

From the DEPARTMENT OF LEARNING, INFORMATICS,  
MANAGEMENT AND ETHICS  
Karolinska Institutet, Stockholm, Sweden

**UNDERSTANDING HOW PERSONS WITH  
MILD ACQUIRED COGNITIVE IMPAIRMENT  
USE AND EXPERIENCE INFORMATION  
AND COMMUNICATION TECHNOLOGY:  
AN EXPLORATORY STUDY**

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**Karolinska  
Institutet**

Stockholm 2016

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Published by Karolinska Institutet.

Printed by Eprint AB 2016

Cover illustration by Aboozar Eghdam

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ISBN 978-91-7676-524-1

# UNDERSTANDING HOW PERSONS WITH MILD ACQUIRED COGNITIVE IMPAIRMENT USE AND EXPERIENCE INFORMATION AND COMMUNICATION TECHNOLOGY: AN EXPLORATORY STUDY

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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*“We've always defined ourselves by the ability to overcome the impossible.  
And we count these moments. These moments when we dare to aim higher, to break barriers  
..., to make the unknown known. We count these moments as our proudest achievements.  
But we lost all that. Or perhaps we've just forgotten that we are still pioneers. And we've  
barely begun”*

- Cooper  
from *Interstellar*



## ABSTRACT

Mild acquired cognitive impairment (MACI) is a term used to characterise persons who acquire a minor, non-progressive decrease in cognitive functions due to some physical trauma, or medical conditions, such as benign tumour, cardiovascular diseases (stroke), or side effects of medical treatment. Persons with MACI might suffer from multiple cognitive and/or slight physical disabilities and need rehabilitation to recover and regain their skills. Information and communication technology (ICT) is one approach that can be considered for assisting persons with MACI to improve their skills, support their self-management, and cope with their condition. However, understanding how persons with MACI use and experience ICT tools is a challenging task.

This thesis belongs to the field of consumer health informatics (CHI). The overall aim of this research was to understand how regular ICT tools are used by persons with MACI in their daily lives. In addition, the aim was to explore how to capture their experience while using these tools.

With respect to the field of user experience (UX) several different methods were used in this thesis: a systematic review to find relevant literature about ICT tools for persons with MACI and analysis of the tools' functionality against clinical needs (study I); surveys to explore how persons with MACI actually use and experience ICT and e-services (study II); social network analysis to address the communication and social interaction aspects (study III); and a diary-keeping method to explore the feasibility of a UX field study method and to capture the frequency of using regular ICT tools on a daily basis (study IV).

The findings of this thesis showed a lack of ICT tools developed and evaluated for supporting self-management of persons with MACI. Moreover, a subset of the International Classification of Functioning, Disability and Health (ICF) identified in this thesis showed it to be a valuable analytical framework for exploring the functionality of ICT tools to match the needs of persons with MACI. Considering the lack of data about the persons who did not participate in the studies of this thesis, the findings provided rough information regarding the use of e-services for this population in addition to their cognitive failure levels and the most important aspects of ICT tools and web 2.0 services. Moreover, the participants in this research showed they were as capable of using the existing ICT tools as a healthy population. The findings also showed that social media, in this case Facebook, might be a valuable means of social support over and above its informational benefits for persons with MACI. Last but not least, as a result of a pilot study, the findings provided information about daily activities, feelings and use of computer/Internet as well as the strengths and weaknesses of using the UX field study method for capturing daily experiences of persons with MACI.

To the best of our knowledge, the studies of this thesis were the first to explore the ICT and users' experience for health information consumers with MACI. In conclusion, the main contribution of this thesis relates to the knowledge about the ICT tools and Web 2.0 services that are currently being used by persons with MACI and promoting them among the health informatics research community as individuals with special needs and necessities. The thesis also preliminary addresses some challenges in exploring the user experience of health information consumers with MACI.

## LIST OF SCIENTIFIC PAPERS

- I. **Eghdam A**, Scholl J, Bartfai A, Koch S. Information and Communication Technology to Support Self-Management of Patients with Mild Acquired Cognitive Impairments: Systematic Review. *Journal of Medical Internet research*. 2012;14(6): e159.
- II. **Eghdam A**, Bartfai A, Oldenburg C, Koch S. How Do Persons with Mild Acquired Cognitive Impairment Use Information and Communication Technology and E-Services? Results from a Swedish National Survey. *PLoS One*. 2016;11(7): e0159362.
- III. **Eghdam A**, Hamidi U, Bartfai A, Koch S. Facebook as a Communication Support for Persons with Potential Mild Acquired Cognitive Impairment: A Content and Network Analysis Study. Manuscript
- IV. **Eghdam A**, Bartfai A, Koch S. Experience of Daily Activities with the Focus on Information and Communication Technology for Persons with Mild Acquired Cognitive Impairment: A Pilot Study. Manuscript



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## LIST OF ABBREVIATIONS

AAL	Ambient Assistive Living
ABI	Acquired Brain Injury
CFQ	Cognitive Failure Questionnaire
CHI	Consumer Health Informatics
DRM	Day Reconstruction Method
HCI	Human-Computer Interaction
HI	Health Informatics
ICF	International Classification of Functioning, Disability and Health
ICT	Information and Communication Technology
IT	Information Technology
MACI	Mild Acquired Cognitive Impairment
MCI	Mild Cognitive Impairment
SNA	Social Network Analysis
TBI	Traumatic Brain Injury
UX	User experience
WHO	World Health Organisation



# 1 INTRODUCTION

## 1.1 HUMAN-COMPUTER INTERACTION

Human-computer interaction (HCI) is a cross-disciplinary field that lies at the intersection between computer science and social and behavioural sciences which deals with the theory, design, implementation, and evaluation of the ways humans interact with computing devices [1, 2].

### 1.1.1 Scientific foundation

The early focus of HCI was generally on office systems and the evaluation of user interfaces. It was used to develop basic visualisation concepts of operating systems and the focus was mostly on the graphical user interface and software commands such as windows, menus, icons, and mouse pointing [3]. Originally HCI professionals who came from different academic disciplines such as human factors, psychology, cognitive science, ergonomics and computer science were the pioneers in terms of adding colour, videos, voices and interactive elements to graphical user interfaces. The initial vision for HCI was to apply cognitive science methods and theories to software development [4]. During the 1980s, new scientific ideas such as 1) the increasing internationalisation of HCI, 2) technology, 3) differentiation within the original cognitive-science community of HCI, and 4) the growing multidisciplinary constituency of cognitive science itself contributed to the HCI mainstream to make it a vast, rich and diverse scientific foundation [2].

One of the main concerns of the HCI field is to improve usability. Throughout the years, in order to understand the tasks and work practices, a large variety of methods has been developed in HCI to provide new possibilities for supporting people by enhancing the usability of systems and devices [2]. In the past decades, HCI academics have tried to create a mutual understanding about usability for different disciplines, such as computer science and information technology (IT). Today, a variety of standards exists for producing information and communication technology (ICT) tools, but the designers' knowledge about the tools' usability is still insufficient [5, 6].

### 1.1.2 Human-computer interaction and human cognition

The human cognitive process consists of a variety of mechanisms such as artifacts, tools and socio-technical environments that are involved in distributed human cognition [7]. It is far beyond the process that just simply happens in the brain. The healthy human mind has a limited capacity for problem-solving, decision-making, language and information processing [8, 9]. The advancement of IT confronted the traditional software development methods to change their viewpoint from experienced users with technical backgrounds, to the general public, and even specific users with specific cognitive characteristics [10]. Today, IT has become ubiquitous and necessary, and the interactive computing contexts have influenced the pre-existing social, motor and cognitive skills of different users [7, 11]. Instead of designing a

universal machine for everyone, different users with different information processing abilities have to be taken into account [12].

The focus of HCI professionals is to provide relevant information in addition to opportunities for communicating with computer systems based on human cognitive capability [13, 14]. Essentially, their mission is more than just designing user interfaces. They try to support human problem-domain interaction by making computers invisible, and understanding different users' behaviours and cognitive skills [15, 16]. By using the right "languages of doing" and analysing the social and technical contexts, they make it easier for different users to obtain suitable systems based on their own cognitive problem-solving and information processing skills [17].

### **1.1.3 User experience**

The phenomenon of user experience (UX) has been adapted by HCI researchers and practitioners as "*a person's perceptions and responses resulting from the use and/or anticipated use of a product, system or service*" [18] which includes a broad range of dynamic concepts in the human-technology interaction; concepts such as "*users' emotions, beliefs, preferences, perceptions, physical and psychological responses, behaviours and accomplishments that occur before, during and after use*" [18]. The experience is a summation of "*judgment, attitude, behaviour, sentiments, feeling, sensation, opinion, memories actions and reactions*" [19].

Despite the heterogeneous views among UX academics and practitioners, there is a common way to understand how the individual's product experiences will be influenced by social interaction and collaborative product use [20, 21]. By studying products, users' interactions with them, and their experiences, UX research aims to deliver an enhanced understanding of the people, contexts, and activities to provide better solutions for usability problems [20].

### **1.1.4 User experience research methods**

The field of user experience has an extensive variety of research methods in order to understand user behaviours, needs, and motivations while using ICT tools. Generally, UX made it possible to capture users' experience by using various types of methods and tools such as analytical models, focus groups/interviews, on-line/paper-based surveys and guidelines, field studies of different contexts, usability experiments/tests with real users, and applying user-centred system design methods [2, 10, 22]. Using these methods allows users to participate in the design process as the representatives of their community in designing the appropriate system, for the right users, to provide the appropriate tool in the right context, and to be adaptable to different situations in different environments.

The types of selected methods depend on the phase of the project and the researcher's approach towards understanding the user as well as the software, system, or context. Such an approach can be taken from a wide range of available methods from simple observational field studies to lab-based usability methods or hidden UX assessment loggers [23]. However, understanding experience is an extremely precarious matter because of various human cognition models

which require experts from multi-disciplinary fields. Moreover, using the full set of methods for one project is not necessary and realistic [24].

### **1.1.5 User experience and healthcare**

Since the healthcare sector deals with human lives, the adaption of IT has been carried out more cautiously. Considering that ICT offers a valuable means of supporting the exchange of information, and besides cognitive complexity, the UX field has contributed significantly towards developing and designing usable healthcare products for better accessibility [25]. Advancements in ICT have revolutionised healthcare services, elevated patients' and practitioners' capabilities, and changed the behaviours of both patients and practitioners. ICT has offered new possibilities for chronic disease management and administration both for an individual and general public level [26].

Conceivably, HCI, and especially UX, have been helpful in providing the best user experience and in engaging people in their healthcare to its fullest. UX methods have been enormously accommodating in the introduction and familiarisation of mobile/Internet based ICT tools, in their design for usability and understanding of behavioural changes [27, 28].

The UX process for a healthcare product is different from that of normal products because of various laws and regulations, the context, user involvements and implementation. It has been some decades since large software companies incorporated UX into their product development process. However, in healthcare organisations, health information systems were initially designed to fulfil the needs of administrators and decision makers in care organisations, and incorporating UX to design around the individual users has not been the main concern [19].

There is now a growing interest in UX, and many health informatics (HI) companies and researchers have started rethinking their design process. For example, in 2007, the National Health System of England reformed their policies towards "*incentives to respond to patients [rather] than top-down target setting*" [29] and in their latest operating framework they emphasise the need to involve the general public in the healthcare process which emphasises the role of UX in using technology for this matter [30]. So far the focus has been mostly on practitioners and clinicians in clinical settings rather than on persons with chronic conditions. The key to using the advancement of technology would be to understand patients' needs and base designs on that knowledge. However, the work in the area of UX for health information consumers is still insufficient, and the majority of publication resources are in the context of health information systems for healthcare organisations [19, 31-33].

### **1.1.6 Consumer Health Informatics**

Over the past decades, the field of medical informatics has grown rapidly. In parallel, the interest in interactive consumer health technology applications has also increased [34]. Today, citizens no longer wait for an appointment with their medical doctor. They first go onto the Internet to seek the information regarding their health condition in order to be well informed when meeting a healthcare professional [35]. In modern medicine, the advancement of

technology has changed the way health information consumers seek clarification and explanation of their condition. Therefore, both patients and health care professionals should be well informed about the diagnoses, prognosis and treatment options [35]. This could be done by having the ability to share and access the right information for making the right decision [36]. The field of consumer health informatics (CHI), as a subfield of medical informatics, researches the role of ICT for healthcare consumers.

CHI has been defined as a field that *“analyses consumers’ needs for information; studies and implements methods of making information accessible to consumers; and models and integrates consumers’ preferences into medical information systems”* [37].

Consumer health applications can be implemented in different platforms. In order to provide the ideal tools/services, the consumers’ perspectives and experiences have to be taken into account. This could be done by employing HCI/UX methods for involving patients and citizens in the design of these tools/services in order to understand their perceptions in managing their own health and to address the challenges of providing a usable technology [34, 38]. The challenge is how to use UX approaches to understand health information consumers with special needs and disabilities.

## **1.2 MODELS OF DISABILITY**

In order to provide and analyse accurate ICT tools for persons with special conditions, different models of disability have been used. There are two main approaches to understand disability: the medical and social models [39].

### **1.2.1 Medical and social approaches**

The medical model of disability is based on the perspective of healthcare professionals using the classification of “impairment” and “disability”. This model is originated from the World Health Organisation (WHO) [39, 40]. According to the WHO, “impairment” is *“any loss or abnormality of psychological, physical, or anatomical structure or function”* [40] and “disability” is when the impairment prevents a person from *“perform[ing] an activity in the manner or within the range considered normal for a human being”* [40].

The social model of disability is developed mostly from the associations of disabled people’s point of view and therefore presents the perspective of disabled advocates and activists. It originated from the Union of Physically Impaired Against Segregation (UPIAS) [41]. The “impairment” is *“the functional limitation caused by physical, sensory, or mental impairments”* [39] and “disability” is *“the loss or reduction of opportunities to take part in the normal life of the community on an equal level with others due to physical, environmental, or social barriers”* [39].

The focus of the social model is on the social barriers and the society rather than the individuals with disability, whereas the medical model that focuses on the individual’s health and



contextual factors. Based on these social and medical models, different modelling approaches have been developed by different organisations.

### **1.2.2 International Classification of Functioning, Disability and Health**

The International Classification of Functioning, Disability and Health (ICF) is a classification for disability that offers an international and inter-professional scientific basis for understanding and studying persons' skills in their daily lives by providing a common language and scientific basis for defining health and health-related issues [42]. This classification is based on the medical model of disability and in this thesis has been used to measure the capability of persons with some sort of disability for using ICT tools.

The ICF consists of a hierarchical schema based on two major parts, and sub-categories: the "functioning and disability" part, and "contextual factors". The "functioning and disability" covers "body function and structures" and "activities and participation". The "contextual factors" cover the "environmental and personal" factors. The personal factors are contextual factors such as age, gender, and other personal background information without any further classification. The WHO also provides a checklist of major categories as a practical tool to produce and record information on the functioning and disability of an individual [42]. Figure 1 shows the overview of the ICF checklist. The original checklist has to be completed by the extent (severity) of the impairments, difficulties, barriers, and facilitators. However, not all categories and sub-categories would be relevant for persons with different sorts of disabilities [43].

## Functioning and Disability

## Contextual Factors

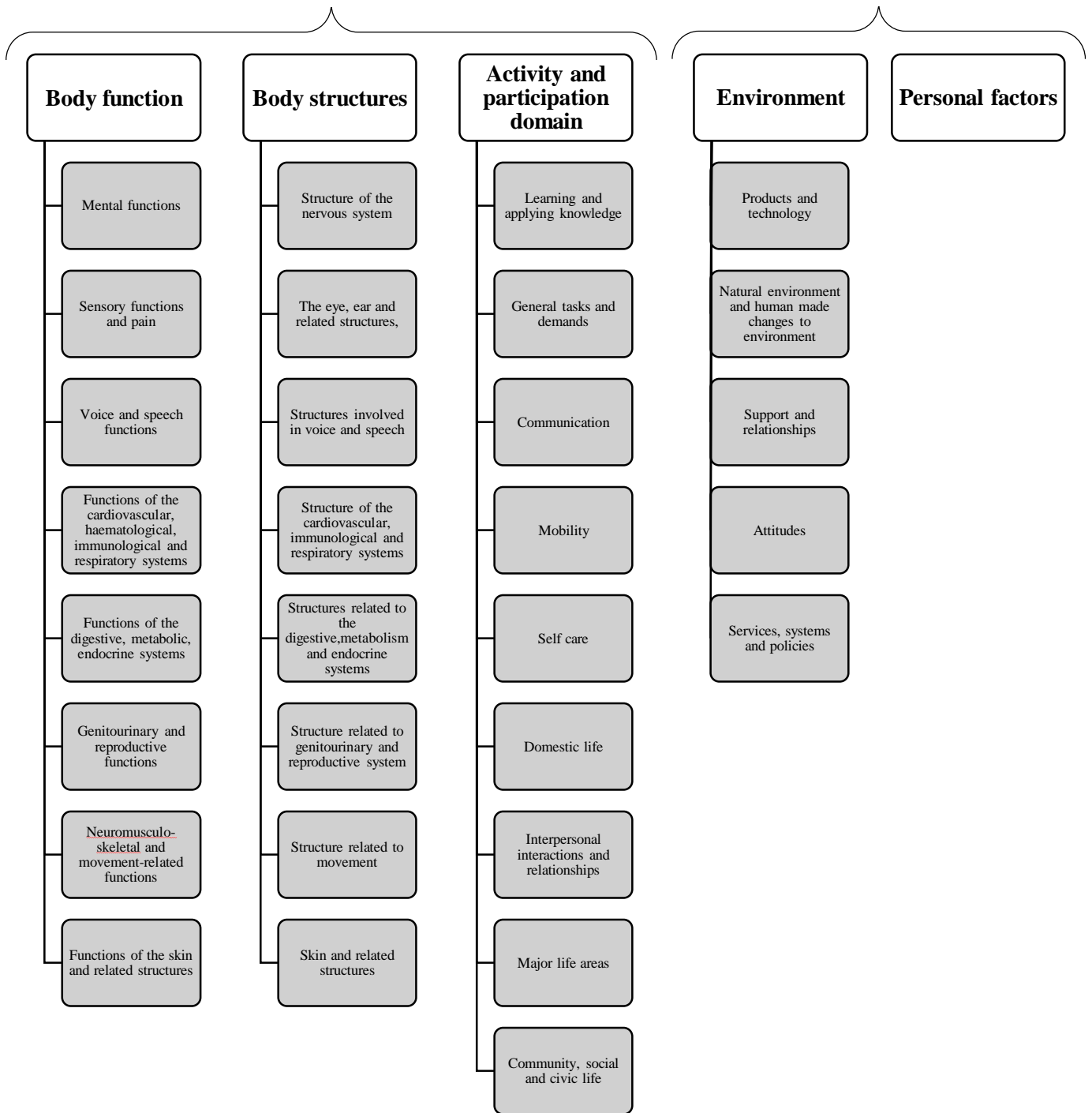


Figure 1 – An overview of International Classification of Functioning, Disability and Health (ICF) checklist [42].

### 1.3 ACQUIRED BRAIN INJURY

Acquired brain injury (ABI) is a critical global public health problem. It is one of the major causes of death, and lifelong impairments are common in those who survive [44].

The term ABI can be defined as a traumatic or non-traumatic injury to the brain which occurs after birth. It has been estimated that each year 775 000 people in Europe (EU “old” member states) sustain a traumatic brain injury (TBI) [45]. By a conservative estimate (an average assumption of 10 years’ disability), the prevalence of different types of TBI in the USA is about 5.3 million. In Sweden, about 70 000 people suffer from brain injuries every year [46]. However, the severity of consequences and disabilities in these persons is unknown [45].

### 1.3.1 Traumatic brain injury

TBI occurs when the brain acquires an injury from a sudden trauma [47]. Generally, TBI occurs when an object violently and suddenly hits the head, or when an object enters into brain tissue by piercing the skull [47]. The occurrence of TBI has a bimodal distribution, arising in the second and seventh decade of people’s lives, and equally, both men and women are at risk in their 60s, but the injury incidence in men is twice to three times more than women in lower ages [48].

Common events that cause TBI include falls, vehicle-related collisions, violence, sports injuries, explosive blasts and other combat injuries [49]. Depending on the extent of the damage to the brain, the great majority of reported TBIs are mild (80%), followed by 10% moderate, and 10% severe [45]. A person with mild TBI may experience short loss of consciousness or remain conscious [50]. Also, they may suffer from various symptoms such as problems with attention, memory, concentration or sleep patterns, dizziness, behavioural changes, confusion and light headaches [47]. About 10–40% (depending on the country and study group) of people with mild TBI develop persistent cognitive impairments or somatic disabilities [51].

### 1.3.2 Levels of cognitive impairment

There is neither a universal, well-accepted definition nor a methodology for establishing the severity of cognitive impairment [52]. In their work on neuropsychological assessment of work-related injuries, Bush and Iverson differentiate the levels of cognitive impairment from a neuropsychological point of view [52]. A summary of their differentiation is shown in Table 1.

Table 1 - Levels of Cognitive Impairment according to Bush and Iverson’s differentiation [52].

Levels of Cognitive Impairment		Description
Mild Cognitive Diminishment	<b>Severity</b>	<ul style="list-style-type: none"> <li>• No cognitive “impairment”</li> <li>• Mild diminishment in cognitive functioning.</li> <li>• May or may not be identifiable using neuropsychological tests.</li> <li>• Does not always have a mild adverse impact on a person’s social and/or occupational functioning.</li> <li>• May or may not be noticeable by others.</li> </ul>
Mild Cognitive Impairment		<ul style="list-style-type: none"> <li>• Identifiable using neuropsychological tests.</li> <li>• Has a mild (sometimes moderate) adverse impact on a person’s social and/or occupational functioning.</li> </ul>
Moderate Cognitive Impairment		<ul style="list-style-type: none"> <li>• Has a substantial impact on everyday functioning.</li> <li>• Noticeable to others with regard to the person’s social and/or occupational functioning.</li> </ul>
Severe Cognitive Impairment		<ul style="list-style-type: none"> <li>• Has a substantial adverse impact on everyday functioning</li> <li>• The person would be incapable of competitive employment</li> <li>• The person should not drive a motor vehicle, and might have difficulty with the activities of daily living.</li> </ul>
Profound Cognitive Impairment		<ul style="list-style-type: none"> <li>• The person would need 24-hour supervision and assistance with daily activities in any context</li> </ul>

### **1.3.3 Mild cognitive impairment**

The term Mild cognitive impairment (MCI) is used to describe an early stage of progressive cognitive decline in degenerative diseases, such as dementia [53-56]. However, the diagnosis of MCI is a difficult task for neuropsychologists and the potential for misclassification is relatively high [57]. The ability of neuropsychologists to accurately diagnose and identify the real/true difficulties is inversely related to the severity of the trauma to the head. This means that MCI is more difficult to diagnose when it is milder. A few examples the definitions for MCI would be Mild Cognitive Disorder [58], Cognitive Disorder Not Otherwise Specified [59], Mild Neurocognitive Disorder, Major Neurocognitive Disorder [60] and Dementia [58, 59]. According to DSM-5, it is a disorder that goes beyond aging and “*requires compensatory strategies and accommodations to help maintain independence and perform activities of daily living*” (Mild Neurocognitive Disorder) [60].

Persons with MCI may have impairments in attention/processing speed, language, learning and memory, perceptual-motor-spatial skill, social cognition abilities and executive functioning [61]. However, according to Iverson et al., 37% of healthy adults have met the testing criteria for DSM-5 Mild Neurocognitive Disorder which shows the complexity of diagnosis [62].

### **1.3.4 Mild acquired cognitive impairment**

#### *1.3.4.1 Definition*

Mild acquired cognitive impairment (MACI) is used to characterise persons who acquire a minor, non-progressive decrease in cognitive functions due to some physical trauma, or medical conditions, such as benign tumour, cardiovascular diseases (stroke), or side effects of medical treatment. The term MACI is not a coded diagnosis. Persons with MACI are anticipated to reach a stable cognitive level compared to persons with a slow deteriorating cognitive impairment, such as Parkinson’s disease and Alzheimer’s disease [43, 63-65]. Persons with MACI might suffer from multiple cognitive and/or slight physical disabilities. However, a considerable number of these persons report social, emotional, psychological, and cognitive function impairments for longer periods of time [66, 67].

To classify persons with MACI, Eghdam et al. propose three criteria: a person who 1) fits the general definition of having some sort of MCI; 2) acquired the MCI as the result of a known medical condition or trauma, and 3) his/her cognitive state is expected to improve over time with treatment [43].

#### *1.3.4.2 Treatments*

Persons with MACI might need rehabilitation to recover and regain their skills, and the treatment strategies intended for persons with moderate and severe acquired brain injuries and progressive condition are not directly applicable for this group. The rehabilitation for persons with MACI could be provided through different actors, types and contexts [66].

Despite the extent of the brain damage, the duration and type of rehabilitation will also depend on the person's attitude and ability [68]. Generally, a person with MACI needs rehabilitation in a broader range of situations than others with severe conditions or Alzheimer's disease. Since most of their disabilities are not apparent, it is difficult for healthcare professionals, and even for persons with MACI themselves, to realise the true nature of their disabilities and to seek treatment and rehabilitation. Frequently, they need help to recover their productivity-related, interpersonal-emotional skills in social situations and work environments [63, 69].

Self-management is one suggested approach to improve and support treatment [70]. It is a fairly broad concept and a wider perspective has to be considered for developing treatments and services that support self-management. To include both social and medical aspects of one's life, the individual plays the central role in managing his/her long-term condition [71]. From the social model of disability's point of view, self-management can be interpreted as the environment that has the potential to facilitate the identified requirements [72]. In the medical model of disability, self-management is "*the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition or disability*" [73].

For persons with MACI, the quality and quantity of participation are affected by their cognitive impairment, their personality and the environment [74]. Therefore, constructing new instruments for measuring participation that are able to "*address issues in conceptualisation and operationalisation*" [74] of different aspects of one's life, is a challenging task because of existing physical, social and cultural barriers [74].

#### **1.4 SUPPORTING PERSONS WITH MACI THROUGH ICT**

ICT is one approach that can be considered to assist persons with MACI and improve their skills. It can also fulfil their needs in accessing the already limited rehabilitation services.

ICT provides a broad range of beneficial services in different contexts. Today, it has become an essential part of the lives of individuals with chronic conditions as a means of self-management in coping with their disabilities [75-79]. Studies in the CHI field have shown the importance of supporting citizens' independence in ordinary environments [36]. By applying different concepts (e.g. ambient intelligence), ICT is capable of providing tools for persons with special needs. It can be used to help them live in the ordinary environment and to empower them through the promotion of self-care [80]. Considering the role of ICT in supporting self-management, an extensive amount of research has been done on assisting persons with chronic conditions. Through HCI frameworks, the socio-technical approaches have been used to provide healthcare in the residential context of persons with disabilities [81, 82]. However, in terms of supporting persons with brain injury, most of the existing ICT tools are developed for persons with more extensive cognitive impairment, such as Alzheimer's disease, or moderate to severe brain injury [83, 84].

ICT tools exist in different forms such as Web 2.0 services, mobile technologies, simple software (e.g. mobile and tablet apps), communicable sensors (e.g. fall sensors or bed sensors),

Internet of things (e.g. networked home accessories), complex interactive systems and social media [80].

Web 2.0 health and healthcare services have several benefits for organisations, clinicians, patients and the general public [85, 86]. In addition to all provided services, Web 2.0's social network aspect is an important factor in supporting persons with disabilities. It is used to establish connections between persons with similar problems and to fulfil their social interaction needs on a long-term basis [86]. However, persons with mild or moderate cognitive impairment have received less attention, and there is still a lack of knowledge about how ICT tools can be incorporated in their daily lives.

Generally, the use of smart assistive devices support a person's independence in his/her home or work environment, but they unconsciously decrease the social relations of people [87]. When it comes to communication, the main focus of ambient assistive living (AAL) systems has been on the conversation between doctors and patients, and mainly on exchanging medical data. However, AAL studies have pointed out the importance of supporting formal and informal caregivers [87]. Although AAL systems have provided great assistance for persons with special conditions, the significance of social activities is less remarked. Therefore, social media might be an important means of maintaining the social needs for different people living with disabilities. On the topic of social media, the increasing use of it over the past few years has changed health information consumers and healthcare providers' communication [88, 89]. In addition to socialising, social media would be a valuable service for sharing experience and gaining knowledge from others with the same condition [90]. Nowadays, social media has become an efficient way to share up-to-date medical knowledge and to improve the quality of care within healthcare communities [91].

For persons with MACI, because of the impairments after brain injury, the amount of physical interaction with others decreases while the need for socialising still remains [92]. When persons with MACI lose the connection with outside world, assisting them with their impairments, without considering the social aspect, would merely help them survive safely but not live dynamically. Social media would be a valuable solution to increase their attention span, decrease distractibility, and improve their limited capacity for multi-tasking. The person can regulate and use it when energised, or simply stop using it when tired. Social media would also support them by providing social support in a non-noisy and distracting social context. It also shortens the long physical distance between persons without draining their energy [93]. In addition, social media could play a valuable role in supporting the self-management of different individuals. However, there is a lack of research into social networking services and very little is known about how people with MACI use popular social media sites (e.g. Facebook) [94]. Regarding the context of this thesis, Swedish individuals are among the top number of Europeans who use the Internet to participate in social networking [95].

## 2 AIM AND OBJECTIVES

### 2.1 GENERAL AIM

This thesis belongs to the field of consumer health informatics, “*a sub-specialty of medical informatics which studies from a patient/consumer perspective the use of electronic information and communication to improve medical outcomes and the healthcare decision-making process*” [96]. The goal was to explore the use of ICT tools and social media from the perspective of persons with MACI in order to improve their own healthcare. The main aim of this thesis was *to explore how and why persons with MACI use ICT and social media in their daily lives*.

Considering the difficulties in measuring participation for persons with MACI with respect to the use of ICT tools [74], the secondary aim was *to explore which methods would be suitable to capture their experiences while using ICT tools*.

#### 2.1.1 Specific objectives

The specific objectives of the four studies included in this thesis are to:

- Present an overview of the existing scientific literature about ICT tools for assisting persons with MACI in self-management and analyse their functionality based on a subset of the ICFchecklist (study I).
- Present how regular e-services and social media are currently used by persons with mild or moderate cognitive impairment and capture their opinions and experiences (study II).
- Show user-behaviours of persons with potential MACI while communicating through social media and classify and visualise their involvement (study III).
- Explore the feasibility of using experience sampling UX methods for persons with MACI to study their daily activities with respect to the role of ICT tools (study IV).

### 3 RESEARCH APPROACH

In order to provide the appropriate service for the right user, it is essential to understand the target group from different perspectives by using methodological pluralism [97]. Various approaches have been used by UX researchers to “know the user” [98].

This research has been influenced primarily by UX approaches for understanding the target group, their context of use, and attitudes towards regular ICT tools. This thesis represents the “understanding” or “research” component of the design process where new knowledge and evidence about the needs and requirements of a specific user group are collected [99].

The four studies of this thesis deal with different UX research approaches to obtain a deeper understanding of how and for what purpose persons with MACI use existing ICT tools [2, 23]. This research started by conducting a systematic literature review to find relevant literature about ICT tools for persons with MACI. A subset of the ICF checklist was adapted as an analytical framework to assess if and how the identified studies considered persons with MACI disabilities during their development/evaluation process (study I). Based on the results of study I, this research was followed by a national survey study regarding how persons with MACI actually use ICT and e-services (study II). The participants in study II indicated the use of regular ICT tools for different purposes, but mostly for communication and social interaction. These results, then, were used to conduct two parallel studies. Study III was conducted as a social network analysis to address the communication and social interaction aspects, and study IV was performed to capture the frequency of using regular ICT tools on a daily basis and to explore the feasibility of using a diary-keeping method for persons with MACI. A graphical overview of the individual studies is presented in Figure 2.



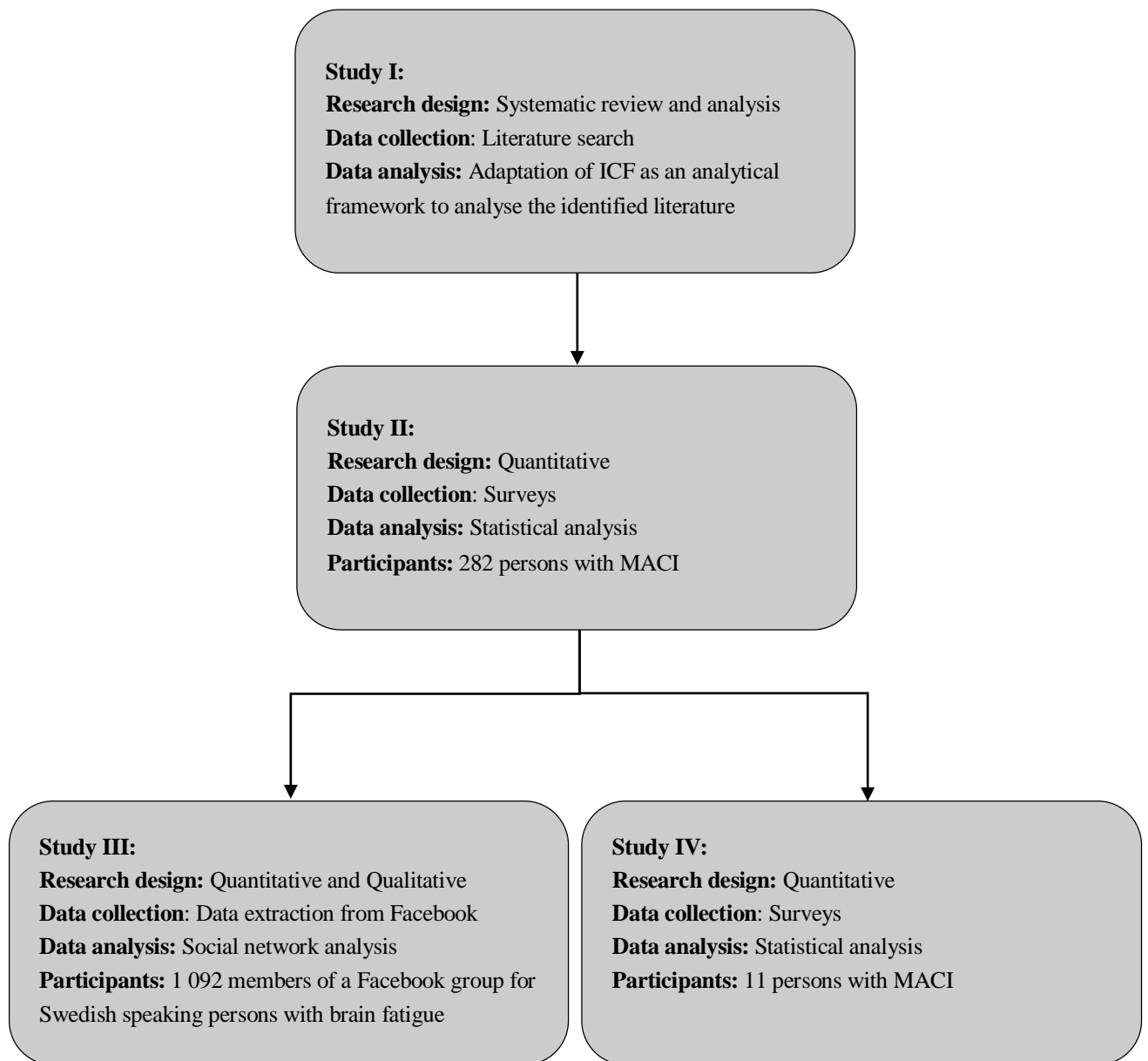


Figure 2 - Overview of the thesis. The square boxes represent the individual studies in the thesis.

This chapter is divided into different sections: section 3.1 describes the setting and provides an overview of the participants in this research; sections 3.2 and 3.3 describe the methods that have been used for performing different studies of this thesis, and section 3.4 describes the ethical considerations for this research.

### 3.1 SETTING

The study context of this thesis is persons with MACI in Sweden. In general, persons with MACI receive less external support in acquiring new skills after their brain injury, and rehabilitation resources for them are limited [43].

The participants of this study were persons with mild cognitive impairment who acquire a minor, non-progressive decrease in cognitive functions due to some physical trauma, or medical conditions.

The first study was done in the international context as a systematic literature review and analysis of ICF features against need of persons with MACI. Studies II and IV were done in collaboration with the Swedish Association of Brain Injury (Hjärnkraft). The association was founded in 1988 by families who sought support from each other in a situation where a beloved one suffered from acquired brain injury. Study III was conducted in a public Facebook group for Swedish-speaking persons with brain fatigue after brain injury.

## **3.2 DATA COLLECTION METHODS**

### **3.2.1 Systematic literature review**

Systematic review is a reproducible methodology that is used for providing an overview of primary empirical studies, their objectives, methodologies and results, as an explicit statement [100]. The goal is to accumulate a comprehensive literature review and find best practices in associated scientific fields. Nowadays information overload is a common phenomenon and it has become clear that not all information is knowledge. Systematic review is one method of organising and evaluating the value of information on which policy decisions are often based [101].

Since MACI is a new term used to describe a specific group of persons with MCI after acquired brain injury or medical conditions, a systematic review was used to gain a holistic picture of the available scientific literature about the design, evaluation and development of ICT tools for this group. In this method, inclusion and exclusion criteria were defined to cover the whole scientific literature, both in the clinical and technical context. The systematic review in this research was based on Stroup et al.'s guidelines for conducting meta-analysis of observational studies in epidemiology [102].

### **3.2.2 Analytical framework based on ICF**

Since UX designers work with different types of users, they lack knowledge about their specific behaviour and abilities, specifically for persons with some sort of disability. Thus, the medical and social models of disability classifications would be good guidelines to help them understand different aspects of a person with special needs. On the other hand, these classifications have been built for a wide range of people with special needs, and UX researchers in HI need to collaborate with clinicians and patients to understand the relevance and degree of impairment for specific users.

In many cases this process is oriented towards one project and the results of the collaboration are not documented as an analytical framework for future researchers. Therefore, providing an analytical framework is essential for reducing the time/cost of future UX projects. In this research the approach was taken to use a subset of the ICF checklist as an analytical framework.

### 3.2.3 Surveys

One simple and common type of data collection methods used in HI is the survey. Surveys are used when the available information is insufficient regarding a specific topic, and can be used to explore participants' opinions and feedback on a particular matter. In product development, surveys are used in the beginning to consider new ideas and opportunities [23].

Typically, surveys are considered as quantitative data collection methods for establishing frequencies and means. However, by providing proper open-ended questions, it is possible to capture qualitative data about participants' diversity (not distribution). The first step in conducting a survey study is to determine the needs for creating a new survey instead of using an existing one. In any case, the content of the survey should be able to answer the relevant research questions effectively.

Several issues such as inclusion criteria, type of questions (open or closed-ended), scales (nominal, ordinal, interval and ratio) have to be considered for building a new survey. This is usually done by involving an advisory committee of experts in the topic of the study. Once the survey is ready, to measure the validity and reliability of the results, it has to be pilot-tested with small groups of participants similar to the target group. By using an existing survey, the researcher would benefit from the results of other studies that used the same method, in order to compare and validate. An existing survey could be adapted by slightly modifying the content to fulfil the needs for specific factors influencing the target group.

In the studies used in this thesis, the appropriate steps, based on HI methods, principles and practice [101], were taken to create new surveys, or using the existing ones, for understanding different aspects of persons with MACI characteristics, opinions, preferences and attitudes towards ICT.

#### 3.2.3.1 Cognitive failure questionnaire

Cognitive failure is defined as “a person's failure to complete a task that he/she is normally capable of completing” [103]. The cognitive failure questionnaire (CFQ) is a self-administrated survey designed to measure difficulties/failures in performing everyday tasks [104]. The questionnaire consists of 25 items, gathered from general incidents that happen to most people occasionally. This questionnaire has been used for diverse persons and occupational groups all over the world and it contains questions such as, “Do you lose your temper and regret it?” or “Do you forget whether you've turned off a light, or a fire, or locked the door?” To respond to each question, the participant uses a 5-point Likert-scale (i.e. 0 = never, 4 = always) and considering the 25 items, scores range from 0 to 100.

Originally CFQ was developed to measure failures in perception, memory and motor functions. The initial idea by Broadbent et al. was that CFQ only assesses the cognitive failure factor, but several researchers attempted to assess additional or altered factors (e.g. 1, 3 and 7 factors) [104-108].

Generally, confirmatory and exploratory factor analysis was used to understand the correct factor structure of this questionnaire and associate one item or group of questions with factors. However, for different populations, different numbers of factors were discovered and neuropsychologists attempted to connect those statistically derived factors as different failures [104-108].

The Swedish version of CFQ was used in this research to measure the general cognitive failure of the participants to provide a better understanding about their cognitive level (Chapter 9, Appendix study II).

### 3.2.3.2 *E-services questionnaire*

As stated at the beginning of this section (3.2.3), using or adapting an existing survey by adding questions or rephrasing them would generate more valid and reliable results. However, in the field of HI, since many new research topics are being explored for the first time, different researchers have discussed whether it is necessary to create new surveys all the time, or to adapt surveys from other fields [101]. In this thesis, with respect to the aim and based on a subset of ICF checklist as an analytical framework stated in section 3.2.2, a survey was needed to assess persons with MACI experience and use of ICT tools/e-services and social media. E-services are defined as “*deeds, efforts or performances whose delivery is mediated by IT (including the Web, information kiosks and mobile devices)*” [109] and the Internet is considered as the main channel for using e-services.

Initially, a literature review was performed to find an adequate survey, but since this topic was being explored for the first time, no acceptable survey was available. Thus, based on the most common and important problems for persons with MACI, and the subset of the ICF checklist, a new questionnaire with closed and open-ended questions was created. Primarily, an advisory committee of MACI and ICT experts were gathered to assist the authors in phrasing the questions, and make recommendations for the content in regard to the study objectives.

The development process started by reviewing different available ICT questionnaires regarding experience of using regular ICT tools for health and social support [110-112]. As a result of this review, 12 areas were identified as e-services and cross-validated with the subset of the ICF checklist. In order to provide a better understanding of e-services, a few examples for each area were added. Also, to understand all aspects of using e-services, a few questions regarding ownership and use of personal computers, mobile phones/smart phones or tablets, open-ended questions regarding their preferences, positive/negative aspects of using e-services, and specific questions regarding social group/media memberships were added. Table 2 shows the examples used in the survey to specify every item. The e-services questionnaire is presented in Chapter 9, Appendix study II.

Table 2 - Examples presented in the survey for e-services items.

<b>e-services</b>	<b>Proposed examples</b>
<b>Navigation</b>	GPS (Global Positioning System)
<b>Alarm</b>	Reminders to sleep and/or wake up, reminders to take medicine
<b>Memory</b>	Digital notes, calendars, journals, to do lists, shopping lists, contact lists
<b>Watching</b>	Such as videos from YouTube or similar services
<b>Listening</b>	Audio books, music from Spotify, internet radios or similar services
<b>Playing</b>	Through various computer games or consuls
<b>Reading</b>	eBooks
<b>Writing</b>	Taking notes or similar services
<b>Communication</b>	Via email, chat and Facebook. Find out the facts through Google, news aggregators, subscribe to newsletters, etc.
<b>Banking</b>	Economy management, count and make purchases such. E.g. save your receipt, calculator and pay and make transfers via Internet banking, paying bills, wallet
<b>Health-promotion apps and services</b>	Such as measuring blood pressure, weight, pulse, sleep or diet apps
<b>Seeking health information</b>	Seeking health information

### 3.2.3.3 *The Day Reconstruction Method*

Field studies are valuable approaches to set the direction of a UX project, and to discover the unmet user needs in the real contexts of use and natural settings [113]. Generally, field studies are considered complicated processes requiring a team of anthropologists. However, researchers in multi-disciplinary fields often lack such a specialty. Therefore, a wide range of methods have been proposed for performing short or long-term field studies. One method that has been used in the field of UX for characterising daily life experience, is the day reconstruction method (DRM) [114].

The questionnaire was developed as a diary-keeping method by Kahneman et al., based on assessments of the moods of individuals, to measure their wellbeing during their daily activities [114]. The questionnaire was intended to be used by medical researchers to measure the burdens and health consequences of an illness or stress. In addition, epidemiologists and economists use this questionnaire for measuring social and environmental stressors, or evaluating non-market activities. The method was considered not to be significantly influenced by memory biases, compared to other experience-sampling methods [115]. The DRM has an episodic structure to capture respondents' experience based on memories about different activities that they have been doing during the previous day. In every episode, the respondents select the type of activity from a list with 16 different pre-defined options and their feeling from 12 adjectives on the Likert-scale of 0–6. In addition to demographic information, the questionnaire covers two major issues, day reconstruction (all activities of the day) and experience narration (context of use, type of interaction and their feeling). Furthermore, there are some questions regarding general satisfaction and mood at home or work.

This questionnaire has also been used by UX researchers, as it is able to provide precise memories and a rich qualitative interpretation within single episodes. In addition, it does not interrupt respondents' daily activities, and takes less time compared to other experience sampling methods [116].

As mentioned in the beginning of section 3.2.3, several time-and-money-consuming tasks have to be performed for designing new questionnaires. In addition, it is important to include the perspective of persons in assessing their participation when living independently. However, for persons with MACI, it is difficult to measure their participation and understand their user experience [74]. Therefore, in this research, the Swedish translation of DRM as a standard questionnaire for diary-keeping was used to capture one-day experiences, actual feelings and thoughts of persons with MACI with respect to the use of regular ICT tools. The questionnaire is presented in Chapter 10, Appendix Study IV.

### **3.3 DATA ANALYSIS METHODS**

#### **3.3.1 Social network analysis**

One of the features of the Internet is easy communication via social networks. When it comes to UX, another useful method for investigating the overall user experience and usability of a social network, through a non-direct observational study, is to conduct social network analysis (SNA). SNA is a quantitative and qualitative analysis of a social network, to map the relations and flows between social entities (individuals or organisations), and their activity patterns within social media groups [117-119]. Generally, these entities would be considered as “nodes” and, rather than individuals, they could also be groups, nations, software such as web sites, or hardware such as computers or mobile phones. In some cases, only the quantitative approach has been considered as SNA [120, 121].

The focus of SNA is on nodes and their relations, how they are connected, and how involved they are in the communication. In most cases, the focus of SNA is on humans, to understand their social behaviour and interaction within the network [122]. In social media, the individual members or actors could be conceptualised as nodes and their communication/interaction such as friendship, likes, dislikes or common interest as relations between them.

Today SNA has moved from simply an analytical approach to a theoretical statement with its own methods. SNA has arisen as a significant method for understanding people's behaviour and attitudes used in HCI, and modern social psychology. Health informaticians have contributed to the development of SNA in order to understand human contact patterns in information awareness programs or infectious diseases [117].

##### *3.3.1.1 Quantitative analysis*

In SNA, the data on the nodes and their relations are systematised in metrics and graph theory has been used to describe and visualise the network. In social media, graph theory has been used to transform the metrics of nodes and their relationships to points and dots. These points

and dots can be connected with directed or undirected lines. When the information flow is not specified in the network, the lines merely present the relationship between two nodes (undirected graphs). In a group structure, the SNA provides an understanding of every node's location in the network, groups within the groups, and active group members and their own network within the group.

In this thesis, the SNA was performed on a Facebook group for Swedish-speaking persons with brain fatigue, to analyse and visualise the distribution of involvement in the information exchange amongst members. The members have been conceptualised as nodes, and their "comments" and "likes", as relations. The "comments" and "likes" around the "posts" between two unique nodes were considered as *edges*. The number of nodes that were in relation with a node, was termed a *centrality*. The density of each centrality based on the number of edges, was considered as *weighted-centrality*.

### 3.3.1.2 Qualitative analysis

Qualitative methods have been used for interpretation of non-numerical observations in SNA. The non-numerical information is the content of "comments" and "posts" as sentences and words. By using the content analysis, SNA researchers are able to examine textual data to detect recurring terms, and to define themes and factors that represent the population's culture [101]. Based on the degree of involvement and inductive reasoning, Hsieh et al. have discussed different content analysis approaches [123]. Previously, numerous researchers analysed the Facebook content for different purposes [124-126], and various studies focused on persons with chronic disease for evaluating the type, and frequency of their interactions [127, 128]. Since the study by Gaysynsky et al. provided a suitable theoretical framework, a *directed content analysis approach* was used in this research. To be consistent in the coding process from the beginning, the initial starting codes and semantics for the themes were retrieved from the work of Gaysynsky et al. and adapted to this study [129]. Figure 3 shows the direct content analysis process.

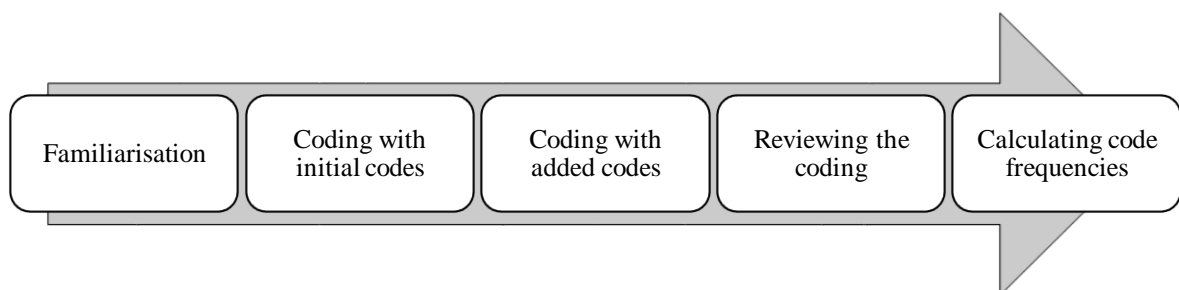


Figure 3 - The direct content analysis process used in this thesis.

### **3.4 ETHICAL CONSIDERATIONS**

The Ethical approval for three studies of this thesis were obtained from the Regional Research Ethics Committee at Karolinska Institutet in Stockholm [Studies II, IV (case number 2014/513-31/3 and amendment 2016/186) and study III (case number 2015/1287-31/5)]. The study I of this thesis did not require an ethical approval since it was a literature review. The participants in studies II and IV received information letters outlining the purpose of the study, the procedures for data collection, and ethical considerations such as confidentiality and anonymity. In addition, informed consent forms were provided to all participants and their signatures were obtained when returning the questionnaires. The data collection for study III was performed by using a Facebook application [130] that allows researchers to collect anonymous data from open Facebook groups without collecting any information regarding the members' profile attributes.



## 4 THE EMPIRICAL STUDIES

### 4.1 STUDY I

Study I consists of a systematic review of existing literature and analysis of the functionality of described ICT tools based on the subset of ICF checklist (as an analytical framework) as a medical model of disability for persons with MACI. Study I contributes to the direction of future research about ICT tools that can be recommended by healthcare professionals who are seeking to assist persons with MACI in self-management.

#### 4.1.1 Aim

This study aimed to present an overview of studies reporting on the development and/or evaluation of ICT tools for assisting persons with MACI in self-management, and to analyse how these ICT tools meet the needs of persons with MACI. The study further aimed to explore the level of existing evidence about the benefits of such tools and the existing gaps with respect to ICF for assessing their functionality. Finally, the study aimed to identify the impairment of persons with MACI in a subset of the ICF checklist for further assessment of ICT tools for self-management.

#### 4.1.2 Methods

##### 4.1.2.1 Study setting

The systematic review of existing literature (see section 3.2.1) was conducted for scientific articles published between 1995 and 2011 about the development and evaluation of ICT tools for persons with MACI using eight electronic databases (Table 3).

Table 3 - Electronic scientific databases used in study I.

Electronic scientific databases
MEDLINE (PubMed)
Association for Computing Machinery (ACM) Digital Library
Scopus (ScienceDirect)
Ovid
Physiotherapy Evidence Database (PEDro)
SpringerLink
ISI Web of Science (Science Citation Index Expanded)
The Institute of Electrical Electronics Engineers (IEEE) Xplore Digital Library.

##### 4.1.2.2 Procedure

After consulting MACI experts in Sweden, the following inclusion and exclusion criteria were defined in order to perform a precise and accurate systematic review (Table 4).

Table 4 - Inclusion and exclusion criteria for literature review of ICT used for persons with MACI.

Criteria	Study characteristics	Study participants
<b>Inclusion</b>	<ul style="list-style-type: none"> <li>• Original articles</li> <li>• English language</li> <li>• Adult participants only</li> <li>• Where the technology was either created, evaluated or applicable for MACI patients</li> <li>• Studies focused on technologies and tools that are developed to support patients' self-management (involving patient's responsibility for managing some aspects of their condition together with care professionals)</li> </ul>	<ul style="list-style-type: none"> <li>• Mild/moderate cognitive impairments and dysfunctions</li> <li>• Mild/moderate acquired cognitive impairment and dysfunction</li> <li>• Severe injury but the mild/moderate outcome after certain period of time</li> <li>• Non-progressive diseases</li> </ul>
<b>Exclusion</b>	<ul style="list-style-type: none"> <li>• Conceptual frameworks and literature reviews</li> <li>• Studies focused on technologies that are developed for patients with a more severe cognitive decrease than for MACI patients</li> <li>• Studies focused on technologies and tools that are developed for assessment and diagnostic purposes</li> <li>• Studies that included participants with mild cognitive impairments but with severe physical dysfunctions</li> </ul>	<ul style="list-style-type: none"> <li>• Severe cognitive impairments and dysfunctions</li> <li>• Aphasia</li> <li>• Alzheimer disease</li> <li>• Schizophrenia</li> <li>• Psychotic disorder</li> <li>• Developmental cognitive disabilities</li> </ul>

Since MACI was a new term, the search keywords were expanded to 55 different search phrases to include broader studies about ICT tools for cognitive and traumatic brain injuries. Table 5 shows the search phrases that have been combined with “assistive technology”, “Information technology”, “informatics” and their combinations (five combinations for each search phrase). After retrieval from the databases, citations were imported into a reference management software for removing duplications and managing bibliographies.

Table 5 - Keywords used in the study I and combined with “assistive technology”, “Information technology”, “informatics”.

Keywords
"cognitive impairment"
"mild cognitive impairment"
"mild acquired cognitive impairment"
"traumatic brain injury"
"mild traumatic brain injury"
"mild head injury"
"mild acquired brain injury"
"memory disorder"
"concussion"
"post-concussive"
"mild acquired cognitive dysfunction"

The process was followed by eliminating articles firstly based on their titles, abstracts, and finally, their full texts when there was uncertainty about meeting the inclusion criteria. In the last phase after final selection, the studies were genuinely analysed and information extracted from their full texts. In parallel, the latest version of the ICF checklist at that time was used to classify relevant impairments for persons with MACI (section 3.2.2).

### 4.1.3 Results

The results of the literature review showed that from 5969 identified publications, only seven articles met the inclusion criteria. Figure 4 shows a summary of the results of every step in the process.

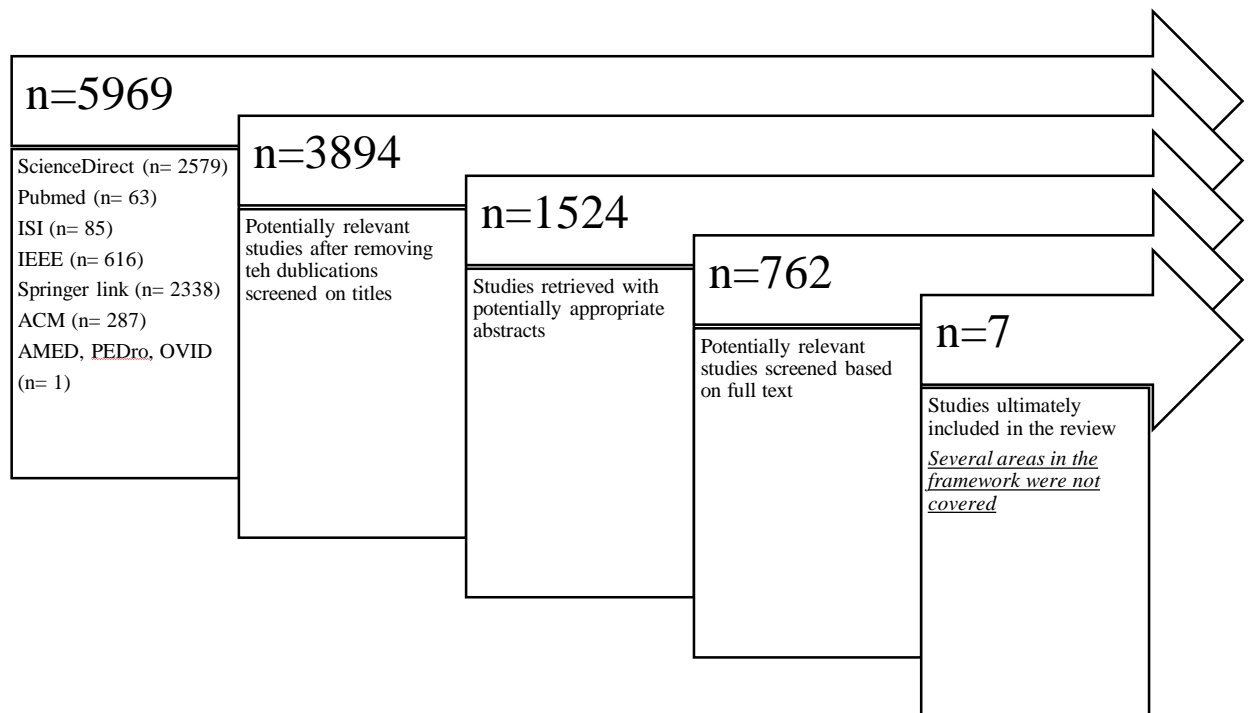


Figure 4 - Summary of identified publications in every step of the systematic review process in study I.

The identified articles were assessed based on their study types, research methods, development processes, setting, participants’ characteristics, and severity of impairments. The ICT tools provided in the articles were evaluated based on their functionality, improvement aims, types, interface and hardware types. Most of the identified studies (4 out of 7) had fewer than 10 participants and the ICT tools were mostly (6 out of 7) mobile technologies focused on memory aids (5 out of 7) followed by undertaking multiple tasks at the same time and problem solving [131-137].

A subset of the ICF checklist as an analytical framework was used to assess the identified ICT tools and all seven studies fitted the described profile for persons with MACI. However, numerous areas in the framework were not covered by identified ICT tools. Table 6 presents the subset of the ICF checklist as an analytical framework to show the most common and important problems faced by persons with MACI.

A comprehensive description of the results has been provided in study I of this thesis.

Table 6 - The subset of ICF checklist used as an analytical framework in study I.

<b>Body functions</b>	<b>Activity and participation domain</b>	<b>Environment</b>
<p><b>Mental functions</b></p> <ul style="list-style-type: none"> <li>• Energy and drive functions</li> <li>• Sleep</li> <li>• Attention</li> <li>• Memory</li> <li>• Emotional functions</li> <li>• Perceptual functions</li> <li>• Higher level cognitive functions</li> </ul> <p><b>Sensory functions and pain</b></p> <ul style="list-style-type: none"> <li>• Seeing</li> <li>• Hearing</li> <li>• Vestibular</li> <li>• Pain</li> </ul>	<p><b>Learning and applying knowledge</b></p> <ul style="list-style-type: none"> <li>• Listening</li> <li>• Solving problems</li> </ul> <p><b>General tasks and demands</b></p> <ul style="list-style-type: none"> <li>• Undertaking multiple tasks</li> </ul> <p><b>Communication</b></p> <p>Conversation</p> <p><b>Mobility</b></p> <ul style="list-style-type: none"> <li>• Fine hand use (picking up, grasping)</li> </ul> <p><b>Interpersonal interactions and relationships</b></p> <ul style="list-style-type: none"> <li>• Basic interpersonal interactions</li> <li>• Complex interpersonal interactions</li> <li>• Relating with strangers</li> <li>• Formal relationships</li> <li>• Informal social relationships</li> <li>• Family relationships</li> <li>• Intimate relationships</li> </ul>	<p><b>Products and technology</b></p> <ul style="list-style-type: none"> <li>• For personal use in daily living</li> <li>• Products for communication</li> <li>• Design, construction and building products and technology of buildings for private and public use</li> </ul> <p><b>Support and relationships</b></p> <ul style="list-style-type: none"> <li>• Immediate family</li> <li>• Friends</li> <li>• Acquaintances, peers, colleagues, neighbours and community members</li> <li>• People in position of authority</li> <li>• Personal care providers and personal assistants</li> <li>• Health professionals</li> <li>• Health related professionals</li> </ul>

#### **4.1.4 Discussion**

This study aimed to present an overview of existing studies about the design and evaluation of ICT tools to support persons with MACI. The main finding of this study was that there is a general lack of published research in this matter. The number of identified studies was very limited and a high number of them focused on providing ICT tools for persons with more severe impairments. The subset of ICF checklist used as an analytical framework in this study proved to be a valuable framework for investigating the functionality of ICT tools to meet the needs of persons with MACI from the perspective of a medical model of disability that would assist them in self-management. The functionality of all identified studies fell within the analytical framework but those studies covered only 13% of the subset. Considering the importance of understanding users towards assistive technology, none of the studies reported their development process or evaluations using a strong methodology that offered a high degree of evidence on the usability of provided ICT tools.

## **4.2 STUDY II**

Bearing in mind the results of study I, this study was conducted to address the lack of knowledge about how persons with mild or moderate cognitive impairment use regular ICT tools.

### **4.2.1 Aim**

The aim of this study was to explore the opinions and experiences of persons with MACI regarding the use of existing e-services and social media.

### **4.2.2 Methods**

#### *4.2.2.1 Study setting*

This study was performed in collaboration with the Swedish Association of Brain Injury (Hjärnkraft). This association is a non-political interest organisation that aims to increase awareness about the consequences, minimise the impact of and promote effective rehabilitation for acquired brain injuries, and to stimulate prevention and research. Membership of the association is voluntary, with a membership fee. At the time of the study, the association had about 1 300 members from different regions of Sweden. Considering this population, and to determine the frequency factor, a sample size of 600 members was estimated based on sample size calculation with 99% confidence level [65].

#### *4.2.2.2 Procedure*

The study started with the development of an e-service questionnaire (see section 3.2.3.2). A pilot test was performed with two persons with MACI and the questionnaire was revised in response to their comments. Next, a booklet containing this questionnaire, the CFQ (see section 3.2.3.1) and several demographic questions, in addition to information letters containing the purpose of the study, the procedures for data collection, ethical considerations and informed consent forms were sent to 600 members of Hjärnkraft who had valid addresses and could be

contacted by paper/regular mail. The data collection was performed in two phases (an initial phase and a reminder). In the second phase, participants who had not replied were asked if they were not able to participate in the study due to physical or mental disabilities, or were simply not interested.

#### *4.2.2.3 Statistical analysis*

Descriptive statistics were used to describe the baseline characteristics. For continuous variables, normal distribution was verified by the Shapiro-Wilk normality test and the 1-sample Kolmogorov-Smirnov test. Depending on normality and types of independent variables, and to determine the significant differences, statistical tests such as the Welch 2-sample t-test for normally distributed variables; and the Kruskal-Wallis rank sum test, the Mann-Whitney U, or the Wilcoxon rank sum test with continuity correction for non-normally distributed variables were used. To identify major trends in the participants' positive and negative opinions towards using e-services, open-ended questions were analysed. In addition, a confirmatory and exploratory factor analysis was conducted to test the factor structure of the CFQ.

### **4.2.3 Results**

#### *4.2.3.1 Participants' characteristics*

In total, 66% of invited members replied to the participation inquiry letter and in the end, 47% (282) were interested and able to participate in this study. Considering the total population size, the degree of confidence was close to 95%. The largest subgroup of participants (45%) was between 50–60 years old and about 56% were males. The majority had a high school education (42%) followed by college/university (32%) and 21% were employed (meaning that they had a half or fulltime job). The participants' characteristics are presented in Table 7.

#### *4.2.3.2 Cognitive failure level*

As shown in Table 7, the majority of participants (40%) suffered from TBI and most (65%) acquired the brain injury more than 10 years ago. The mean of total CFQ scores for the participants of this study was  $44.9 \pm 18.2$  (on the scale of 0–100). However, females had significantly higher scores compared to male participants ( $p < 0.05$ ). The confirmatory analysis did not support any factors proposed by previous studies and the results of exploratory factor analysis supported the one factor solution [108, 138].

Table 7 - Participants' demographic characteristics in the study II.

<b>Demographic characteristics</b>	<b>Responses</b>	<b>Number of participants n(%)</b>	<b>Total CFQ scores Mean±SD</b>	<b>P-value</b>
<b>Sex</b>	Male	157(56)	41±18	0.000
	Female	125(44)	50±18	
<b>Age</b>	13-29	21(7)	46±20	0.592
	30-49	82(29)	42±19	
	50-65	126(45)	47±18	
	66-81	53(19)	44±16	
<b>Education</b>	Elementary	61(22)	47±21	0.844
	High school	118(42)	45±17	
	College/University	91(32)	45±18	
	No Answer	12(4)	-	
<b>Employment</b>	Employed	58(21)	42±18	>0.05
	Studying	11(4)	40±21	
	Sick leave	24(9)	44±20	
	Sickness compensation	72(26)	50±18	
	Unemployed	7(2)	42±14	
	Retiree	108(38)	44±18	
	No Answer	2(1)	-	
<b>Period of brain damage</b>	< 2 years	13(5)	41±22	>0.05
	2 to 5 years	33(12)	42±21	
	5 to 10 years	53(19)	48±16	
	> 10 years	182(65)	44±18	
	No Answer	1(0)	-	
<b>Type of brain damage</b>	TBI	113(40)	45±20	>0.05
	Anoxia	2(1)	52±19	
	Stroke	58(21)	47±19	
	Tumor	17(6)	50±12	
	Encephalitis	11(4)	47±19	
	Other / Unclear	25(9)	41±18	
	No Answer	56(20)	-	

#### 4.2.3.3 E-services

The majority of participants owned mobile phones (81%) half of which (41%) were smart phones. The participants' electronic device ownership for different age ranges is shown in Figure 5.

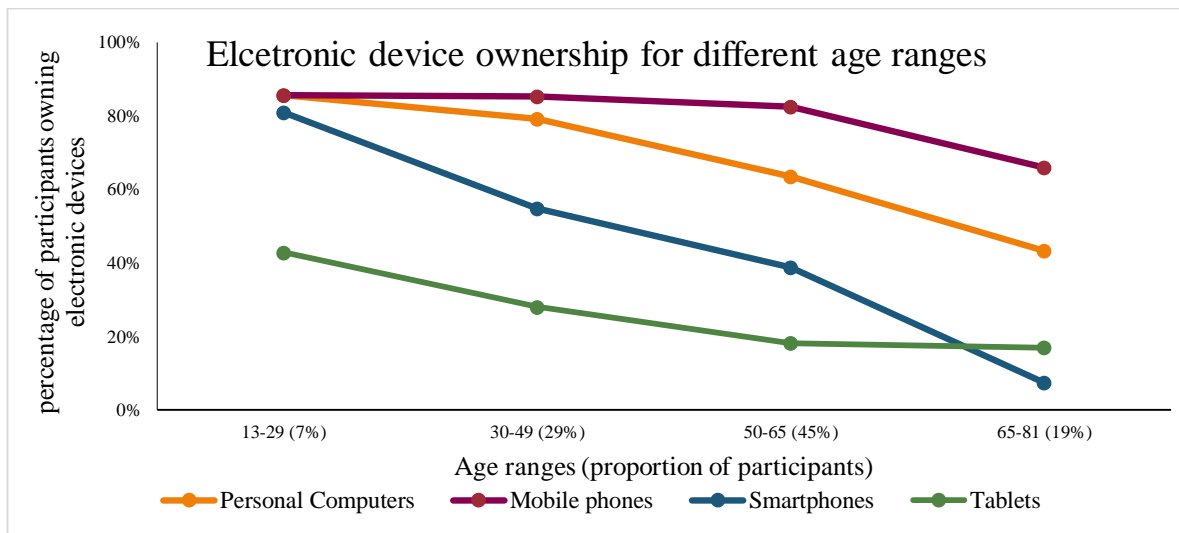


Figure 5 - Electronic device ownership of different age ranges for participants in study II.

For persons who owned a smart phone, the total CFQ score was significantly higher ( $p < 0.05$ ). About 66% of the participants owned/used personal computers, and 23% owned electronic tablets. Based on participants' responses, the most frequently used e-services were communication and banking; reading and health promotion services (Apps) were the least used ones. The average age for 89% of participants who used some type of e-services was 43 years old. For participants who used reminders, such as an alarm or memory, listening and communication, the total CFQ score was significantly higher ( $p < 0.05$ ), and generally e-services were used by participants with higher total CFQ scores. Figure 6 shows the participants usage of different e-services regardless of their total CFQ scores. The comparison of participants' use of e-services based on their total CFQ score is presented in study II of this thesis. The participants' response to the open-ended questions indicated a positive attitude towards using e-services; generally, the Internet and different e-services were considered a great support in terms of education, training and entertainment. However, they considered behavioural influence (such as addiction to using the Internet and tiredness while using), difficult design, and technical downsides as negative aspects of e-services.

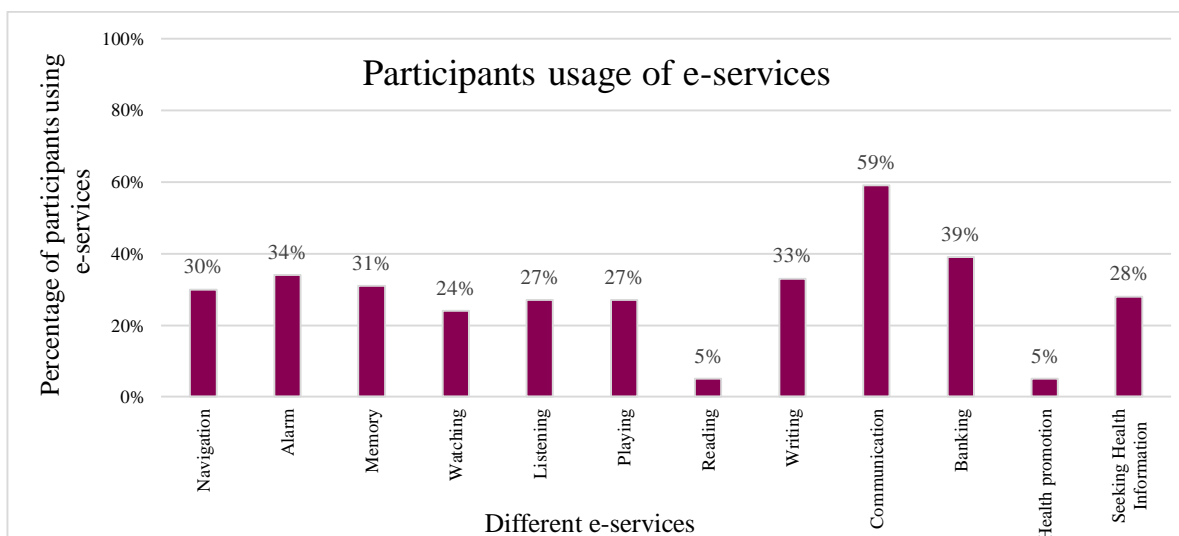


Figure 6 – Participants' use of e-services in study II.



#### **4.2.4 Discussion**

Considering the lack of data about the members who did not participate in this study, the results of this survey showed that most of the participants had a positive attitude towards using e-services for achieving a self-regulating and independent life. In this study, new insight was provided regarding the relation of different aspects of e-services and social media for persons with MACI. The results indicated that, given the diversity of e-services, the ICF classification was a valuable tool for exploring the functionality of the e-services.

The mean of participants' total CFQ scores estimated by self-ratings was very close to what others have reported for different study populations [106, 108]. Due to the variation between participants in terms of age and type/period of brain damage, the total CFQ score did not correlate with either of those demographic characteristics. Based on the results, different e-services, such as navigation, alarms, memory, video and music services, writing, banking, seeking health information and essentially, social interaction and communication were the most important aspects of ICT for this group. The Internet was considered as a valuable source of health information and generally, ICT tools were considered as reliable support equipment. However, the participants were concerned about privacy and security issues in addition to behavioural influences; concerns which also exist in a healthy population and can be solved by correct guidance in a specific context [139]. The use of e-services among these participants with cognitive failure was comparable to the Swedish general population, indicating the interest of this group in using regular e-services, similar to healthy people. However, they did not use social media as often as the general public, although Facebook use was quite noteworthy, given their cognitive problems.

The results of this study indicated that there is a need for popularising persons with MACI in the ICT research community as a group with special needs in using ICT tools. Furthermore, future research is needed on utilising these identified aspects of ICT to support persons with MACI with their conditions as well as exploring usage of the Internet and social media at a mass and individual level, considering their cognitive function level.

### **4.3 STUDY III**

Based on the results of study II that emphasised the social interaction and communication aspects of ICT, study III was conducted to address the lack of research examining social media and the potential value of on-line support for persons with MACI.

#### **4.3.1 Aim**

This study aimed to explore how persons with MACI communicate through social media, classify and visualise their involvement, and recognise different actors in such a virtual society.

## 4.3.2 Methods

### 4.3.2.1 Study setting

This study was conducted within a Facebook group for Swedish-speaking persons with brain fatigue after brain injury. The data collection was performed in October 2015 and all content that appeared on the group's timeline for a whole year was collected to avoid seasonal effects on individuals' behaviour [140]. At the time of data collection, the group had 1 310 members.

### 4.3.2.2 Procedure

The collected content was analysed using the SNA method quantitatively and qualitatively (see section 3.3.1). In the quantitative SNA, the *centrality* and *weighted-centrality* of the nodes (active group members) were measured and the distribution of involvement in the information exchange among them was analysed and visualised. For quantitative analysis, the ForceAtlas2 algorithm in Gephi 0.802 beta software was used for constructing and modifying the graph density in the visualisation setting.

In the qualitative analysis of the "posts" and "comments", as described in Chapter 4.3.1.2, the five major categories for social support, according to the social support behaviour code (SSBC) developed by Cutrona and Suhr, were used to code them into "informational", "emotional", "esteem", "network", and "tangible support" categories [141]. For other categories, the initial codes were retrieved from the Gaysynsky et al. study [129] and during the analysis, additional categories emerged and were classified by the authors of this study. The context of the "post" and "comment" was used to understand the intention of the message. Furthermore, the "likes" contributed to the content, and for the "posts" and "comments" which fell into support category, "seeking" or "providing" support was considered.

## 4.3.3 Results

During the data collection, all content that appeared on the group's timeline from 1 September 2014 to 31 August 2015 was collected. In total, 630 "posts", 4 323 "comments" (23% self-comments on their own "posts") and 10 187 "likes" on "posts" were collected from 1 092 unique active members (17% of the members did not make any contribution to the group's content). The number of "posts" and "comments" was the highest during May 2015.

### 4.3.3.1 Qualitative analysis

During the analysis process, 57% of the "posts" and 62% of the "comments" were coded as different types of social support. The analysis showed that most of the "posts" and a large number of "comments" were peer-to-peer exchange of "informational" social support. Table 8 summarises the results of the content analysis. In the "posts", the members were more interested in providing support (40%) than in seeking support (17%).

Table 8 - The incidence of “posts” and “comments” based on different categories in study III.

Type of Categories	Categories	“Posts” (%)	“Comments” (%)
<b>Main social support</b>	Informational	41	26
	Emotional	9	20
	Esteem	5	14
	Network	2	<1
	Tangible assistance	<1	<1
<b>Other</b>	Expressions of gratitude	7	2
	Offering congratulations	0	<1
	Administrative/engagement in group	1	<1
	Banter	14	1
	Socialising	13	5
	Group cohesion	<1	1
	Negative interaction	<1	<1
	Community protection	2	1
	Non-verbal cues	1	3
	Miscellaneous	1	<1
	Advertising	2	0
	Questions	1	2
	Self-comment	0	23

The contents of informational support “posts” and “comments” were mostly about sharing an experience of their deficiencies and strategies about how to deal with them. Given the members clinical differences in their deficiencies, they gained emphatic feeling merely by sharing their experiences.

#### 4.3.3.2 Quantitative analysis

The network analysis provided a clear visualisation in addition to data regarding members’ behaviours in the group. Most of the members’ contribution was in the form of “likes” (93%) followed by “comments” (49%) and only 16% of the members contributed “posts” to the group. As described in Chapter 4.3.1.1, the centrality determination showed that the majority of members were sparsely-connected. Table 9 shows the node division based on their centrality.

Table 9 - Nodes division based on connectivity in study III.

Levels of connectivity	Amount of Nodes	Centrality	Weighted-centrality	Only made “likes”	Only made “comments”	Only made “posts”
<b>Zero-connected</b>	1 (0%)	0	0	0	0	1 (<1%)
<b>Single-connected</b>	297 (27%)	1	1-10	243 (82%)	41 (2%)	1 (<1%)
<b>Bi-connected</b>	155 (14%)	2	2-7	112 (72%)	12 (1%)	1 (<1%)
<b>Sparsely-connected</b>	381 (35%)	3-10	3-36	85 (22%)	30 (1%)	3 (<1%)
<b>Intermediate-connected</b>	240 (22%)	11-94	11-127	20 (1%)	0 (0%)	3 (<1%)
<b>Well-connected</b>	15 (1%)	100-254	158-534	0 (0%)	0 (0%)	0 (0%)
<b>Very-well-connected</b>	3 (<0%)	411-516	1700-2308	0 (0%)	0 (0%)	0 (0%)

Despite the low density element value for the graphs generated from SNA visualisation (0.011 in 0–1 range representing the complete connectivity between the nodes), the edges between different nodes were difficult to distinguish (Figure 7). This proved to be due to a few nodes having a relationship with many, and many nodes with one or a few. In this study, 18 nodes with higher levels of centrality (well-connected and very-well-connected marked as A-R), in addition to two other nodes who just made “comments” and “likes” (marked as x and y), were chosen for further analysis to understand their individual personality and the nature of their contribution to the group. A more comprehensive analysis of the node’s activities is presented in study III of this thesis.

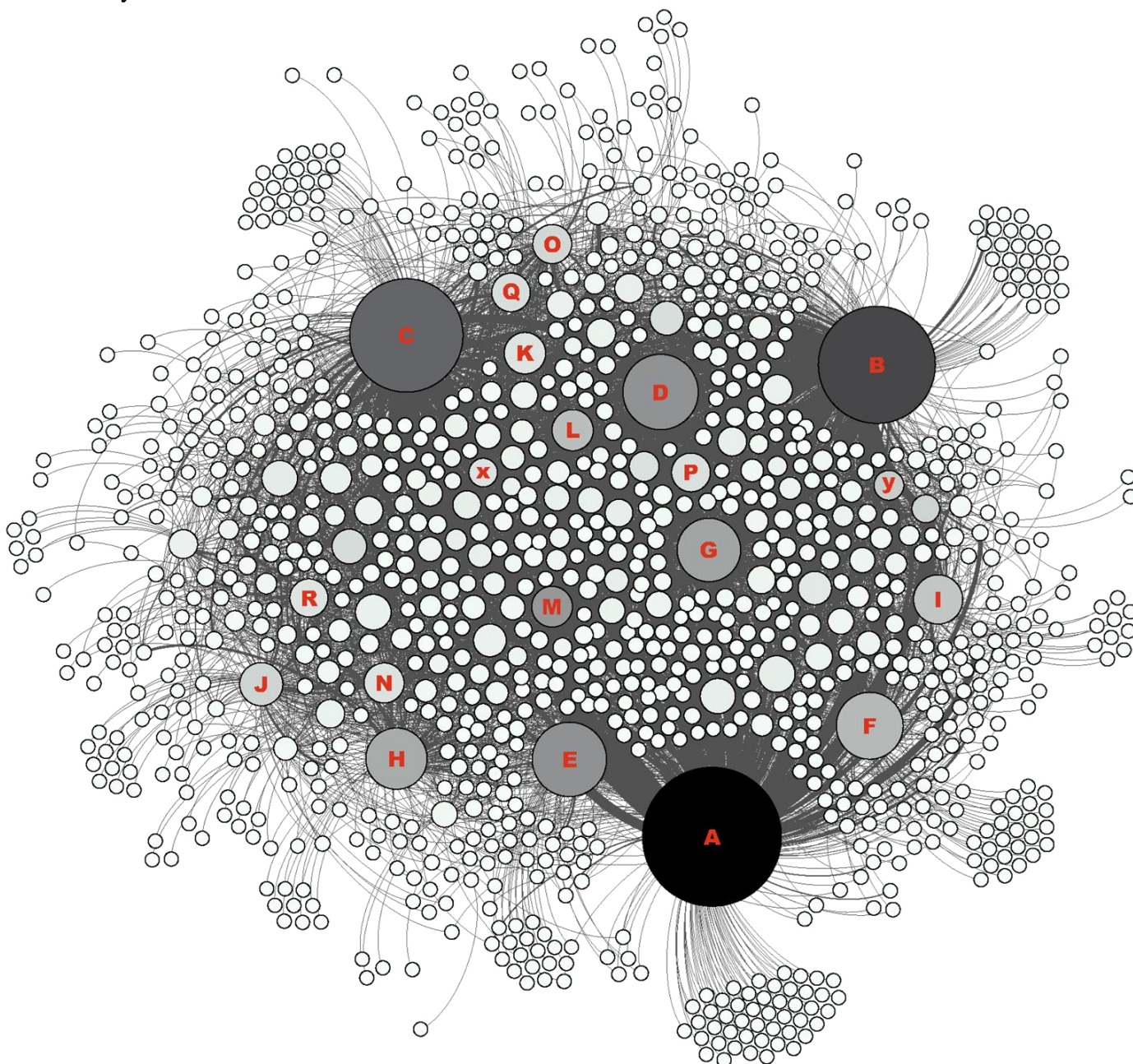


Figure 7 - The network analysis graph for all nodes in study III. In this figure the size of each node represents the **centrality** and the darkness indicates **weighted-centrality**. The marked nodes A-R are well-connected and very-well-connected nodes in the network. The x and y nodes are two other active nodes who just made “comments” and “likes”.

In addition to having the highest centrality and weighed-centrality in the group, the A, B and C nodes had the highest number of “posts” and they responded more frequently to the “posts”

by other nodes. Further, the semantics of active members' "posts" and "comments" was analysed with the intention of getting deeper into their contribution. The results showed that, on average, most of their "posts" were "socialising related" followed by "informational support" and they were providing support in different categories rather than seeking it (with the exception of "emotional support").

#### **4.3.4 Discussion**

The results of this social network analysis showed the capacity of persons with brain fatigue after acquired brain injury to use Facebook as a means for communication and support for their condition. The members of this group used the Facebook platform's features in a way similar to other typical users. The most used feature was "likes" followed by "comments" and the themes for the content were mostly informational support and socialising. The results showed that providing any type of support was valued and appreciated by the members. Considering different behavioural patterns in members' activities, they showed interest in being in contact with people in similar situations. Bearing in mind that members trust others with a similar condition, a suggestion for the healthcare system and patient organisations would be to identify the active users through a social network analysis and voluntarily provide them with basic training to moderate or monitor the group in a way that other members benefit from the knowledge of the effects of brain injury. This idea has to be further explored with clinicians to comprehend the burdens regarding choosing a patient ambassador. Further studies with more controlled variables regarding the persons' cognitive levels and passive members' activities would probably provide more reliable results for this specific group.

### **4.4 STUDY IV**

Based on the results of study II about using different ICT tools on a daily basis, study IV was conducted to address the lack of information about how these tools have been incorporated into the daily lives of persons with MACI, and to address the difficulty of gathering user experience data due to their concentration problems and tiredness in this group.

#### **4.4.1 Aim**

The aim of this study was to capture the frequency of using regular ICT tools and user experience, and to explore the feasibility of the DRM [114] as a diary-keeping method for persons with MACI.

#### **4.4.2 Methods**

##### *4.4.2.1 Study setting*

The participants of this study were recruited in March 2016 by a recruitment email which was sent to 88 members of the Swedish Association of Brain Injury (Hjärnkraft) who had participated in study II of this thesis and showed interest in participating in further studies.

#### 4.4.2.2 Procedure

The principle method of data collection for this study was a postal survey consisting of the Swedish translation of the DRM questionnaire, an informed consent, and the required instruction for filling in the questionnaire. The participants were asked to fill in the questionnaire by themselves, based on their episodic experience from the day before receiving it. CFQ values for this study’s participants were retrieved from study II of this thesis and used to estimate their general level of cognitive failure.

#### 4.4.2.3 Statistical analysis

Initially, the participant’s responses were stored in comma-separated value files. Then, the descriptive analysis of the study participants, determination of normality and the analysis of significant differences within different demographic data, DRM answers and total CFQ scores were performed by using the “SPSS” version 23.0.0.0 statistical software package.

### 4.4.3 Results

#### 4.4.3.1 Participants’ characteristics

After receiving the recruitment email, 21 members showed interest in getting more information about the study and sent their postal addresses to receive the paper questionnaires. Finally, after receiving the information about the study and the actual questionnaire, 11 persons agreed to participate in the study by posting back the signed informed consents, as well as valid responses to the questionnaire. The mean for participants’ total CFQ scores was  $51 \pm 19$ ; 82% suffered from TBI. The participants were mostly females (64%) and all of them had at least a high school degree. The majority of participants (45%) were in their 50s and all of them owned mobile phones and mostly (82%) smart phones. Only two out of 11 owned tablets, and all except one owned a personal computer. Data regarding participants’ characteristics are presented in Table 10.

Table 10 - Participants’ demographic characteristics in study IV.

Age (years)	Sex	Education	Employment	Type of brain damage	Time since brain damage (years)	Total CFQ scores
25	M	High school	Sick leave	TBI	>2 and <5	20
50	M	College/ University	Unemployed	TBI	>10	26
52	F	High school	Sickness compensation	N/A	>10	31
18	M	High school	Studying	TBI	>2 and <5	45
49	F	College/ University	Sick leave	TBI	>2 and <5	53
62	M	College/ University	Sickness compensation	Stroke	>2 and <5	54
68	F	High school	Employed	TBI	>10	55
31	F	College/ University	Sick leave	TBI	>2 and <5	62
50	F	College/ University	Employed	TBI	>2 and <5	65
55	F	College/ University	Sick leave	TBI	<2	70
27	F	High school	Sick leave	TBI	>2 and <5	80

#### 4.4.3.2 Participants experience during the trial day

The participants rated their life satisfaction as medium and they felt mildly pleased being at home. On average they reported about 10 episodes per participants with the median length of 70 minutes and the most frequently pre-defined reported activities were eating and socialising. More than half (six out of 11) of the participants used computer/Internet during the trial day. The participants in this study experienced mixed feelings (both positive and negative). Their most positive feelings were when they were taking care of children, using the phone, exercising, and using computer/Internet (Table 11).

*Table 11 - Mean of feelings by situation [114] for participants in study IV. Positive feeling is the average of happy, warm/friendly, enjoying myself. Negative affect is the average of frustrated/annoyed, depressed/blue, hassled/pushed around, angry/hostile, worried/anxious, criticised/put down. For each situation, the table shows the mean ratings on feeling descriptors, the average amount of time all participants spent in the situation. The mean is presented as an average of 0-6 Likert-scale.*

	Mean affect rating					Average time-spend (min)	Total number of reported episodes
	Positive	Negative	Impatient	Competent /Capable	Tired		
<b>Activities</b>							
Commuting	2.2	1.0	0.3	2.3	3.6	37	9
Shopping	0.0	0.3	3	0	4	30	1
Doing housework	3.4	0.1	0.1	2.6	1.6	56	9
Eating	3.0	0.8	1.1	2.5	3.1	62	30
Socialising	3.6	0.9	1.3	3.5	3	72	25
Nap/Resting	1.5	1.5	2.8	1.4	5.3	76	10
Relaxing	3.2	0.8	1.4	3	3.5	75	18
Intimate relations	2.6	1.5	2.5	2.5	3.7	80	4
Working	3.3	1.1	0.4	4.2	2.3	137	12
Preparing food	2.5	1.3	1.8	3.2	3.5	58	13
Taking care of children	5.3	0.2	0.5	5.3	0.7	47	6
Praying/Worshipping/Meditating	-	-	-	-	-	-	0
Watching TV	3.2	0.8	1	2.4	3.7	91	9
Computer/Internet	3.8	0.3	1.4	3.8	2.7	115	12
On the phone	3.9	0.2	1.2	4.6	3.2	131	9
Exercising	3.9	0.1	0.7	4.7	2.4	87	9
Others	3.1	0.4	1.1	2.9	2.6	73	30
<b>Interaction partners</b>							
Spouse	2.7	1.2	2.7	2.9	4.1	83	22
Friends	4.6	0.4	0.4	3.2	1.2	61	14
Co-worker	2.7	1.6	1.2	4.2	3.5	86	12
Students/patients	2.8	0.3	1.4	3.4	2.1	112	11
Children	3.7	0.4	1.1	3.9	3.6	71	7
Relatives	3.2	1.0	0.7	1.8	3.2	106	7
Boss	3.8	1.7	0	4.5	2.2	86	6
Others	3.0	0.1	0.9	2.5	1.4	74	14
Alone	2.5	0.9	1	2.5	3.7	57	48

To measure the correlation between different feelings and age, time spent, and total CFQ scores, a bi-variate correlation procedure was performed, which did not show any significance. For participants who used computer/Internet during the trial day, the happy, warm/friendly and competent feelings were correlated with age ( $p < 0.01$ ). To address the overall feelings during the day, the linear component of time for each feeling (adjectives) was examined. Unlike the low ranking of negative feelings, the participants ranked the positive and competent feelings quite high. The participants who used computer/Internet during the trial day had mostly higher levels of positive and lower levels of negative feelings compared to others.

#### **4.4.4 Discussion**

The results of this pilot study provided information about the daily activities, feelings and use of computer/Internet, in addition to strengths and weaknesses of using DRM for capturing daily experiences of persons with MACI. The participants of this study suffered mostly from MCI due to TBI. The results indicated that the home context is a pleasant environment for social activities, increasing interpersonal relationships, and spending time using the phone, the computer/Internet, and watching TV. With respect to the small sample size for this study, the participants who used computer/Internet to some extent had higher ranked positive feelings during daily activities and their age correlated with happy, warm/friendly and competent feelings.

Regarding the feasibility of using DRM for this group, this study showed that DRM is a well-structured and assumedly understandable tool for the participants of this study. However, the great risk for bias, such as providing information on personality traits instead of the activities themselves, extensive memory problems in persons with MACI, the limitations of DRM to capture in-depth information about the nature of the activities and the numbers of drop-outs all have to be considered while capturing the experience of persons with MACI. According to the results of this pilot study, the current form of DRM has to be slightly modified, both the content, and the system of administration in order to provide more comprehensive information about the user experience concerns for persons with MACI. Further studies with a larger sample over a longer time period are needed to confirm the results of this study.



## 5 DISCUSSION

The overall aim of this research, with respect to the CHI field, was to understand how regular ICT tools are used by persons with MACI in their daily lives. In addition, the aim was to explore how to capture their experience while using these tools. In this chapter the methodological considerations, primary findings, future research, and contributions and limitations of the four studies will be discussed.

### 5.1 METHODOLOGICAL CONSIDERATIONS

Different research approaches have been used in the studies of this thesis. The main data collection was performed by using a systematic review and surveys, followed by the SNA method. The open-ended questions in the e-services questionnaire in study II and episodic forms of daily activities in study IV provided qualitative interpretations of participants' activities, thoughts and attitudes towards using regular ICT tools. Therefore, this research is exploratory in nature since it has attempted to provide new insights about the use of regular ICT tools by persons with MACI in their daily lives. To address special needs of persons with MACI in using ICT tools and because they have received less attention from the research community, the exploratory approach of these studies appeared to be more appropriate for this thesis.

### 5.2 PRIMARY FINDINGS

The research presented in this thesis was focused on the user experience of persons with MACI, while using regular ICT tools. The participants in the studies of this thesis lead independent lives with or without differing needs for assistance by their family members or the Swedish health services. As a first stage in the design process, this thesis contributed to the understanding of research principles regarding persons with MACI for future UX researchers. In this section, the focus is on placing the results in a wider context to understand the main contributions of this research.

#### 5.2.1 Understanding persons with MACI

##### 5.2.1.1 *Current research*

As mentioned in the introduction of this thesis, and emphasised by researchers in the CHI field, delivering the required mental and physical healthcare services to cover the needs of persons with disabilities is a challenging task (especially for persons for whom the healthcare system is incapable of fully understanding their complexity and variation) [37]. Given the complexity of understanding MACI and its consequences, supporting a person's self-management would play a key role in assisting this group. Certainly, ICT has the potential to help persons with MACI in managing their health, easily and safely. However, their cognitive ability to access and manage obtainable and appropriate technology has to be considered [142].

The results of study I showed that the identified studies and current research are still not enough to help persons with MACI for coping with their condition, to meet their needs in their daily

life, to maintain their independence, and to support their self-management. The results indicated the lack of robust and transferable design and/or evaluation methodology in identified studies. At the same time, the results indicated that there are still unknown issues regarding how persons with MACI experience their conditions.

Given the benefits of the medical model of disability [39], providing an analytical framework based on what healthcare professionals consider as disability would also be beneficial in designing new tools or mapping the available ones for persons with MACI [42]. Further efforts are needed to provide a universal analytical framework in order to understand the criteria of different populations with different cultures in different contexts. This can be done by employing socio-technical design methods to understand different healthcare processes [143].

#### *5.2.1.2 Current technology*

Today the market is filled with various types of software and apps. Although providing useful or small tools (apps) might support the person's needs, such tools might not fit the cohesive larger vision of supporting their information and communication needs. Understanding persons with MACI has to start from the user experience and work backwards to the technology. The investigation should start from what benefits can be given to the person rather than merely ascertain how to find the target user for current existing technology [3]. The challenge is not to prepare persons with MACI to use the current technology, but to make the technology ready to meet their needs and expectations.

Regarding different ICT tools, the results of this thesis showed that using new devices (e.g. smart phones) is becoming more popular amongst persons with MACI, who are as capable of using this technology as a healthy population. As indicated by Luxton et al., the existing technology and preferences for incorporating them in people's daily life are changing regularly and it is essential to consider the usability, safety and data security aspects of them for all members of society (with or without full abilities) [144].

#### *5.2.1.3 Web 2.0*

Researchers in HI have emphasised the role of information, social interaction and Web 2.0 services for further development of AAL systems [87]. The results of this thesis indicated that social media might be a valuable means of social support plus informational benefits for persons with MACI. Previous studies in the field of CHI have shown that use of the Internet for accessing/searching health information has increased, and that consumers are always trying to gain access to more information regarding their health in the same way as healthy individuals, and use different platforms, devices, and technologies to find this information [35, 145]. The results of this thesis (studies II and III) have verified this matter by showing persons with MACI's preferences in seeking the Internet for their own "Information Therapy" [37, 146]. Persons with MACI were able to use the Internet on different devices such as their personal computers, smart phones and tablets. Furthermore, this thesis showed that adding social media to address the social aspect of persons with a special conditions could address the challenges of building effective, efficient and satisfactory AAL systems [87]. Usually, people

with similar conditions trust each other [147], so by contributing to attractive and relevant content, social media would be promoted to help persons with MACI.

#### 5.2.1.4 *User experience*

The users' experiences in exploring the potential of assistive services and AAL systems are essential for improving their healthcare [87, 148]. In addition, involving persons with special conditions in the development of required tools, and paying attention to the tools' usability from the beginning of persons' illness, has been emphasised by CHI researchers [145]. A potential solution to this matter would be to consider persons as active partners in understanding their own situation while using available ICT tools or during development and implementation of new ones. This can be done by doing field studies and using various UX approaches for understanding persons' specific needs. However, understanding experience is extremely difficult and it requires using many more than a single method. As indicated in Chapter 3, only a few approaches from the various UX field study methods have been used in this thesis. This research is an initial step to show how UX approaches can reveal unexpected issues regarding persons with MACI who are capable of taking care of themselves and living among healthy populations.

In this thesis, in addition to the surveys and social media behaviour analysis, a pilot study was performed to explore the feasibility of an actual UX field study method for capturing the daily experience of persons with MACI with the focus on regular ICT tools. The results showed that conducting field studies with persons with MACI requires consideration of issues such as personality traits, administration of data collection, usability aspects of ICT tools, and the person's general ability to participate in the field studies.

#### **5.2.2 Design for all**

The results of this thesis showed the importance of providing aids through regular ICT tools to fulfil the needs of individuals with disability. Considering the social and medical model of disability [39, 40], the results indicated that individuals with varying skills will try to use the existing ICT tools in the same way as a healthy population. This shows the importance of society's services to consider the principle of "design for all" rather than user-specific design approach [149].

To address this issue, the national health systems in different countries have started a "patient-led" process [150]. For example, the "National Cancer Institute" in the USA has invested substantially in "*understanding its audience needs to avoid costly development mistakes by employing different methods and theories derived from psychology, human factors, communication, and informatics engineering*" [145] and to elevate the ability of using ICT for assisting them in treating cancer. From the CHI point of view, it is important that persons with disabilities gain independent and equal access to new ICT tools and Web 2.0 opportunities in the same way as the healthy population does [145]. Therefore, special effort is required by public and private ICT providers to consider persons with MACI in the design and development of health- and non-health-related tools and services. In addition, the guidelines and standards

(e.g. section 508 in United States Access Board [151]) could be improved to achieve the above-mentioned objectives.

### **5.3 FUTURE RESEARCH**

Future research may explore the use of UX approaches for further understanding of persons with MACI. In addition, future research can be done in improving the analytical framework from the point of view of actual persons with MACI rather than what clinicians consider as impairments (classifications in the medical model of disability). It would also be interesting to explore new ways for providing more information about the existing self-care services (apps) through the healthcare system. Another aspect that could be followed in future research is the idea of having a patient ambassador in social media groups for moderating and monitoring the group to see how other members could benefit from the existing clinical and neuropsychological knowledge. The potential benefits of using ICT for supporting persons with MACI also have to be further investigated. Finally, exploring new administration methods for performing UX field studies are needed.

### **5.4 CONTRIBUTION OF THIS RESEARCH**

This thesis has contributed towards:

- Promoting persons with MACI amongst the HI and CHI research community as a group with special needs and necessities for using ICT tools and Web 2.0 services
- The direction of future research regarding ICT tools that can be used by healthcare professionals who are seeking to assist persons with MACI
- Uncovering problem areas where ICT could support persons with MACI
- Knowledge about the ICT tools and Web 2.0 services that are currently being used by persons with MACI
- A framework for analysing and understanding the social media content (in this case Facebook)
- Employing UX field study methods for capturing user experience of persons with MACI with respect to ICT
- Challenges in exploring the user experience of health information consumers with MACI

### **5.5 LIMITATIONS**

#### **5.5.1 Study I**

This study aimed to provide a systematic review of scientific articles on the topic of supporting self-management of persons with MACI through ICT. The main limitation of this study was information on ICT tools, their development, and implementation which was not published in scientific journals. In addition, the results of this study were limited to studies published before September 2011 and therefore scientific studies in this field, particularly in the past few years,

when the advancement of mobile technology has revolutionised the healthcare process and rehabilitation for different chronic conditions, were not considered.

### **5.5.2 Study II**

This study aimed to explore how persons with MACI use and experience the use of regular e-services and social media. The major limitation of this study was that it relied on self-reported responses. This might be especially problematic regarding capturing cognitive problems since the participants might not be fully aware of their own situation. In addition, generalisation of the results for this study might be difficult since all participants were members of one patient organisation. Moreover, Sweden is among the top European countries with the highest levels of IT use, even in the older population, so the results of this study cannot be generalised to populations and countries which are not equally familiar with the use of regular ICT tools and e-services. Furthermore, the intention of this survey was not to show the daily usage and financial aspects of obtaining ICT tools for the participants. Another limitation for this study was the lack of information about the members who did not participate in the study, their age, cognitive impairment levels, and their use of e-services. Therefore, the results simply represent the members who agreed and participated in the study.

### **5.5.3 Study III**

This study aimed to explore the user-behaviour for persons with brain-fatigue following potential MACI while communicating through Facebook. The major limitation of this study was the lack of information and clinical data about actual cognitive failure levels of the participants as individual profiles on Facebook. In addition, this Facebook group was intended for Swedish-speaking persons with brain fatigue which might have influenced their behaviour in terms of culture and way of interaction. Another limitation of this study was the lack of information about passive members of this group, the participants' passive activities (rather than "posts", "comments" and "likes") and the direction of information flows. It has to be emphasised that, for practical and technical reasons, this study only examined detailed behaviours for members with high centrality and the comprehensive behaviour analysis was not performed for all individuals present in the group.

### **5.5.4 Study IV**

This study aimed to explore the feasibility of using the DRM as a diary-keeping method for capturing the frequency and user experience of persons with MACI using regular ICT tools. One limitation for this pilot study was the selection bias since the participants were admittedly capable of taking care of themselves and were selected from persons who participated in study II of this thesis and who were interested in further studies regarding ICT tools. In addition, this study could not provide any comprehensive understanding of persons with MACI since, as with study II, it relied on self-reported cognitive problems and daily activities and feelings. Another limitation was the validity and reliability of results since it was not possible to collect episodic data for more than one day. The activities in the questionnaire were pre-defined and could not be adapted to more specific ICT use. Another issue was overlapping activities, which

made it difficult to understand the exact focus of one activity. Also, there was a lack of information about how the participants of this study used computer/Internet.

## 6 CONCLUSIONS

This thesis is an exploratory attempt at understanding how persons with MACI use ICT tools/social media to cope with their conditions and to investigate new methods for capturing their experience while using them.

To the best of our knowledge, the studies of this thesis were the first to explore the ICT and users' experience for health information about consumers with MACI. Findings in this thesis showed that ICT provides usable tools to support persons with MACI in their daily activities. In addition, social media would provide informational and social support for them, as it does for the healthy population. On the other hand, providing the appropriate ICT tools and/or social support for persons with MACI requires a comprehensive understanding of their experience, context of use, content management and capability of the technology.

We explored different UX research methods, concepts and means in this thesis. We showed that UX research approaches would provide valuable means for understanding the person's needs, attitudes and the impact of the technology. However, adaptations to existing UX methods are necessary to capture the experience of persons with MACI while using ICT tools.

This thesis showed that developing new ICT tools might not be necessary for everyone who is suffering from MACI, but the need for more assistance in learning how to use them might be essential. However, the lack of information about non-responders who did not participate in the studies of this thesis, their age, and cognitive impairment levels has to be emphasised. This thesis also showed that a considerable proportion of persons with MACI have the capacity to use regular ICT tools and e-services. However, further efforts by the healthcare system are required in better administration and recommendation of these tools in order to provide the right tools for the right users in the right context. Considering that this thesis was the first stage of the UX design process, further stages have to be considered for following up the results of this research.

## 7 ACKNOWLEDGMENTS

*“No man's knowledge here can go beyond his experience.” John Locke (1689)*

I would like to express my sincere gratitude to all the people who encouraged me and played along with my every step. I believe no scientific work can be carried out by one person and, in the PhD process, everyone that you meet is a teacher. For me, the PhD process was definitely about the journey and not the destination. Thanks to everyone who supported me directly and indirectly through this journey and made it a great experience for me.

Sabine Koch, my main supervisor and probably the best supervisor ever! For giving me the opportunity to accomplish this research as a PhD student; for your patience and listening to my nonsenses all the time; for motivating me with your great knowledge and expertise; for your in-depth analysis of my work and constrictive feedback. Thank you for believing in me and standing by my side through this journey.

Aniko Bartfai, my co-supervisor. I would like to express my gratitude for your honesty, kindness, care, encouragement, knowledge, and for making me write and talk in a way that everyone would be able to understand. For your interest in my work and making me part of your team.

Jeremiah Scholl, my former co-supervisor and current colleague and friend. Thanks for your continuous constructive feedback, for motivating me through this journey and helping me understand the principles of working as a researcher.

Stanisław Zabramski, my mentor. For being there and making me feel secure that I have a friend who will always support me even when we don't meet for a long time. Thank you for giving me the motivation and confidence to pursue my career in academia. Thanks also to Mats Lind for introducing me to this journey and motivating me with your great guidance in scientific research. Thanks to Else Nygren for your great support and kindness.

I would also like to acknowledge everyone who contributed to this research. My sincere thanks go to Christian Oldenburg, Mesfin Tessma, Eva Hagel, Ulrika Hamidi, David Komar, Marie-Jeanette Bergvall, the Swedish Association of Brain Injury (Hjärnkraft) and its designated members.

During this journey I had the privilege of collaborating with many brilliant people. Thank you Farhad Abtahi, Thomas Wollmann, Juan Feng, Md Akteruzzaman, Gabriela Markovic and Marika Möller.

Special thanks to my dear colleagues at HIC. Thanks for providing me a great, enjoyable learning environment: Nadim Anani, Peter Bolin, Stefano Bonacina, Rong Chen, Iago Corbal, Nadia Davoody, Sherry Fahimi, Johanna Forsman, Anisia Fotiadou, Maria Hägglund, Marie Lind, Sara Lyckstedt, Eva MacDonald, Anja Perlich, Sara Riggare, Therese Scott Duncan, Sebastian Stocker, Thorsten Weires, Anna Wikström and Yamrot Woldemariam.



I am also grateful for the spiritual support offered by all my colleagues and friends at LIME and KI. I would also like to thank Mats Brommels, the head of department of LIME. I have enjoyed the spirit of fun and creativity in the planning group of LIME Doctoral Network.

This journey was impossible without the love and support of my family and friends.

I would like to express my deepest gratitude to all my dear friends around the world, from Australia, Asia, Middle East, Africa, Europe, North and South America, who truly supported, motivated and helped me in this journey. Thanks for your encouragement and being there for me.

Dad: I know you will be the proudest person when I will defend my thesis. Thanks for always being there for me, believing in me and supporting my decisions in life. Mom: I have no words to express my gratitude for your love and support. Thank you for your continuous care and love. And my sister: you mean the whole world to me. Thanks for always being there and holding everything together in my absence.

Last but not least, my lovely partner, Shohreh. For motivating me and standing by me thorough the ups and downs of this journey. Thanks so much for your kindness and love. I am grateful to share my life with you.

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## 9 APPENDIX STUDY II

### The Cognitive Failures Questionnaire (CFQ)

Frågorna tar upp saker alla kan råka ut för då och då och en del kanske oftare än andra. Vi vill nu veta, hur ofta det som tas upp i frågorna, hänt dig de senaste sex månaderna. Kryssa i det alternativ som bäst motsvarar rätt/ditt svar.

	Mycket Ofta	Ganska Ofta	Ibland	Mycket sällan	Aldrig
1. Måste du läsa om det du precis läst för att du inte tänkt på innehållet?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Går du från ett rum till ett annat och upptäcker att du glömt, vad du gått för att göra?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Missar du skyltar vid väggkanten?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Brukar du blanda ihop höger och vänster när du ger riktning beskrivningar?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Händer det att du stöter ihop med andra?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Händer det att du glömmet huruvida du släckt lyset, stängt av spisen, eller låst dörren?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Missar du att lägga märke till människors namn när du träffar dem?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Säger du saker som du i efterhand inser kan tas som förolämpande?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Missar du vad andra säger till dig när du är upptagen med annat?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Förlorar du humöret och ångrar dig efteråt?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Lämnar du viktiga brev obesvarade i dagar?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Glömmet du var du ska svänga av på en väg du är välbekant med men sällan använder?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Händer det att du inte upptäcker det du söker i en affär, fastän det finns där?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Händer det att du plötsligt funderar över om du använt ett ord i dess rätta sammanhang?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Har du svårt att bestämma dig?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Glömmet du avtalademöten?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Glömmet du var du lagt saker som t ex en tidning eller bok?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Händer det att du slängt bort sådant du tänkt spara och sparar sådant du tänkt slänga, t ex du slänger tändsticksasken och stoppar den använda tändstickan i fickan?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Tänker du på annat när du egentligen borde vara uppmärksam på något som sägs?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Glömmet du människorsnamn?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Händer det att du påbörjar saker hemma och senare finner att du distraherats till att göra något annat, oavsiktligt?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Händer det att du inte riktigt kan minnas något fastän du "har det på tungan"?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Glömmet du vad du kommit till affären för att handla?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Tappar du saker?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Händer det att du inte kommer på något att säga?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## The e-services questionnaire

Hur använder du dator, mobiltelefon/smartphone, surfplatta samt Internet.

1. Ålder:.....
2. Kön: Man                      Kvinna
3. Vilket arbete har du? .....
4. Vilken skolgång har du?  
Grundskola 9 år      Gymnasium (antal år 2,3,4)      Universitet/högskola (antal år)
5. Sysselsättning:
  - Arbetar du: Heltid                      Deltid → Ange procent: .....
  - Studerar
  - Sjukskriven → Ange procent: .....
  - Sjukersättning → Ange procent: .....
  - Arbetslös
  - Pensionärer
6. Hur fick du din hjärnskada? .....
7. Hur länge sen är det du fick din skada?
  - Mindre än 2 år sedan
  - Mellan två och fem år sedan
  - Mellan fem och tio år sedan
  - Mer än 10 år sedan
8. Använder du dator regelbundet? Ja                      Nej
9. Använder du mobiltelefon?      Ja                      Nej
  - Om ja, är det en smartphone? Ja                      Nej                      Jag vet inte
10. Använder du en surfplatta?      Ja                      Nej

**OBS: Om du inte använder någon av de tjänster som nämns i frågorna 8,9 och 10, slutar enkäten här och du behöver inte gå igenom resten av frågorna. Även om du bara använder en av dem så fortsätt gärna att fylla i enkäten!**

11. På vilket sätt använder du surfplatta/ mobil / dator idag? (Vänligen välj från alternativen nedan):
- Hitta väg med hjälp av kartor (t.ex. GPS)
  - Larm eller påminnelse - för att sova och/eller vakna, påminnelse att ta mediciner
  - Minnesstöd– anteckningar, kalendrar, dagböcker, att göra lista, inköpslista, kontaktlista mm...
  - Tittar på film (t.ex. filmer från youtube eller ...)
  - Lyssna (t. ex. Ljudböcker, musik via spotify, Internetradio)
  - Spelar spel (t.ex. genom olika dataspel)
  - Läser – eBöcker
  - Skriva – göra anteckningar, lägga upp adresslistor t. ex. över vänner mm.
  - Kommunicerar – via ePost, Chatt, Facebook mm. Ta reda på fakta via Google, nyhetsförmedlare, prenumererar på nyhetsbrev, mm.
  - Ekonomihantering, räkna och göra inköp, t. ex., Spara kvittot, miniräknare samt betala och göra överföringar via Internetbanken, betala fakturor , plånbok)
  - För min hälsa (t.ex. mäta blodtryck, vikt, puls, sömn eller kost appar)
  - Söka sjukvårdsinformation .....
  - Annat, nämligen
12. Använder du några Internettjänster som hjälper dig med din glömska, koncentrationssvårigheter eller andra kognitiva problem?      Ja                      Nej
- Om ja, vänligen beskriv vilka tjänster .....
13. Använder du Internet för att få kontakt med andra personer med liknande kognitiva problem?                      Ja                      Nej
14. Är du medlem i några sociala nätverksgrupper på Internet?      Ja                      Nej
- Om ja, vilken/vilka? .....
15. Vad upplever du som mest positiv med att
- Använda surfplatta/ smartphone /mobil / dator .....
  - Vara ute på Internet?.....
16. Vad upplever du som mest negativ med att
- Använda surfplatta/ smartphone /mobil / dator .....
  - Vara ute på Internet?.....
17. Är du intresserad av att medverka i framtagningen av datoriserade/elektroniska hjälpmedel för personer med kognitiva svårigheter?                      Ja                      Nej

Om du är intresserad bjuder vi in dig till ett möte, där vi talar vidare om medverkan och tillvägagångssätt. För att vi ska kunna bjuda in dig till mötet behöver vi dina kontaktuppgifter;

Namn: .....      Telefon: .....                      e-postadress: .....

**Sida 2 va 2**

The Day Reconstruction Method  
(DRM) Swedish Version

# Häfte 1

Innan vi börjar vill vi fråga dig ett par generella frågor om ditt liv. Vänligen svara på frågorna genom att göra en markering bredvid det svarsalternativ som bäst förmedlar vad du tycker.

1) För att summera allt i en fråga, hur nöjd är du med din livssituation i det stora hela idag?  
Är du

\_\_\_ väldigt nöjd    \_\_\_ lite nöjd    \_\_\_ lite missnöjd    \_\_\_ ganska missnöjd

2) Nästa fråga, låt oss gå vidare på ditt liv hemma. I sin helhet, hur nöjd är du med ditt liv hemma? Är du

\_\_\_ väldigt nöjd    \_\_\_ lite nöjd    \_\_\_ lite missnöjd    \_\_\_ ganska missnöjd

3) Och din anställning? I det stora hela, hur nöjd är du med din nuvarande anställning?  
Är du

\_\_\_ väldigt nöjd    \_\_\_ lite nöjd    \_\_\_ lite missnöjd    \_\_\_ ganska missnöjd



4) Nu undrar vi hur du känner dig och vilket humör du är på när du är hemma. När du är hemma, hur många procent utav tiden är du

på dåligt humör \_\_\_\_\_ %

lite nere eller irriterad \_\_\_\_\_ %

på ett någorlunda bra humör \_\_\_\_\_ %

på ett väldigt gott humör \_\_\_\_\_ %

Totalt 100%

5) När du befinner dig på din arbetsplats, hur känner du dig och på vilket humör är du när du är på ditt arbete. När du är på ditt arbete, hur många procent av tiden är du

på dåligt humör \_\_\_\_\_ %

lite nere eller irriterad \_\_\_\_\_ %

på ett någorlunda bra humör \_\_\_\_\_ %

på ett väldigt gott humör \_\_\_\_\_ %

Totalt 100%

**Härefter, skulle vi vilja veta ha lite mer information om din bakgrund, för statistiskt syfte.**

1) Vart är du född? \_\_\_\_\_

2) Vad har du för kön? \_\_\_\_\_ Man \_\_\_\_\_ Kvinna

3) Vad är ditt civilstånd?  
 \_\_\_\_\_ singel (ogift) \_\_\_\_\_ gift \_\_\_\_\_ skild \_\_\_\_\_ änka/änkling

4) Hur många barn har du? \_\_\_\_\_

5) Om du har barn, hur många av dem bor fortfarande hemma? \_\_\_\_\_

6) Om du räknar med dig själv, hur många familjemedlemmar bor i ditt hushåll? \_\_\_\_\_

7) Vad är ditt hushålls totala årsinkomst?

\_\_\_\_\_ 100.000 kronor eller mindre

\_\_\_\_\_ 100.001 – 200.000 kronor

\_\_\_\_\_ 200.001 – 300.000 kronor

\_\_\_\_\_ 300.001 – 400.000 kronor

\_\_\_\_\_ 400.001 – 500.000 kronor

\_\_\_\_\_ 500.001 – 600.000 kronor

\_\_\_\_\_ 600.001 – 700.000 kronor

\_\_\_\_\_ 700.001 – 800.000 kronor

\_\_\_\_\_ 800.001 – 900.000 kronor

\_\_\_\_\_ 900.001 – 1 miljon kronor

\_\_\_\_\_ mer än 1 miljon kronor totalt

Tack så mycket för dina svar! Du kan nu gå vidare till häfte nummer 2.

## Häfte 2

### Igår

I detta avsnitt vill vi veta vad du gjorde och hur du mådde igår. Alla dagar liknar inte varandra – vissa är bra, vissa är mindre bra och andra är relativt lika. Här undrar vi bara om gårdagen.

Eftersom många upplever att de har svårt att komma ihåg vad som exakt hände igår och vad de upplevde, kommer detta moment göras i tre steg:

- 1) På nästkommande sida, kommer vi att fråga vid vilken tid du vaknade och när du gick och lade dig igår.
- 2) Vi vill sedan att du återberättar hur din dag var, ungefär som om det vore en dagbok. Var du befinn dig? Vart du var på väg och vad du kände? Hur mådde du? Genom att besvara frågorna på nästa sida kommer det att hjälpa dig med att komma ihåg gårdagens aktiviteter.

*Detta dagboksformulär är endast till för dig, som hjälp för att du ska komma ihåg och kunna beskriva vad som hände under den första halvan utav gårdagen. Anmärkningarna är endast till för dig och de är högst personliga och hemliga. Du behöver inte lämna in dessa. Ingen kommer heller att läsa det du skrivit.*

- 3) Efter att du är färdig med att ha åtgervit din dag i dagboken, kommer vi att ställa specifika frågor om dessa tillfällen (dessa frågor är i Häfte 3). Vid besvarandet utav dessa frågor råder vi dig att gå tillbaka till dina anteckningar i dagboken för att bli påmind om vad du gjorde och hur du mådde.

Till att börja med, ringa in vilken veckodag det var IGÅR:

Måndag      Tisdag      Onsdag      torsdag      Fredag      Lördag      Söndag

## Dagbokssidor

Ungefär vid vilken tid vaknade du upp igår? kl \_\_\_\_\_

Och vid vilken tid gick du och läde dig? kl \_\_\_\_\_

På följande tre sidor, vänligen beskriv din dag. Föreställ dig dagen som en rad sammanhängande avsnitt likt en serie eller som en film. Ge varje avsnitt ett kort namn som hjälper dig att komma ihåg aktiviteten (till exempel "åka till jobbet", eller "lunch med B" där B är en person eller sällskap). Skriv därefter ned den ungefärliga tiden då varje aktivitet började och när den slutade. De flesta aktiviteter folk brukar komma ihåg varar oftast mellan 15 minuter till 2 timmar. Det som indikerar att en aktivitet är slut är oftast då man beger sig till en annan plats, avslutar en aktivitet och börjar en ny, eller en förändring utav de människorna du umgicks med.

Det kommer att finnas en sida avsedd för varje hälft utav en hel dag – Morgon (från att du vaknade fram till lunch), Eftermiddag (från lunchtid fram till kl. 6 på kvällen) och till sist Kväll (från kl. 6 tills det att du går och lägger dig). Det finns plats att lista 10 stycken aktiviteter för varje del utav dagen, men du behöver inte fylla i så många beroende på dagen. Det är alltså inte nödvändigt att fylla i alla 10 fält – skriv därför det som var mest betydelsefullt som du kommer ihåg och som utmärker sig bäst samt hur du mätte just då.

Försök att minnas varje aktivitet i detalj, skriv ett par ord som hjälper dig att minnas exakt vad det var som hände. Men även, försök att minnas hur du mätte, hur ditt humör var under varje aktivitet. Det som du skriver behöver endast vara betydande och speciellt för just dig och för att hjälpa dig att minnas vad som hände när du fyller i svaren i häfte nummer 3.

*Kom ihåg, det du skriver i din dagbok kommer inte att visas för någon annan. Häfte nummer 2 kan du behålla för dig själv om du vill, du behöver alltså inte skicka med det med resten utav frågeformulären.*

## Morgon

(från att du vaknade till och med lunch)

Aktivitetens namn	Tid det började	Tid det slutade	Hur mätte du?
1M	_____	_____	_____
2M	_____	_____	_____
3M	_____	_____	_____
4M	_____	_____	_____
5M	_____	_____	_____
6M	_____	_____	_____
7M	_____	_____	_____
8M	_____	_____	_____
9M	_____	_____	_____
10M	_____	_____	_____

## Eftermiddag

(från lunchtid tills middagstid)

Aktivitetens namn	Tid det började	Tid det slutade	Hur mättde du?
1E	_____	_____	_____
2E	_____	_____	_____
3E	_____	_____	_____
4E	_____	_____	_____
5E	_____	_____	_____
6E	_____	_____	_____
7E	_____	_____	_____
8E	_____	_____	_____
9E	_____	_____	_____
10E	_____	_____	_____

## Kväll

(från middagstid till dess att du gick och lade dig)

Aktivitetens namn	Tid det började	Tid det slutade	Hur mättde du?
1K	_____	_____	_____
2K	_____	_____	_____
3K	_____	_____	_____
4K	_____	_____	_____
5K	_____	_____	_____
6K	_____	_____	_____
7K	_____	_____	_____
8K	_____	_____	_____
9K	_____	_____	_____
10K	_____	_____	_____

Var vänlig att se över din dagbok för gårdagen ännu en gång. Är det någon aktivitet som du vill ändra eller lägga till något på? Finns det någon aktivitet som du vill dela upp i två delar? Om det är så, var vänlig och gå till förgående sida och gör de nödvändiga ändringarna i din dagbokssida. Om du är klar, kan du nu gå vidare till Häfte nummer 3.

**Tack så mycket  
Du kan nu gå vidare till Häfte 3.**

## Häfte 3

## Hur Kände Du Dig Igår?

Innan vi börjar, ber vi dig att titta tillbaka till dina aktiviteter i dagboken.

Hur många aktiviteter antecknade du på Morgonen? \_\_\_\_\_

Hur många aktiviteter antecknade du på Eftermiddagen? \_\_\_\_\_

Hur många aktiviteter antecknade du på Kvällen? \_\_\_\_\_

Nu, skulle vi vilja veta lite mer detaljerat hur du kände dig under dessa aktiviteter. För varje aktivitet, finns det flera frågor över vad som hände och hur du mädde. Använd gärna anteckningarna från din dagbok så mycket som du behöver.

Vänligen besvara frågorna för varje aktivitet du skrivit ner, starta med den första aktiviteten som inträffade på morgonen. För att göra det lättare för dig att hålla ordning, ber vi dig att skriva in det nummer för varje aktivitet, som du kan se i början på varje linje i dagboken. Till exempel, den första aktiviteten som inträffade på morgonen var nummer 1M, den tredje aktiviteten på eftermiddagen var nummer 3E, den andra aktiviteten på kvällen var 3K och så vidare.

Det är väldigt viktigt att vi får höra om alla dina aktiviteter som du var med om igår, därför är det viktigt att du noggrant svarar på alla frågor som rör respektive aktivitet. Efter att du besvarat samtliga frågor för varje aktivitet, inklusive gårdagens sista aktivitet (precis innan du lagt dig), kan du gå vidare till Häfte 4.

## Morgonens Första Aktivitet

Var vänlig att gå tillbaka till din dagbok och välj den fidzigaste aktivitet du antecknat på Morgonen.

Vid vilken tid påbörjade du denna aktivitet och när slutade den (t.ex. 7:30 på morgonen)?  
Försök att minnas tiderna så exakt som möjligt.

Det här är aktivitet nummer \_\_\_\_\_, som började klockan \_\_\_\_\_ och slutade klockan \_\_\_\_\_.

Vad gjorde du? (markera alla som stämmer)

- \_\_\_\_\_ pendlade \_\_\_\_\_ arbetade
- \_\_\_\_\_ shoppade \_\_\_\_\_ gjorde mat
- \_\_\_\_\_ gjorde hemsysslor \_\_\_\_\_ tog hand om barnen
- \_\_\_\_\_ åt \_\_\_\_\_ mediterade/bad till Gud
- \_\_\_\_\_ socialiserade \_\_\_\_\_ såg på TV
- \_\_\_\_\_ vilade \_\_\_\_\_ använde dator/internet/epost
- \_\_\_\_\_ tog det lugnt \_\_\_\_\_ talade i telefon
- \_\_\_\_\_ intima relationer \_\_\_\_\_ tränade
- \_\_\_\_\_ annat (var vänlig att specificera: \_\_\_\_\_)

Vart befann du dig?

- \_\_\_\_\_ hemma \_\_\_\_\_ på jobbet \_\_\_\_\_ någon annanstans

Interagerade du med någon (detta inkluderar via telefon, i en telefonkonferens etc.)?  
\_\_\_\_\_ ingen → (hoppa över nästa fråga)

Om du interagerade med någon (vänligen markera allt som stämmer)

- \_\_\_\_\_ make/sambo \_\_\_\_\_ mina barn
- \_\_\_\_\_ vänner \_\_\_\_\_ föräldrar/släktingar
- \_\_\_\_\_ arbetskollegor \_\_\_\_\_ chef
- \_\_\_\_\_ klient/kund \_\_\_\_\_ andra ej listade personer
- \_\_\_\_\_ elever/patienter

Hur mätte du under denna aktivitet?

Var vänlig att värdera följande känslor på nedanstående skala. Vid värdet 0 betyder det att du inte upplevde denna känsla något alls. Med värdet 6 så betyder det att denna känsla var väldigt viktig för just denna aktivitet. Var vänlig att göra en cirkel runt den siffran mellan 0 – 6 som bäst beskriver hur du mätte under denna aktivitet.

	Ingenting alls					Väldigt mycket								
	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Otålig att det skall ta slut	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Glad	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Frustrerad/irriterad	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Deprimerad/ensam	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Skicklig/kunnig	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Belastad/hunsad	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Varm/mottaglig	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Arg/aggressiv	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Orolig/ångestladdad	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Hade trevligt	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Motarbetad/medtryckt	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Trött	0	1	2	3	4	5	6	0	1	2	3	4	5	6

## Nästa aktivitet

Vid vilken tid påbörjade du denna aktivitet och när slutade den (t.ex. 7:30 på morgonen)?  
Försök att minnas tiderna så exakt som möjligt.

Det här är aktivitet nummer \_\_\_\_\_, som började klockan \_\_\_\_\_ och slutade klockan \_\_\_\_\_.

Vad gjorde du? (markera alla som stämmer)

- \_\_\_ pendlade \_\_\_\_\_ arbetade \_\_\_\_\_
- \_\_\_ shoppade \_\_\_\_\_ gjorde mat \_\_\_\_\_
- \_\_\_ gjorde hemsysslor \_\_\_\_\_ tog hand om barnen \_\_\_\_\_
- \_\_\_ åt \_\_\_\_\_ mediterade/bad till Gud \_\_\_\_\_
- \_\_\_ socialiserade \_\_\_\_\_ såg på TV \_\_\_\_\_
- \_\_\_ vilade \_\_\_\_\_ använde dator/internet/epost \_\_\_\_\_
- \_\_\_ tog det lugnt \_\_\_\_\_ talade i telefon \_\_\_\_\_
- \_\_\_ intima relationer \_\_\_\_\_ tränade \_\_\_\_\_
- \_\_\_ annat (var vänlig att specificera: \_\_\_\_\_)

Vart befann du dig?

- \_\_\_ hemma \_\_\_\_\_ på jobbet \_\_\_\_\_ någon annanstans \_\_\_\_\_

Interagerade du med någon (detta inkluderar via telefon, i en telefonkonferens etc.)?  
\_\_\_ ingen → (hoppa över nästa fråga)

Om du interagerade med någon (vänligen markera allt som stämmer)

- \_\_\_ make/sambo \_\_\_\_\_ mina barn \_\_\_\_\_
- \_\_\_ vänner \_\_\_\_\_ föräldrar/släktingar \_\_\_\_\_
- \_\_\_ arbetskamrater \_\_\_\_\_ chef \_\_\_\_\_
- \_\_\_ klient/kund \_\_\_\_\_ andra ej listade personer \_\_\_\_\_
- \_\_\_ elever/patienter \_\_\_\_\_

Hur mätte du under denna aktivitet?

*Var vänlig att värdera följande känslor på nedanstående skala. Vid värdet 0 betyder det att du inte upplevde denna känsla något alls. Med värdet 6 så betyder det att denna känsla var väldigt viktig för just denna aktivitet. Var vänlig att göra en cirkel runt den siffran mellan 0 – 6 som bäst beskriver hur du mätte under denna aktivitet.*

	Ingenting alls					Väldigt mycket								
	0	1	2	3	4	5	6	0	1	2	3	4	5	6
Otålig att det skall ta slut	0	1	2	3	4	5	6							
Glad	0	1	2	3	4	5	6							
Frustrerad/irriterad	0	1	2	3	4	5	6							
Deprimerad/ensam	0	1	2	3	4	5	6							
Skicklig/kunnig	0	1	2	3	4	5	6							
Belastad/hunsad	0	1	2	3	4	5	6							
Varm/mottaglig	0	1	2	3	4	5	6							
Arg/aggressiv	0	1	2	3	4	5	6							
Orolig/ängestladad	0	1	2	3	4	5	6							
Hade trevligt	0	1	2	3	4	5	6							
Motarbetad/nedtryckt	0	1	2	3	4	5	6							
Trött	0	1	2	3	4	5	6							

Om du har fler aktiviteter att gradera, vänligen fortsätt till nästa sida.

Har du graderat alla dina aktiviteter, inklusive den sista aktiviteten för dagen, precis innan du gick och lade dig? I sådana fall, kan du gå vidare till Häfte 4. (sida 39)

## Häfte 4



## Ett par ytterligare frågor om gårdagen

Nu när du har berättat för oss om din gårdag i detalj, har vi ett par ytterligare mer generella frågor.

Nu skulle vi vilja veta lite mer **generellt** hur du mår och hur ditt humör var igår. **Om du bara fokuserar på gårdagen, hur många procent utav tiden var du**

på dåligt humör \_\_\_\_\_ %

lite nere eller irriterad \_\_\_\_\_ %

på ett någorlunda bra humör \_\_\_\_\_ %

på ett väldigt gott humör \_\_\_\_\_ %

Totalt 100%

Nu skulle vi vilja veta hur typisk gårdagen var i förhållande till hur en vanlig sådan dag brukar vara (till exempel som en måndag, tisdag osv). Jämfört med hur just den dagen oftast brukar vara, så var gårdagen (ringa in ett alternativ)

	Mycket värre	Något värre	Väldigt lik	Något bättre	Mycket bättre
1	2	3	4	5	5

Nu skulle vi vilja veta lite mer om hur du mår och hur ditt humör var på jobbet igår. Om du bara fokuserar på gårdagen och den tid du spenderade på din arbetsplats igår, hur många procent utav tiden var du

på dåligt humör \_\_\_\_\_ %

lite nere eller irriterad \_\_\_\_\_ %

på ett någorlunda bra humör \_\_\_\_\_ %

på ett väldigt gott humör \_\_\_\_\_ %

Totalt 100%

Nu skulle vi vilja veta hur gårdagen var i förhållande till en vanlig dag på jobbet. Jämfört med hur en vanlig dag på jobbet brukar vara, så var gårdagen (ringa in ett alternativ)

	Mycket värre	Något värre	Väldigt lik	Något bättre	Mycket bättre
1	2	3	4	5	5

## Ditt jobb

Nu skulle vi vilja veta lite mer om ditt nuvarande jobb.

Har du fler än ett jobb?    Ja    Nej

Om du har fler än ett jobb, vänligen svara på dessa frågor endast för ditt huvudsakliga jobb.  
Med huvudsakliga jobb menar vi det arbete du spenderar mest tiden och timmarna per vecka.

När började du din tjänst på din nuvarande arbetsplats? \_\_\_/\_\_\_ (månad / år)

Om du tidigare arbetat för din nuvarande verksamhet men med annan position, när påbörjade du då denna position? \_\_\_/\_\_\_ (månad / år)

Inom din arbetsplats, är din nuvarande position ansedd som

- \_\_\_ en lågt rankad position
- \_\_\_ en medelrankad position
- \_\_\_ en högt rankad position

Vilken typ utav verksamhet arbetar du för?

- \_\_\_ statlig
- \_\_\_ privat vinstdrivande företag
- \_\_\_ icke-statlig ej vinstdrivande organisation
- \_\_\_ egen företagare
- \_\_\_ arbetar i familje företag

Vilken industri befinner sig din arbetsplats i? (markera alla som passar)

- \_\_\_ jordbruk, skog och fiske
- \_\_\_ gruvarbete, naturtillgångar
- \_\_\_ allmännytt, samhällsarbete
- \_\_\_ byggproduktion, konstruktion
- \_\_\_ fabrik
- \_\_\_ grossist, återförsäljare
- \_\_\_ detaljhandeln
- \_\_\_ transport
- \_\_\_ information (tidningar, nyheter, mjukvara)
- \_\_\_ finans, försäkring
- \_\_\_ fastigheter, uthyrning
- \_\_\_ yrkestjänst / profession (ingenjör, konsult, jurist, bokföring)
- \_\_\_ administrativt, support
- \_\_\_ utbildning
- \_\_\_ sjukvård
- \_\_\_ konst, underhållning, nöjen
- \_\_\_ fastighetsuthyrning (såsom hotell, pensionat etc.)
- \_\_\_ annan typ av service (såsom bilverkstad, städfirma, trädgårdsverksamhet)
- \_\_\_ statsförvaltning

Inräknat alla placeringar bolaget är verksamt, vad är den totala andelen anställda i bolaget?

- \_\_\_ 25 eller mindre
- \_\_\_ mellan 25 och 100
- \_\_\_ mellan 100 och 500
- \_\_\_ mellan 500 och 1000
- \_\_\_ 1000 eller mer

Vad för typ utav syssla har du, vad är din arbetstitel? (t.ex. rörmokare, skrivhjälp, bonde)

Vad brukar vara dina typiska arbetsuppgifter eller aktiviteter för detta jobb? (T.ex. skriva, arkivera, bokföra, sälja bilar, boktryckare, mura)

För en vanlig arbetsvecka, hur många timmar jobbar du på ditt huvudsakliga jobb?  
 \_\_\_ timmar per vecka

Skulle du vilja jobba fler timmar, färre timmar eller ungefär lika många timmar som du gör?

mindre timmar                      ungefär lika många timmar                      fler timmar

För ditt arbete, är du medlem i en facklig organisation eller en förening associerad till en facklig rörelse?

Ja    Nej

Erbjuder din arbetsplats en sjukförsäkringsplan för dig?

Ja    Nej

Erbjuder din arbetsplats tjänstepension för dig?

Ja    Nej

Vidare, så vill vi veta vilka utav påståendena som bäst beskriver din arbetsituation

*Var vänlig att gradera varje påstående i skalan nedanför. Var vänlig att gör en cirkel runt en siffra för att indikera hur bra påståendet stämmer överens med din arbetsituation.*

**Beskriv detta påstående din arbetsituation?**

Påstående	Stämmer helt	Stämmer inte alls	Stämmer viss del	Stämmer mestadels
	1	2	3	4
Det krävs speciell utbildning eller träning för mitt arbete	1	2	3	4
Min arbetsgivare erbjuder alla slags nödvändiga redskap för att klara av att utföra mitt arbete	1	2	3	4
Ge råd till andra kollegor hör till mina arbetsuppgifter	1	2	3	4
Det finns möjligheter till att göra egna beslut för att hjälpa klienter/kunder/studenten/patienter	1	2	3	4
Folk i min position är nära att bli avskedade eller behöva sluta	1	2	3	4
Ofta förekommande interaktioner med medarbetare är en viktig del utav mitt arbete	1	2	3	4
Det finns många tillfällen till att visa och ta eget initiativ	1	2	3	4
Är under konstant och nära handledning	1	2	3	4

## Beskriver detta påstående din arbetsituation?

Påstående	Stämmer helt	Stämmer till inte alls	Stämmer viss del	Stämmer mestadels
Handleda andra	1	2	3	4
Kan samtala med kollegor under arbetstid	1	2	3	4
Kan planera mitt eget arbete	1	2	3	4
Möjlighet att arbeta hemifrån	1	2	3	4
Flexibla arbetstimmar	1	2	3	4
Ha möjlighet att arbeta övertid	1	2	3	4
Ha möjlighet att arbeta nattskift	1	2	3	4
Ha möjlighet att arbeta variera skift från dag till dag eller vecka till vecka	1	2	3	4
Raster är oregelbundna och korta	1	2	3	4
Ha möjligheten att resa ofta	1	2	3	4
Behöva göra samma uppgifter under hela dagen	1	2	3	4

## Beskriver detta påstående din arbetsituation?

Påstående	Stämmer helt	Stämmer till inte alls	Stämmer viss del	Stämmer mestadels
Innebär en markant risk för skada	1	2	3	4
Kräver konstant uppmärksamhet för att förhindra fel	1	2	3	4
Små misstag kan ha förödande konsekvenser	1	2	3	4
Har direkt kontakt med missnöjda kunder/klienter/student/patienter	1	2	3	4
Exponerad för störande buller	1	2	3	4
Exponerad för damm, smuts, dålig luft och lukt	1	2	3	4
Exponerad för väder	1	2	3	4
Är tvungen att arbeta ståendes mestadels av tiden	1	2	3	4
Arbetet är fysiskt påfrestande och kräver bra fysik	1	2	3	4
Utomordentliga fördelar	1	2	3	4
Jag är överkvalificerad för mina arbetsuppgifter	1	2	3	4

Hur är ditt nuvarande arbete jämfört med ditt före detta arbete du hade ett år tidigare?

- \_\_\_ bättre än för ett år sedan  
 \_\_\_ ungefär lika som för ett år sedan  
 \_\_\_ sämre än för ett år sedan

Hur lätt skulle det vara för dig att hitta ett annat arbete som är minst lika attraktivt som ditt nuvarande arbete? (var vänlig ringa in en siffra)

Väldigt Svårt	0	1	2	3	4	5	6	Väldigt Lätt
------------------	---	---	---	---	---	---	---	-----------------

För ditt arbete, hur är det lättast för dig att rapportera totalt ihoptjänat belopp/lön före skatt eller annat avdrag?

- \_\_\_ timvis  
 \_\_\_ veckovis  
 \_\_\_ varannan vecka  
 \_\_\_ två gånger per månad  
 \_\_\_ månadsvis  
 \_\_\_ årligen  
 \_\_\_ annan, (beskriv) \_\_\_\_\_

Inkluderat övertidstimmar, bonusar och annat arvode, före skatt och andra avdrag, vad är den normala lönen för den period du angav i föregående fråga?

\_\_\_\_\_

## Hur Andra Uppfattar Dig

I den här delen, skulle vi vilja veta hur andra uppfattar dig.

Vad skulle dina närstående ha att säga om dig? För en utav följande exempel, var vänlig markera vart de skulle placera dig i skalan nedanför.

*För denna skala, betyder -3 att detta alternativ är allra minst karaktäristiskt för dig jämfört med andra människor. En 0 betyder att andra ser dig som medelmåttigt. Värdet +3 betyder att denna egenskap är mycket mer karaktäristisk hos dig än hos andra. Var vänlig att markera en cirkel kring värdena -3 till +3 som bäst beskriver vad andra skulle säga om dig.*

	Mycket mindre än andra	Ungefär som alla andra	Mycket mer än alla andra
entusiastisk	-3	-2	-1
optimistisk	-3	-2	-1
lättroad	-3	-2	-1
se allt från den ljusa sidan	-3	-2	-1
är trygg överallt	-3	-2	-1
gillar att vara i sällskap	-3	-2	-1
pessimistisk	-3	-2	-1
oroar sig ofta för inget	-3	-2	-1
lite deprimerad	-3	-2	-1
ofta arg	-3	-2	-1
spänd och obekvämt	-3	-2	-1

Under den senaste månaden, hur skulle du betygsätta din totala sömnkvalitet?

\_\_\_ väldigt bra \_\_\_ rätt så bra \_\_\_ rätt så dålig \_\_\_ väldigt dålig

Under den senaste månaden, i genomsnitt hur många timmar av *riktig sömn* har du fått per natt?

Unggefärligt antal timmar av sömn per natt \_\_\_\_\_

Igår natt, hur många timmar av *riktig sömn* fick du?

Timmar utav sömn igår natt \_\_\_\_\_

Under den senaste månaden, hur ofta hade du svårighet med att hålla dig vaken medans du körde bil, åt mat eller var aktiv i ett socialt sammanhang?

\_\_\_ inget under senaste månaden  
 \_\_\_ mindre än en gång i per vecka  
 \_\_\_ en till två gånger per vecka  
 \_\_\_ tre eller fler gånger per vecka

Under den senaste månaden, hur svårt har det varit för dig att bibehålla så pass mycket entusiasm för att få saker gjorda?

\_\_\_ inga problem alls  
 \_\_\_ endast minimala svårigheter  
 \_\_\_ något utav ett problem  
 \_\_\_ ett väldigt omfattande problem

Hur nöjd är du med din hälsa nuförtiden? Är du

\_\_\_ väldigt nöjd \_\_\_ nöjd \_\_\_ inte så värst nöjd \_\_\_ inte alls nöjd

Hur viktiga är religiösa aktiviteter i ditt liv?

\_\_\_ väldigt viktiga \_\_\_ rätt så viktiga \_\_\_ inte så värst viktiga \_\_\_ inte alls viktiga

Du har nu slutfört din medverkan för studien. Var vänlig att kontrollera varje häfte för att säkerställa att du svarat på alla frågor. Tack så mycket för din medverkan.

Efter det att du har gått igenom alla dina svar, lägg i samtliga av de numererade häftena (förutom din dagbok/loggbok om du önskar behålla denna) i det stora kuvertet och postar till oss. Du hittar ett frankerat returkuvert som du lägger i dina svar i och postar.