehabilitation is essential for many patients who suffer from long-term or chronic conditions affecting physical or mental abilities. Stroke is one of the conditions where rehabilitation can have a fundamental impact on the patient's quality of life [29, 30].

### **1.2.3 Stroke**

Stroke is a long-term condition and common cause of morbidity and disability, and also a global healthcare problem [31, 32]. Stroke is a brain damage and occurs due to blockages or narrowing of the arteries that provide blood to the brain (ischemic stroke) or blood leakage (hemorrhagic stroke). Stroke is commonly associated with older age, but approximately 10% of all strokes occur in people at the age of 18 to 50 years and hospitalizations for ischemic stroke have increased among young adults [33]. Most stroke patients suffer from several physical, cognitive, and psychosocial disabilities [34] and therefore require care from different care providers and healthcare professions. The need for support in daily activities has an impact on the life of both patients and their next-of-kin. Long-term stroke prevention and the recovery process after stroke are of great importance as the human, economic and social burdens of stroke have made it a costly disease [35, 36]. Self-management and rehabilitation programs have therefore received attention as potential means to reduce the burden of the disease and improve quality of life. A recent review by Lennon et al. explored the importance of self-management programs specific to stroke patients [37]. The review provides preliminary support for the potential importance of self-management interventions after stroke, however the most appropriate content and best approach for delivery of these interventions remains to be determined.

Rehabilitation after stroke plays an essential role in the recovery process. Stroke rehabilitation involves “(1) assessment, to identify the patient's needs; (2) goal setting, to define realistic and attainable goals for improvement; (3) intervention, to assist in the

achievement of goals; and (4) reassessment, to assess progress against agreed goals” [29]. Principles of rehabilitation include: establishment of specific, measurable, time-dependent goals; increased therapy or interventions (e.g. cognitive rehabilitation interventions, outpatient rehabilitation service etc.); multidisciplinary team care (e.g. a team of care professionals and social-work staff); and task-specific training [29].

Goal setting has been identified as one of the most prominent strategies in self-management programs focusing on increasing participation and functional ability [38]. The importance of patient involvement in rehabilitation after stroke has been studied [39] and studies have shown that goal setting has a positive impact on the patients’ perceptions of self-care ability and involvement in the rehabilitation process. Goal setting also seemed to improve patients’ recovery, their performance and goal achievement [40]. Other studies explored the reliability of goal attainment scaling and it seemed to be a rigorous measure for use in rehabilitation settings [41].

#### *1.2.3.1 Aphasia*

Aphasia is a common condition after stroke. Every year about 8000 to 10 000 persons suffer from aphasia in Sweden and almost 35 per cent of them are in working age [42]. Aphasia occurs if one or both language centers are damaged. Stroke patients suffering from aphasia can have difficulties in verbal expression, reading and/or writing and understanding what other people say [43, 44]. Involving this group of patients in the care and rehabilitation processes is of great importance as they have difficulties in communication and have specific needs during their journey.

Appropriate HISs and eHealth services have the potential to involve patients throughout their journey, improve their self-management and empower them during their care and rehabilitation processes [45, 46]. In addition, designing supportive ICT-based interventions which give patients opportunity to make their purposive choices and take informed actions and meet their needs throughout the care and rehabilitation processes is crucial in stroke care.

### **1.3 eHealth**

A number of new terms started to appear during the 1990s as the Internet came into public awareness. One of these terms was eHealth which represented the promise of ICT to improve health and healthcare systems [47].

In 2001, Eysenbach defined eHealth as “an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve healthcare locally, regionally, and worldwide by using information and communication technology” [48].

In a systematic review from 2005, Oh and colleagues [49] found 51 unique published definitions of eHealth. All definitions “specifically mentioned health which referred explicitly

to healthcare as a process rather than to health as an outcome”; and technology “viewed both as a tool to enable a process/function/service and as the embodiment of eHealth itself (e.g. a health website on the Internet)”.

More recently, the term eHealth has been adopted in e.g. governmental work, and then has a broader definition. According to the European commission eHealth refers to “tools and services using ICT that can improve prevention, diagnosis, treatment, monitoring and management.” In addition, it “can benefit the entire community by improving access to care and quality of care and by making the health sector more efficient” [50]. A similar broad definition is used in the Swedish eHealth Strategy from 2010, stating that “the concept of eHealth is based on the World Health Organization’s definition of health as “a state of complete physical, mental and social well-being”. By adding the prefix “e” to the concept of health, we maximize the possibility of achieving these benefits for the individual through widespread use of information and communication technologies (ICT). The definition of eHealth extends the concept of health from something that primarily concerns a single individual to a change process with the potential to work as a catalyst for reform within the entire health and social care sector” [51].

However, a recent definition by Koch et al. describes eHealth in 2010 as “We see eHealth not in the broader scope of encompassing the entire field of health and medical informatics but as a continuation of the fields of telemedicine and telehealth that in combination with the rising field of consumer informatics has the potential to revolutionize the way healthcare and prevention is provided, shifting the balance of power and responsibility from healthcare professionals to patients and citizens” [52].

Regardless of whether you use the broader or more narrow definition of eHealth, it is clear that patients and their next-of-kin are important users of eHealth who need to be involved in the design, implementation and evaluation of eHealth interventions.

Outside the healthcare field, similar developments of digitalization of services are also taking place. The term e-service is often used to describe this. Rowley defines e-services as “deeds, efforts or performances whose delivery is mediated by information technology (including the web, information kiosks and mobile devices)” [53]. In this thesis the term eHealth services refers to e-services within the health domain which can be used by patients and/or care providers, that is health or self-care services delivered through information technology e.g. online tools and mobile applications.

Such ICT-based interventions or services can be a possible alternative to traditional methods of care delivery, and have even been shown to potentially be more effective than traditional medical care [54]. However, poor usability has been identified as a major impediment to the acceptance and routine use of many types of ICT systems in healthcare for quite a long time [55-57], and yet still remains a problem [58]. As eHealth is increasingly developed with patients as the main user group, human factors, sociocultural aspects, disabilities, health literacy, language, and other individual characteristics are becoming increasingly important in

the design of eHealth services. It is therefore of great importance to involve end-users in the design and evaluation of eHealth services to be able to develop services considering end-users' needs and to achieve the expected impact of eHealth.

### 1.3.1 User-centered design

In 1986, Norman and Draper emphasized that “[t]he needs of the users should dominate the design of the interface, and the needs of the interface should dominate the design of the rest of the system” [59]. A UCD approach makes it possible to involve the end-users throughout the process. Human-centered design (human-centered design and user-centered design are often used synonymously) is an “approach to systems design and development that aims to make interactive systems more usable by focusing on the use of the system and applying human factors/ergonomics and usability knowledge and techniques” [60]. In order to have a successful ICT development, user involvement is crucial [61]. Although a UCD project can be implemented in many different ways, the main steps identified in the international organization for standardization (ISO) standard (Figure 1) are; (1) to understand and specify the context of use, (2) to specify the user requirements, (3) to produce design solutions to meet user requirements and (4) to evaluate the designs against requirements [60]

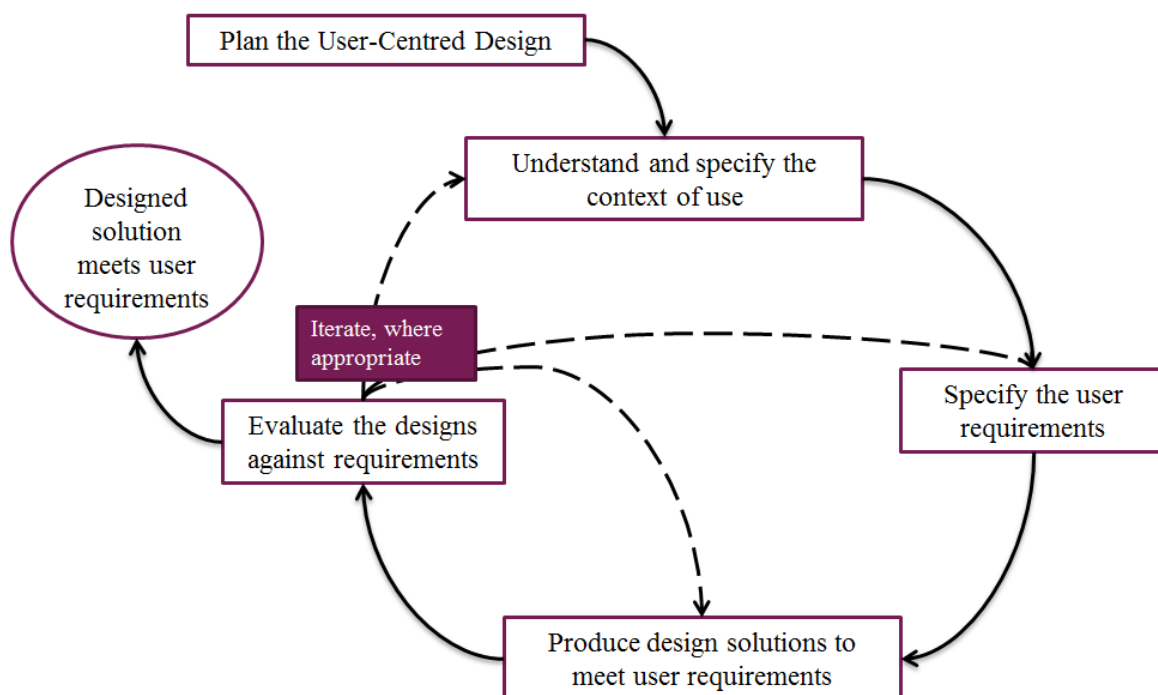


Figure 1. User-Centered Design. The figure is modified based on ISO 9241-210:2010 (E) [60].

#### 1.3.1.1 UCD of eHealth for patients

To be able to improve patient involvement through HISs and eHealth services, there is a need of involving patients in the design and evaluation of ICT-based interventions. Understanding the context of use is crucial in a UCD process of eHealth for patients especially for chronically ill patients who suffer from a chronic condition for a long time and require care from different care providers. In addition, taking patients' experiences of the patient journey into account in the design process is a way of understanding the patients' needs and involving

them in the design process. Customer journey mapping [62] is a tool used in service design [63] to understand customers' experience of using a service and the tool has lately been applied in healthcare [64, 65]. A patient journey model gives a common picture of the process and the way patients experience their care and rehabilitation processes. Understanding the patients' experiences of their journey is essential in order to design eHealth services which provide patients with a holistic overview of their often fragmented care. Evaluation of the designs against requirements can result in valuable input from the end-users. When designing eHealth that is to be used by patients, it is essential to involve representative patients in different phases of prototyping in an iterative process to evaluate design ideas.

#### *1.3.1.2 Evaluation*

A systematic review from 2011 by Black et al. [66] shows that there is also a lack of rigorous research about the cost-effectiveness and the risks of implementation of ICT tools. Despite the fact eHealth interventions have the potential to improve healthcare, implementing poorly designed HISs and eHealth services have shown a risk for benefit fail and also patient safety [67, 68]. Therefore, evaluation throughout all phases of the technology's life cycle is vital for future eHealth technologies [66, 69]. The European Health Information Society defines health informatics evaluation as "the act of measuring or exploring properties of a health information system (in planning, development, implementation, or operation), the result of which informs a decision to be made concerning that system in a specific context" [70].

As mentioned in the previous section user-centered evaluation is a crucial part of a UCD process [71]. Before being able to evaluate the effectiveness of an eHealth intervention, it is essential to perform thorough formative evaluations involving patients during the development process. Usability is of great importance for the acceptability and adoption of eHealth and is defined as "the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use" [60].

### **1.3.2 Interoperability of eHealth**

Although usability is often related to user-interface design and human-computer interaction issues, it can also be affected by contextual factors such as infrastructure and integration with other systems. In a recent Swedish study of eHealth usability, lack of interoperability between health information systems was identified as a major usability issue [58, 72]. When health information systems cannot exchange information, this results in manual transfer of data, double documentation and in the worst cases threats to patient safety due to lack of important information at the point of care. Interoperability is therefore an important focus of medical informatics research and several standards such as Health Level Seven (HL7) Version 3 [73], openEHR [74], and the European Standard for Electronic Health Record Communication EN 13606 [75] are developed to enhance interoperability and improve health information exchange. However, challenges with information exchange remain, causing problems not only for collaboration and communication between healthcare professionals, but also when

giving patients access to their health information. These challenges are particularly noticeable for chronically ill patients who receive care from several care providers. As a patient's health information is documented and stored in different HISs and eHealth services, there is a need for interoperability between different systems for it to be possible to give patients access to their health information in one view.

Giving patients access to necessary health information documented in their electronic health records (EHRs) will mainly provide patients with a retrospective perspective on care provided. Many patients suffering from chronic or long-term conditions, however, require having access to a more prospective view of the necessary information about what is planned in their care process in the future [76]. Having such a prospective view is possible through having access to care plans. To be able to provide patients with both a retrospective and prospective view of their health information, it is crucial to give patients an overview of their journey throughout their care and rehabilitation processes. However, in order to give patients such an overview there is need of an appropriate infrastructure for information exchange and interoperability.

In Sweden, a national health information exchange (HIE) platform aiming to facilitate the communication between different HISs and eHealth services has been implemented. Exchange of healthcare data between different HISs, care organizations, patient communities, and governmental agencies is possible through this platform. Different EHRs or eHealth services can request health information from other source systems/EHRs. According to predefined service contracts relevant health information will be provided from the source systems/EHRs to the platform and then sent to the EHRs or eHealth services which requested access to this type of information.

### **1.3.3 eHealth to support patient empowerment**

Currently, eHealth gives patients a completely different opportunity to gain insight into their care and to influence and follow their progress throughout their care processes. Studies show that ICT-based interventions have a positive effect on patient empowerment [77]. Giving patients online access to their health information has been seen as a way to increase patients' engagement and patient empowerment. Several initiatives both in the US with the OpenNotes project [78], and in Europe with e.g. the SUSTAINS project [79] are ongoing to provide patients with online access to their full EHR.

However there is still a need for studies that help us to understand how these types of solutions should best be developed and designed.

## 2 AIM AND OBJECTIVES

The overall aim of this research was to explore how a health information system/eHealth service (in this context an electronic care and rehabilitation planning tool) used by post-discharge stroke patients can be designed to improve patient self-management and collaboration between patients, their next-of-kin and different care professionals. In order to achieve this aim, the current context of post-discharge stroke care was explored and the interaction points throughout the care and rehabilitation processes of post-discharge stroke patients were identified. In addition, the stroke patients' information needs were studied and potential eHealth services were proposed by the researchers and discussed with the patients. Based on the patients' information needs, through a UCD process, a prototype 'My care plan' was designed. The aim of the prototype was to provide post-discharge stroke patients with necessary health and administrative information throughout their care and rehabilitation processes and act as a tool for collaboration between the patients and different care providers. The prototype was then evaluated from the care professionals' perspective as well as patients' perspective. Table 1 provides specific aims for the individual studies in this research.

Table 1. An overview of specific aims for the individual studies.

<b>Study I</b>	<ul style="list-style-type: none"> <li>Analyzing and modeling current care processes in post-discharge stroke care</li> <li>Identifying the interaction points between patients and different key actors involved in the care and rehabilitation processes of post-discharge stroke care</li> <li>Describing current information exchange between patients and the key actors</li> <li>Analyzing the implications for design of supportive health information systems and/or eHealth services for this group of patients</li> </ul>
<b>Study II</b>	<ul style="list-style-type: none"> <li>Identifying and describing the post-discharge stroke patients' information needs using patient journey mapping</li> <li>Exploring the patients' perceived needs to propose appropriate eHealth services supporting them throughout their care and rehabilitation journey for this group of patients</li> <li>Designing the care and rehabilitation planning tool using a user-centered design approach</li> </ul>
<b>Study III</b>	<ul style="list-style-type: none"> <li>Studying the information flow between the care and rehabilitation planning tool in relation to the Swedish national HIE platform</li> <li>Exploring the opportunities and limitations of accessing and interacting with important health information through the Swedish national HIE platform.</li> </ul>
<b>Study IV</b>	<ul style="list-style-type: none"> <li>Studying the effectiveness and user satisfaction of the care and rehabilitation planning tool from the perspective of post-discharge stroke patients suffering from aphasia</li> <li>Analyzing design implications for health information systems and/or eHealth services based on the aphasic stroke patients' needs</li> </ul>





### 3 OVERVIEW OF THE THESIS

The four studies in this thesis focused on different parts of a UCD approach to design a care and rehabilitation planning tool which aims to provide patients with necessary information and support them throughout their care and rehabilitation processes. Figure 2 illustrates an overview of the individual studies in this thesis. Study I explores the current care and rehabilitation processes of post-discharge stroke care in Stockholm County Council and identifies the interaction points between patients and different care professionals who are involved in the patients' care and rehabilitation journey. Study II focuses on identification of post-discharge stroke patients' information needs to propose appropriate HISs and eHealth services. Based on the results from study I and II a care and rehabilitation planning prototype was designed. In study III, the information flow between the care and rehabilitation planning tool with the Swedish national HIE platform is studied. The prototype was evaluated throughout the thesis project from the perspectives of both post-discharge stroke patients [80, 81] and care professionals in a neurology team [82]. However, study IV focuses on the evaluation of the final prototype through usability tests involving post-discharge stroke patients suffering from aphasia.

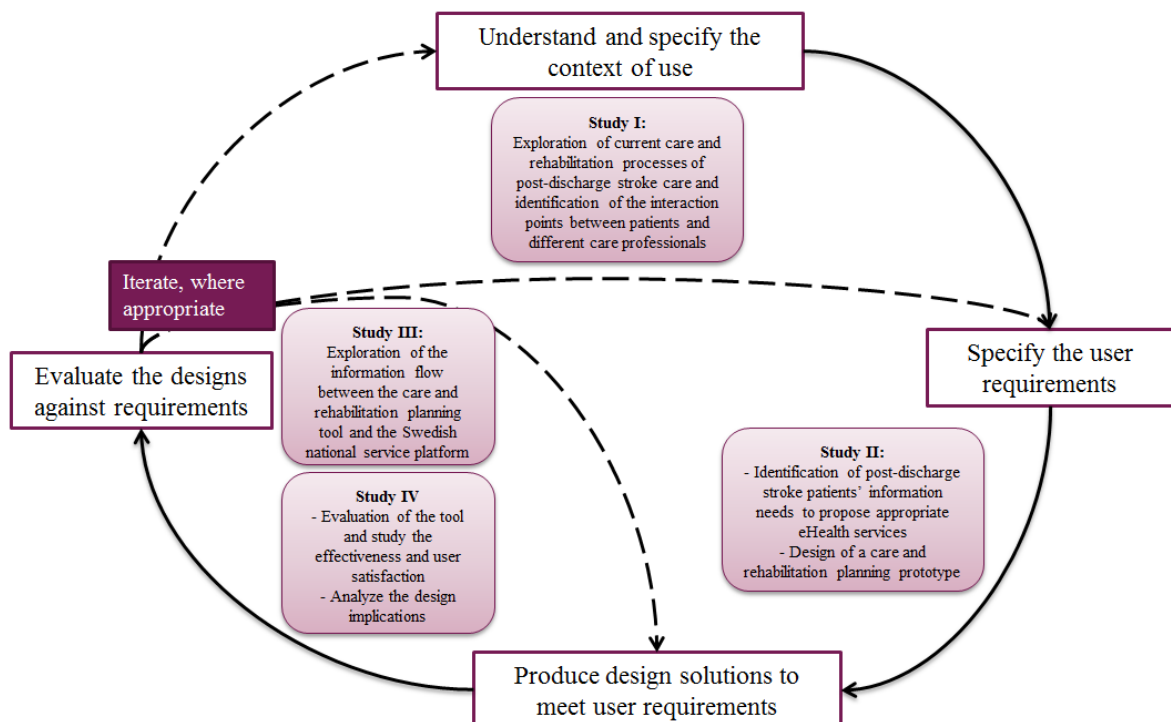


Figure 2. Overview of the thesis. The figure is modified based on ISO 9241-210:2010 (E) [60].



## 4 METHODS

In the field of health informatics research, as in other information systems or computer science research, one approach to research is to design and evaluate new artefacts. Oates refers to this as a design and creation research strategy [83], but it has also been referred to as a design science in the literature [84]. A new artefact can be models or methods, but can also include working systems (instantiations) which demonstrate how suggested models and methods can be implemented using ICT. In this thesis, an instantiation of an online care and rehabilitation planning was designed and evaluated to contribute to the knowledge base on patient involvement in both design of eHealth and in their care through use of eHealth. In addition to the design and creation research strategy, a qualitative case study approach was also used in this research. A case study focuses on gaining an in-depth understanding of the subject studied. It takes place in a natural setting and provides a holistic perspective [83].

Oates stresses that regardless of what type of ICT artefact is being produced in a design research, it is essential to base the research on established principles of systems development [83]. A user-centered design approach was chosen in this research project as involvement of end-users was considered essential for the design and evaluation processes of an electronic care and rehabilitation planning tool. The design process started with an exploration of the care and rehabilitation processes and identification of the interaction points between patients, their next-of-kin and different care professionals who were involved in the post-discharge stroke care. The work then continued with identification of patients' problems and information needs through focus groups. Based on the collected data, paper prototypes were created and were discussed with the participants in further meetings. The prototypes were improved based on the users' feedback and an interactive prototype was designed and evaluated by post-discharge stroke patients in Stockholm County Council. Based on the evaluation results, the prototype was improved further and was evaluated from the care professionals' perspective using unified theory of acceptance and use of technology (UTAUT) [82]. The final version of the interactive prototype was even evaluated from the perspective of post-discharge stroke patients suffering from aphasia using usability testing [85].

Qualitative research methods [86, 87] with different data collection techniques were used in all four individual studies. This chapter is divided into different sections: section 4.1 describes the setting, section 4.2 provides an overview of the participants in this research, section 4.3 describes the study design, data collection techniques, and analytical methods for each individual study in this thesis and section 4.3 describes the ethical considerations for this research.

## 4.1 Setting

### 4.1.1 Stroke care in Stockholm

In Stockholm County Council, post-discharge stroke patients who are in need of continuing rehabilitation, receive care from a neurology team for at most one year. The patient is often also in need of some medical treatments. In this case a referral will be sent to a primary care center where the patient can receive care from physicians, nurses, and/or district nurses.

The care professionals in the neurology team visit the patient at home and based on the patient's rehabilitation needs, a paper-based rehabilitation plan is established together with the patient and possibly a family member. The rehabilitation plan is then documented in the patient's EHR. Currently, the paper-based rehabilitation plan used by neurology teams consists of identification of the patient's rehabilitation problems, defining goals, activities and outcomes (Figure 3). Based on the patient's progress, the rehabilitation plan in the patient's EHR gets updated. Once the patient has achieved the intended goals and is not in need of continued rehabilitation, the neurology team stops providing rehabilitation support. If the patient is still in need of more rehabilitation after one year, the care professionals in the neurology team send referrals to other rehabilitation providers. The care professionals in the neurology team also provide necessary information about patient associations and other support organizations.

This research was performed within stroke care in Stockholm County Council. Several care professionals including physicians, nurses, district nurses and the members of a neurology team (speech therapist, occupational therapist, counsellor, and physiotherapist) as well as stroke patients participated in different studies.

(Rehabilitation plan)

### Rehabiliteringsplan

(Date)	(Goal)	(Check off)
Datum	Mål	Avstämning
21/5	Bli självständigare i trappan.	
	Säkerare vid gång med stick/kryckestöpp.	
	Upprätthålla rörlighet i arm, hand.	
	Öka viljemässig rörlighet i arm, hand, axel	
✓	Rörlighet i benet.	
	Öka ordförrådet. Inställt/utföra Lexia övningar!	
	Se över utomhusrollator.	
	Pröva roller med hemtjänst.	

(Date)	(Goal)	(Check off)
Datum	Mål	Avstämning

Figure 3. Paper-based rehabilitation plan at patient's home. The English translations are indicated in parentheses.

## 4.2 Overview of the study participants

Care professionals who participated in study I were recruited from a primary care center in Stockholm County. Both care professionals in the primary care center and the neurology team had experience of stroke care. Participants in study II were recruited through the Swedish stroke association using purposive and snowballing sampling strategies. Participants for the design of paper prototypes were post-discharge stroke patients who were also recruited through the Swedish stroke association. Study III was mainly a document study where the authors explored the current infrastructure. However, in addition to the authors, 2 key stakeholders were involved as providers of information; a clinical expert and an infrastructure architect. Stroke patients who participated in study IV were selected through Aphasia Association in Stockholm County Council using a purposive sampling strategy. In addition, care professionals in the evaluation study using UTAUT were recruited from the neurology team in Stockholm County (Table 2).

Table 2. An overview of the participants in this research.

Studies	Participants		
	Care professionals	Patients	Next-of-kin
Study I	Interview with physicians, district nurses, home care district nurses, speech therapist, occupational therapist, physiotherapist, and counsellor (n=11)  Observation of home care district nurses, speech therapist, occupational therapist, and physiotherapist (n=10)	Patients (n=3)	Next-of-kin (n=2)
Study II		Identification of information needs Focus Group I (n=4) Focus Group II (n=4) Focus Group III (n=4)  Designing an interactive prototype (n= 5)  Improving the interactive prototype (n=2)	Improving the interactive prototype (n=1)
Study IV	Evaluation of the tool through UTAUT Care professionals in the neurology team :	Evaluation of the tool through usability testing  Post-discharge stroke	

	Focus Group I: Speech therapist (n=1) Physiotherapist (n=1), Counsellor (n=1) Focus Group II: Physiotherapists (n=2) Focus Group III: Speech therapist (n=1), Occupational therapist (n=1), Counsellor (n=1)	patients suffering from aphasia (n= 9)	
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Studies II & IV in this research project consist of several parts. Figure 4 provides an overview of different studies in this research project.

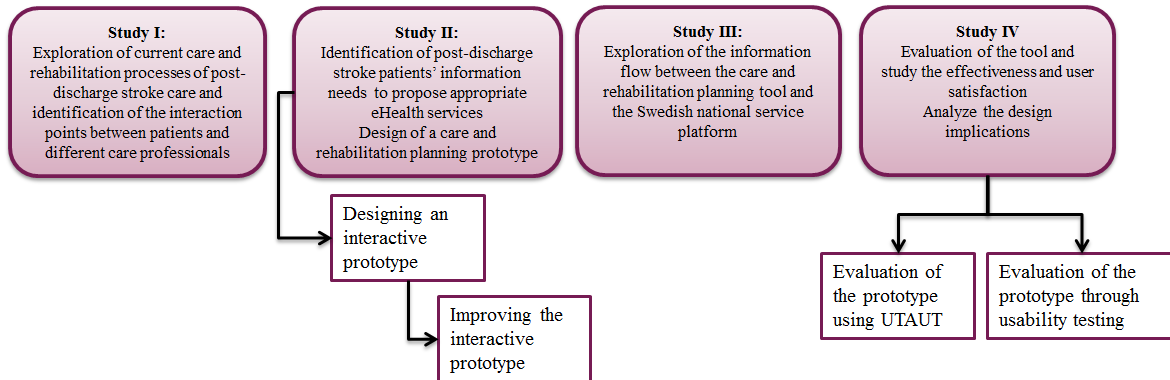


Figure 4. An overview of different studies in this research project.

### 4.3 Exploring interaction points

The aim of this study was to explore the current care and rehabilitation processes of post-discharge stroke care and to identify the interaction points between patients and different care professionals.

#### 4.3.1 Studying the current care and rehabilitation processes in stroke care and exploring the interaction points

##### 4.3.1.1 Study design

An in-depth qualitative case study [86] was used to explore the current care and rehabilitation processes of post-discharge stroke patients in Stockholm County Council and to gain insight into the collaborative relationship between care professionals, patients and their next-of-kin.

##### 4.3.1.2 Data collection and analysis

**Sampling strategy:** A purposive sampling strategy was used to recruit physicians, nurses, district nurses, and home care district nurses in a primary care center. In addition, care professionals in the neurology team (a speech therapist, an occupational therapist, a counsellor, and a physiotherapist) were also recruited through a purposive sampling strategy. The participants' experience of stroke care and work with stroke patients was one of the main inclusion criteria in this study. Care professionals in the primary care center received approximately 50 referrals of stroke patients from different hospitals and the neurology team had about 80 stroke patients annually.

Data collection technique: Initially, the research group prepared an interview template with pre-defined questions focusing on the care and rehabilitation processes of post-discharge stroke patients and the collaborative relationship between different actors involved in the patient's journey. The interview template was then verified by two physicians and a district nurse to ensure the simplicity of the interview questions. Based on the comments from the consulted care professionals, necessary changes were made in the interview template. Two pilot interviews were then performed with a physician and a district nurse in the primary care center. Subsequently, thirteen semi-structured interviews with open-ended questions [88] were used to get an overview of a patient's journey. Care professionals in this study were asked to describe the care and rehabilitation processes of post-discharge stroke patients as well as their interactions with each other, patients and their next-of-kin. Physicians were asked to describe the process of monitoring and treatment of the main risk factors. The home care district nurses were asked to describe the process considering activities performed during home visits, after home visits and the follow up. The care professionals in the neurology team were asked to describe the rehabilitation process and their collaboration with the patients and their next-of-kin. Interview questions for care professionals in the neurology team were based on the work process for each profession and his/her collaborative relationship with other members in the team, patients and their next-of-kin.

The work process and home visits of home care district nurses and the neurology team were observed to gain an in-depth understanding of the documentation process in the patient's EHR and the interaction between patients and care professionals. Five non-participatory observations [88] were carried out to complement the interviews and capture missing aspects of the studied area. The first and the second observations were carried out at the primary care center and the focus was on the preparation of activities before a home visit and also entering information in patients' EHR. However, the third, fourth and fifth observations were at the patients' home and the focus was on the involvement of the patients and their next-of-kin in the care and rehabilitation processes and also on their participation in the establishment of rehabilitation plans.

Data analysis: The analysis of data was divided into two parts. For the first part qualitative content analysis [86, 89] was used for analyzing the interviews and observations. The second part was about modeling the identified interaction points throughout the care and rehabilitation processes of the patients.

Interviews in this study were audio recorded and transcribed verbatim. Nvivo 9.0 software was used to organize and code the collected data through interviews and observations. Microsoft Office Visio was used to model the care and rehabilitation processes. The interaction points were then identified throughout the processes and were divided into two different types, namely touchpoints and intersection points [90]. In service design touchpoints refer to interactions between a customer and a service provider [63]. Touchpoints in this study referred to interactions between patients and different care professionals, and intersection points referred to the interactions among different care professionals throughout

the post-discharge stroke patients' care and rehabilitation processes. The interaction points in this study were studied for both home care patients (those who received care at home) and non-home care patients (patients who were able to visit the primary care center for receiving care).

#### **4.4 Identification of information needs and design of an interactive prototype**

This section includes several studies. The first part is about identification of post-discharge stroke patients' information needs and corresponds to paper II. In addition, we also worked interactively with the development of the prototype which resulted in additional publications [80, 81]. The study design and procedure of data collection and analysis of the development process are presented under headings 'Designing an interactive prototype and improving the interactive prototype' in this section.

##### **4.4.1 Identification of post-discharge stroke patients' information needs**

###### *4.4.1.1 Study design*

To gain a deep understanding of the users and their needs, a user-centered design approach [59] was applied. Qualitative research methods [86, 88] were also used in this study to gain a deep understanding of post-discharge stroke patients' information needs and their experiences throughout their care and rehabilitation processes. Patient journey modeling was used to identify the stroke patients' information needs at different phases. In this study we used customer journey mapping to study patients' experiences and processes during the course of a disease and its treatment. In addition, the stroke illness trajectory framework described by Kirkevold was used throughout the study [91]. Initially, the chronic illness trajectory framework was developed by Corbin and Strauss [92] and included eight phases. However, the stroke illness trajectory is based on the chronic illness trajectory framework and consists of four phases, namely 'trajectory onset', 'initial rehab', 'continued rehab', and 'semi-stable'. In this study the focus was on the latter two phases as they were relevant to post-discharge stroke care.

###### *4.4.1.2 Data collection and analysis*

**Sampling strategy:** The recruitment process of post-discharge stroke patients in Stockholm County started with a purposive sampling strategy. After the first focus groups another sampling strategy called snowballing strategy was used to recruit new participants through patients who participated in the first focus groups. Both older patients ( $\geq 65$  years) and younger ( $< 65$ ) were selected for this study. Both patients who suffered stroke in recent years and those who had suffered stroke for more than 10 years were included in the study.

**Inclusion criteria:** The inclusion criteria were specified as follows: patients with milder physical, cognitive and/or psychosocial disabilities who could handle computers and were living in their own homes.

**Data collection technique:** Data were collected through focus groups which lasted approximately 2-3 hours each. To facilitate discussions in the focus groups several personas



and scenarios [93, 94] were developed and used. Based on the discussions in the first focus group and the flowchart of the stroke care in Stockholm County in study I a patient journey model was developed and used in the second and the third focus groups. Patients' information needs were discussed considering different phases of the patient journey, and potential eHealth services were proposed by the research group and discussed during the focus groups. An online rehabilitation plan was one of the potential eHealth services. The specific information needs related to the rehabilitation plan were then collected through further focus groups with other post-discharge stroke patients [80, 95].

Data analysis: Content analysis was used to analyze the data collected through the focus groups. Categories and themes were identified by two researchers independently and the results were discussed in the research group.

#### **4.4.2 Designing an interactive prototype**

##### *4.4.2.1 Study design*

An explorative qualitative research approach was used to identify post-discharge stroke patients' information needs regarding the rehabilitation plan and design an interactive prototype. The results are presented by Woldemariam [95] and LyckstedtVis [80].

Sampling strategy: A convenience sampling strategy [96] was used to recruit post-discharge stroke patients through Swedish stroke association. After the first focus group, a snowballing strategy was used to recruit more participants through participants in the first focus groups. In addition, a purposive sampling strategy was used to select a neurology team in Stockholm County who used a paper-based rehabilitation plan.

##### *4.4.2.2 Data collection and data analysis:*

Data collection technique: Three focus groups were carried out at Karolinska Institutet. Each focus group lasted approximately two hours with an interval of two weeks. In addition, a two hours focus group was carried out with the neurology team in one of Stockholm County's care centers.

Data analysis: A qualitative content analysis was used to analyze the data collected through focus groups. A care and rehabilitation planning prototype focusing mainly on the rehabilitation plan was developed based on the results from the focus groups and the preliminary version was evaluated [80]. Screenshots of the overview page and *My rehabilitation* from the first version of the care and rehabilitation planning prototype are presented in chapter 10 Appendix Study II.

#### **4.4.3 Improving the interactive prototype**

##### *4.4.3.1 Study design:*

Based on the results from the evaluation of the interactive prototype and the focus groups, potential eHealth services were suggested and the electronic care and rehabilitation planning

prototype was developed further. The latest version of the tool was initially evaluated through performing a number of usability tests with two post-discharge stroke patients and a next-of-kin of a stroke patient. The results of this study are presented by Stocker [81].

**Sampling strategy:** A purposive sampling strategy was employed for recruiting post-discharge stroke patients with milder disabilities, who can handle computers and live in their homes. The participants were recruited from the Swedish stroke association. A family member of a stroke patient was recruited through snowball sampling.

#### *4.4.3.2 Data collection and analysis*

**Data collection:** Each test lasted approximately one hour and each participant received 10 tasks to complete within 30 minutes. For recording the screen movements along with all mouse movements the free open-source software CamStudio [97] was used during the tests.

### **4.5 Exploring interoperability**

The aim of this study was to explore the information flow between different eHealth services within the care and rehabilitation planning tool designed with and for post-discharge stroke patients with other HISs and eHealth services through the Swedish national HIE platform.

#### **4.5.1 Accessing and sharing health information through the national HIE platform**

##### *4.5.1.1 Study design*

A case study approach [86, 98] was applied for this study to gain an in-depth understanding of the subject. A patient case with fictive health information was created in consultation with a stroke coordinator in Stockholm County.

##### *4.5.1.2 Data collection and analysis*

**Data collection technique:** Relevant literature and available documents regarding the architecture of the national HIE platform and available service contracts and application programming interfaces (APIs) were studied. A stroke coordinator in Stockholm County was consulted for creating a patient case with fictive patient health information. In addition, a deputy Chief Technical Officer familiar with the architecture of the national HIE platform was interviewed.

**Data analysis:** We started the analysis process by visualizing the patient case in the patient journey modelled in the previous study. Different usage scenarios were then developed to present different situations in which a stroke patient needs to have access to different types of health information and/or administrative information. Based on these scenarios the information flow between some of the eHealth services within the care and rehabilitation planning tool and the national HIE platform was studied and analyzed. Data collected from relevant literature and available documents as well as data from interviews with key stakeholders were used to map the patient case and the scenarios to the national HIE platform

and study the information flow regarding accessing, updating, and sharing information through the national HIE platform.

## **4.6 Evaluation of the care and rehabilitation planning tool**

This section includes several studies. The first part is about evaluation of the tool using UTAUT. This is a study that we performed before the usability testing to evaluate the tool from the care professionals' perspective [82]. The study design and procedure of data collection and analysis regarding paper IV is presented under the heading 'Usability testing' in this section.

### **4.6.1 Evaluating the tool using Unified Theory of Acceptance and Use of Technology**

#### *4.6.1.1 Study design*

The final version of the prototype was evaluated from the care professionals' perspective using UTAUT [82].

Sampling strategy: A purposive selection strategy was carried out to select the care professionals in a neurology team in Stockholm County who participated throughout this research.

#### *4.6.1.2 Data collection and data analysis*

Data collection technique: Three focus groups with care professionals in the neurology team (speech therapist, occupational therapist, counsellor, and physiotherapist) were performed. Not all members were able to attend all focus groups due to their workload. All focus groups were carried out at the neurology team's workplace at a primary care center in Stockholm County. Each focus group lasted approximately one hour.

Data analysis: The focus groups were audio recorded and transcribed verbatim. A predefined coding scheme based on the four concepts of the UTAUT model was used for the analysis of the collected data. The data were analyzed deductively and meaning units, codes and categories were identified. During the focus groups, the functionality and the content of the care and rehabilitation tool were discussed with the care professionals. In addition, the usefulness and impact on work routines and the acceptability of the tool were discussed in the focus groups.

### **4.6.2 Usability testing**

#### *4.6.2.1 Study design*

A qualitative approach [86] was used to formatively evaluate [71] the final functional version of the care and rehabilitation planning tool. A number of usability tests were performed to study the effectiveness and user satisfaction aspects of the tool. In this study, the tool was evaluated with post-discharge stroke patients suffering from aphasia using usability tests.

Sampling strategy: A purposive sampling strategy for recruiting post-discharge stroke

patients suffering from aphasia was used in this study. The sampling procedure started with contacting the aphasia association. A short description of the project and information letters about the evaluation study including the aim of the study, data collection techniques and ethical considerations were sent to the contact person at the aphasia association. In addition, the inclusion criteria were sent by email to the same person. The inclusion criteria have been described as follows: post-discharge stroke patients who had stroke less than 5 years ago, suffer from milder disabilities, are able to talk, live in their own homes, and can handle computers.

#### *4.6.2.2 Data collection and analysis*

**Data collection technique:** The data were collected through several usability tests, a post-test interview and a post-test questionnaire. Since the idea behind the care and rehabilitation planning tool was to enable patients to use the tool independently or with some support from their next-of-kin and/or care professionals, participants in this study were divided into two groups: group I (participants who performed the tasks without any support from the moderator) and group II (participants who received some minor support during the test). In total nine usability tests were performed with participants in this study. The plan was to perform all tests at Karolinska Institutet in order to have the same environment for all test participants. However, the research group managed only to perform four tests at Karolinska Institutet. Five tests were carried out in another location in Stockholm as some patients had difficulties to get to Karolinska Institutet. However, to provide almost the same circumstances for all participants, the same equipment was used in all tests.

**Data analysis:** The tests were audio recorded and transcribed verbatim. The screen activities were video recorded using Camtasia Studio 8.Ink (version 8.4) software for retrospective analysis. The tasks performance of participants was studied for both patient groups. The post-test interviews and questionnaires were analyzed using qualitative content analysis.

### **4.7 Ethical considerations**

An ethical approval for the four studies in this thesis was obtained from the Research Ethics Committee (2011/2093, 31/5, 19 January 2012) at Karolinska Institutet. For each individual study, participants received an information letter containing the purpose of the research and the procedure of data collection and ethical considerations e.g. anonymity and confidentiality. In addition, participants were provided a short description of the study verbally. Informed consent was obtained from the participants. All interviews, focus groups, and usability tests were audio recorded and stored safely. In study IV, the screen was video recorded for further analysis of the patients' tasks performance. The material was then transcribed verbatim and the names of the participants were not revealed in the presentation of the findings to ensure confidentiality.

## 5 FINDINGS

### 5.1 Post-discharge stroke care processes and interaction points (study I)

The aim of this study was to explore the current care and rehabilitation processes in post-discharge stroke care, to describe the information exchange throughout these processes, and to identify the interaction points between care professionals, patients and their next-of-kin.

The interaction points varied significantly throughout the care and rehabilitation processes for different patient groups (home care patients and non-home care patients). The care and rehabilitation were studied considering different risk factors as monitoring and treatment of risk factors are crucial for preventing a recurrent stroke. Depending on patients' risk factors and their ability to manage their illness, the number of touchpoints and intersection points differed. The home care patients who had severe disabilities and suffered from several risk factors, and required care at home, often had less touchpoints and instead, there were more intersection points between different care professionals. This group of patients had a passive role and their next-of-kin or care professionals had an essential role in initiating the care process. However, the non-home care patients who suffered from fewer disabilities and were able to visit the primary care center had a more active role in initiating the interactions with different care professionals. Therefore the care and rehabilitation processes for this group of patients consisted of more touchpoints than intersection points.

Both groups of patients were to some extent involved in the care planning, participating in monitoring the risk factors, and participating in rehabilitation planning. Since the care professionals considered the care plan as their working tool and not as a means to involve patients in the care planning process, the patients' involvement was however low.

Both patient groups were asked to actively take necessary actions to monitor the risk factors throughout the care and rehabilitation processes. Home care patients, however, required support from a next-of-kin or a district nurse to take the responsibility for taking actions in monitoring the risk factors on their behalf. On the other hand the non-home care patients actively took necessary actions in monitoring their risk factors and interacted with care professionals.

The rehabilitation planning actively involved both group of patients and their next-of-kin. The plan was established at the patients' home and care professionals together with the patients and possibly their next- of-kin discussed the rehabilitation needs, identified problems, and defined the goals and activities.

The analysis of the information provision to patients and their next-of-kin showed that patients received general information about stroke and its consequences mainly from the care professionals at the hospital where they had received care and rehabilitation at the stroke occurrence. The care professionals who were involved in the care and rehabilitation process of post-discharge stroke patients informed patients and their next-of-kin mainly about their

responsibilities, risk factors, the care processes, support organizations and patient associations.

## 5.2 Patients' information needs and supportive ehealth services (study II)

The aim of this study was to explore the information needs of post-discharge stroke patients using patient journey mapping and to use the patients' information needs to propose supportive eHealth services.

The results showed that patients' information needs differ at different phases of the patient's care and rehabilitation processes. The patient journey model which was developed in this study consisted of several phases and events. The analysis indicated that the post-discharge stroke care consists of four main events: discharge from hospital, discharge from rehab clinic, coming home, and clinical encounters; and two phases: at rehab clinic and at home (Figure 5).

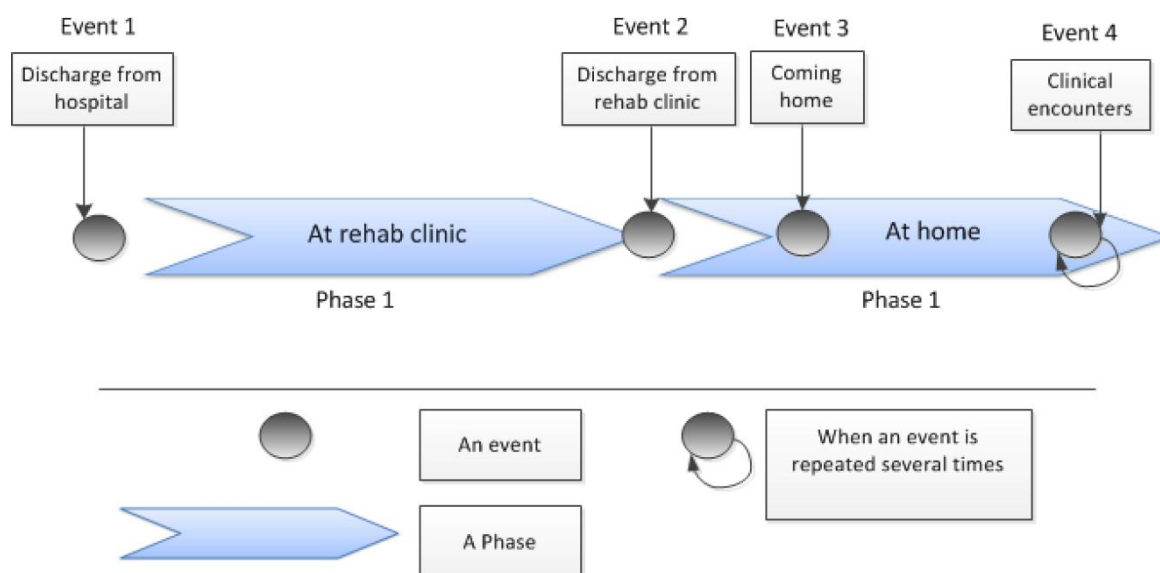


Figure 5. An overview of the post-discharge stroke patient's journey [76].

The main information needs of participants in this study included: a holistic overview of the care process, understanding the illness, collaboration with care providers, tracking the rehabilitation process, and practical guidance through healthcare and community services.

Based on the patients' information needs, potential supportive eHealth services were suggested by researchers and discussed with the participants. The suggested eHealth services throughout the patient journey included: *My discharge notes*, *My calendar*, *My referrals*, *My health information*, *My medication*, *My risk factors*, *My disabilities*, *My caregivers*, *My diary*, *My rehabilitation*, *My rights & responsibilities*, *My assistive devices*, *My insurances*, and *My patient associations and support organizations* (Figure 6).

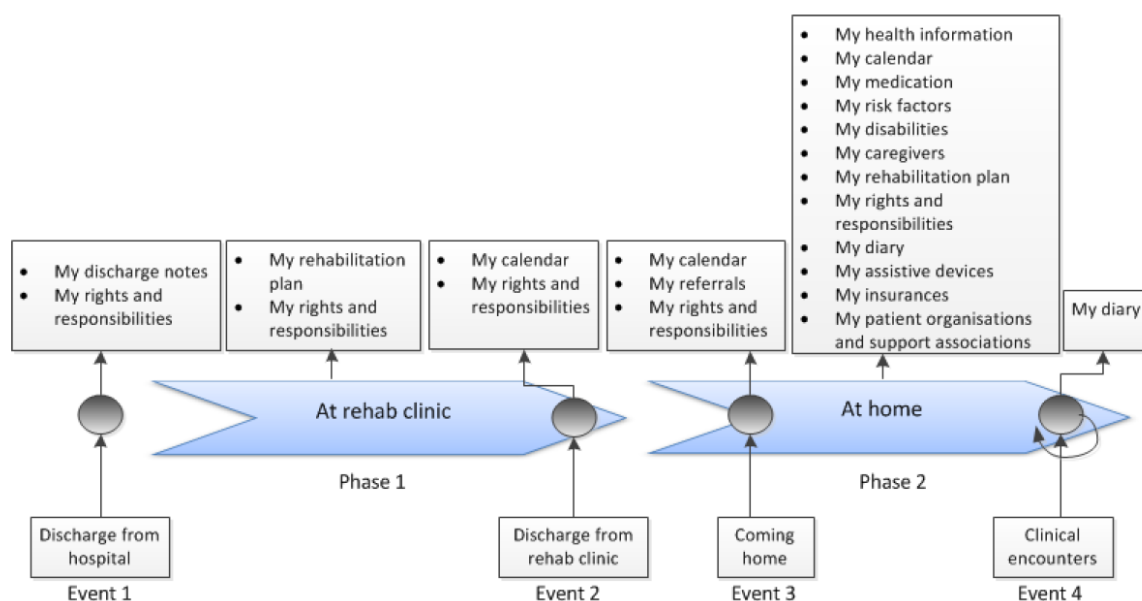


Figure 6. An overview of potential eHealth services in relation to the patient journey [76].

The analysis from further focus groups regarding the rehabilitation plan, resulted in designing an interactive prototype consisting mainly of *My rehabilitation*, *My notes*, *My contact information*, and *My calendar*. *My rehabilitation* consisted of goals, sub-goals, and training program with the possibility to access the training history. *My notes* gave patients the opportunity to document their mood history. In *My contact information*, patients had the possibility to collect all their care contacts, and *My calendar* gave patients the possibility to put reminders and manage their time. (chapter 10 Appendix Study II)

The preliminary evaluation of the prototype showed e.g. that defining goals and visualizing the goal achievement are motivational factors for the patients. In addition, patients believed that using the tool would be easier if the amount of information in the prototype was minimal [80].

The interactive prototype was further improved based on the results of the stroke patients' information needs, proposed eHealth services and also the results from the preliminary evaluation of the prototype [81]. The latest version of the interactive prototype consisted of two main parts: the menu bar and the content part in the middle of the page (Figure 7). The different eHealth services proposed based on the information needs were implemented in the home page of the interactive prototype.

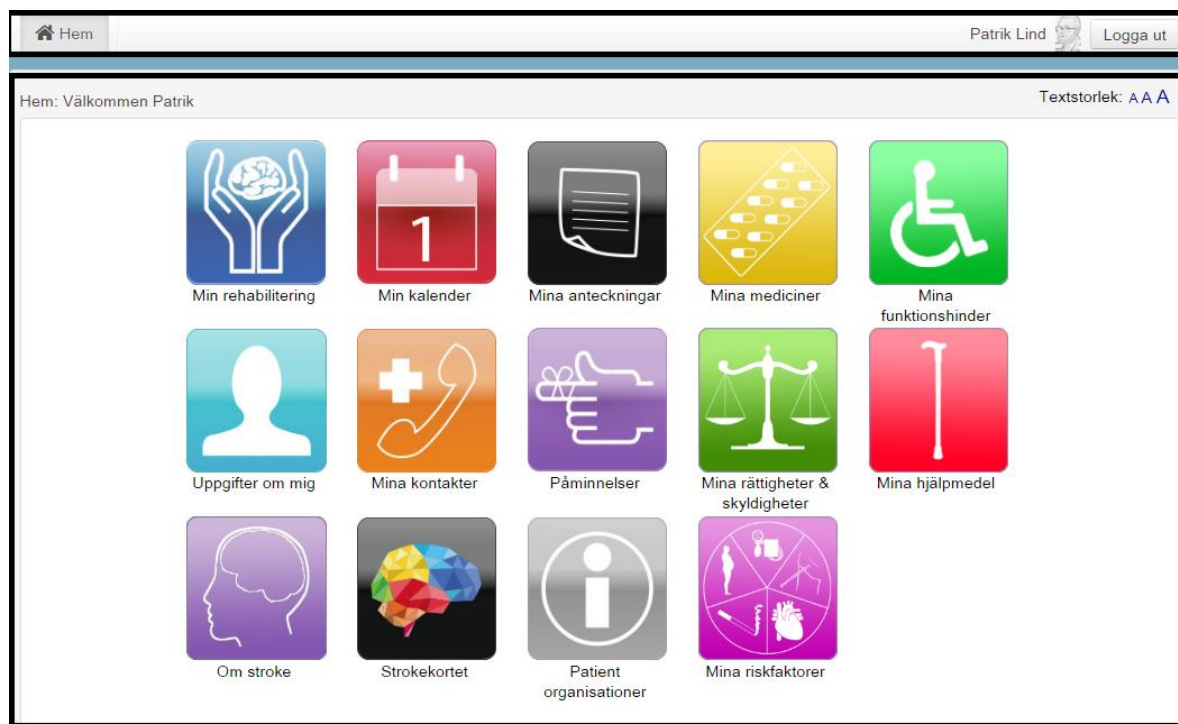


Figure 7. The menu-bar and the content part of the home page of the latest version of the care and rehabilitation planning tool.

Not all eHealth services in the care and rehabilitation planning tool were fully implemented. However, *My rehabilitation* included dynamic pages and consisted of an overview page in which the problems, goals, and activities were connected to each other using color-coding (Figure 8).

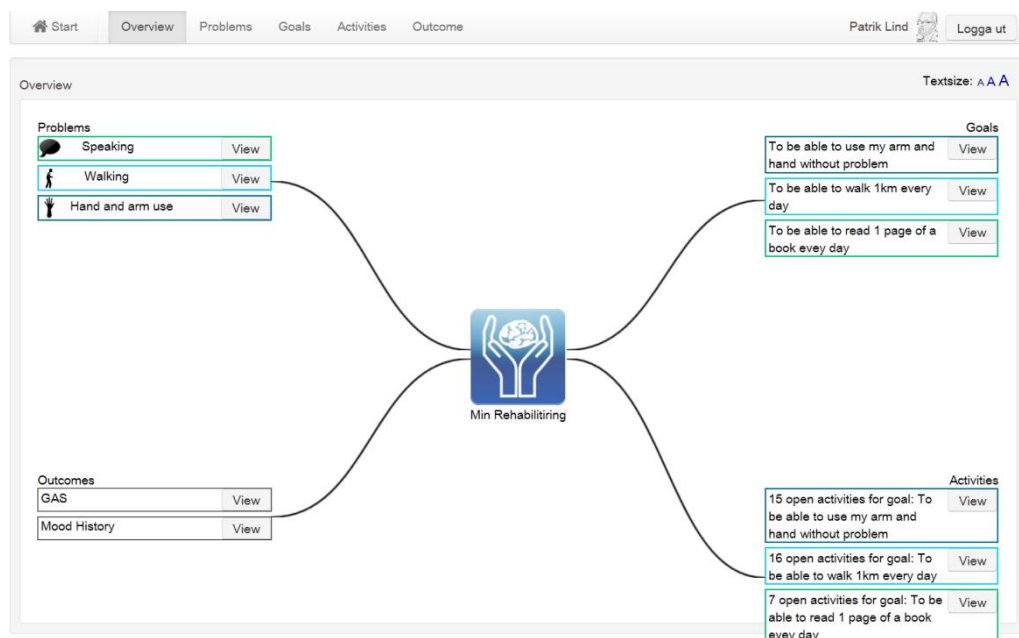


Figure 8. An overview of the connection between different problems, goals, and activities using color-coding (the figure is retrieved from the paper IV).

Two different ways are offered for setting up a new problem in the rehabilitation plan. The patient is able to add a new problem either using predefined international classification of functioning, disability and health (ICF) problems or entering a new problem as free text. The



patient is also able to connect each problem to a care profession in the neurology team and choose a color attached to the chosen care profession (Figure 9).

**Add a problem** [X]

Predefined ICF Problems ▾

Choose a therapie: Sjukgymnast [v] [Color Selection Bar]

Problem:  
Walking

Description:  
Moving along a surface on foot, step by step, so that one foot is always on the ground, such as when strolling, sauntering, walking forwards, backwards, or sideways.

Cancel Add

Figure 9. Adding a problem using predefined ICF problems, connecting the problem to a care professional, attaching a color to a specific therapist [81].

Two different types of goals are included in the rehabilitation plan, namely Simple and SMART (Specific, Measurable, Achievable, Relevant, and Time-bound) goals. Setting up a SMART goal is quite different from a Simple goal (Figure 10). For setting up a SMART goal the patient needs to set the baseline of the SMART goal and the importance and difficulty level of the goal.

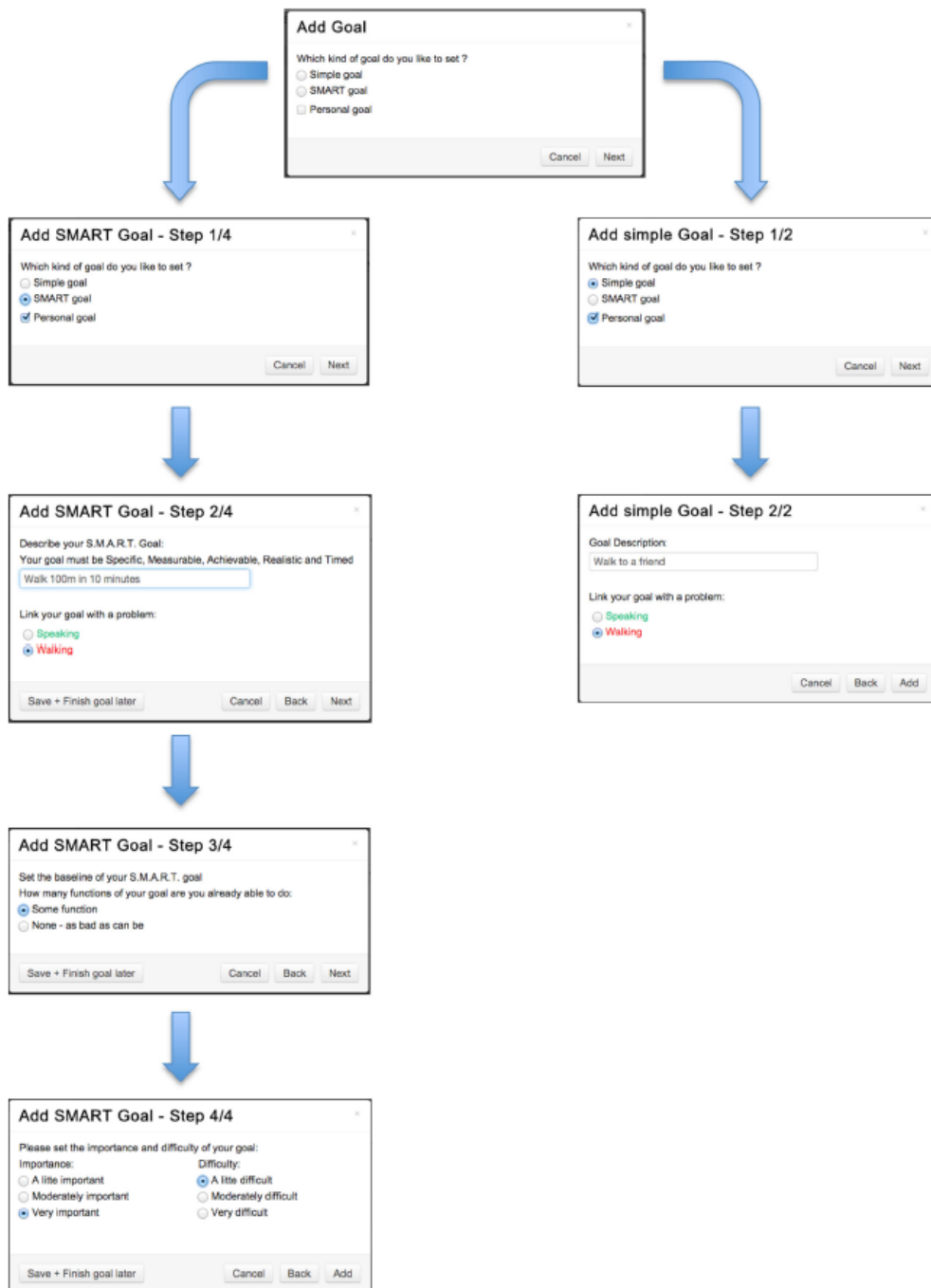


Figure 10. Steps to take to set up SMART goals vs simple goals [81].

There is the possibility to review the SMART goals and receive an overview of the progress in achieving the goals using the goal attainment scale (GAS). The overview page also provided the GAS for visualization of the goal achievement and mood history box for accessing an outcome view (Figure 11).



Figure 11. GAS and Mood History.

For adding an activity, the patient has the possibility to e.g. connect the activity to the related goal, start and end date for performing the activity, select the specific days of the week for repeating the activity (Figure 12).

### Add a new activity

Activity for goal: To be able to walk 1km

Activity description: Walk 1km

Day to start activity: 2016/09/22 11:00

Add a link for a tool: http://

Repeat your activity?: ☒ Yes ☐ No - Single Activity

On which days in the week do you want to do your activity?

Mån Tis Ons Tor Fre Lör Sön

Select the enddate: 2016-10-27

SUMMARY

Duration: 2016-9-22 - 2016-10-27

Repetitions	Per week	Weeks
15	3	5

Cancel Save

Figure 12. Steps to take for setting up a new activity [81].

The improved version of the interactive prototype was then evaluated with two post-discharge stroke patients and a next-of-kin. The results from the prototype evaluation using usability testing showed some usability problems with the prototype [81]. In addition, none of the participants could explain the difference between different types of goals. The GAS and mood history were appreciated by the participants and were seen as helpful tools for having

an overview of the participants' progress and mood history throughout the rehabilitation process. In addition, the home page with different icons appeared useful to the users. However, the tool was complicated for the participants as they had difficulties with understanding all terms used in the tool and had trouble with some visualization in the rehabilitation plan such as different colors used for different care professionals. The participants were, however, positive towards using the tool.

### **5.3 Information flow through the Swedish national HIE platform (study III)**

The aim of this study was to explore how the infrastructure of the Swedish national HIE platform meets the information needs of post-discharge stroke patients, as implemented in the care and rehabilitation planning tool. Therefore the opportunities and limitations of accessing and interacting with necessary health information through the HIE platform was studied.

The results of mapping the patient journey model with the patient information needs showed that different amounts of information are created during different phases and events of the patients' care and rehabilitation journey. The information created by different care professionals is documented and stored in the patient's EHR in different healthcare organizations.

The analysis of the HIE platform, in which service contracts and APIs make health information available, indicated that not all the information which would be requested by the care and rehabilitation tool could be made available today. However, patients are able to access information about their referrals, discharge notes, health information (diagnosis, symptoms, and disease history), medication lists, contact information for care contacts, disabilities, and care plan including rehabilitation plan.

Some of the patients' desired information such as patients' rights and responsibilities and patient associations are available publicly through webpages such as webpage 1177 vårdguiden (a national Swedish website and telephone service which provides information, counselling and services in healthcare) [99].

The analysis of the information flow using different usage scenarios regarding (1) basic access to health information, (2) interactive access to complex health information, and (3) access to borderline health information provided different results.

In the scenario for basic access to health information in which a patient needs to have access to his/her medication list, the analysis indicated that the patient is able to retrieve the necessary information regarding medication list as the relevant service contract is available.

The second scenario was related to accessing the rehabilitation plan and sharing the updates with the care professionals in the neurology team. The results showed that even though the patient is able to access the desirable information regarding rehabilitation plan, there is currently no support to send the possible changes or updates to the care professionals in the neurology team.

In the third and last scenario, the patient needs to have access to information about assistive tools using the eHealth service *My assistive tools* in the care and rehabilitation planning tool. The results indicated that even though information about the patient's assistive tools are documented in the patient's EHR, the patient is not able to access the information. The reason for this would be that the assistive tools are stored in free text in a medical record note and therefore no service contract has been implemented for this type of information. On the other hand, more structured information about the patient's assistive tools might be documented and stored in other HISs e.g. in the prescription database for assistive tools management. However, these HISs are not yet connected to the Swedish national HIE platform and consequently access to this type of information is not possible for the post-discharge stroke patients.

#### **5.4 Evaluation of the prototype (study IV)**

The aim of this study was to evaluate the final version of the care and rehabilitation planning tool to study its effectiveness and user satisfaction from the perspective of the post-discharge stroke patients suffering from aphasia.

Before evaluating the final version of the prototype with stroke patients, the prototype was evaluated from the care professionals' perspective in the neurology team using UTAUT [82]. The results of this evaluation showed that care professionals believed that the tool would facilitate the follow-up process and it would support patients to understand their journey. One of the main challenges as expressed by the care professionals related to the responsibility for the system. They believed that the system is the patients' tool and the patients should therefore have the main responsibility for it. The care professionals expressed concerns that they would need to use yet another tool, and stressed the importance of integrating the system with e.g. the EHR they used to reduce the need to double document or manually transfer data. Despite the challenges mentioned by the care professionals in this study regarding e.g. time shortage and responsibility for the tool, they were positive towards the tool and its usefulness for helping post-discharge stroke patients to understand the care and rehabilitation processes.

The tool was then evaluated from the post-discharge stroke patients' perspective using usability testing (paper IV). The analysis of the data collected through usability tests was divided into two different parts, (1) studying the effectiveness of the tool by analyzing the task performance by participants in the study (2) studying user satisfaction, identifying the design implications and perceived usefulness through qualitative analysis of the users' feedback.

As the idea was that the tool should be used by post-discharge stroke patients either independently or with some support from their potential next-of-kin or a care professional, the participants in this study were divided into two groups, namely group I & II. Group I included patients who did not receive any support during the tests and group II included participants who had some minor support with performing the tasks during the tests. In addition, the tasks were mainly divided into two different categories: tasks related to

establishing a rehabilitation plan; and tasks related to finding relevant information. When it comes to task performance for the participants in group I, only one participant was able to accomplish half of the tasks successfully. The other participants in this group had major difficulties in performing the tasks, particularly the tasks related to the rehabilitation planning. However, the analysis of the task performance by the participants in group II showed that all participants accomplished the tasks related to information seeking successfully without any support from the moderator. In addition, all participants accomplished most of the tasks related to establishment of a rehabilitation plan successfully with some support from the moderator. The results from these two groups of participants showed that the care and rehabilitation planning tool is not effective for post-discharge stroke patients suffering from aphasia. However, the results indicated that the effectiveness of the tool increases significantly if patients receive some support in using the tool either from their next-of-kin or a care professional.

The qualitative analysis of the participants' feedback resulted in several categories and sub-categories (Table 3).

Tabel 3. An overview of the categories and sub-categories (the table has been retrieved from paper IV).

Categories	Sub-categories
Satisfaction	Time to learn and support from next-of-kin
	The appropriate time for using the tool after stroke occurrence
Design implications related to fatigue and concentration difficulties	Information overload
	Complexity of concepts
Visualization	Using graphics
	Results visualization
	Using color-coding
Perceived usefulness	

Despite the fact that the tool was not effective for the participants in this study, they were positive towards using the care and rehabilitation planning tool to track their goals and activities. Some participants believed that the tool was not difficult to use and working with it was enjoyable. However, most of the participants mentioned that some parts of the tool were quite complicated and difficult to understand.

Time, training and support from next-of-kin were mentioned to be of great importance for using the care and rehabilitation planning tool. Some participants believed that time and training is needed to understand different parts of the tool. They also mentioned that having access to the tool earlier in their care and rehabilitation processes would be more helpful for them as many patients suffer from severe communication problems.

#### **5.4.1 Design implications**

Since many stroke patients experience brain fatigue and have concentration difficulties, several design implications in designing screen-based applications like the care and rehabilitation planning tool should be taken into consideration. Many stroke patients suffering from aphasia have difficulties in reading and understanding large amounts of text. Therefore, it is of great importance to consider information overload and reduce the amount of information presented in eHealth services aimed at this user group. Despite the fact that some of the participants were satisfied with the quantity of the information in 'home page' (Figure 4), most of them would like to be able to select only the information that met their needs. In addition, some of the participants were not satisfied with the information amount in the 'overview' page for *My rehabilitation* (Figure 5), which was considered to contain too much information and be difficult to understand.

In addition to the information overload the size and the number of the icons in the 'home page' was an issue from the participants' perspective. However, the big icons in 'home page' were perceived as easy to access indicating that this type of layout may be preferable.

Although the care and rehabilitation planning tool was designed using a user-centred design approach, some concepts such as SMART and Simple goals, ICF codes etc. were difficult and complex for participants to understand.

##### *5.4.1.1 Visualization*

Participants appreciated the graphs, symbols and icons used in the care and rehabilitation planning tool and believed that these features would support them in understanding the care and rehabilitation processes better. Visualization of the results e.g. using GAS and mood history was seen as a motivational factor for patients to do their activities. Participants appreciated the mood history and liked the idea of having an overview of their mood history over time.

Using color-coding for linking the problems, goals and activities and also for distinguishing different care professions in the neurology team was another positive factor for using the tool. However, the participants had difficulties to understand how the color-coding worked, indicating that a more intuitive design would be required.

##### *5.4.1.2 Perceived usefulness*

Having access to a care and rehabilitation planning tool which e.g. support patients throughout their journey and provides them with necessary health information, seemed to be useful from the participants' perspective.

## 6 DISCUSSION

The overall aim of this research was to explore how eHealth, in this case a care and rehabilitation planning tool, can be designed to support post-discharge stroke patients' self-management and improve collaboration between patients, their next-of-kin and care professionals involved in stroke care. Before continuing to discuss the findings presented in this thesis, I will discuss some methodological aspects of the research.

### 6.1 Methodological considerations

A qualitative research approach was used throughout this research. Data were collected through different qualitative techniques such as interviews, focus groups, and observations. Using only qualitative methods and techniques has been seen as a strength of this research as an in-depth understanding of the subjects studied has been gained. In addition, there was a need of a comprehensive overview of the care and rehabilitation processes of post-discharge stroke patients. Moreover, using a case study approach provided us with a deep understanding of the information flow between different eHealth services within the care and rehabilitation planning tool and other HISs through the national HIE platform. Understanding the patients' information needs and studying the effectiveness and user satisfaction of the care and rehabilitation planning tool also needed a thorough investigation using focus groups, interviews and observations. Due to the fact that there was a need of an in-depth understanding of the subject in different studies, using qualitative approaches appeared to be more appropriate for this research.

#### 6.1.1 Limitations of the four studies

##### 6.1.1.1 *Study I*

This study aimed to explore the care and rehabilitation processes of post-discharge stroke patients and identify the interaction points between care professionals, patients, and their next-of-kin. The participants in this study included physicians, registered nurses, district nurses, home care district nurses and care professionals in a neurology team (a speech therapist, an occupational therapist, a counsellor, and a physiotherapist) in primary care in Stockholm County Council.

This study had to deal with a number of limitations: We consciously decided to only study a specific part of the stroke chain and only certain care professionals. To have a comprehensive overview of the whole stroke care and rehabilitation processes, there is a need of involving other actors involved throughout the care chain of stroke. We also decided to exclude the inpatient processes of stroke care as this had been studied in previous studies [100]. In addition, social care processes, nursing homes, and other kinds of housing for elderly had been excluded in this study. The interaction points throughout the care and rehabilitation processes of post-discharge stroke care were studied from the care professionals' perspective and not the patients' nor their next-of-kin's, although observations were done of care planning meetings with patients. In addition, in this study we only focused on the information



provision by the care professionals and did not study the patients' information needs which are of great importance in the design of any eHealth service. However, patients' information needs were studied in study II of this research.

#### *6.1.1.2 Study II*

This study aimed to identify post-discharge stroke patients' information needs to propose appropriate eHealth services. The participants in this study were a number of post-discharge younger (< 65 years) and older ( $\geq$  65) stroke patients recruited from the patient association in Stockholm.

Since the stroke patients in this study suffered from milder disabilities and were able to handle computers, they might not be representative of many stroke patients. This study had to deal with an additional weakness which was the low number of the participants in the focus groups. Since these participants received care and rehabilitation within the same County Council, namely Stockholm, the transferability of the results regarding participants' experiences and the potential eHealth services might be limited. Another weakness of this study was that none of the participants had any experience of rehabilitation planning. It is a challenge to recruit patients who are in a middle of a course of events such as stroke occurrence. In addition, there might be changes in care organizations, available assistive tools and efforts for including patients and changes in the care and rehabilitation processes of patients once the patients are able to participate in a study. Therefore it is essential to also explore the context of patient care and other stakeholder perspectives, as was e.g. done in study I.

#### *6.1.1.3 Study III*

This study aimed to explore the opportunities and limitations of accessing and interacting with necessary health information through the Swedish national HIE platform. Ideally, study III would have included a real integration of the care and rehabilitation plan with the national HIE platform, but this was not feasible within the scope of this thesis. As the national HIE platform introduces major changes in the eHealth landscape in Sweden, and few academic studies have been performed to explore this, we considered it an important topic to still include. Therefore, a method using realistic scenarios based on the results of study I and II was constructed to enable a first evaluation of the national HIE platform. The likelihood is high that other challenges would be identified if a real integration and data access were implemented, but we consider this an important step in analyzing the emerging Swedish eHealth context.

In addition, we chose not to study a real patient case and real health information in the patient's EHR due to ethical issues. An issue that can be anticipated is that even if data are made available through the national HIE platform, poor quality of data in the source systems may make the data less useful to the patient than expected. Further studies of the impact of the national HIE platform would therefore be required to provide a richer picture of the effects it will have on patient empowerment and involvement.

#### *6.1.1.4 Study IV*

This study explored the user satisfaction and effectiveness of the care and rehabilitation planning tool through usability tests.

This study had to deal with some limitations. A weakness of the study was the low number of participants. Approximately twenty post-discharge stroke patients suffering from aphasia were informed about the study. However, only nine patients fulfilled the inclusion criteria due to their severe physical disabilities, their communication difficulties, and understanding the study.

Another weakness of this study was the moderator's bias that might occur during the tests as performing usability tests with patients suffering from aphasia was challenging and required sufficient skills and knowledge about how this group of patients receive and interpret information.

Another limitation in this study was the test setting. Since some participants were not able to visit Karolinska Institutet where the main testing environment had been prepared, the tests were performed in two different places. However, except location, the tests were performed under the same circumstances for all patients.

## **6.2 Discussion of main findings**

The research presented in this study is of a rather practical nature, focusing on the design and evaluation of an eHealth tool for post-discharge stroke patients. In this discussion, focus is on placing these results in a broader context to consider the main contributions of this research.

### **6.2.1 Designing eHealth to support patient-centered care**

As mentioned in the introduction of this thesis, patient-centered care is about providing patients with necessary information and engaging them in the decision making process throughout their patient journey. Giving patients access to their health information and involving them throughout their care and rehabilitation processes has the potential to empower patients and facilitate self-management. Empowering patients and supporting self-management is of great importance for chronically ill patients who suffer from a chronic disease for a long time and require care from different care providers. Using ICT in healthcare and designing appropriate eHealth services can be a potential solution for empowering patients and supporting them throughout their journey. However, digitalization of healthcare can also result in an increased digital divide [101, 102]. When a certain group of patients, in this case, chronically ill patients suffering from different disabilities are excluded from the design and evaluation of eHealth services there is a very real risk that they will not be able to utilize the resulting tools. Patients' information needs the severity of the disease and, their disabilities need to be taken into consideration in the design of eHealth services for patients. It is therefore crucial to involve all kinds of patients in the design and evaluation of eHealth to be able to develop services which are based on each specific patient group's needs.

Increasing patient participation in care processes has long been in focus of studies nationally and internationally. A study on patient participation in Sweden has shown that patients experience involvement when they are e.g. engaged in a decision making process that occurs based on their knowledge and needs and when they receive necessary information about their needs [103]. However, chronically ill patients and particularly stroke patients suffer from unmet information needs and also a lack of access to necessary health information. Several previous studies have also focused on stroke patients' unmet information needs [104, 105] and the results from our research confirm their findings. Despite the fact that Wiles et al. in 1998 [106] divided necessary information to stroke patients into different categories, namely clinical, practical information, and information on continuing care and resources in community, there is still a lack of appropriate HISs and eHealth services to provide patients with this information.

Hoffmann et al. designed a computer system to improve information provision customized according to patients' information needs and to facilitate collaboration between stroke patients and care professionals [107]. In our research post-discharge stroke patients' information needs were identified and appropriate eHealth services were suggested by researchers and discussed with the patients.

The results from our research also confirm the finding from previous studies regarding patients' access to their EHRs [78, 79, 108, 109], care professionals' experiences about giving patients online access to their health information [110] and the effects of providing online access to patients [111]. These studies and our research showed that despite some concerns by care professionals and limitations in accessing health information online, patients and care professionals are positive towards this reform.

### **6.2.2 Designing eHealth to support collaboration**

The primary aim of the care and rehabilitation planning tool was to support post-discharge stroke patients throughout their care and rehabilitation processes by providing them with necessary information and support for self-management. However, it was also intended as a collaborative tool between patients and different care professionals. The data collected from interviews in study I indicated that there was limited support for providing information to the patients and their next-of-kin and an improvement was needed. We believe that a two-way information exchange would improve collaboration between patients and different care professionals. Despite the challenges and limitations of accessing and sharing health information identified in study III, the results from evaluating the tool using UTAUT indicated that healthcare professionals perceived the tool as a useful support of the patient's own activation, as well as cooperation within the team (including patients and next-of-kin) through patients reporting and sharing the performed activities and reflecting on their outcome. In addition, the care professionals in this study believed that the tool could support collaboration between the team and other actors e.g. in home care through having access to an overview of information about e.g. a patient's assistive tools and appointments with different care professionals.

### **6.2.3 Patient participation in eHealth design and evaluation**

To design appropriate eHealth services which meet patients' needs and support them throughout their journey, patients need to be involved in the design and evaluation processes of these services. A strength with this research has, therefore, been the engagement of post-discharge stroke patients in the design and evaluation of an electronic tool which aims to support them throughout their journey, providing them with necessary information and giving them opportunity to plan their activities and improve their collaboration with different care professionals. An additional strength with this research is using eHealth to empower a patient group who is in great need of supporting tools for improving their self-management. This research provides a deep understanding of the information needs of this patient group throughout their care and rehabilitation processes. Involving post-discharge stroke patients suffering from aphasia in the evaluation process of the care and rehabilitation planning tool provided us with unique information about this group's needs concerning design of eHealth interventions. It is essential to involve chronically ill patients in the design and evaluation processes of eHealth services as these patients are of great need of having appropriate eHealth services to feel empowered and confident throughout their journey.

### **6.2.4 Infrastructure to support empowering and collaborative eHealth**

Giving patients online access to their health information would not be possible without an infrastructure for information exchange between different eHealth services and different EHRs and other HISs. Patients have different information needs throughout their care and rehabilitation processes. Information is created and stored in different source systems during different events and phases of patients' journeys. Therefore, having access to a national HIE platform which facilitates the information exchange between different HISs and eHealth services is of great importance. The results of exploring the national HIE platform from a patient perspective presented in this thesis are however only a first step in evaluating the impact of this new infrastructure. Further evaluations with real integrations, real data and real users, both patients and healthcare professionals, are needed to fully describe and analyze both challenges and opportunities that the national HIE platform introduces. From an international perspective, the focus on the Swedish context may appear quite limited. However, the identified challenges in supporting collaborative eHealth through a large-scale infrastructure for interoperability can be generalized beyond the Swedish case.

### **6.2.5 Generalizations and transferability of the results**

Generalizability [88] and transferability of results are discussed as problematic in case studies and other forms of qualitative research [86]. This also applies to research with a design strategy, where researchers are often faced with questions of how their project is different from any other development project. It is therefore essential in this type of research, to provide detailed descriptions of contexts, participants and artefacts; so that the results can be understood by the audience and their potential transferability to other contexts can be assessed. This has been an aim throughout all the studies in this thesis.

The overall results from this research can be transferred to similar contexts where care and rehabilitation processes are similar. The results may, however, not be representative in all settings and for all patient groups as the tool is designed only based on the care and rehabilitation processes for post-discharge stroke patients in Stockholm County Council and is based on their needs. Therefore, in order to transfer parts of the results to other contexts, it is essential to also understand those contexts fully to be able to determine how similar they are. Does another patient group experience similar needs? Are the structures for collaboration and interaction similar?

From a methodological perspective, the concept of designing such a care plan based on the patients' needs could be used for other patient groups who require having access to prospective overviews of what is planned in their care process in the future.

The methods used in this study for involving patients as well as for identifying the patients information needs could be used for other chronically ill patients who require care from different care providers and experience similar situations throughout their care processes. Patient experiences and patient journey mappings in the design of eHealth services for stroke patients could be used for design of eHealth for other patient groups who suffer from a chronic condition for a long time.

### **6.3 Future work**

Future research may further explore problems regarding involvement of patients in the design and evaluation of eHealth associated with severe disease. In addition, further evaluation of the care and rehabilitation plan is needed to study the effectiveness and user satisfaction of the tool after a period of use by patients. There is also a need of continued research regarding using patient experiences and patient journey mapping in the design of eHealth for other groups of patients than stroke patients. Further studies of how the national HIE platform can support the implementation and use of collaborative and empowering eHealth are needed. Here, the results from study III provide a starting point, from both a methodological perspective, and as a first description of the national HIE platform and the challenges and opportunities it provides.

## 7 CONCLUSIONS

An in-depth understanding of the care and rehabilitation processes in post-discharge stroke care was gained through this research project. Collaborative interaction points between patients, their next-of-kin and different care professionals involved in post-discharge stroke care were identified. Based on the patients disabilities and risk factors patient involvement varied significantly. Patients' activity levels at interaction points may affect the design of eHealth services. A supportive tool for patients with low participation might focus on supporting patients' next-of-kin or home care professionals in their interaction with different care professionals while a supportive tool used by patients with higher activity levels should mainly focus on supporting the patient in coordinating his/her care.

To provide eHealth services which meet patients' needs, it is crucial to involve patients. Excluding e.g. elderly patients who suffer from cognitive and physical disabilities in the design and evaluation of eHealth can be detrimental to their opportunities to use digital tools for empowerment and inclusion in the future. Involving different patient groups, especially those who require care from different care providers due to their different disabilities and health problems, can on the other hand improve the design of eHealth for these groups of patients who might be in a great need of appropriate eHealth for the management of their disease, thereby potentially reducing the digital divide. Use of different data collection methods and techniques and patient journey mapping which has not been used often in eHealth studies can provide us with a deep understanding of patients' experiences and their needs throughout their care and rehabilitation processes.

Despite the fact that several standards have been developed to improve interoperability in eHealth, there are still challenges and limitations with information exchange between different HISs and eHealth services. The Swedish national HIE platform provides opportunities for information exchange, however needs to be further evaluated from a patient perspective to determine how it can support and impact on patient empowerment and collaboration in care. As this is an area rapidly evolving and of high priority in Sweden today, the results presented in this thesis will provide important input to future research, development and policy in this field.

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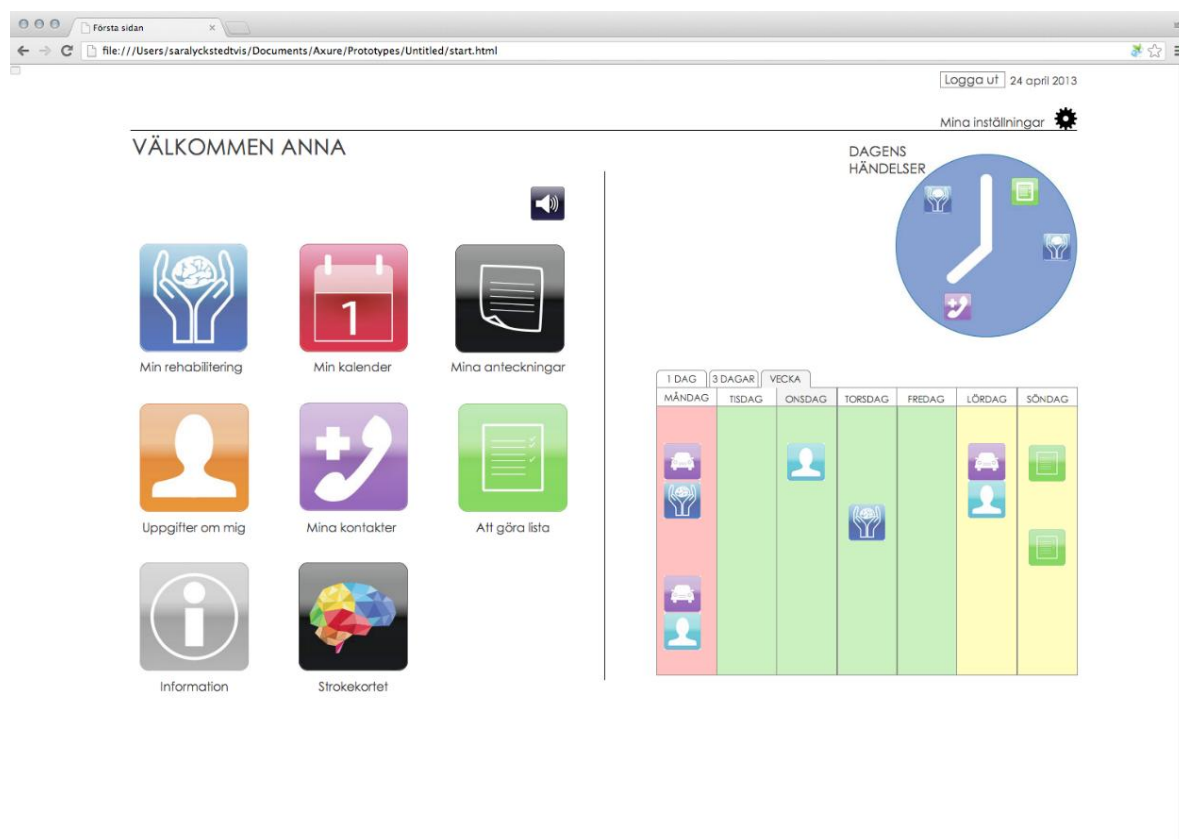
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## 10 APPENDIX STUDY II

The overview page of the first version of the electronic care and rehabilitation planning tool [in Swedish]. The figure is retrieved from [80].



*My rehabilitation* as an eHealth service in the care and rehabilitation planning tool. My rehabilitation consists of goals and sub-goals. The figure is retrieved from [80].

