

UNIVERSITY OF TWENTE

# Fatigue management after Acquired Brain Injury

*A qualitative study aimed to uncover perspectives regarding an eHealth  
fatigue management intervention after Acquired Brain Injury (ABI)*

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Master thesis (25EC)  
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Date of Submission: 27-06-2021

## Abstract

***Introduction:*** Acquired Brain Injury (ABI) is brain damage that occurs during the life course and is not related to congenital disorders, developmental disabilities, or processes that progressively damage the brain. ABI is among the most prevalent neurological impairments. Among a wide range of persistent symptoms, fatigue is one of the most prevalent symptoms reported after an ABI. Fatigue is a barrier to ABI survivors' lives and has negative effects on social, physical, and cognitive functioning. Although fatigue has negative effects on quality of life, there is little evidence regarding the effectiveness of fatigue management interventions for ABI survivors. Due to the limited evidence of fatigue management interventions, it is important to investigate perspectives of ABI survivors and health professionals regarding an eHealth intervention for fatigue management after ABI. This information can be valuable for intervention developments targeted at ABI survivors. Especially since eHealth interventions are increasingly used to improve healthcare. The current study aims to answer the following research question: 'What are the perspectives of health professionals and survivors of Acquired Brain Injury (ABI) about an eHealth intervention that targets fatigue management for patients who did not receive any kind of clinical rehabilitation following their Acquired Brain Injury?'

***Methods:*** This study was set up as a qualitative research to investigate the preferences for an eHealth intervention for fatigue management after ABI. Thirteen eligible participants (5 health professionals and 8 ABI survivors with CVA or TBI) were included in the current study. Face-to-face in-depth online interviews were conducted to collect data about the current health system, fatigue (management) after ABI, and eHealth requirements for a fatigue management intervention. All 13 interviews were transcribed, axially coded, and analysed. To secure the reliability, the coding process, the coding schemes, and results were discussed with the supervisors of this study.

***Results:*** ABI survivors have to deal with ABI-related difficulties and barriers in the current health system. Fatigue has many negative consequences on the lives of ABI survivors. Professional fatigue management materials and tools, and uniformity among health professionals in addressing fatigue management after ABI are currently not available. ABI survivors still have many support needs regarding fatigue management. These needs were mainly regarding more professional involvement. Health professionals and ABI survivors stated several desired and undesired eHealth requirements for an eHealth intervention for fatigue management after ABI. Some desired elements are: a daily activity planner, tips and tricks, professional involvement, and iterative monitoring. Busy layout, lots of texts, and the same intervention for every patient are some undesired elements and should be excluded from the eHealth intervention.

***Conclusion:*** A negative emphasis was given on the current health system for ABI survivors, and healthcare options for fatigue management after ABI. An eHealth intervention is desirable and much needed to add new healthcare options to the current health system for fatigue management after an ABI. The desired and undesired eHealth elements and eHealth requirements should be taken into account when designing a fatigue management eHealth intervention for ABI survivors.

***Keywords:*** *Acquired Brain Injury, Fatigue management, eHealth.*

## Samenvatting

**Inleiding:** Niet Aangeboren Hersenletsel (NAH) is hersenbeschadiging die optreedt tijdens de levensloop en is niet gerelateerd aan aangeboren aandoeningen, ontwikkelingsstoornissen of processen die de hersenen progressief beschadigen. NAH is een van de meest voorkomende neurologische stoornissen. Onder een breed scala van aanhoudende symptomen is vermoeidheid een van de meest voorkomende symptomen die wordt gemeld na een NAH. Vermoeidheid vormt een barrière voor het leven van NAH-overlevenden en heeft negatieve effecten op het sociaal, fysiek en cognitief functioneren. Hoewel vermoeidheid negatieve effecten heeft op de kwaliteit van leven is er weinig bewijs met betrekking tot de effectiviteit van vermoeidheidsmanagement interventies voor NAH-overlevenden. Vanwege het beperkte bewijs van interventies voor vermoeidheidsmanagement is het belangrijk om de perspectieven van NAH-overlevenden en gezondheidsprofessionals te onderzoeken omtrent een eHealth-interventie voor vermoeidheidsmanagement na NAH. Deze informatie kan waardevol zijn voor interventieontwikkelingen gericht op NAH-overlevenden. Zeker nu eHealth-interventies steeds vaker worden ingezet om de zorg te verbeteren. De huidige studie heeft het doel de volgende onderzoeksvraag te beantwoorden: 'Wat zijn de perspectieven van gezondheidsprofessionals en overlevenden van Niet Aangeboren Hersenletsel (NAH) omtrent een eHealth-interventie die gericht is op vermoeidheidsmanagement voor patiënten die geen enkele vorm van klinische revalidatie hebben ontvangen na hun Niet Aangeboren Hersenletsel (NAH)?'

**Methoden:** Deze studie is opgezet als kwalitatief onderzoek om de voorkeuren voor een eHealth-interventie voor vermoeidheidsmanagement na NAH te onderzoeken. Dertien deelnemers (5 gezondheidsprofessionals en 8 NAH-overlevenden met CVA of TBI) werden geïncludeerd in de huidige studie. Face-to-face diepgaande online interviews werden uitgevoerd om gegevens te verzamelen over het huidige gezondheidssysteem, vermoeidheid (management) na NAH en eHealth-vereisten voor een interventie voor vermoeidheidsmanagement. Alle 13 interviews werden getranscribeerd, axiaal gecodeerd en geanalyseerd. Om de betrouwbaarheid in deze studie te waarborgen zijn het coderingsproces, de coderingsschema's en de resultaten besproken met de supervisors van dit onderzoek.

**Resultaten:** NAH-overlevenden hebben te maken met NAH-gerelateerde problemen en barrières in het huidige gezondheidssysteem. Vermoeidheid heeft veel negatieve gevolgen voor het leven van NAH-overlevenden. Professionele materialen en hulpmiddelen voor vermoeidheidsmanagement en uniformiteit onder gezondheidsprofessionals voor het aanpakken van vermoeidheidsmanagement na NAH zijn momenteel niet beschikbaar. NAH-overlevenden hebben nog steeds veel ondersteuningsbehoeften met betrekking tot vermoeidheidsmanagement. Deze behoeften hadden vooral betrekking op meer professionele betrokkenheid. Gezondheidsprofessionals en overlevenden van NAH gaven verschillende gewenste en ongewenste eHealth-eisen aan voor een eHealth-interventie voor vermoeidheidsmanagement na NAH. Enkele gewenste elementen zijn: een dagelijkse activiteiten planner, tips en tricks, professionele betrokkenheid en iteratieve monitoring. Drukke layout, veel teksten en dezelfde interventie voor elke patiënt zijn enkele ongewenste eHealth elementen en moeten worden uitgesloten van de eHealth-interventie.

**Conclusie:** Er werd een negatieve nadruk gelegd op het huidige gezondheidssysteem voor NAH-overlevenden, en gezondheidszorgopties voor vermoeidheidsmanagement na NAH. Een eHealth-interventie is wenselijk en hard nodig om nieuwe zorgopties toe te voegen aan het huidige gezondheidssysteem voor vermoeidheidsmanagement na NAH. De gewenste en ongewenste eHealth-elementen en eHealth-vereisten moeten in consideratie worden genomen bij het ontwerpen van een eHealth-interventie voor vermoeidheidsmanagement voor NAH-overlevenden.

**Trefwoorden:** *Niet Aangeboren Hersenletsel, Vermoeidheidsmanagement, eHealth.*

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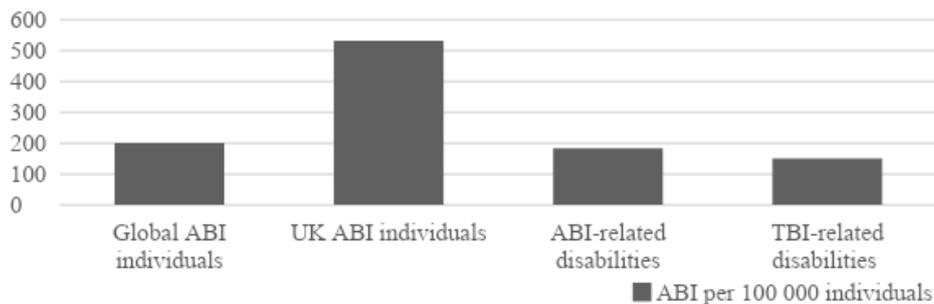
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# 1. Introduction

With affecting approximately 200 per 100 000 individuals globally, Acquired Brain Injury (ABI) is among the most prevalent neurological impairments (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007). ABI can be defined as ‘damage to the brain that occurs during the life course and which is not related to congenital disorders, developmental disabilities, or processes that progressively damage the brain’ (Toronto Acquired Brain Injury Network, 2020). Meaning that ABI includes traumatic brain injury (TBI), cerebrovascular accident (CVA), brain anoxia, brain tumour, or cerebral infection (Verdugo, Fernández, Gómez, Amor, & Aza, 2019). Of all these possible ABIs, traumatic brain injury is the most prevalent form (Jones et al., 2011).

In 2016, 17,348.453 people were admitted to the hospital in the UK following an ABI, equivalent to 533 per 100 000 of the population (Ezekiel, Field, Collett, Dawes, & Boulton, 2020). Comparable to the UK, about 140 000 individuals suffer from ABI in the Netherlands. This is equivalent to 3.8% of the Dutch population (Hersenz, 2020). Because of the global nature of a brain injury, many brain areas and their associated functions are adversely affected (Ciuffreda et al., 2007). Research from Jones et al. (2001) shows that ABI is associated with a high likelihood of life-long functional changes and an increased mortality risk. The functional changes resulting from these injuries include a range of physical, cognitive, emotional, social, and behavioural changes (Jones et al., 2001). These changes include headaches, memory loss, depression, and aggression (Nestvold & Stravem, 2009).

**Figure 1**  
*Prevalence of ABI and Related-Disabilities*



*Note.* Acquired Brain Injury (ABI), Traumatic Brain Injury (TBI)

The prevalence of adults with ABI-related disabilities in Belgium is 183 per 100 000 population (Lannoo, Brusselmans, Eynde, Van Laere, & Stevens, 2004). Lannoo et al. (2004) found that the prevalence of TBI disability survivors in the UK is estimated to be 100 to 150 per 100 000 population. Research from Ciuffreda et al. (2007) indicated that about 8 million individuals suffer from a TBI in the United States. About 60% of those affected do not return to the workforce, with an estimated national economic loss of \$4 billion. The findings are similar for CVA (Ciuffreda et al., 2007). Although one in five people with ABI resume education or regain full employment, over half of the individuals spend their days at home with no specific activity (Lannoo et al., 2004). Van Velzen, van Bennekom, van Dormolen, Sluiter, & Frings-Dresen (2011) revealed in their research that the most common limiting factor to return to work after an ABI was tiredness. Indicating that both TBI and CVA, and ABI in general, are major economic, social, medical, and public health concerns (Ciuffreda et al., 2007).

Despite the fact that Ciuffreda et al. (2007) revealed that ABI survivors have major concerns, Odumuyiwa et al. (2019) on the other hand, indicated in their study that the impact of ABI is often poorly understood or

overlooked by professionals within the United Kingdom. Although there is a lot of evidence available about the ABI-related disabilities, it is surprising that these patients are still overlooked. Patients being overlooked leads to limited access to rehabilitation and support services (Odumuyiwa et al., 2019). Odumuyiwa et al. (2019) found that this limited access was particularly true when it came to cognitive, executive and psychological difficulties. The hidden nature of these symptoms leaves ABI survivors unsupported since assessment processes are often focused solely upon physical impairments (Odumuyiwa et al., 2019). This leads in many instances to long-term social consequences including poor social reintegration, social isolation and social deprivation (Odumuyiwa et al., 2019).

Even though there is a growing public awareness of deficits in service provision for ABI survivors, no study reveals information on their specific needs (Lannoo et al., 2004). Therefore, Lannoo et al. (2004) investigated the needs of ABI survivors. This study revealed that almost half of the patients had needs for specific care at home and one in five had living needs for specialized accommodation or supported living. ABI survivors who do not receive professional assistance have unfulfilled needs in the area of day services aiming at a maximal social and professional reintegration (Lannoo et al., 2004). Despite the fact that Lannoo et al. (2004) revealed some needs about ABI survivors, this does not take away the fact there is a lack of studies that investigate the specific needs on the different life domains of these patients. Hence, it is important to investigate the specific needs of the group of ABI survivors that do not receive any kind of professional assistance after discharge from the hospital.

Among a wide range of ABI-related disabilities, fatigue is one of the most prevalent symptoms reported after an ABI (Cooper, Reynolds, & Bateman, 2009). Problematic and persistent fatigue is frequently experienced by ABI survivors. The prevalence of fatigue in ABI survivors range from 27% to 73%, with a significant proportion still experiencing fatigue six or more years after their brain injury (Ezekiel, 2020). Because fatigue overlaps with lay concepts of tiredness, fatigue as a clinical symptom is difficult to define (Ezekiel et al., 2020). Therefore, the term ‘central fatigue’ is increasingly used to describe fatigue after ABI. Central fatigue can be defined as ‘The failure to initiate and/or sustain attentional tasks (‘mental fatigue’) and physical activities (‘physical fatigue’) requiring self-motivation’ (Chaudhuri & Behan, 2000). Two separate dimensions of fatigue are used in this definition. In the current study, mental fatigue and physical fatigue are also considered as separate dimensions. Mental fatigue is characterised by limited energy reserves to accomplish ordinary daily activities that require alertness and retrieval of information stored in memory (Johansson & Rönnbäck, 2013). Physical fatigue on the other hand, is characterised by a reduction in capacity to perform physical work as a function of prior physical effort (Gawron, French, & Funke, 2001). Visser-Keizer, Hogenkamp, Westerhof-Evers, Egberink, & Spikman (2015) indicated that mental fatigue was more frequent following ABI than physical fatigue. Christensen et al. (2018) on the other hand, have asserted in their study that stroke patients reported higher levels of physical fatigue compared to the general population. Regardless of the dimension, fatigue in general has negative effects on social, physical, and cognitive functioning (Ziino & Ponsford, 2006).

Fatigue is a barrier to ABI survivors’ social engagement, leisure, physical activities, and work resumption (Andersen, Christensen, Kirkevold, & Johnsen, 2011). Patients living with fatigue post-brain injury tend to reduce their physical and social activities and increase their sedentary and home based activities (Eilertsen, Ormstad, & Kirkevold, 2012). This means that physical activity levels for ABI survivors tend to be lower than those recommended by physical activity guidelines (Ezekiel et al., 2020). The benefits of physical activity and social

engagement to health and wellbeing in the general population are well established, so it is concerning that a significant proportion of ABI survivors experience long-term difficulties in these areas (Ezekiel et al., 2020). Given these points, the current study indicates that both dimensions of fatigue are important to take into consideration for fatigue management of ABI survivors in the home based and clinical rehabilitation.

The clinical rehabilitation of ABI survivors is challenging due to multiple cognitive deficits and experiences of persistent complaints. Because of the cognitive deficits, ABI survivors also experience deficits in their self-regulation (Ownsworth, McFarland, & Young, 2002). Self-regulation is important for individuals because it influences motivation for treatment and participation in the rehabilitation process (McGlynn & Schacter, 1989). Research from van der Horn, Liemburg, Aleman, Spikman, & van der Naalt (2016) revealed that the development of persistent complaints is affected by interindividual differences in adaptation. A key construct of adaptation is coping and refers to strategies to deal with new situations and serious life events (van der Horn et al., 2016). An important element of coping is the ability to process emotions (van der Horn et al., 2016). Radice-Neumann, Zupan, Tomita, & Willer (2009) revealed that neural structures associated with emotional processing are vulnerable to brain injury damage. Therefore, patients frequently experience symptoms of emotion dysregulation (Wang et al., 2017). Because coping with fatigue is important to adapt to the new situation, emotion processing is essential in fatigue management interventions. Note, that all available information in the literature is targeted at ABI survivors in the clinical rehabilitation setting. There is no scientific literature available about ABI survivors who are not eligible for this setting. This is alarming since Lannoo et al. (2004) revealed that the large majority of ABI survivors remain at home without professional care. This large majority stays out of sight of health professionals, do not have any professional care, and have to deal with multiple barriers in their everyday lives.

Despite the multiple barriers and negative effects that fatigue has on quality of life, there is little evidence regarding the effectiveness of fatigue management interventions (Cooper et al., 2009). Cooper et al. (2009) found no studies on non-medical treatment of fatigue following brain injury. A reason for the lack of fatigue management interventions may be that fatigue is often overlooked due to its hidden and subjective nature (Odumuyiwa et al., 2019). Evidence suggests that fatigue after ABI is of a different nature than fatigue in other patient groups (Visser-Keizer et al., 2015). ABI survivors describe their fatigue as ‘new and different tiredness’ (Visser-Keizer et al., 2015). Because of the hidden and subjective nature of the fatigue experiences, fatigue management interventions should take into account the different needs and preferences of ABI survivors.

There are different ways to offer a fatigue management intervention that takes into account the different needs and preferences of ABI survivors. Note, that the different offers are not mutually exclusive and can be combined into one intervention. A first way is to offer a stepped-care model. With stepped-care, low intensity treatments are provided to most of the patients while they are closely monitored so that those who are not benefitting are upgraded to higher intensity treatments (Kneebone, 2015). Stepped-care is proven useful for a wide range of disorders such as depression and chronic illnesses (Espie, 2009). Stepped-care is also time efficient (Tummers, Knoop, & Bleijenberg, 2010). A second way is to offer a blended-care model. Blended-care is a combination of face-to-face and online (eHealth) therapy to obtain an optimal benefit of these two treatment styles (Wentzel, van der Vaart, Bohlmeijer, & van Gemert-Pijnen (2016). eHealth is the use of technology to support health, well-being and healthcare (Gemert-Pijnen, Kelders, Kip, & Sanderman, 2018). Blended-care is increasingly

applied in the healthcare and promising results are reported (Wentzel et al., 2016). A final way is to offer a patient-centred care model. With patient-centred care, the individual needs of the patients are in focus and healthcare is provided based on a collaboration between patients and health professionals (Davoody, Koch, Krakau, and Hägglund, 2016). Patient-centred care requires an active involvement of patients throughout care and the design and development of eHealth services (Davoody et al., 2016). eHealth services embrace the application of communication and information technologies to healthcare and comprises a broad range of web-based and mobile health interventions (Hines et al., 2017). eHealth has the potential to revolutionise healthcare by maximising efficiencies and supporting optimal client outcomes through improved quality of care (Hines et al., 2017). Therefore, an eHealth intervention can be of added value in the current healthcare system for ABI survivors. Also, different care offers for fatigue management can be suitable to tailor care for patients with ABI who do not receive any professional assistance.

In order to design a fatigue management eHealth intervention for ABI survivors, there must first be looked at the available evidence for such interventions. Because this study considers mental and physical fatigue as separate dimensions, available fatigue management interventions for ABI survivors are organised according to this distinction. Note, that all interventions mentioned in the following paragraphs are not eHealth interventions. Interestingly, no eHealth interventions were found among the available fatigue management interventions for ABI survivors.

In terms of mental fatigue, Cooper et al. (2009) investigated whether a weekly fatigue education group had effect on reported fatigue, anxiety, depression, sleepiness, and quality of life. Patients needed to fill in a 10-point rating scale to assess mental fatigue and needed to complete a self-report concerning the impact of fatigue on daily life, their perceptions of fatigue, and their fatigue management strategies. Results of this study showed that there was a significant change in the quality of life measure, but not in the other measures. In written qualitative accounts, participants reported managing their mental fatigue better and finding group support helpful (Cooper et al., 2009). National clinical guidelines from the UK to address problematic and persistent fatigue after ABI recommends educational and self-management approaches to manage mental fatigue despite limited evidence to support these approaches in the brain injury population (Ezekiel et al., 2020). The national guidelines are targeted at stroke patients and only give recommendations, no specific exercises or therapies are mentioned (Bowen, James & Young, 2016). However, these guidelines do make a distinction between physical and mental fatigue.

In terms of physical fatigue, there were no interventions found for ABI survivors that mainly focus on this dimension of fatigue. Although activity scheduling is recommended, current approaches to understanding an individual's daily experience of physical fatigue and activity are limited (Ezekiel et al., 2020). Currently, self-report fatigue scales and activity diaries are used to gather information about an individual's experience of physical fatigue. However, fatigue scales reflect a summation of an individual's fatigue experience and activity diaries are unreliable when completed retrospectively (Ezekiel et al., 2020). When looking at physical fatigue management interventions for other neurological diseases with similar fatigue experiences, a meta-analysis for Multiple Sclerosis (MS) targeted at exercise, education, and medication was found (Asano & Finlayson, 2014). Results showed that rehabilitation interventions appeared to have stronger and more significant effects on reducing the impact or severity of patient-reported physical fatigue compared to medication. Pharmacological agents are

important but do not enable MS patients to cope with their existing disabilities (Asano & Finlayson, 2014). It is important to take the effectiveness of this intervention into consideration since fatigue management in MS appears better established than for ABI (Cooper et al., 2009).

One intervention that targets both mental and physical fatigue is the COGRAT programme of Zedlitz, Rietveld, Geurts, & Fasotti (2012). COGRAT combines cognitive therapy (CO) with graded activity training (GRAT) and is developed to alleviate fatigue and fatigue related symptoms for chronic stroke patients. The COGRAT was presented as a 12-week programme with a group size to a maximum of 4 patients (Zedlitz et al., 2012). The CO protocol includes emphasis on pacing and relaxation and the GRAT protocol includes walking on a treadmill and strength training. During the 12-week programme, all participants received daily homework assignments to enhance the therapeutic objectives. After each session, therapists rate the patient attendance, patient adherence to treatment, and homework on a 5-point Likert scale (Zedlitz et al., 2012). Results showed that the COGRAT programme significantly reduced persistent fatigue in patients with chronic stroke in the rehabilitation setting. The beneficial effects remained stable at follow-up and were not only found on 2 different measures of fatigue but also on functional health status, symptoms of depression, sleep, and physical endurance (Zedlitz et al., 2012). The study of Zedlitz et al. (2021) is the first to report a significant reduction of post stroke fatigue and related symptoms after a comprehensive treatment specifically tailored to the needs of this population.

Although the study of Zedlitz et al. (2012) showed beneficial effects and sets an example for the field, this intervention is targeted at patients with chronic stroke in the rehabilitation setting. The large majority who remain at home are not eligible to receive this beneficial intervention. For this reason, a more in-depth understanding of the way ABI survivors without professional assistance perceives and manage their fatigue is required in order to design a fatigue management eHealth intervention for this target group. Because of the little available literature of ABI survivors who did not receive any professional assistance for fatigue and the severity of their disabilities, it is important and innovative to investigate the needs and perspectives of this group. Also, no information is available about the perspectives of health professionals regarding ABI fatigue management. These perspectives are important since no effective interventions for fatigue management are reported in literature. Therefore, the experiences from the practise of different health professionals need to be taken into consideration when designing an eHealth intervention for fatigue management post ABI. Indicating that investigating the perspectives of ABI survivors and health professionals about a fatigue management eHealth intervention can result in an added value in the current field.

This current study is set up to investigate the perspectives of health professionals and ABI survivors about an eHealth intervention that targets fatigue management after ABI. This study focuses on ABI survivors who did not undergo any kind of clinical rehabilitation. The aim of this study is to understand the different perspectives of health professionals and ABI survivors and to identify aspects that are important to include in an eHealth intervention for fatigue management. Such results can be valuable for intervention developments targeted at ABI survivors. This study aims to answer the following research question: *‘What are the perspectives of health professionals and survivors of Acquired Brain Injury (ABI) about an eHealth intervention that targets fatigue management for patients who did not receive any kind of clinical rehabilitation following their Acquired Brain Injury?’*

## 2. Methods

### 2.1 Study design

This study was set up as a qualitative study. Qualitative research is able to capture the meanings that people attach to healthcare social phenomena and is essential to enhance clinical knowledge and care (Collingridge & Gantt, 2008). Qualitative studies use non-quantitative methods to contribute knowledge and to provide new perspectives in healthcare (Tong et al., 2007). The current study used a face-to-face in-depth online interview as a qualitative research instrument. Interviews are a fundamental data collection method used in qualitative health research (Hutchinson, Wilson, & Wilson, 1994). Central by qualitative research interviews is the meaning that experiences hold for the interviewees (DiCicco-Bloom & Crabtree, 2006). This current study was ethically approved by the BMS Ethics Committee of the University of Twente (file number 210095).

### 2.2 Participants

Participants were recruited for two different groups: a group of ABI survivors without clinical rehabilitation trajectory and a group of health professionals. Participants for the group of ABI survivors were recruited from the patient organisations NAH-Oost and Hersenletsel.nl. Participants for the group of health professionals were recruited from different healthcare institutions in the Netherlands. These institutions were: the hospital 'Medisch Spectrum Twente (MST)', occupational therapy practise 'Plan4', care provision 'Het Baken', rehabilitation centre 'Roessingh', and general practitioner group Haaksbergen. All participants were selected using a purposive sampling method. Purposive sampling is the deliberate choice of a participant due to the qualities or characteristics of the participant (Etikan, 2016). This study aimed to enrol 8 ABI survivors and 5 health professionals. Eventually, 13 eligible participants were enrolled in the current study. In order for the ABI survivors to be eligible, the participants needed to have suffered from ABI in the last 5 years and needed to have suffered from CVA or TBI without rehabilitation treatment. In order for the health professionals to be eligible, the participants needed to have treated or be in contact with at least two patients with ABI in the past year. This study also used the following inclusion criteria: (1) Participants need to speak either English or Dutch, (2) Participants need to live in the Netherlands and, (3) Participants need to be  $\geq 18$  years. All participants signed an informed consent before the start of this study (see Appendix 1).

### 2.3 Data collection

The data in this study was collected by using face-to-face in-depth online interviews. The in-depth interview is a technique designed to elicit a clear picture of the perspective of the participant on the research topic (Milena, Dainora, & Alin, 2008). With open-ended questions, topics are in-depth explored, processes are understood, and potential causes of observed correlations can be identified (Weller et al., 2018). Participants were asked to answer as extensively as possible and were stimulated to freely express their opinions and perspectives. An interview scheme was developed to enhance the process of structuring (see Appendix 2). In this interview scheme, an introduction about the research was firstly given to the participants of both groups. In this introduction, participants were also pointed out to the fact that their participation was completely voluntary and their answers would be processed anonymously. Subsequently, demographic information was collected. For the group of ABI survivors, demographic information about their age, gender, type of ABI, work situation, and living situation was collected. For the group of health professionals, demographic information about their gender, age, profession, and

years of work experience with ABI was collected. Next, for the participants of the group with ABI survivors, general questions about participants' experiences with ABI and their recovery process were asked. For the participants of the group with health professionals on the other hand, questions about the current health system for ABI survivors were asked. Finally, questions targeted to uncover the opinions and perspectives about an eHealth intervention for fatigue management were asked to both groups. To minimise any kind of possible burden for the participants, all interviews were conducted within a maximum time limit of 60 minutes. All interviews were audio recorded for the purpose of transcribing and analysing.

## 2.4 Data analysis

For the purpose of analysing, the interviews were first transcribed. All interviews were transcribed using the program Otranscribe. After transcribing the interviews, two independent coding schemes for the ABI survivors and health professionals were deductively developed (see Appendix 3). In both coding schemes, three core themes were central. For the coding scheme for the ABI survivors, there was one core theme regarding the recovery process after ABI, one core theme regarding fatigue (management), and one core theme regarding eHealth. For the coding scheme for health professionals, there was one core theme regarding the current healthcare system for ABI, one core theme regarding fatigue (management), and one core theme regarding eHealth for ABI survivors. For each core theme in both coding schemes, different subcategories were developed. This resulted in a set of mutually exclusive codes. After the development of the coding scheme, the final coding started. All interviews were coded using Atlas.ti version 9 to enhance the process of clear data coding. In the actual coding process, all data of the current study was first thoroughly read. Irrelevant or incomplete data were deleted from further analysis. Then, the axial coding technique was used to analyse the interviews. Axial coding identifies relationships between core codes and subcodes (Williams, & Moser, 2019). The interviews of the two different participant groups were separately coded. All interviews of this study were coded by one researcher. To secure the reliability of the study, the coding process, different versions of the coding schemes, and results of the coding were discussed with the supervisors of this study. Possible discrepancies were discussed and adjusted to establish a consensus between the researcher and the supervisors.

## 3. Results

### 3.1 Demographics

The current study conducted 8 interviews with ABI survivors and 5 interviews with health professionals. As seen in Table 1 and Table 2, there was a variation between the ABI survivors in terms of gender, age, type of ABI, work situation, and living situation. As seen in Table 3 and Table 4, there was variation between the health professionals in terms of age, work experience, gender, and profession.

**Table 1**  
*Characteristics participants ABI survivors*

	N	Minimum	Maximum	Mean
Age (in years)	8	24	62	46.4
Time with diagnosis (in years)	8	4	5	4.5

**Table 2**  
*Characteristics participants ABI survivors*

		Frequency	Percentage
Gender	Male	3	37.5
	Female	5	62.5
Type of ABI	CVA	5	62.5
	TBI	3	37.5
Work situation	Full time	0	00.0
	Part time	2	25.0
	No work	6	75.0
Living situation	Single	1	12.5
	With partner	1	12.5
	With family	6	75.0
	Other	0	00.0

*Note.* Cerebrovascular Accident (CVA), Traumatic Brain Injury (TBI).

**Table 3**  
*Characteristics participants health professionals*

	N	Minimum	Maximum	Mean
Age (in years)	5	37	54	45.6
Work experience with ABI (in years)	5	12	25	18.0

*Note.* Acquired Brain Injury (ABI).

**Table 4**  
*Characteristics participants health professionals*

		Frequency
Gender	Male	1
	Female	4
Profession	Psychologist (PSY)	1
	Occupational therapist (OT)	1
	Physiotherapist (PT)	1
	Rehabilitation physician (RP)	1
	General practitioner (GP)	1

In the following section, the results from the ABI survivors are first showed. These results are ordered on the basis of the three core themes of the coding scheme. The quotations of the ABI survivors are characterized in the following way: (participant number, age, gender, type of brain injury). Thereafter, the results from the health professionals are showed. These results are also ordered on the basis of the three core themes of the coding scheme. The quotations of the health professionals are characterized in the following way: (participant number, age, gender, profession).

## 3.2 Results group 1: ABI survivors

### 3.2.1 ABI Recovery process

#### *ABI related difficulties*

##### *Different life domains*

All ABI survivors experienced difficulties in different life domains during their recovery process. Because of these difficulties, all participants concluded that ABI has had a huge impact on their lives. The most common

mentioned difficulty was regarding the cognitive level (N=7). Specific types of these cognitive difficulties differed among participants: *“When I put something down and I turn around, I forget that I had it in my hands”* (F, 26, F, TBI), and *“You notice that you just cannot do the simplest things because you just cannot multi-task for example”* (C, 47, F, CVA).

The majority of participants also experienced difficulties on the physical level (N=6): *“I can walk but with a brace and on the left, I can hardly move my arm”* (A, 55, M, CVA), and *“As a result [of the ABI], I couldn’t move my arm. I still suffer from that. I do not use it very much”* (B, 55, M, CVA).

Participants also experienced difficulties on the emotional level (N=5): *“It has been very difficult for me and my family to accept it [ABI]”* (G, 24, F, TBI) and *“You also have a mourning process for a bit . . . . So that was tough, because I wanted so badly to return to my old life”* (A, 55, M, CVA).

A minority of the participants mentioned difficulties regarding the behavioural level (N=2): *“In the beginning I did not realise [the impact of ABI]. I also just did way too much. I really wanted to be able to do everything right away”* (C, 47, F, CVA) and *“You cannot just go out with girls because you really have to plan what your day will look like”* (G, 24, F, TBI).

Next to difficulties on different life domains, participants also experienced difficulties regarding the access to care and the compassion and recognition for their complaints from health professionals.

### Access to care

Almost all participants experienced difficulties regarding the access of care for ABI survivors (N=7). Difficulties regarding this area differed from availability of recovery services to difficulties with eligibility for recovery care:

*I asked [in the hospital] if they do something for people with a PCS [Post-concussion syndrome] /Whiplash and she immediately said ‘No, we have nothing to offer in that area in our hospital’ . . . I have been to two large hospitals here in the region and they both said ‘Well, PCS / Whiplash, no we do nothing with that, sorry’. Actually, very strange* (H, 44, F, TBI),

and *“I had to prove that I was eligible to rehabilitate, even in the hospital. That was a struggle”* (B, 55, M, CVA). It is notable that both TBI and CVA participants experienced difficulties regarding this domain.

### Compassion and recognition

Results regarding the compassion and recognition from health professionals were striking. Almost all participants experienced difficulties in this area (N=6). Participants felt not heard nor recognised in their complaints which broke their trust in certain health professionals:

*In four years, it [the TBI] has actually never been recognised. I also had to change hospitals because they [health professionals] simply did not help or did not want to have contact anymore . . . . I now have a different GP because the previous one retired and said every time ‘It [the complaints] is between your ears and you are too fat, so you have to lose weight and then it [the complaints] will pass’* (F, 26, F, TBI),

and *“I have very much lost trust . . . in the medical people . . . . You came up with your story and then you got the feeling that you were not believed. So, I really lost trust”* (G, 24, F, TBI).

### *Unfulfilled needs*

All the mentioned ABI related difficulties resulted in that participants still have many unfulfilled needs. These unfulfilled needs concerned the access to care and available recovery services (N=4) and the compassion and recognition from health professionals (N=3).

Answers made clear that participants would have liked more efforts regarding recovery services:

*What I have missed the most is a case manager. That someone took my hand and took a look with me like 'Okay, what are your difficulties? how are we going to do this?' You know, you are very tired and very over-stimulated and, in the meantime, you have to read all kinds of things about your ABI and what kind of treatments there are" (H, 44, F, TBI),*

and

*Not much was said in the hospital. It was actually mainly focused on the physical. . . . You know, you get a cerebral infarction and then you know that your body is failing for a moment, but all those other things around it, that was never really communicated to us. I think that is a great loss (D, 58, F, CVA).*

Participants also would have liked that health professionals showed compassion and that the participants would have been recognised in their complaints: *"That I felt heard more. . . . a listening ear would have meant a lot for me, I have not really had one" (G, 24, F, TBI), and*

*Understanding, but on the other hand clarity . . . Everyone has pushed it [the complaints] to one side every time and they have never been honest about it. . . . If they have just said 'It is a difficult subject there is just not much', but that was never said because it was always between my ears that I had those complaints (F, 26, F, TBI).*

### *Positive experiences*

Although the data revealed an emphasis of ABI-related difficulties and unfulfilled needs, the data also revealed some positive experiences regarding the ABI recovery process (N=5). Interestingly, these positive experiences also concerned access to care and the compassion and recognitions from health professionals: *" [Institution X] is a fantastic institution. I have benefited a lot from the occupational therapist. . . . they understood everything" (B, 55, M, CVA), "The physiotherapist and the occupational therapist were very understanding" (D, 58, F, CVA), and "It [recovery care] partially helped and especially with the occupational therapy, I started to distribute my strength better" (E, 62, M, CVA).* It is notable that all positive experiences emerged when participants actually received a recovery service. Participants who did not receive any kind of recovery service could not mention positive experiences regarding their recovery process.

In sum, the results from the paragraphs of the ABI recovery process showed that ABI survivors experienced diverse difficulties on cognitive-, physical-, emotional-, and behavioural levels during their recovery process. These difficulties did not result in unfulfilled needs on these different levels. Interestingly, difficulties regarding the access to care and compassion and recognition from health professionals were the reason that ABI survivors still have many unfulfilled needs. While participants expressed their unfulfilled needs in the areas of access to care and compassion and recognition, these two areas were also the only mentioned areas where positive experiences had arisen.

### 3.2.2 Fatigue (management)

All participants experienced both dimensions of fatigue, namely mental fatigue and physical fatigue (N=8). A Participant described mental fatigue as follows:

*If I have to think a lot, if I have to perceive things intensively, if I have to start using the cells [brain cells] properly, I notice that it becomes a bit too much. It is not that I get a headache, but it is that I am just mentally happy that I can sit on the couch for a while and think 'do not do a thing right now'' (E, 62, M, CVA).*

Another participant described physical fatigue as follows:

*Like you have bricks on your arms and the fatigue could only get worse and the next morning it [fatigue] might have been 10% lighter. . . It is like working 80 hours a week for a whole year in a row and with that fatigue you walk around all year, every day actually (F, 26, F, TBI).*

Although the data revealed fatigue experiences on both dimensions, the extent of the experience of the different dimensions differed among participants. The majority of participants experienced mental fatigue to be the most prevalent form: “I have 80% mental fatigue” (A, 55, M, CVA), “Mental fatigue is always the first to come up” (B, 55, M, CVA), and “Mental [fatigue] comes first. So, the concentration really starts to gradually disappear. . . . and once I get home the physical fatigue comes” (G, 24, F, TBI).

#### Consequences of fatigue

Data about the consequences of fatigue revealed that fatigue has negative effects on multiple life domains. All participants experienced negative consequences due to fatigue (N=8).

#### Emotion processing

Results showed that all participants experienced negative consequences in their emotion processing due to fatigue (N=8):

*In the beginning it [being fatigued] was quite a grieving process . . . quite a bit like failure . . . First, you experience a part of the grieving process, sadness, and anger. Before you come to acceptance, you really are quite a while further (D, 58, F, CVA),*

*“It [fatigue] does have a big impact . . . In the beginning it [fatigue] was really a grieving process because I was so active” (C, 47, F, CVA), and*

*I think that it [experiencing fatigue] is mainly sadness and a bit of frustration. Like, if I want to do something fun then I have to take it into account all day and actually preferably the day before and the day after as well (H, 44, F, TBI).*

#### Social engagement and leisure

The majority of the participants also experienced negative consequences in their social engagement and leisure due to fatigue (N=7). The participants experienced a decrease in their activities on this domain in comparison with activities before their ABI: “Birthdays and visitors were simply out of the question. That is simply

*not possible anymore. . . . I still have much trouble then and also now to keep in touch with people” (F, 26, F, TBI), “I do not actually have any social activities anymore” (D, 58, F, CVA), and*

*It [fatigue] just works everywhere in everything. When I go to the supermarket and it is busy there, then I run out . . . You can never do anything spontaneously; you have to consciously plan everything . . . When you do something spontaneously, you often pay the price for it because unexpected things happen that cost a lot of energy. I think that is very bad. You get many restrictions with everything at once (H, 44, F, TBI).*

### Physical activity

Half of the participants experienced negative consequences in their physical activity levels due to fatigue (N=4). Some participants experienced total inability to perform any physical activity, while others could still perform physical activity but in an adjusted form:

*I had a super physical condition when I got it [ABI] and that has become a bit less of course. . . . I now spend much time sitting at home and in the chair and I watch much television to get through the days (B, 55, M, CVA),*

*“I actually worked out, I also did body balance, or in the gym, but I do not do that anymore” (C, 47, F, CVA), and “I now go to the gym, I did that together with my husband in the evening before the CVA. That was nice. But now I do that alone. I go early in the morning, on quiet days” (D, 58, F, CVA).*

### Work reduction

Although all participants experienced work reduction due to their ABI, only one participant explicitly mentioned fatigue to be part of the reason for work reduction:

*I could feel good again and it could also be that I was just too fatigued, had too many problems and that the concentration was completely gone. . . . At work, this [fatigue] also caused some problems for colleagues. They could not count on me (E, 62, M, CVA).*

### Invisibility of fatigue

Participants also experienced negative consequences due to the invisibility of fatigue. Participants stated that because of this invisibility, other people easily assume that participants do not have to deal with fatigue:

*You are ashamed of it [fatigue]. People do not see me and I have to say ‘I have to lie down for a while’ . . . . You know, that is very difficult to convey to other people. The fatigue is not seen (D, 58, F, CVA),*

*Fatigue is invisible. Nobody sees me when I lie on the couch. . . . People from the outside see me when I go out. When I go out, I am always reasonably well. If I am really bad, I would not go out at all. . . . I think that is why it [fatigue] is a subject that still has so little attention because it is not visible (H, 44, F, TBI),*

and *“Because energy cannot be measured. Fatigue, of course, is internal. You have to indicate that. . . . some have no idea of my fatigue” (A, 55, M, CVA).*

These paragraphs show that fatigue had a negative impact on the different life domains of the participants. Participants experienced many negative consequences due to fatigue with emotion processing, social engagement

and leisure, physical activity, work, and difficulties due to the invisibility of fatigue. These consequences resulted in that participants have to face multiple difficulties during their everyday lives.

### *Self-management efforts*

Almost all participants performed some sort of self-management effort to deal with their fatigue (N=7). The specific form of effort differed between participants. Almost all participants mentioned self-management efforts as ways to deal with fatigue. However, there was one participant who still hoped that fatigue after ABI would eventually disappear automatically.

### *Relaxing activities*

Participants used activities that they experienced as relaxing as self-management effort: *“I like to listen to music. I put on the headphones. . . . then I really relax more”* (E, 62, M, CVA), *“We are lucky if the weather is nice, we have a nice garden, then I sit in the garden. . . . then you actually feel energy”* (A, 55, M, CVA), and *“When I am tired, I have to take my rest and everyone in my environment already knows that this is how it works”* (B, 55, M, CVA). The specific activities of participants differed and were related to activities that they personally enjoyed.

### *Physical activity*

Participants also used physical activity as a self-management effort to deal with fatigue (N=4). The most common form of physical activity was walking and fitness: *“When I have had this interview, I feel a pressure in my head. Then I immediately start walking. Because then the mental fatigue is over”* (A, 55, M, CVA), *“I try to walk a bit. . . . When the weather gets warmer, it works better to walk and then I can also cycle better”* (B, 55, M, CVA), and *“I started doing fitness. That helps me a lot”* (H, 44, F, TBI).

### *Educational approaches*

Two participants also used educational approaches as a self-management effort to deal with fatigue: *“I started to read some more stuff too. Go and find out”* (D, 58, F, CVA), and

*What helped me a lot is the smartwatch that I have, which has a Body Battery function. . . . I start on half the battery of a healthy person and then every activity I do also costs me more energy than someone who does not have a brain injury . . . Then you learn very quickly. It also made it really insightful* (H, 44, F, TBI).

All educational approaches were used to obtain some sort of understanding of fatigue and fatigue management.

### *Coping and acceptance*

Almost all participants stated the importance of coping and accepting fatigue (N=7). The results made clear that although it is very hard to cope and accept the fatigue, fatigue was something that could not be ignored and coping and acceptance was crucial to manage fatigue: *“Learning to accept that you now have a new you and that you should actually anticipate on it . . . It [fatigue] simply cannot be ignored”* (C, 47, F, CVA), *“There is no escape anymore. If you have fatigue, you just have to stop. Just put it down, just recover”* (B, 55, M, CVA), and

*When you are fatigued, you are just fatigued. Then you stop and then you try again tomorrow or later. It is really accepting that the fatigue is there. Because if you get angry, it just does not help you. Then you*

*get even more fatigued and then that circle of being angry and getting fatigued just continues* (F, 26, F, TBI).

### Nutrition

One participant used nutrition as a self-management effort to deal with fatigue: *“I pay much attention to my diet. I also went to an orthomolecular cPNI [clinical Psycho-Neuro-immunology] physician, so I now also work with keto food, with fasting and with supplements”* (H, 44, F, TBI). This participant found that nutrition has direct effects on fatigue. Therefore, it is noteworthy that no other participant mentioned nutrition as self-management effort.

### Sound blocking earplugs

One participant used sound blocking earplugs to delay the occurrence of fatigue: *“We ordered special earplugs. You could lower the decibel with that. It really worked when I was at home, but not when I went to the supermarket, for example. Then it hardly worked”* (F, 26, F, TBI).

Results in these paragraphs showed that different self-management efforts were performed by the participants. The specific strategies were different between participants. Participants mentioned relaxing activities, physical activity, educational approaches, coping and acceptance, nutrition, and sound blocking earplugs as self-management efforts. It is notable that the majority of participants used self-management efforts that they thought would help them. The effectiveness of those efforts was determined by their own knowledge or experience.

### Professional fatigue management support

The majority of the participants who received a form of professional fatigue management support had negative experiences (N=6). Causes for these negative experiences varied between participants: *The occupational therapist also gave me some things for physical [fatigue] to use and an app. . . . You know, the physical fatigue, they cannot help me much with that, but they could at least explain it”* (D, 58, F, CVA),

*The occupational therapists have those ‘Don’t run but plan’ [modules], of which they themselves say: ‘That is a bit cringing what I have to hand you now’. Because they actually already see for themselves that this [module] is impossible to do visually [it is not tailored to the target group]* (H, 44, F, TBI),

and

*At a certain point there was contact with the neurologist, but they just thought that I was doing too little. Because if I were to exercise more, it [fatigue] would pass faster and I could return to my education more quickly. But I just could not* (F, 26, F, TBI).

Only one participant could mention a slightly positive experience for professional fatigue management support. However, this experience was contradicted with a negative experience: *“I had a test two years ago. A trial for mindfulness. That was good, but for me it was not manageable [because of the ABI]”* (A, 55, M, CVA). Specific reasons for why mindfulness was not manageable were not mentioned by the participant. Note that not all participants received fatigue management support: *“I actually learned nothing about it [fatigue management] and got nothing for the fatigue* (E, 62, M, CVA).

## Social support

Data regarding social support from their informal networks showed somewhat ambivalent experiences. Almost all participants could mention positive experiences (N=7): *“The more information we received, the better the family responded. . . . we have a very social family. That is really nice”* (F, 26, F, TBI), *“My family does [support]. . . . My eldest daughter is also very fond of me”* (E, 62, M, CVA), and *“My family accepted it and they really helped. They really pay attention to me”* (G, 24, F, TBI).

There were also some difficult experiences mentioned (N=2): *“Friends do not always understand it [fatigue] . . . . It is so difficult to explain what mental fatigue is. Very few people understand that”* (B, 55, M, CVA), and *“From the family, the support was there but I did not allow it myself. So, they did not notice it [fatigue] so quickly in the beginning”* (D, 58, F, CVA).

## Support needs

### Professional involvement

The majority of participants had the desire for more involvement from health professionals regarding fatigue management (N=6). The participants stated that they missed some kind of guidance during their recovery process. The types of involvement differed among participants: *“Everything I have learned in 4 years now, I might have learned that more quickly with professional help. So, help in how I can best plan a day and learn to recognise my limits earlier. I really missed that”* (G, 24, F, TBI),

*I would actually like to have some kind of coach. . . . Someone who actually guides you such as ‘where is your limit?’ and that may be difficult to find out. But then you will know it at some point. . . . that you just find out together how to prevent some things* (F, 26, F, TBI),

and *“I think it is nice that such an occupational therapist, for example, watches you every week”* (G, 24, F, TBI).

### Educational approaches

Three participants stated their desire for more educational approaches for fatigue after their ABI. Participants revealed that they did not receive any kind of information on the cognitive difficulties after their ABI. This information was more than welcome but need to be presented in a very simplistic and visual manner:

*I think when you are so young, still in life like that, then it is a job of the hospital, the rehabilitation team, no matter who, before they send me home to have a conversation with me, my husband, and maybe my kids. A piece of explanation, I think that would just have been very important. . . . I think the hospital has left a very important task there* (D, 58, F, CVA),

*“Plan an informative day or so. Like, this is it [fatigue] . . . . Purely to get an understanding even sooner”* (G, 24, F, TBI), and

*All tools we used at work were very visual and actually very simplistic. . . . I actually think they should have those kinds of tools to learn how to plan and deal with your brain injury and fatigue. That you no longer get those packages of paper that you have to read through, it just has to be simple and visual* (H, 44, F, TBI).

## Remaining support needs

A minority of participants stated some other desires. These desires were more compassion and understanding for ABI (N=1), the involvement of the loved ones during the recovery process (N=1), and guidance on different domains from an ABI-buddy or peer group (N=2): *“Perhaps more understanding for the ABI situation in general. They can help me with that a little bit more. But for the younger generation that would really make a big difference. A great deal of fighting”* (G, 24, F, TBI), *“Maybe you should also include those people close to you. How does he or she see that [ABI]? Because in the beginning you do not realise that yourself”* (D, 58, F, CVA), and *“Then [with an ABI buddy] you have confirmation and also small simple tips. Because of course a professional can teach you, but he has learned that [fatigue management] in the books. But an ABI expert learns in practise”* (A, 55, M, CVA).

In sum, participants had many desires regarding different aspects of support needs. The aspects that the majority of the participants mentioned were more involvement of health professionals and more educational approaches. A minority also mentioned more compassion and understanding, the involvement of loved ones, and guidance from an ABI-buddy or peer group. It is striking that only one desire was mentioned regarding actively changing the own behaviour of the participants. All other desires that were mentioned were out of control of the participants’ own behaviour.

### 3.2.3 eHealth preferences

#### *eHealth experiences*

Not all participants had experiences with eHealth. Those participants who had experiences with eHealth had dominantly negative experiences (N=5). Reasons for these negative experiences were mainly that the eHealth intervention was too difficult or user-unfriendly:

*I found an app that could help you plan. I think it was mainly aimed at young people and you had to buy it. I saw in the reviews that there were many negative things, that it was not user-friendly, not that easy* (H, 44, F, TBI),

and *“I also had ‘het ommetje’ [physical activity app] on my phone. . . . from Erik Scherder. I actually did not do anything with that”* (B, 55, M, CVA).

Although there were mainly negative eHealth experiences, there were also some positive experiences. One participant had a positive experience with the app ‘de activiteiten weger’ [activity planner]: *“Actually a great insight into your energy level. . . . Unconsciously you start to think, then you have an unconscious insight”* (A, 55, M, CVA). Two other participants had positive experiences with a Smartwatch as eHealth intervention: *“Actually, I like it. I bought it to give me extra motivation to go for a walk”* (B, 55, M, CVA), and *“It helped me a lot to get insight. Like, how much energy do I have now and how much energy do certain activities cost me. . . . it is a helping hand for me, also in terms of structure”* (H, 44, F, TBI).

#### *eHealth requirements*

##### Desired eHealth elements

When analysing which elements are desired to include in an eHealth intervention for fatigue management, participants stated several different elements. These elements were a daily activity planner (N=3), tips and tricks

for fatigue management (N=3), contact with a health professional (N=4), physical activity (N=3), involvement of loved ones (N=2), recognise and acknowledge boundaries (N=4), help with other topics (N=6), and monitoring and feedback (N=4).

### Daily activity planner

Answers made clear that participants have desires for an element by which they can plan their day to make their activities and moments of rest comprehensible. The need for scheduling daily activities became clear in the following quotes: *“In any case, a daily schedule. . . . That is intensive and it really costs energy, but it does yield more. Does give you more balance. That is really what should be included”* (C, 47, F, CVA),

*If there is a schedule in which you can put in what you did that day, you just look like ‘Yesterday it went wrong what did I do?’ . . . . That you can also plan a bit in that app”* (F, 26, F, TBI),

and

*What you should really include in my opinion is that you develop a tool that makes it clear to someone with brain damage and fatigue how their battery works. What energy do I have and how can I spend it? To learn to plan better as a result* (H, 44, F, TBI).

### Tips and tricks

Participants also stated their desire for useful tips and tricks for fatigue management: *“Perhaps useful little tips for everyday problems. So, suppose you get tired, what should you do until you get home. . . . Very small tips would be very interesting for me”* (G, 24, F, TBI), *“Maybe tips. ‘You are tired, maybe you can also rest for 15 minutes’, for example”* (A, 55, M, CVA), and *“When fatigue is not heavy, I would like to use that app for useful tips”* (F, 26, F, TBI).

### Contact with health professional

An eHealth intervention for fatigue management should also include contact with a health professional. Participants mentioned this to be important because they need professional guidance:

*I think contact with someone once a week. For me that was with the occupational therapist. She said: ‘How are you walking, what have you been doing last week and how are things going?’ So that is quite an incentive. It is childish but that is an incentive* (D, 58, F, CVA),

*If you are actually in contact with people who indeed understand it [fatigue] and that you can send a message every now and then, that would help a lot. I really need guidance and not an app telling me ‘You should do this’. I need someone to tell me how to do it. Because if I do not understand something, then I will stop very quickly because I do not have the energy to think about how things should be done differently* (E, 62, M, CVA),

and *“I think it might also be a good thing that you can create some sort of chat group or something [with a health professional]”* (C, 47, F, CVA).

## Physical activity

There was also a desire for including physical activity: *“That he [the eHealth intervention] stimulates me to go for a walk. You want to get better and walk further. Just an overview that you are making progress. I think that is important”* (B, 55, M, CVA),

*Maybe you should also include the piece of physical activity. Because I know of myself that I was really dreading that at first. Just the fear of ‘Oh gosh, what am I going to do?’. . . . That people dare to take the step to go straight to the gym* (D, 58, F, CVA),

and *“I think it is really good to include the physical and mental [fatigue]. . . . So that you still get a little exercise, even if it is only fifteen minutes”* (C, 47, F, CVA).

## Personal limits

The desire for learning to recognise and acknowledge personal limits became clear in the following quotes: *“Setting limits would be useful”* (E, 62, M, CVA),

*I think the most important thing is discovering, learning to recognise and acknowledge what your own energy arrow is. That your energy arrow is just not like it was before your accident. Learning and gaining insight into the fact that things cost more energy than they used to* (H, 44, F, TBI),

and *“You should enter your limits, for example. If you just have had a cerebral infarction, you will have trouble setting limits”* (A, 55, M, CVA).

## Involvement of the system

The desire for involvement of a loved one became clear in the following quotes: *“I also think for the environment to see things better. . . . I think if you had a very nice practical tool, you could involve the family with you”* (H, 44, F, TBI), and *“Maybe with the help of a partner, a caregiver and also the therapist. Because you have hardly any insight into your own situation”* (A, 55, M, CVA).

## Number of topics

When looking at the number of different topics in an eHealth intervention, the majority of participants mentioned that they also like to include help with other difficulties patients are facing: *“Anyone with a brain injury, with fatigue, gets stuck in several areas. If you suffer from fatigue, it is more important than ever that you keep moving and that you pay close attention to your diet”* (H, 44, F, TBI), and *“Multiple [topics]. The reintegration into social life, that is of course very difficult for someone with ABI because how do you go back into your social life?. . . . So, also tools for how to deal with it”* (G, 24, F, TBI).

## Monitoring and feedback

Participants also expressed their desire for fatigue monitoring in general and warnings for fatigue in the following quotes: *“An app that measures your fatigue and gives you a warning such as ‘Please note, your energy level is dangerously dropping’”* (A, 55, M, CVA), *“If something is added where you can monitor yourself. When you are tired, what happens in your body? That you have to pay attention . . . . Because I do not notice that regularly”* (E, 62, M, CVA), and *“If there was an app that can measure your activities. . . . that would be nice if*

*it reminds you that you need to rest and have to take a break as a result of your activities. That would be great”* (B, 55, M, CVA).

One participant stated the desire for monitoring sleep and a feature where you can fill in the moments that you have eaten that day: *“With that app, you can also put your sleep in it. . . . and the times when you eat. Because just not eating one day does not help with your fatigue”* (F, 26, F, TBI).

Interestingly, results also made clear that participants would like iterative monitoring and feedback in the eHealth intervention. Besides monitoring and feedback of general fatigue, sleep, and nutrition, monitoring and feedback was also a recurring desire for the elements: daily activity planner, contact with a health professional, and physical activity.

### Undesired eHealth elements

Two participants stated that lots of text and a busy layout should be excluded from the intervention: *“It should not be much text”* (H, 44, F, TBI), and *“That app should actually be aphasia-friendly. Which means, not a busy layout. So, simple and basic”* (A, 55, M, CVA). One participant stated that the intervention should not have options to change health information. The intervention should measure activity by itself: *“You should not be able to change it [health information] yourself”* (B, 55, M, CVA).

### Type of technological support

Data regarding the type of technological support revealed that almost all participants would like an app which they can access with their mobile phone (N=7). Reasons for this type were that a mobile phone is easily accessible and computers are difficult to use for the participants: *“On the laptop is a bit tricky. It is easier on the phone. You can do that in the chair for a while”* (A, 55, M, CVA), *“On your phone because you just have it with you. I do not have the laptop on every day”* (D, 58, F, CVA), and *“Not the laptop because I do not go well on computers anyway. Screens are a difficult thing, I quickly grab my phone, do what you have to do and you put it away again”* (H, 44, F, TBI).

Two participants also revealed their preference for a smartwatch: *“The easiest thing for me is that I have a smartwatch”* (E, 62, M, CVA), and *“A smartwatch also appeals to me”* (G, 24, F, TBI).

### Frequency of use

Almost all participants stated that they would like to use the eHealth intervention daily (N=7). The reason for this daily use was that participants would like to make fatigue management a habit. To achieve this, participants stated that daily use is needed. This became clear in the following quotes:

*I think you should do it consistently. For the structure and also for the memorization, I would say every day. . . . Once a week is too little if you really want to make it your own and want it to be effective* (C, 47, F, CVA),

*“I think you should use it daily. Because you really have to make it your own”* (H, 44, F, TBI), and *“I would use it continuously”* (B, 55, M, CVA).

## Time of use

All participants would use an eHealth intervention to help prevent them from being too fatigued (N=8). To achieve this, participants stated that they would like to use the intervention in the morning: *“It would be most reasonable for me to do it [the intervention] in the morning. Then I still have the most energy and the concentration is still good”* (G, 24, F, TBI), *“Pretty much in the middle of the morning. . . then I still have enough energy”* (E, 62, M, CVA), and *“I think around 11 A.M. . . . So basically, in a kind of break moment”* (C, 47, F, CVA).

Overall, participants mentioned many desires for an eHealth intervention. The desired elements that should be included in the intervention are: a daily activity planner, tips and tricks, contact with a health professional, physical activity, involvement of loved ones, recognise and acknowledge personal limits, help with other topics, and monitoring and feedback. Remarkably, iterative monitoring and feedback was a recurring inclusion desire by different topics. Only two participants mentioned that lots of texts and busy layout are undesired and should be excluded from the intervention. The majority of the participants could not mention undesired elements. Almost all participants stated that they would like the intervention to be accessible by mobile phone and use the intervention daily to create a habit. All participants mentioned that they would use the intervention in the morning to help prevent fatigue.

## Ways to offer eHealth care

When analysing the ways to offer eHealth care, it became clear that the opinions of the participants were divided.

### Stepped-care

The majority of the participants were positive about the stepped-care eHealth offer (N=7). Reasons for this were that not every person experiences fatigue the same and with this form, fatigue management could be tailored: *“Very well. Because some require more care than others. . . . Look, every person is different, no one is the same. . . . One needs more care than the other”* (G, 24, F, TBI),

*Maybe you could say we start high [with care] and we can always go down a bit if you notice if someone can do it [manage fatigue] easily. I think that might be even better. . . . if it is monitored by a professional, I think that you can start low, but you should indeed reflect together often enough* (C, 47, F, CVA),

and *“That [stepped-care] seems good to me. Then you get more customization”* (H, 44, F, TBI).

### Blended-care

Data about the blended-care eHealth offer revealed that four participants were less optimistic about this form. Reasons were that blended-care might be too difficult for ABI survivors: *“I do not think it is suitable for everyone to do it online. That is also quite difficult, isn't it? To do this with brain injury patients”* (B, 55, M, CVA), *“I think that is very different per person”* (H, 44, F, TBI), and *“People with ABI usually have difficulty with changes. So that is tricky”* (A, 55, M, CVA).

Despite some reluctant opinions, the majority still would like to try this form (N=5): *“I think it [blended-care] is very good. . . . Then you can just discuss the things you have encountered and then you discuss it with a professional”* (D, 58, F, CVA), *“I had tried that anyway. . . . That also sounds like support and I definitely would*

have tried that [a blended-care intervention]” (F, 26, F, TBI), and “*That could be useful. . . . That someone is going to point out to you a bit more such as ‘You can already try this, do not try that yet’*” (E, 62, M, CVA).

### Patient-centred care

The majority of participants were positive about patient-centred care (N=6). This offer could be expressed in the form of a basic level for health professionals of knowledge and skills for fatigue management. Participants thought that many ABI survivors could benefit from this form of care. Also, the idea that people would be able to receive professional help for fatigue management was experienced positively:

*That [patient-centred care] is of course very handy. . . . You expect more from those professionals. So, it would be very good if those need to be trained. You know, they have the theory; ‘how does a cerebral infarction or a brain haemorrhage occur’, but there is also a person behind it* (D, 58, F, CVA),

*“I think it [patient-centred-care] would actually be a good outcome for many people. That many people will benefit from it”* (E, 62, M, CVA), and *“That [patient-centred-care] is actually quite nice. . . . I think that would have made me a lot less depressed”* (F, 26, F, TBI).

Two participants were reluctant about this form. One participant thought that an ABI-buddy would be better and the other had doubts about if patient-centred care would work: *“Actually, you should have a personal buddy, an ABI-buddy. Because they have experience with ABI”* (A, 55, M, CVA), and

*I wonder if it works like that. I think when it really comes to managing and dealing with fatigue, I think that you are most at home with the occupational therapist. . . . If you have several professionals and you feel more comfortable discussing things with one [professional], you automatically discuss a little more there than with another* (H, 44, F, TBI).

Results from this paragraph showed that the majority of participants were positive about stepped-care. The main reason for this was that fatigue is individually experienced and every individual needs different fatigue management efforts. Opinions about blended-care on the other hand, were ambivalent. Participants found this form difficult to understand and also depended on the preferences of an individual. Almost all patients were positive about patient-centred care. Participants mentioned that this form could be beneficial for lots of people. However, two participants were doubting this form due to interest in another form and scepticism about this form.

## 3.3 Results group 2: Health Professionals

### 3.3.1. Current health system for ABI survivors

#### *Barriers*

Participants experienced barriers in the current health system for patients with ABI. These barriers were present in different domains. These domains were access to care (N=4), compassion and recognition (N=3), knowledge (N=4), unfulfilled needs (N=4), motoric focus (N=2), and time (N=1).

#### *Access to care*

Data made clear that the access to care is particularly difficult for ABI survivors with milder complaints:

*In particular, people with milder complaints [ABI related complaints] who do not come to the hospital or who are quickly sent home because everything seems to be going well, those are the people who may sometimes fall between the cracks (J, 37, F, PT),*

and *“You hear that there is kind of a gap when people resign, that they miss follow-up afterwards. I mainly think that things go wrong with the people with the very subtle complaints” (I, 45, F, PSY).*

### Compassion and recognition

Participants also stated barriers regarding the compassion and recognition of ABI. Answers made clear that being compassionate can be difficult and that ABI patients are not always recognised: *“The impact [of ABI] in healthcare is sometimes a bit difficult. This deserves a lot of attention. . . . Especially with the professionals who are somewhat inexperienced. In particular towards misunderstood behaviour and fatigue or depression” (J, 37, F, PT), and “I think nationwide and also here, that people with a mild brain injury, those less visible complaints, are not always recognised. In primary care for example and also not by other specialists” (K, 52, F, RP).*

### Knowledge about healthcare options

The knowledge from the health professional about finding the connection with the right health professional, the referral of the patient, or familiarity with the current care possibilities was also considered as a barrier:

*Some people are not in the picture. So, if they have not been admitted to a rehabilitation centre, I see that GPs have little knowledge of how to refer and with which question to refer. Thus, people are without help for a long time. I think that is a downside of the system (M, 40, F, OT),*

and

*It is sometimes difficult to find each other as professionals, from [Institution Y] to primary care and vice versa. The network does exist on paper and also in practise, but I think that could also be better, that you know how to find each other more easily (K, 52, F, RP).*

### Unfulfilled needs

Almost all participants thought that ABI survivors still have unfulfilled needs regarding healthcare options. Participants considered these unfulfilled needs as a barrier. However, they thought it was difficult to fully meet the patients in their needs: *“It is difficult to fully meet that need. Because a large proportion of the patients [with ABI] do not oversee their complaints regarding fatigue or depression or cognitive disorders. . . . the complaints that remain are often neglected” (J, 37, F), and*

*Returning to the social network sometimes goes very well. . . . But if people have behavioural problems or serious cognitive problems, that turns out to be very difficult. But there is certainly a need. I think it is very big. But in practise that is one of the most difficult things (K, 52, F, RP).*

### Motoric focus

The motoric focus in hospitals was also mentioned as a barrier. Participants mentioned that hospitals often do not look at the cognitive conditions of ABI survivors:

*The degree of severity [of ABI] . . . is often based on a motoric score. Then someone is referred to as 'a motorically light patient'. In fact, all recover well in the first days. But saying 'motoric bad' or 'motoric good' does not mean 'cognitively good'. That is not the same. I think that is where things sometimes go wrong (I, 45, F, PSY),*

and

*What catches the eye is the motoric loss or the phatic disorders. You see that when people have recovered their motoric skills and etcetera, that there is actually nothing to be seen on the outside (L, 54, M, GP).*

This focus was also related to the lack of compassion and recognition.

### Time

Time was also considered as a barrier:

*It [healthcare] is very compact. We must provide the best possible care, but preferably in as little time as possible. That is a bit of the task we have to keep healthcare affordable. So that is the case in recent years, it has to be increasingly concise. But it is not really like that in life (I, 45, F, PSY).*

### Facilitating factors

Although there was more emphasis on the barriers of the current health system, there were also some facilitating factors mentioned. These factors ranged from the co-operation of professionals (N=2), rehabilitation care (N=4), and knowledge and skills (N=3).

Facilitating factors regarding the co-operation of professionals in the form of chain care became clear in the following quotes: *"The chain care, for example. Because those chains have been set up, you have very good references and very clear networks. As a result, expertise is also clear"* (M, 40, F, OT), and *"I think healthcare professionals know how to find each other fairly well"* (J, 37, F, PT). Note that not all regions in the Netherlands have a chain care for ABI survivors.

Another facilitating factor was that the rehabilitation care is well organized: *"I think the rehabilitation programmes are going quite well. . . . Those people who end up there have a whole team that actually work towards the same goals. So that someone can get their old skills back"* (I, 45, F, PSY), and *"I think that in itself there is a very good safety net. . . . there are of course many ABI professionals, not only in [rehabilitation institution X] but also in primary care"* (K, 52, F, RP).

Answers of the participants made clear that health professionals have good knowledge and skills regarding ABI: *"I think those disciplines. . . . occupational therapists, physiotherapists, speech therapist, occupational physicians, that they are perfectly capable of guiding a patient in this [ABI difficulties]"* (L, 54, M, GP), and *"I think the level of knowledge [of health professionals] is of a high level"* (J, 37, F, PT).

In sum, these paragraphs made clear that health professionals mentioned more barriers than facilitating factors. Barriers mentioned were: access to care, compassion and recognition, knowledge about healthcare options, unfulfilled needs, motoric focus, and time. Remarkably, the majority of participants mentioned access to care to be a prominent barrier for ABI survivors with mild complaints. There were also some facilitating factors

mentioned. These facilitating factors were: co-operation of health professionals, well-organized rehabilitation care, and knowledge and skills of health professionals. There were no differences in answers between professions.

### 3.3.2 Fatigue (management)

All health professionals experienced fatigue to be present in their patients with ABI (N=5). Fatigue after ABI is a very prevalent symptom: *“I think of all ABI patients, that at least 80% suffer from it [fatigue] to some extent. That is not a scientific number, but more an estimate”* (K, 52, F, RP), *“I see about 8 people a day in the practise of which at least 6 have fatigue complaints. So, 80% of the people I see suffer from fatigue. That is the referral we get the most”* (M, 40, F, OT), and *“You can see it in almost everything. . . . Actually, by all people with brain disorders you see that they suffer from fatigue”* (I, 45, F, PSY).

Answers of participants regarding the occurrence of the different dimensions of fatigue made clear that two dimensions are present. Two participants stated that mental fatigue is the most common dimension: *“My experience is that it is more the mental fatigue than the physical fatigue”* (L, 54, M, GP), and *“It is often not just that physical fatigue in ABI but much more that mental fatigue”* (M, 40, F, OT).

Participants stated that attention to the two dimensions is crucial (N=5). Three participants also stated that those dimensions could not be seen separately: *“I think if physical fatigue is present, then you cannot do a good job with mental fatigue. I see it as a kind of basic condition”* (M, 40, F, OT), *“I think that it is also quite difficult to separate that [mental and physical fatigue]. . . . I think seeing it completely separate from each other is very difficult”* (I, 45, F, PSY), and *“You cannot see it [mental and physical fatigue] separately. . . . the social, the person, the physical [fatigue], the mental [fatigue], all those things belong together”* (L, 54, M, GP).

However, equal attention to these dimensions gets often forgotten: *“I think that could also get more attention. Mental fatigue is sometimes mentioned, but I think that from my own field I actually prefer chronic fatigue complaints more than the mental study”* (J, 37, F, PT), and

*I recognise that there is much attention for only the mental [fatigue] or only the physical [fatigue]. I think we may not always do the integration well. I sometimes wonder if you should not just oblige that physical side of the programme. Sometimes much emphasis is placed on the mental, which is of course also very important. But I think the physical part is sometimes underestimated* (K, 52, F, RP).

Note that answers regarding the attention to these dimensions differed between professions. Those participants who have a more physical profession mentioned to pay less attention to the mental dimension themselves and vice versa. Participants did not explicitly express their willingness to pay attention to the other dimension.

### *Consequences of fatigue*

#### *Social engagement and leisure*

The majority of the participants experienced that fatigue was a negative consequence to their patients' engagement in social activities and leisure (N=4). The severity differed among patients and had to do with the characteristics of the patients: *“It also depends on how you are as a person. So, if they are avoidant, people will cancel all appointments or parties. . . so then it has an impact on your social life”* (I, 45, F, PSY), *“People who were skilled socially, now no longer have the highest word at a birthday party . . . . that has many social consequences”* (L, 54, M, GP), and

*They [ABI survivors] can do a lot of what they did before but much shorter and much more limited. This means that they indeed need more rest and therefore sit at home more and really have to reject activities that they did before (K, 52, F, RP).*

### Emotion processing and self-regulation

Participants also experienced negative consequences of fatigue in emotion processing and self-regulation by their patients (N=4). The acceptance of fatigue is something that was difficult:

*It is kind of like a grieving process . . . You are of course in a process in which you have to come to the acceptance over time that there is a new situation with a new balance. An end situation in which it would no longer be the way it was before. So that can make you angry, it can make you sad and it can make you rebellious (L, 54, M, GP),*

*“Of course, it [fatigue] has a huge impact on mood. On acceptance of the limitations, one has. That is a kind of vicious circle that people enter” (K, 52, F, RP), and “People are sometimes more difficult to motivate to do activity. That slows down the rehabilitation process. . . . So basically, it is a kind of conflict all the time” (J, 37, F, PT).*

### Work reduction

Only one participant explicitly mentioned work reduction to be a negative consequence of fatigue for ABI survivors in combination with other negative consequences of fatigue: *“As a result [of fatigue], people have difficulties with their relationship, difficulties with social contacts, with work, with their role in the family. In all areas of life, you actually see that it [fatigue] plays a role” (M, 40, F, OT).*

The data in these paragraphs revealed that participants from all professions experienced fatigue by their patients to be a prevalent symptom. The majority of participants mentioned fatigue to have many negative consequences. Participants mentioned negative consequences of fatigue regarding the domains: social engagement and leisure, emotion processing and self-regulation, and work. There were no differentiations between professions regarding experiences and consequences of fatigue. However, answers regarding attention to the two dimensions of fatigue differed between professions. The health professionals who focus more on the physical aspects in their profession did not pay much attention to the mental aspects themselves and vice versa.

### Current healthcare options for fatigue

When analysing the current healthcare options for fatigue management after ABI, it became clear that all participants could mention multiple negative aspects (N=5). Many benefits can still be achieved in this area: *“I think there is actually still a whole target group that needs to be served. . . . the total subject should receive more attention from all healthcare professionals” (J, 37, F, PT).*

### Fatigue management materials

The majority of the participants mentioned the lack of adequate fatigue management materials tailored to ABI survivors as a negative aspect of the current health system (N=4): *“We now work with a BORG-scale. But those tables are just awfully difficult for the patients. . . . there is no reliable measuring instrument. It is very subjective” (J, 37, F, PT),*

*For some target groups there is no clear explanation yet. So really good psycho-education material. . . . A good explanation of what is exactly the cause of the fatigue?. . . I think that is missing in the system, that there is uniformity in explanation (M, 40, F, OT)*

and *“A bit of the disadvantage is that there is also a tendency to approach all patients in the same way. While I think it is really about those personal characteristics and that personal context” (I, 45, F, PSY).*

### Uniform and consistent techniques

The lack of uniform and consistent techniques to enhance fatigue management also played a role in the negative aspects of current healthcare options for ABI survivors (N=3):

*I think that there is no fatigue care product. So, they [health professionals] do have experience and they can also coach and guide it. But I think that displaying it as a product is not getting enough attention, while that is where the knowledge and expertise lies (J, 37, F, PT),*

*With us in [rehabilitation institution X] it is a huge discussion point about how we can best tackle those fatigue complaints. . . . there is often much discussion of ‘What is the best way to do this?’ The conclusion is that the cause of fatigue is slightly different for each patient (K, 52, F, RP),*

and

*People very quickly turn to strategy use. If you use a strategy at the wrong time, it will not be effective. . . . So, the most important thing is that the diagnostic phase is done properly. That someone gets insight into his situation and that you first analyse properly. . . . and that someone will understand it himself. It usually goes wrong when therapists go too quickly to solutions and strategies (M, 40, F, OT).*

Answers made clear that there is not much evidence for effective fatigue management techniques specifically for the ABI survivors and uniform and consistent techniques are not available in the current healthcare system.

### Co-operation of disciplines

One participant stated that the co-operation of different disciplines is a challenge in the current healthcare system (N=1):

*What I think is the main challenge is co-operation. . . . Making optimal use of the knowledge and skills available in different disciplines. There is sufficient knowledge and skills, I think there is enough, the art is to make them work well together (L, 54, M, GP).*

This participant mentioned competition between disciplines to be the reason for this challenge:

*You have occupational therapists or physiotherapists who compete with each other for their right to exist. What you often see is that the challenge in integrating good primary care is to convince those people that it is best not to compete with each other but to make optimal use of the expertise that everyone has (L, 54, M, GP).*

### Positive health-care options

There were also some positive aspects of the current system mentioned. All participants stated positive aspects about efforts from their own workplace in general or regarding their own fatigue management efforts

(N=5): *“I think things are going quite well for us. Our healthcare professionals are also trained in ABI”* (J, 37, F, PT), *“I am satisfied with my own efforts. . . . I work with a partner in which we also develop lots of therapy material ourselves”* (K, 52, F, RP), and *“I think that we now have so much experience here that the patient is approached quite completely by our multidisciplinary team”* (K, 52, F, RP).

These paragraphs showed that mainly negative aspects regarding current healthcare options for fatigue management were mentioned. Participants mentioned the lack of adequate fatigue management materials for the target group, uniform and consistent techniques to improve fatigue management, and co-operation of different disciplines as negative aspects. This paragraph showed differentiation in answers based on the profession of the participants. Participants who actively help patients with alleviating fatigue in their profession could mention more negative aspects regarding the current healthcare options for fatigue. Interestingly, results showed that all participants mentioned positive healthcare options regarding their own workplace or own efforts.

### *Effectiveness of self-management strategies*

Data regarding effective self-management strategies revealed strategies regarding physical activity (N=3), insight into one’s own fatigue (N=2), knowledge of how to reduce fatigue (N=1), monitoring progress (N=1), visualization (N=1), involvement of the system (N=2), and professional involvement (N=1).

#### *Physical activity*

Participants mentioned physical activity to be an important self-management strategy for managing fatigue. The effectiveness of physical activity as strategy became clear in the following quotes: *“I think increasing their physical capacity is very important. That people also keep moving physically and keep working on their fitness”* (K, 52, F, RP), and *“What is often missing by ABI is that you are very quickly talking about those invisible consequences, about that mental fatigue, but you must not forget the physical fatigue and sleep”* (M, 40, F, OT), *“The condition tests are working well. They say something about the degree of fatigue”* (J, 37, F, PT).

#### *Insight*

Insight into ABI survivors’ own fatigue and working mechanisms of fatigue after ABI were also stated as important strategies:

*First people need to know ‘What about me?’ is it really a limited energy or a battery that quickly drains due to the brain injury . . . that a build-up takes place where you get to know your limits . . . dosing around the border. That you know where it [the boundary] is, that you can recognise it very well* (I, 45, F, PSY),

and

*It is mainly a great deal of education and insight into how the brain works. How they can deal with it [fatigue] . . . providing insight into what people do in a day, what costs energy, how much energy a certain activity costs, how you can best distribute it over the day. I think that is very important* (K, 52, F, RP).

#### *Knowledge*

Knowledge of how to reduce fatigue was also mentioned as an important strategy:

*Important strategies are to first get stable in the situation. That you say ‘I know what to do to reduce the complaints’. That has to do with taking a break in time. . . . alternating, varying, pausing. . . dealing with*

*time pressure is an important one, reducing time pressure. A positive mindset is also very important, which you build from positive experiences (M, 40, F, OT).*

### Visualization

Writing everything down was mentioned as another important self-management strategy for ABI survivors:

*Everything out of the head on the paper. It works very well to draw things out for them [ABI survivors] and to actually have them do assignments . . . But at least it has to be memorized, on the paper. That is important for this group. That works well (M, 40, F, OT).*

### Monitoring

One participant stated the importance of monitoring:

*Monitoring progress is an important strategy that people will keep up 'how was my day?'. Because there is a danger that they will focus on something different or something such as 'It is going well' and actually forget that they use up a little too much [energy] every day (M, 40, F, OT).*

### Communication with the patient's network

One participant mentioned the importance of communication with the network of the ABI survivor: "Communication in the system [patient's network]. Perhaps it is important to mention, that if people have to apply strategies at work, or in their busy family, or mixed family, that you also pay enough attention to 'how do you do that?'" (M, 40, F, OT) and "Education of the patients' environment [is important]" (K, 52, F, RP).

### Professional involvement

One participant revealed that ABI survivors should get help from professionals to enhance the self-management process:

*I think those people just need to be under more control. . . . to be able to better map that fatigue and to re-test the load and resilience. . . . So, I think an evaluation every now and then is desirable (J, 37, F, PT).*

### Ineffective strategies

No participant explicitly mentioned ineffective self-management strategies for fatigue management. One participant did mention that as a health professional, you should not deny complaints:

*If you deny complaints, the person feels more and more misunderstood and becomes more and more powerless, which actually makes the problems worse. So, you can never deny complaints. That is the worst thing you can do as a counsellor. You should always take the complaint seriously. The underlying cause can be different and you just have to look at that (I, 45, F, PSY).*

The data from these paragraphs showed multiple effective self-management strategies for fatigue management. Participants mentioned: physical activity, insight into one's own fatigue and working mechanisms of fatigue, knowledge of fatigue reduction, visualization, monitoring, communication with the patient's network, and professional involvement as effective strategies. No specific ineffective strategies were mentioned. Answers

in these paragraphs differed between professions. Those health professionals who focus more on managing ABI in their profession mentioned more effective self-management strategies.

### *Importance of different interventions types*

Answers regarding the importance of different types of interventions specifically for ABI survivors to include in an eHealth intervention are described in the following paragraphs. Data was gathered regarding the intervention types emotion processing, educational approaches, self-management, and the COGRAT intervention.

#### *Emotion processing*

Almost all participants pay attention to emotion processing (N=4):

*I myself kind of see it [emotion processing] as part of the mental fatigue. Those emotions simply consume a lot more energy. So, it is always a point of attention in therapy. . . . It must be part of your management interventions by explaining that it [emotions] can affect (M, 40, F, OT),*

and “*I think it [emotion processing] is getting attention of healthcare professionals, but maybe not from the patient*” (J, 37, F, PT).

One participant revealed that there may not always be enough room for emotion processing:

*I do think there is not always room to take that [emotion processing] with you. Whether that is not always looked at, I believe that too. But I think that depends on where in the chain you are and who is on the opposite side of you (I, 45, F, PSY).*

Data also revealed that despite the attention, emotional processing remains quite difficult for the patient and the process differs among patient:

*I think we pay much attention to that. . . . I do not know how patients experience it themselves, but what my experience with ABI patients is, is that it sometimes is never enough. Because they cannot accept their limitations. No professional can change that according to me (K, 52, F, RP),*

and “*People need time to take the loss of course. Some people can do that a bit more easily than others*” (L, 54, M, GP).

One participant stated the importance of patient associations to play a role in emotion processing: “*At some point, the patient association has to take it over. . . . Ultimately, the patient should have a kind of peer contact. That can be very valuable*” (K, 52, F, RP).

#### *Educational approaches*

The majority of the participants find educational approaches very important (N=3). Data made clear that the educational approach should be tailored to the patient and that it is not a strategy on itself:

*I think it is super important. But that is kind of a first step. So, psychoeducation can only be tailored. . . . If you look at insight into disease, someone must first understand what they exactly have. I think it is very important. . . . Psychoeducation alone is not an energy management strategy (M, 40, F, OT),*

*That [the educational approach] is already used. The people in care receive psychoeducation as a standard part of treatment. There is also much psycho-education material available I think. . . . The point is that it is important that it [education] is personal. The general terms do not always apply to everyone (I, 45, F, PSY),*

and *“Extremely important. I think that it is the core of the whole treatment” (K, 52, F, RP).*

One participant also revealed that the effectiveness of educational approaches differs among participants:

*It is sometimes too complex for a specific target group and the other target group thinks it is all nonsense. So, they are not completely open to it. They find it a bit childish while they do have problems in that area. Some are super happy with that intervention. So that varies (J, 37, F, PT).*

One participant was not familiar with psycho-education as an educational approach: *“I am not familiar with it. I am not using the psycho-education offer. . . . I am not aware of that; I am not using that” (L, 54, M, GP).*

### Self-management

Data about self-management approaches revealed ambivalent opinions. The majority of the participants were positive (N=3). They thought that self-management interventions are eventually the goal of fatigue management. The effectiveness of this strategy depends on the preferences of the patient:

*I think that is where it has to go eventually. People have to experience that they [ABI survivors] regain control of their complaints. That psychoeducation is of course very important for that and also practicing in practise with everything that they learn. In the end, they have to do it themselves (K, 52, F, RP),*

*That is of course very good because it should actually be part of every treatment. Because only a conversation once a week or once every 2 weeks, that does not change that much. So, it is also about people learning to recognise what is going on in their daily lives and how to deal with it (I, 45, F, PSY),*

and *“That [self-management] are all tools, of course. That seems fine to me. . . . Look it is all good, but it is not all good for everyone” (L, 54, M, GP).*

Two participants were sceptical about this intervention type. They thought that self-management approaches are too difficult for the target group:

*I do not really believe in that. When I look at practise, people need some guidance. . . . I think you are failing patients with full self-management. One may only need twice and the other eight times [of guidance], but completely independently, I do not really believe in that (M, 40, F, OT),*

and

*I notice that they [the patients] find some things very difficult. . . . We have tried quite a few things [for self-management], but many things are too fast for the clients. They are slowed down in their thinking, work pace, and in execution. That part [self-management] is not always designed for that (J, 37, F, PT).*

### The COGRAT

Almost all participants knew the COGRAT and were positive about it (N=4):

*I think that is very good. I think that if it [COGRAT] works for a patient, that it is the way to increase your resilience and also increase your insight, because you can discuss everything. But people also have to feel and experience it. That is a very good combination (K, 52, F, RP),*

and

*I think that [COGRAT] is a very nice addition. Because it is very accessible and I think it is good to get people in the right direction if necessary because they are well informed and also know 'This is how I can do it' (I, 45, F, PSY).*

Participants also mentioned that this intervention is only suitable and accessible for patients with a higher cognitive level in the rehabilitation care. This intervention is too difficult for severely affected people: *"Graded Activity is of course something that fits very nicely with this target group. Especially for the slightly higher level. Of course, we also see the lower level here. This [the COGRAT] is a bit too difficult for them" (J, 37, F, PT) and "I think it is a pity that the programme is written for the patients with heavier symptoms" (M, 40, F, OT).*

When analysing possible additions for this intervention, a few additions were stated regarding the availability in care (N=3), substantive programme changes (N=3) and other programme options (N=1). Additions regarding availability in care became clear in the following quotes: *"I think I want to use it in the outpatient setting. Because they [ABI survivors] are less focused on the complaints that are often in the foreground in phase 1" (J, 37, F, PT), "In an adapted version, you also have to have something for the group which is doing much better" (M, 40, F, OT). and "This [the COGRAT] could of course just as easily take place at home or in an outpatient setting. . . . there are enough people in primary care conceivable who can do or supervise this" (L, 54, M, GP). Additions regarding substantive programme changes became clear in the following quotes: *"The transfer to keep moving at home. . . . I sometimes find it a shame, I have no idea how many people ultimately keep moving themselves" (K, 52, F, RP), "Of course. you miss the occupational physician part, you miss the social domain, so it [The COGRAT] has of course not everything in it" (L, 54, M, GP), and**

*What I have trouble with is that it [COGRAT] is in a group. So that is not suitable for everyone in such a group form. It also has many sessions. . . . It takes quite a bit of effort from people to be able to do that (M, 40, F, OT).*

One participant had an addition regarding providing other programme options: *"I think that ACT [Acceptance and Commitment Therapy] is a good addition to another group that actually does not benefit from the COGRAT" (I, 45, F, PSY).*

To summarise, these paragraphs showed ambivalent opinions regarding the importance of different intervention types. Almost all participants paid attention to emotion processing and found this type important. However, emotion processing is a difficult process for the patient and there might not always be room to address this. The majority of participants thought that educational approaches are important. This again, depends on the characteristics of the patient. Answers regarding self-management approaches were ambivalent. Although some found this intervention type important, there were also some participants who thought that this type was too difficult for the target group. Answers regarding the COGRAT were positive. However, participants did not agree with the current accessibility of the intervention and mentioned this as a possible addition to the intervention

alongside substantive programme changes and other programme options. As well as in the previous paragraph, answers of participants differed between professions. Health professionals who actively used the different intervention types in their practise could mention more meaningful and critical aspects about the importance of the different intervention types.

### 3.3.3 eHealth for ABI survivors

When looking at general eHealth experiences, opinions were divided. An emphasis on negative experiences was given (N=4). Different reasons for these negative experiences were stated: *“We have done something with eHealth. But it was not a success. . . . it is a bit difficult in practise. That is sometimes due to the apps themselves and sometimes because the preconditions here”* (J, 37, F, PT), and

*The enthusiasm of patients for this [eHealth] is very limited. . . . But I also think that patients, or people in general, like those gadgets, but they also get bored quickly. So, if you have to get all the motivation out of yourself, that often does not work* (K, 52, F, RP).

A risk of eHealth was also mentioned:

*The risk is that if you do too much eHealth alone, you will give the patient the feeling of ‘I have to do it all alone’. That is a risk, because a therapeutic relationship is a very important factor in getting people to change their behaviour* (I, 45, F, PSY).

All participants stated the importance that eHealth should be an addition to treatment, not a replacement and that eHealth could be suitable for some patients, but not for all:

*My experience is that eHealth is suitable for some people but not for everyone. People sometimes start very enthusiastically, but that changes anyway. It [eHealth] must be blended. That has a lot more added value compared to just eHealth* (M, 40, F, OT),

*“It often depends on the generation. For younger people that [eHealth] is very nice and useful and they like that it is used in care. . . . It is not instead of, but it can be additionally”* (L, 54, M, GP), and

*I think it is very good to use this kind of technology. I only think that personal contact with a practitioner, that does not have to be a doctor . . . is very important* (K, 52, F, RP).

Only one participant explicitly mentioned a positive experience with eHealth: *“I do have positive experiences with eHealth for prosthetics. A number of nice apps have been developed there”* (J, 37, F, PT).

### *eHealth requirements*

#### Desired eHealth elements

Data about which elements are desired to include in an eHealth intervention for fatigue management revealed diverse opinions. The following desired elements were mentioned: tailoring (N=2), visible and invisible consequences (N=2), energy management (N=3), physical activity (N=1), educational efforts (N=2), and professional involvement (N=1).

## Tailoring

Participants mentioned that the intervention should be tailored to the target group and that certain conditions should be kept in mind:

*That it is not written so small. So, adjust the font properly. The text should be put in the middle and not that far to the left or right, if they have neglect-like complaints. Also, do something with the colour red, because that is the colour that catches their eye. . . . Lots of visual pictures. That you may have a picture and narration that you can click on if you need it. That you are guided in the pace of the exercise that you have to do. . . . Explain everything step by step and also being able to adjust the tempo (J, 37, F, PT),*

and *“I think it should be a bit low in stimuli, not too busy and not cluttered” (K, 52, F, RP).*

## Visible and invisible consequences

The eHealth intervention should have attention for both the visible and invisible consequences of ABI: *“Add something about depression, I think. Like ‘How do you recognise the signals’” (J, 37, F, PT), and “That you have responsible attention for physical [fatigue] and mental [fatigue]. I think those are the two main parts of the rehabilitation process” (L, 54, M, GP).*

## Energy management

Energy management should play a crucial part in an eHealth intervention for fatigue management. Participants mentioned different ways of how energy management could be shaped: *“Tension, relaxation and fatigue load and resilience, what can you handle in a day? Dividing your energy management. I would like to pay some attention to that then” (J, 37, F, PT), “It would be nice if there was a daily schedule that indicates whether you are doing well in terms of dosage and in terms of the distribution of your amount of energy” (K, 52, F, RP), “Building it [the energy level] up. In combination with that CBT [Cognitive Behavioural Therapy]. So, what is in the COGRAT. I think that is the basic element of the fatigue treatment” (I, 45, F, PSY).*

## Physical activity

One participant mentioned that the eHealth intervention should also have attention for physical activity:

*If you have an app that occasionally alerts you like ‘Did you go for a walk today?’ and who offers you exercises, that suit your level, that you can do or remember about things to do in a day. That is really good (K, 52, F, RP).*

## Educational efforts

Educational efforts are also desired to include in the eHealth intervention for fatigue management: *“I can imagine that you can also use some of that psycho-education. . . . Maybe you could combine it with exercises” (K, 52, F, RP), and*

*It would be great if you have information in it that they can also show to their environment. Or a piece in which you say ‘Fill this in with your employer, or discuss this with your employer’ (M, 40, F, OT).*

## Contact with health professional

One participant mentioned that the eHealth intervention should have the possibility to contact the health professional: *“It would be nice to be able to have contact with your professional there as well” (K, 52, F, RP).*

## Undesired eHealth elements

There were also four participants who mentioned different undesired elements for an eHealth intervention for fatigue management. These participants mentioned that many advices, pushing people, the same intervention for every patient, and denying complaints should be excluded from the intervention:

*I think you should not give too much advice. I will just give more examples. They can of course take advice quite literally. If an eHealth app says something and your healthcare provider says something else, then I think you will have a conflict quickly. So, I would be a little careful about that (J, 37, F, PT),*

*I think you have to be very careful in pushing people. . . . That is the danger of eHealth like 'I am going to measure the number of steps per day or something', but you do not measure the consequences (L, 54, M, GP),*

*"That it [the intervention] is not the same for everyone. I think that should not be in it. Because not everyone with ABI needs the same intervention" (M, 40, F, OT), and "If you are going to deny complaints like, 'But you do have complaints, but nothing is wrong, so, between the lines, you are overreacting', that should not be in it" (I, 45, F, PSY).*

## Type of technological support

Data regarding the type of technological support revealed ambivalent opinions. Two participants would like to see an app that could be used with mobile phones because it is easily accessible: *"I would go for the app. Computers disappear from the picture. People come in with their phones. That is the thing I think they will do the quickest" (J, 37, F, PT), "I think it is very good to use technology that is easily accessible with your mobile phone. That is ideal" (K, 52, F, RP).*

Two participants found it difficult to give an answer that can be applied for each patient:

*People with ABI have many different problems: they have cognitive problems, they also have mood or behaviour problems and depending on the problem, I think a different app is useful. I do not know if I have a general answer to that (I, 45, F, PSY),*

and *"That also depends on the patient. . . . It must meet the needs of the patient" (L, 54, M, GP).*

One participant had opinions in favour and against an app:

*I notice that I am not much in favour of an app because it is a very small screen. The amount of information that you see on such a screen is proportional, I do not find that optimal. I also think that an eHealth intervention should invite people to really sit down and pay attention to it. . . . An advantage of an app on the other hand is that it is very accessible to people (M, 40, F, OT).*

## Professional involvement

All participants agreed that an eHealth intervention should involve professionals (N=5). They agreed on the fact that patients should have the option to be monitored and should receive guidance in their process:

*I think a professional should monitor the patient. If you think 'Hey, someone skips a step here', or 'I see how he makes his questions, it is not that good', I think you should intervene. That you can monitor it in one way or another (M, 40, F, OT),*

*That [involvement] will have my preference. Because then you can still guide the client a bit. Because you often see overestimation and underestimation in this target group and you see an overload of the informal caregiver. I would use a professional for that. . . . that they are monitored (J, 37, F, PT),*

and *"I think that it is good to involve professionals with that [the eHealth intervention]" (K, 52, F, RP).*

One participant mentioned that there should be really strict guidelines on how to realise this: *"You should make very clear agreements about this. Who is responsible and within what term you can expect an answer? . . . It is not that simple"* (L, 54, M, GP).

Overall, these paragraphs revealed that there were many elements that are desired and should be included in an eHealth intervention. These elements were: tailoring, attention for visible and invisible consequences, energy management, educational efforts, and contact with the health professional. Undesired elements that should be excluded were: giving advice, pushing people, the same intervention for every patient, and denying complaints. Answers regarding the type of technological support were ambivalent. Two participants preferred a mobile phone, two participants thought that the preference is dependent on the patient, and one participant had opinions in favour of and against an app. All participants agreed on the fact that the eHealth intervention should include a professional. The answers of participants in this section did not differ between professions.

### **Ways to offer eHealth care**

Answers about the different ways to offer eHealth care revealed ambivalent opinions.

#### **Stepped-care**

All participants were not enthusiastic and somewhat sceptical about stepped-care: *"You can [provide stepped-care], but how do you determine when to scale up? Is that a patient who has to determine this or is it a scaling up by a therapist? I find that complicated"* (M, 40, F, OT),

*You have to be careful not to give patients the unintentional idea that they cannot be helped. If the first phase does not work well enough, then you go to step 2. The first step has failed, if step 2 and step 3 fails, then people really get a feeling of hopelessness. . . . you do not really want that. I can agree with stepped-care, but not always. I think you also need to take the time between phases to look very closely what is needed and map that out broadly. Then, choose what the next step is (I, 45, F, PSY),*

and *"It [stepped-care] is very difficult for the patients and does not replace regular patient contact"* (J, 37, F, PT).

#### **Blended-care**

The majority of the participants were more in favour of blended-care (N=3):

*I am more a supporter of blended-care. There are always a few aspects in your treatment that you focus on and that you want to check such as 'Is someone not doing that right?' From there, you can always intensify or not (M, 40, F, OT),*

*Blended-care makes me more enthusiastic. . . . The most important thing is that you listen carefully to someone and that is often what is most appreciated. I think it can never just be an online app and it should always be blended with offline real-life contact* (K, 52, F, RP),

and *“That [blended-care] is possible based on a complaint such as fatigue or depression or things like that. I should not be used as a substitute for physical training”* (J, 37, F, PT).

Two participants stated that with this way to offer eHealth , it depends on what works the best for the patient: *“Sometimes it is very nice and helpful and sometimes even better than just face-to-face. But it does not work for some people”* (I, 45, F, PSY), and *“I think this depends on the patient. . . . Everything is possible, everything is good, but it is tailor-made. There is no one-size-fits-all model that works for everyone”* (L, 54, M, GP).

### Patient-centred care

Data regarding patient-centred care in the form of a basic level of knowledge and skills for health professionals revealed ambivalent opinions. Some participants were positive about this form (N=3): *“A good idea. In a general sense, I think that too many stroke survivors are being treated by people with insufficient knowledge. . . . I think it is a very good initiative”* (J, 37, F, PT), *“That is very good. . . . it would be very good if people could fall back on 1 person or 1 institution where they can at least obtain a basic set of knowledge”* (K, 52, F, RP), and

*That is nice of course. . . . So that care is really organized around the patient and close by. That there is a kind of shell of people who can jump in. I think that must be the future for care* (I, 45, F, PSY).

One participant did not see the utility of this form:

*I do not really see much in that myself. . . . I think if you make some kind of basic level, I wonder if you get it well enough at a high level then. That you do not get a poor rehash of what they actually need. I think that is the danger. I think there is already a good system. I would not go back to train all kinds of healthcare professionals* (M, 40, F, OT).

One participant did not think that there was a lack of knowledge, but a lack of co-operation: *“According to me, it is not the case that there is a lack of knowledge or skills, but often the challenge is to bring those people together who can help patients”* (L, 54, M, GP).

Data about ways to implement this basic level of knowledge and skill revealed that their first must be explored what is already available by existing chain-cares and institutions, then local agreements about care must be made, and that through training that basic set can be transferred to health professionals: *“You must have the current offer clear. . . . And you have to train, you just have to train those professionals”* (I, 45, F, PSY), *“First investigate ‘what is already available in training’, what is the content of the training and what is still missing”* (K, 52, F, RP), and *“Above all, you have to make sure that you agree on such things locally. Because you cannot do that nationwide. Because every local situation has different care providers, different expertise”* (L, 54, M, GP).

In sum, these paragraphs showed ambivalent opinions regarding ways to offer eHealth care. Answers regarding stepped-care showed that participants were not enthusiastic about this form. Reasons were that the intervention is too complicated in itself and for the target group. Another reason was that patients can get the

unintentional idea that they cannot be helped. The majority of the participants were in favour of blended-care. The reasons that were mentioned were that an eHealth intervention should not replace physical training or contact but should always be an addition to care. Data regarding patient-centred care showed ambivalent opinions. Some participants found this form a good initiative because of the insufficient knowledge of some professionals regarding this topic. Another participant thought that there already was enough knowledge. One participant thought that there is a lack of co-operation, not a lack of knowledge. Data regarding implementation of this form showed that first must be explored what knowledge is already available, then local agreements should be established, and that through training the basic set can be transferred to health professionals. The answers given in these paragraphs did not differ between professions.

## 4. Discussion

The current study indicates that ABI survivors have to deal with ABI-related difficulties during their recovery process. Health professionals and ABI survivors matched in their answers regarding the mentioned difficulties. The most present difficulties were: physical impairments, memory loss, and fatigue, as well as difficulties regarding access to care and the compassion and recognition from health professionals. Besides difficulties in the recovery process, ABI survivors have to deal with multiple barriers of the current health system. These barriers are: the motoric focus of hospitals, the lack of knowledge about healthcare options, and time. All these difficulties experienced in the recovery process result in that ABI survivors still have many unfulfilled needs. These unfulfilled needs concerned the access to care and the compassion and recognition from health professionals.

This study showed that fatigue has many negative consequences on the lives of ABI survivors. A decrease of social activity, leisure, and physical activity were mentioned by both stakeholders as predominant negative consequences. Fatigue management can be used to deal with fatigue after ABI. The current study revealed that fatigue management materials and uniformity among health professionals in addressing fatigue management is currently not available for ABI survivors. Because of this unavailability, ABI survivors use self-management strategies which they personally perceive as effective to deal with fatigue. However, these efforts are not proven effective. Therefore, ABI survivors still have many support needs regarding fatigue management.

Results of the current study revealed that both stakeholders agreed on the fact that an eHealth intervention for fatigue management after ABI is highly desired and needed in the current health system. However, results also revealed that health professionals thought that eHealth might be too difficult for the patient group. ABI survivors on the other hand, were very positive about an eHealth intervention for fatigue management. Nevertheless, both stakeholder groups stated several desired and undesired eHealth elements. The most important desired eHealth elements that should be included in such an intervention were: a daily activity schedule, tips and tricks, monitoring of fatigue, and professional involvement. The most important undesired eHealth elements mentioned were busy layout and lots of text. These elements should be taken into account when designing the eHealth intervention.

### 4.1 Implications

#### 4.1.1 Current health system and ABI recovery process

Results from this study are in accordance with existing evidence of Odumuyiwa et al. (2019) who indicated that the impact of ABI is often poorly understood or overlooked by professionals and that ABI survivors

have limited access to rehabilitation and support services within the United Kingdom. The current study found that the majority of the ABI survivors also experienced this. Mainly the lack of recognition of the cognitive consequences of ABI were reported as a reason for the limited access to rehabilitation care.

This study revealed the motoric focus of hospitals to be a barrier for the acknowledgement and recognition of the cognitive consequences of ABI. Similarly, Odumuyiwa et al. (2019) revealed that ABI survivors' assessment processes are often focused solely upon physical impairments. Meaning that the cognitive consequences of ABI are ignored while patients in the current study have a great need for education about these cognitive consequences. Moore Sohlberg, McLaughlin, Pavese, Heidrich, & Posner (2000) indicated in their study about attention process training and brain injury education in persons with ABI, that brain injury education was effective in improving self-reports of psychosocial functioning (Moore Sohlberg et al., 2000). Thus, patient education about the cognitive consequences of ABI and fatigue should be provided in the hospitals because this can positively influence the psychosocial functioning of ABI survivors. This can overcome the barrier of the motoric focus in the hospitals.

#### 4.1.2 Fatigue (management)

In line with Cooper et al. (2009), this study confirms that fatigue is one of the most prevalent symptoms reported after an ABI. Despite ambivalent findings in previous studies regarding the experiences of the two dimensions of fatigue, this study found that among the majority of the ABI survivors, mental fatigue was more frequent following an ABI than physical fatigue. This finding is in agreement with conclusions from the study of Visser-Keizer et al. (2015) and contradicts the conclusions from the study of Christensen et al. (2018) by finding that mental fatigue was more frequent in the current study in comparison with physical fatigue. All the negative consequences of fatigue on the lives of ABI survivors mentioned in the studies of Andersen et al. (2011); Eilertsen et al. (2012), and Ziino & Ponsford (2006) were confirmed in this study, with the decrease in social engagement, leisure, and physical activity as the predominant negative consequences.

Findings of the current study are in accordance with Cooper et al. (2009) who indicated that there is little evidence regarding the effectiveness of fatigue management interventions after ABI. Odumuyiwa et al. (2019) concluded that there is a need for specialist, tailored and interdisciplinary care provided by trained professionals with ABI experience. The current study supports that finding due to the limited effectiveness of fatigue interventions for ABI survivors. Similar results in the UK and NL might point to the fact that the lack of effective fatigue management interventions for ABI is a prevalent problem among countries.

#### *Importance of different interventions types for fatigue*

##### *Emotion processing*

This study showed that some health professionals pay attention to emotion processing of fatigue but that there is not always enough room to address this and it remains quite difficult for the patients. Milders, Fuchs, & Crawford (2003) indicated in their study that participants with brain injury related impairment of emotional processing had fewer social interactions and an increase in unusual and inappropriate behaviours. These impairments do not improve over time without an intervention (Ietswaart, Milders, Crawford, Currie, & Scott, 2008). Therefore, Radice-Neumann et al. (2009) indicated that skills related to emotion processing need to be addressed in persons with brain injury. This indicates that emotion processing is indeed important and health

professionals should pay attention and support patients with emotion processing of fatigue, even if processing emotions remains difficult for the patient due to symptoms of emotional dysregulation.

### Self-management and educational approaches

Results of the current study do not fully fit with the conclusions from Ezekiel et al. (2020) in which it is stated that educational and self-management approaches are recommended for fatigue management after ABI. Although the majority of the health professionals in the current study found educational approaches very important, they also stated that educational approaches are not a fatigue management strategy in itself. Health professionals also stated that educational approaches should always be tailored to the participant and that the effectiveness of this approach differs between participants. A minority of the ABI survivors stated that they indeed had a desire for more educational approaches.

This study showed ambivalent results regarding self-management approaches. Although some health professionals were very positive about self-management approaches, there were also some health professionals who stated that self-management is too difficult for the target group due to cognitive impairments. All ABI survivors on the other hand, used self-management strategies to deal with their fatigue and perceived these strategies as helpful. In sum, educational and self-management approaches are important to include while these approaches might not be effective for all ABI survivors. Aspects that might be too difficult for ABI survivors are information processing and self-regulation, which are needed for these two approaches.

### The COGRAT

Health professionals mentioned that the COGRAT (Zedlitz et al., 2012) intervention is not suitable for every patient in rehabilitation care. Results showed that the COGRAT is too difficult for patients with moderate to severe cognitive impairments and that it is not available outside the rehabilitation care. Zedlitz et al., (2020) only established the effects of COGRAT in the clinical rehabilitation setting, the effects of this intervention in the home-based setting are not established nor investigated. Since ABI survivors at home have mostly mild cognitive impairments, it might be true that this intervention is effective for this target group. On the other hand, the COGRAT is a complex intervention performed by a professional and might not be suitable for the home-based recovery due to the level of difficulty. Therefore, additions of the COGRAT should be made regarding the availability in the healthcare systems, substantive programme changes, offering other programme options, as well as investigating the effectiveness and possibilities of the COGRAT intervention in the home-based setting.

The current study revealed perspectives regarding the module 'Don't run, but plan' (Baars-Elsinga, Visser-Meily, Geusgens, & van Heugten, 2014). This module is derived from the COGRAT and aims to improve fatigue management for ABI survivors outside rehabilitation care. Patient perspectives showed that this module is still too difficult and not tailored to possible information processing deficits. Therefore, this intervention is also not suitable for all ABI survivors. In sum, the current study reveals that there is a lack of effective evidence based fatigue management materials and tools for ABI survivors who are not eligible for rehabilitation care. This study also reveals that this lack is present among ABI survivors in rehabilitation care. Thus, the lack of effective fatigue management materials and tools is a severe problem in the current health system for all ABI survivors.

### 4.1.3 eHealth requirements

#### Desired eHealth elements

Results from the current study showed several desired eHealth elements. These elements were: a daily activity planner, tips and tricks for fatigue management, contact with a health professional, and attention to physical activity. Furthermore, involvement of loved ones, recognising and acknowledging personal limits, help with other topics, and iterative monitoring and feedback were also desired. Moreover, tailoring, paying attention to visible and invisible consequences of fatigue, energy management, and educational efforts should also be included. Results from the study of Davoody et al. (2016) about needs of post-discharge stroke patients to patient-centred eHealth services in Sweden revealed similar needs. Several elements mentioned in the study of Davoody et al., (2016) match with the current study. The elements that matched were: a need for measurement and documentation of health related parameters, an overview of goals and planned activities, tracking the rehabilitation process, and reminders. Also, understanding the illness, practical guidance through healthcare and community services, and a holistic view of the care process were also elements that match with the current study. These findings might imply that the specific needs regarding eHealth elements correspond among ABI survivors in different countries.

Cooper et al. (2009) indicated in their study about the effect of a weekly fatigue education group, that there was a significant change in the quality of life measure from pre-intervention to post-intervention. In written qualitative accounts, the participants reported managing their fatigue better (Cooper et al., 2009). Thus, the need for educational efforts in the current study is also a fatigue management element that is proven to be effective in the study of Cooper et al. (2009). However, Cooper et al. (2009) did not use this education in an eHealth intervention. Mackert, Love, & Whitten (2008) investigated two e-health interventions to provide health education on mobile devices: one providing diabetes information and one offering childcare information. The diabetes website was effective in providing education to study participants (Mackert et al., 2008). Thus, including patient education in an eHealth intervention for fatigue management might be of added value.

#### Undesired eHealth elements

The current study revealed that busy layout, lots of texts, much advice, pushing people, the same intervention for every patient, and denying complaints should be excluded from the eHealth intervention. Reasons for these undesired elements may be because of the cognitive deficits ABI survivors experience. Cognitive deficits are common following ABI in that it interferes with rehabilitation efforts (Eslinger 2005). Deficits in visual information processing, speed of information processing and memory deficits may be present and can cause problems in attention, memory, learning ability, thinking, creativity, and other aspects of cognition and motor function (Groffman, 2011). Therefore, the undesired eHealth elements should be taken into account when designing an eHealth intervention for this target group.

#### Type of technological support

This study showed that because of the easy accessibility, ABI survivors would like an application which can be accessed by mobile phone. Interventions on computers or laptops may be too difficult for this target group since the screen is too big and information is unclear presented. Kassberg, Malinowsky, Jacobsson, & Lund (2013) found in their study that the ability to manage everyday technology is related to the global severity of disability

after ABI. The term everyday technology (ET) includes a variety of technological, electrical and mechanical artefacts ranging from well-known artefacts, such as telephone services and internet based services (Nygård & Starkhammar, 2007). Kassberg et al., (2013) found in their study that participants in the groups ‘severe disability’ and ‘moderate disability’ had a significantly lower ability to manage everyday technology compared to those in the group ‘good recovery’. Thus, it is possible that an eHealth intervention will not be effective for ABI survivors who cannot manage the everyday technology.

### Frequency of use and professional involvement

Results showed that the intervention should be used daily by ABI survivors to create a habit. The intervention should be used in the morning to help prevent fatigue as much as possible. Health professionals unanimously agreed that the eHealth intervention should involve a professional to monitor and guide the patient. Van Zelst et al. (2021) stated in their study that an eHealth platform can be used by patients themselves on an individual basis or in a blended-care setting. Using an eHealth platform in a blended-care setting means an online collaboration between the patient and healthcare professional (van Zelst et al., 2021). Thus, health professionals state with their desire for professional involvement also their desire for a blended-care eHealth offer. Van Zelst et al. (2021) revealed in their study about the impact of involvement of a healthcare professional on the usage of an eHealth platform for COPD, that COPD patients used the platform more frequently in a blended-care setting compared to patients who used the eHealth platform independently. This study also states that blended-care seems essential for adherence in COPD. Implying that involving health professionals in the fatigue management intervention may also enhance adherence.

### Ways to offer eHealth care

#### Stepped-care

Results of the current study revealed that ABI survivors would like a stepped-care offer because every person needs different intensities of fatigue management. Health professionals on the other hand, are sceptical about this form because it is too complicated and too difficult for the target group. While previous research from Espie (2009) stated that stepped-care models have been proven to be useful for a wide range of disorders such as depression and chronic illnesses, the current study demonstrates that stepped-care might not be the solution for this target group. Mainly because stepped-care is too complicated due to ABI survivors’ cognitive impairments. Baker, Rose, Ryan, & Worrall (2020) stated in their research that specialist training, communication tools, leadership, and specialized staff are facilitators for implementing stepped-care (Baker et al., 2020). These facilitating factors should be considered in practise to increase the feasibility of the stepped-care offer.

#### Blended-care

The current study revealed that ABI survivors are not optimistic about the blended-care offer because this might be too complicated and too unclear for the target group due to the variety of online and offline care. Health professionals on the other hand, are more in favour of blended-care but the preferences of the patient determine the effectiveness of this form. Health professionals also stated that blended-care should be an addition and not a replacement of care. The study of Wentzel et al. (2016) showed similar results. They indicate that in order to benefit from blended-care, face-to-face and online care should be combined in such a way that the potentials of both treatment styles are used optimally, depending on patient abilities, needs, and preferences. However, blended-care is not suitable for every patient since people need to have access to certain practical resources (Wentzel et al.,

2016). These resources include internet access, having experience with computers and the internet, and sufficient eHealth literacy (Wentzel et al., 2016). Thus, the study of Wentzel et al. (2016) is in line with the results of the current study. Indicating that blended-care is not suitable for every ABI survivor. Especially not for those ABI survivors with moderate to severe cognitive impairments and a disability to manage everyday technology.

### *Patient-centred care*

The current study revealed that ABI survivors are positive about patient-centred care because with this form, many survivors could benefit. Health professionals were ambivalent because the effectiveness of this care offer is depended on the personal preferences of the individual and not one single offer is suitable for every ABI survivor. The study from Davoody et al. (2016) shows that as patients' understanding of their illness changes over time, their need for more flexible support throughout the care and rehabilitation processes increases. Oudshoorn, Frielink, Nijs, & Embregts (2020) stated that there should be a match between the functions and features of the technology and the needs and preferences of the service user. When there is a match, the service user will be more inclined to use and benefit from the eHealth application (Oudshoorn et al., 2020). Yardley et al. (2016) stated that the effective use of eHealth is strongly influenced by a person-based approach in which eHealth is tailored to users' abilities, needs and level of language understanding. Meaning that while health professionals in the current study are ambivalent about patient-centred care, there are several studies that indicate that patient-centred care can be the most effective manner for an eHealth intervention.

### *Profession*

Results showed that health professionals differed in answers regarding the current healthcare options for ABI survivors and fatigue after ABI due to profession. Health professionals who actively help patients with managing fatigue after ABI in their profession (e.g., occupational therapist and psychologist) could mention more negative aspects of the current healthcare options for fatigue and more effective self-management strategies. Health professionals who actively use certain intervention types in practise could mention more critical aspects about the different intervention types. Nevertheless, the majority of the participants still indicated that there are enough health professionals with sufficient knowledge of ABI. Indicating that effective fatigue management after ABI can be provided by different professions and is not dependent on a certain profession.

The current study also made clear that some health professionals think that a basic level of knowledge and skills for fatigue management is highly needed and can be an added value in current practise. Others do not see the utility of this. When realising this basic level of knowledge and skills in practise, it may be the case that only those health professionals participate who are intrinsically motivated and convinced that this basic level is needed. Consequently, there will remain a group of health professionals who will not be trained in this basic level for fatigue management. Thus, not all ABI survivors will have an equal chance to benefit from this basic level.

The most surprising finding of this study is that an emphasis on negative aspects of current practises was given while equal attention was given to negative and positive aspects in the interview structure. Hence, there are many improvements possible in practise regarding healthcare options for fatigue management after ABI. In the current study, the ABI survivors and the health professionals are located in different regions in the Netherlands. Meaning that ABI survivors were treated in different institutions and hospitals and health professionals are also working in different institutions and hospitals. Therefore, the results of this study are not attributable to the

performances and healthcare offers of one specific hospital/institution or one specific region. Implicating that a negative emphasis on the current health system for ABI and for fatigue management for ABI is present across different regions in the Netherlands.

## 4.2 Strengths and limitations

The current study has several strengths. First of all, this study adds new knowledge about the current practise of fatigue management after ABI for the group of survivors that have not received clinical rehabilitation. Second of all, because participants were located in different regions across the Netherlands and were treated or active in different hospitals and institutions, this study provides a broad picture of the current situation regarding healthcare options and fatigue management for ABI survivors in the Netherlands. Moreover, this study included both the perspectives of health professionals and ABI survivors with both TBI and CVA which also enhances a more complete picture of the current situation and the needs of these two groups for a future eHealth intervention. Finally, the current study states specific recommendations for an eHealth intervention for fatigue management which can be adopted to practise.

This study also has some limitations. A first limitation is the generalizability of the findings. This study has a small overrepresentation of females in both participant groups. While Jones et al. (2011) revealed that TBI is the most prevalent form of ABI, this study has a small overrepresentation of CVA participants. Therefore, TBI survivors may be under-represented in this study. In the current study, only two of eight participants regained employment. Thus, the generalizability may not be affected that much in the current study since Lannoo et al. (2004) revealed that one in five people with ABI regain employment. Also, this study has a small sample size which means that there might be shortcomings regarding the saturation of the data analysis. By investigating participants from different regions and different institutions and hospitals across the Netherlands, this limitation is somewhat reduced.

A second limitation is that the reliability of this study is impacted by the fact that all interviews were hold and all data is transcribed and coded by one researcher. Meaning that there is no formal intercoder reliability agreement in this study. By discussing the coding process, different versions of the coding schemes, and results with the supervisors, the reliability is secured to its best potential.

A third limitation is that all ABI survivors were recruited from patient organisations. The results cannot tell something about opinions from ABI survivors who do not associate with a patient organisation. Also, it might be true that only the ABI survivors with very mild cognitive impairments associate with a patient organisation. This can all influence the results in such a way that the sample of ABI survivors of this study can be biased. Prummer et al. (2019) investigated the influence of a selection bias on the patient-focused organisation the Acoustic Neuroma Association (ANA). Results indicated that the ANA cohort has Quality of Life (QOL) scores that are clinically, perceptually worse for the domains hearing, balance, energy, anxiety, and total QOL compared to the non-ANA group. The population profile of ANA participants likely differs significantly from the greater population of patients with vestibular schwannoma (VS) (Prummer et al., 2019). Because in the current study, health professionals and ABI survivors agreed on opinions regarding the current healthcare system and fatigue, it may be the case that the results are less affected by the selection of patients.

A fourth limitation is that it might be the case that health professionals did not spoke about ABI survivors who are not eligible for clinical rehabilitation. Since health professionals spoke from their experiences, it might be true that they did spoke from their experiences with ABI survivors with moderate to severe cognitive impairments who they might see in their practice. This can jeopardize the external validity of the study. By investigating the perspectives of both ABI survivors and health professional this limitation is reduced to its best potential but caution must be applied when looking at the generalizability of the results.

A final limitation is that this study was performed during the Covid-19 pandemic. All interviews were hold online. It might be that due to disruptions of the internet, not all relevant information has been collected. Negative consequences of fatigue, such as the decrease of physical activity, could also be reinforced by the limitations of this COVID-19 pandemic. However, results showed that ABI survivors matched in their answers regarding their difficulties, support needs and eHealth preferences. Thus, this limitation might not be that much of an influence on the results of the current study.

### 4.3 Recommendations

Based on the results of this study, some recommendations for the future are formulated. First of all, further research is needed to determine effective fatigue management training materials for the group of ABI survivors who are not eligible for clinical rehabilitation. Based on the results of this further research, uniformity in fatigue management after ABI among health professionals should be established. Further research should also take into account the perspectives of ABI survivors who are not associated with patient organisations to prevent a selection bias. Further research should also take into account the differences of CVA and TBI. The current study revealed that less is known and less is available for the group of TBI survivors than for the CVA group. Since TBI is even less recognised than CVA, more efforts are needed for this specific target group.

Second of all, attention should be paid to an earlier focus on cognitive consequences by giving information to all ABI survivors. This can be achieved by including patient education in the eHealth intervention using information systems (IS) technologies. Information systems help to improve health outcomes and has been used to offer educational content to patients (Mackert et al., 2008). The study of Mackert et al., (2008) revealed that providing health information in an eHealth intervention using information systems technologies were effective on the diabetes website. By using these technologies in practise, patients become aware of what to expect during their recovery process. Patient education that is included in the eHealth intervention may avoid lots of confusion by the ABI survivors in the home-based and clinical rehabilitation setting.

Third of all, more attention should be raised to the importance of recognition and compassion of fatigue after ABI to health professionals in the Netherlands. Fernando & Consedine (2014) indicated in their study that compassion is a central and necessary aspect in the effective delivery of medical care. Compassion is a professional requirement for physicians, is desired by patients, and appears to benefit patient and clinical outcomes (Fernando & Consedine, 2014). Currently, ABI survivors need to deal with the negative effects from the lack of compassion and recognition which also enhances fatigue. This problem should be reduced by raising awareness of the importance of recognition and compassion by health professionals in the Netherlands.

Finally, the results from this study should be shared with practise so that the specific eHealth recommendations can be adopted and implemented to develop an eHealth intervention for fatigue management

after ABI. In sum, an eHealth intervention which can be accessed by mobile phone should be developed. The intervention should include the different substantive desired and undesired elements mentioned in the current study. Health professionals should be actively involved, most preferable in a blended-care setting, to monitor, give feedback, and answer questions of ABI survivors. All information needs to be presented in a simplistic and visual manner. Furthermore, the intervention must be designed in a manner that daily use is possible to create a habit. Most importantly, the eHealth intervention should be available for patients who are not eligible for the clinical rehabilitation setting. By sharing these recommendations, this study can contribute to an added value in the current healthcare options regarding fatigue management after ABI.

#### 4.4 Conclusion

The aim of the current study was to investigate the perspectives from ABI survivors and health professionals about an eHealth intervention for fatigue management after ABI. Based on a qualitative analysis, results indicate that an eHealth intervention is desirable and much needed to add new healthcare options to the current health system. The current study contributed to help with understanding the perspectives of ABI survivors and health professionals about an eHealth intervention for fatigue management after ABI. ABI survivors are very positive regarding an eHealth intervention for fatigue management while health professionals question whether eHealth is too difficult for the target group. This research clearly illustrates that an overall negative emphasis was given on the current health system for ABI survivors in general and healthcare options for fatigue management. This study also addressed a knowledge gap of effective fatigue management strategies and materials targeted for ABI survivors. Especially for the group of ABI survivors with milder fatigue complaints who are not eligible for clinical treatment. The current study confirms the existing literature that little is known about effective eHealth fatigue management interventions for ABI survivors while fatigue is a persistent problem. Thus, many benefits regarding eHealth and fatigue management for ABI survivors can still be achieved in this field.

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# Appendix 1: Informed Consent

UNIVERSITEIT TWENTE.  
FACULTY OF BEHAVIOURAL, MANAGEMENT AND SOCIAL SCIENCES

Informatieblad & Toestemmingsformulier Onderzoek

## Informatieblad voor onderzoek 'Fatigue- management post ABI'

### **Doel van het onderzoek**

Dit onderzoek wordt geleid door Eline te Braake ten behoeve van de Master Health Psychology & Technology. Het doel van dit onderzoek is om perspectieven en meningen in kaart te brengen omtrent een stepped-care eHealth interventie voor fatigue-management die ingezet kan worden na het Niet-Aangeboren Hersenletsel (NAH). Deze interventie is gericht op de groep NAH getroffen en die niet in aanmerking komen voor een klinische revalidatie. Door zowel NAH getroffen als Health professionals te bevragen biedt dit onderzoek een breed perspectief. Dit onderzoek leidt tot specifieke aanbevelingen voor een interventie die gedeeld kunnen worden in de praktijk. De onderzoeksgegevens zullen worden verwerkt in een rapport.

### **Hoe gaan we te werk?**

U neemt deel aan een onderzoek waarbij we informatie zullen vergaren door U te interviewen en uw antwoorden te noteren/op te nemen via een audio-opname/video- opname. Er zal ook een transcript worden uitgewerkt van het interview.

### **Potentiële risico's en ongemakken**

Tijdens uw deelname aan deze studie kunnen u vragen worden gesteld die u als (zeer) persoonlijk kunt ervaren, vanwege de gevoelige aard van het onderwerp. Wij stellen deze vragen enkel en alleen in het belang van het onderzoek. U hoeft echter geen vragen te beantwoorden die u niet wilt beantwoorden. Uw deelname is vrijwillig en u kunt uw deelname op elk gewenst moment stoppen.

### **Vergoeding**

U ontvangt voor deelname aan dit onderzoek geen vergoeding.

### **Vertrouwelijkheid van gegevens**

Wij doen er alles aan uw privacy zo goed mogelijk te beschermen. Er wordt op geen enkele wijze vertrouwelijke informatie of persoonsgegevens van of over u naar buiten gebracht, waardoor iemand u zal kunnen herkennen.

Voordat onze onderzoeksgegevens naar buiten gebracht worden, worden uw gegevens zoveel mogelijk geanonimiseerd, tenzij u in ons toestemmingsformulier expliciet toestemming heeft gegeven voor het vermelden van uw naam, bijvoorbeeld bij een quote.

In een publicatie zullen anonieme gegevens of pseudoniemen worden gebruikt. De audio-opnamen, formulieren en andere documenten die in het kader van deze studie worden gemaakt of verzameld, worden opgeslagen op een beveiligde locatie bij de Universiteit Twente en op de beveiligde (versleutelde) gegevensdragers van de onderzoekers.

De onderzoeksgegevens worden bewaard voor een periode van 5 jaar. Uiterlijk na het verstrijken van deze termijn zullen de gegevens worden verwijderd of worden geanonimiseerd zodat ze niet meer te herleiden zijn tot een persoon.

De onderzoeksgegevens worden indien nodig (bijvoorbeeld voor een controle op wetenschappelijke integriteit) en alleen in anonieme vorm ter beschikking gesteld aan personen buiten de onderzoeksgroep.

Tot slot is dit onderzoek beoordeeld en goedgekeurd door de ethische commissie van de faculteit BMS.

### **Vrijwilligheid**

Deelname aan dit onderzoek is geheel vrijwillig. U kunt als deelnemer uw medewerking aan het onderzoek te allen tijde stoppen, of weigeren dat uw gegevens voor het onderzoek mogen worden gebruikt, zonder opgaaf van redenen. Het stopzetten van deelname heeft geen nadelige gevolgen voor u of de eventueel reeds ontvangen vergoeding.

Als u tijdens het onderzoek besluit om uw medewerking te staken, zullen de gegevens die u

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reeds hebt verstrekt tot het moment van intrekking van de toestemming in het onderzoek gebruikt worden.

Wilt u stoppen met het onderzoek, of heeft u vragen en/of klachten? Neem dan contact op met de onderzoeksleider.

Contactgegevens: Eline te Braake: [E.tebraake@student.utwente.nl](mailto:E.tebraake@student.utwente.nl)

Voor bezwaren met betrekking tot de opzet en of uitvoering van het onderzoek kunt u zich ook wenden tot de Secretaris van de Ethische Commissie van de faculteit Behavioural, Management and Social Sciences op de Universiteit Twente via [ethicscommittee-bms@utwente.nl](mailto:ethicscommittee-bms@utwente.nl). Dit onderzoek wordt uitgevoerd vanuit de Universiteit Twente, faculteit Behavioural, Management and Social Sciences. Indien u specifieke vragen hebt over de omgang met persoonsgegevens kun u deze ook richten aan de Functionaris Gegevensbescherming van de UT door een mail te sturen naar [dpo@utwente.nl](mailto:dpo@utwente.nl).

Tot slot heeft u het recht een verzoek tot inzage, wijziging, verwijdering of aanpassing van uw gegevens te doen bij de Onderzoeksleider.

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#### Door dit toestemmingsformulier te ondertekenen erken ik het volgende:

1. Ik ben voldoende geïnformeerd over het onderzoek door middel van een separaat informatieblad. Ik heb het informatieblad gelezen en heb daarna de mogelijkheid gehad vragen te kunnen stellen. Deze vragen zijn voldoende beantwoord.
2. Ik neem vrijwillig deel aan dit onderzoek. Er is geen expliciete of impliciete dwang voor mij om aan dit onderzoek deel te nemen. Het is mij duidelijk dat ik deelname aan het onderzoek op elk moment, zonder opgaaf van reden, kan beëindigen. Ik hoef een vraag niet te beantwoorden als ik dat niet wil.

Naast het bovenstaande is het hieronder mogelijk voor verschillende onderdelen van het onderzoek specifiek toestemming te geven. U kunt er per onderdeel voor kiezen wel of geen toestemming te geven. Indien u voor alles toestemming wil geven, is dat mogelijk via de aanvinkbox onderaan de stellingen.

	JA	NEE
3. Ik geef toestemming om de gegevens die gedurende het onderzoek bij mij worden verzameld te verwerken zoals is opgenomen in het bijgevoegde informatieblad. Deze toestemming ziet dus ook op het verwerken van gegevens betreffende mijn gezondheid en overtuigingen.	<input type="checkbox"/>	<input type="checkbox"/>
4. Ik geef toestemming om tijdens het interview opnames (geluid / beeld) te maken en mijn antwoorden uit te werken in een transcript.	<input type="checkbox"/>	<input type="checkbox"/>
5. Ik geef toestemming om mijn antwoorden te gebruiken voor quotes in de onderzoekspublicaties.	<input type="checkbox"/>	<input type="checkbox"/>
6. Ik geef toestemming om mijn echte naam te vermelden bij de hierboven bedoelde quotes.	<input type="checkbox"/>	<input type="checkbox"/>
7. Ik geef toestemming om de bij mij verzamelde onderzoeksdata te bewaren en te gebruiken voor toekomstig onderzoek en voor onderwijsdoeleinden.	<input type="checkbox"/>	<input type="checkbox"/>
Ik geef toestemming voor alles dat hierboven beschreven staat.	<input type="checkbox"/>	

Naam Deelnemer:

Naam Onderzoeker: Eline te Braake

Handtekening:

Handtekening:



Datum:

Datum:

## Appendix 2: Interview guide

### Part 1. ABI survivors

**Introduction:** The goal of this study is to investigate the opinions and perspectives about a stepped-care eHealth intervention for fatigue- management post Acquired Brain Injury (ABI). This study is targeted at the group of ABI survivors who did not undergo any kind of clinical rehabilitation. Because this study investigates both ABI survivors and Health Professionals, this study offers a broad perspective. The outcome of this study are specific recommendations for a fatigue-management intervention that can be shared with the practise. The interview will take about 60 minutes. The answers you give are confidential and will be processed anonymously. The answers you give will not be personal identifiable in the study. The data will not be accessed by third parties. Your participation is voluntary: therefore, you can withdraw at any time without any reason.

#### Demographics

Age	
Gender	
Type of ABI	
Years with diagnosis	
Work (full time, part time, no work due to..)	
Living situation (single, with partner, with family, other..)	

Although this study focusses on fatigue management, I would first like to ask you some general questions about the recovery process after your ABI.	
1. Can you tell something about your recovery process from the moment of discharge of the hospital? 2. In general, how much impact has ABI on your life?	
Previous studies showed that the impact of ABI on patients is often poorly understood or overlooked by professionals. The impact of ABI being overlooked leads to limited access to the rehabilitation and support services.	
2. How did you experience the access of recovery services after you ABI?	
3. How did you experience the behaviour of professionals regarding the impact of your ABI?	<i>For example:</i> - Did you felt poorly understood or overlooked?
4. Did you experience any long-term health problems of whom you were not informed? If so, which?	<i>For example:</i> - This might be physical, psychological and or social  <i>Additional question:</i> How did these problems affect your daily life?
Previous studies found that the large majority of ABI survivors remains at home without professional assistance.	
5. Did you receive any form of professional assistance in general after your discharge of the hospital? If so, which?	<i>Additional questions:</i> - In general, what did you need mostly during that time? - In general, did you have had any unfulfilled needs during your recovery process?
As you know, this study focusses on fatigue after ABI.	
6. Are u familiar with the symptoms of fatigue after your ABI?	<i>Additional questions</i> - How do these symptoms of fatigue feel for you? - What does this mean?

Fatigue after ABI can be separated in two dimensions ‘Mental fatigue’ and ‘Physical fatigue’. Mental fatigue is characterised by limited energy reserves to accomplish ordinary daily activities that requires alertness and retrieval of information stored in memory. Physical fatigue on the other hand, is characterised by a reduction in capacity to perform physical work as a function of prior physical effort. It is known that fatigue after ABI is different than fatigue that is experienced by people without ABI.

7. How did you experience your fatigue after the ABI?	<p><i>For example:</i></p> <ul style="list-style-type: none"> <li>- Did you experience more mental or physical fatigue?</li> <li>- Was the experience with fatigue after your ABI different then before your ABI? If so, what was different?</li> </ul>
8. Did you experience any differences in your emotions due to fatigue?	<p><i>For example:</i></p> <ul style="list-style-type: none"> <li>- Did you experience frustration or gloom?</li> <li>- When did you feel these emotions?</li> <li>- What did you do when you felt this way?</li> <li>- How did your environment (spouses/friends/family) react on these differences?</li> </ul>
9. Did you experience any negative consequences of fatigue during your daily life?	<p><i>Did you for example:</i></p> <ul style="list-style-type: none"> <li>- Increased your sedentary and home based activities?</li> <li>- Reduced your social activities?</li> <li>- Reduced your physical activities?</li> </ul>
10. Did you felt supported by your family/friends/health professionals when you were fatigued?	<p><i>Additional questions:</i></p> <ul style="list-style-type: none"> <li>- Did they understand your behaviour when fatigued?</li> <li>- What did you wish to see different?</li> </ul>
11. How did you cope with fatigue during your recovery process?	<p><i>For example:</i></p> <ul style="list-style-type: none"> <li>- Did you learn some coping skills? If so, which?</li> <li>- Did you try relaxation techniques?</li> <li>- Did you receive any education on fatigue?</li> <li>- Did you use some app that might have helped you in some way?</li> </ul> <p><i>Additional question:</i> If you used an app to cope with fatigue, which app was used and what did this app focused on?</p>
12. What have you learned from your fatigue?	
13. Did you received any professional help and support specific for fatigue-management?	<p><i>Additional question:</i></p> <ul style="list-style-type: none"> <li>- If so, what kind of help in fatigue management did you receive?</li> </ul>
14. What did you miss during your recovery process regarding fatigue management?	<p><i>Additional questions:</i></p> <ul style="list-style-type: none"> <li>- What where your needs?</li> <li>- What would you have liked to have assistance with?</li> <li>- What would you absolutely have not liked to have assistance with?</li> </ul>
15. What does fatigue management mean to you?	<p><i>Additional question:</i></p> <ul style="list-style-type: none"> <li>- How would you picture the ideal situation regarding help with fatigue management?</li> </ul>
<p>In the next section of this interview, I would like to ask you some questions about your preferences of an eHealth intervention for fatigue management. eHealth is the usage of information- and communication technology to support or improve the health of patients or the healthcare in general. Some examples of eHealth are telemonitoring or a watch that tracks your heart rate and health related functions (Fitbit). eHealth can for example also be an intervention in form of an application which you can access via your mobile phone.</p>	
16. Do you have experiences with eHealth technology in general?	<p><i>Additional question:</i> If so, what are these experiences?</p>
17. Did you received any form of eHealth during or after your ABI?	<p><i>Additional questions:</i></p>

	<ul style="list-style-type: none"> <li>- If so, what did you receive?</li> <li>- What were the positive sides of this experience?</li> <li>- What were the negative sides of this experience?</li> </ul>
18. What kind of technological support would you prefer?	<p><i>For example:</i></p> <ul style="list-style-type: none"> <li>- Do you like an app that you can access via your mobile phone?</li> <li>- Do you like to have a module that you need to do on your computer or laptop</li> </ul>
19. What would you expect from an (eHealth) intervention?	
20. Would you like an eHealth intervention that you can use for multiple problems, such as fatigue and social reintegration or do you prefer different interventions that addresses 1 problem at the time? and why?	
21. What needs to be present in an (eHealth) intervention for you so that you will actually use the eHealth intervention?	
<p>During the following questions, I would like you to give an answer regarding your preferences for a future eHealth intervention specific for fatigue-management after an ABI.</p>	
22. When are you most likely to use an eHealth intervention about fatigue management?	<p><i>Additional questions</i></p> <ul style="list-style-type: none"> <li>- What do you definitely need in an intervention for fatigue management?</li> <li>- What do you wish to see in an eHealth intervention that you can use when you are fatigued?</li> </ul>
23. When are you most likely to <b>not</b> use an eHealth intervention fatigue management?	<p><i>Additional questions</i></p> <ul style="list-style-type: none"> <li>- Why is that?</li> </ul>
<p>We already talked about when you are most likely to use and to not use an eHealth intervention. Now, I want to know what you think if we apply this for specific aspects of fatigue management.</p>	
24. What are the most important aspects for you that need to be present in an eHealth intervention for fatigue management?	<p><i>For Example:</i></p> <ul style="list-style-type: none"> <li>- Planning of daily activities based on energy reserves</li> <li>- Knowing your limits</li> </ul>
25. What are the most important aspects for you that absolutely <b>do not</b> need to be present in an eHealth intervention for fatigue management?	
26. How much time do you prefer to spend for an intervention (Weekly, daily, monthly)?	
<p>The last two questions are regarding the form of care that will be provided to the ABI survivor. There are different forms of how you can provide care to a patient. For example, you can make an app that will be the same for all patients, but there are also other options. Another option can be to provide a stepped-care intervention. This means that low intensity treatments are provided to most of the patients while they are closely monitored so that those who are not benefitting are quickly upgraded to higher intensity treatments.</p>	
27. What do you think of such a stepped-care intervention?	<p><i>Additional questions:</i></p> <ul style="list-style-type: none"> <li>- Why do you think that?</li> <li>- Is stepped-care something that should be included in a fatigue- management intervention? Why?</li> <li>- Would you participate in a stepped-care intervention?</li> </ul>
<p>Besides stepped-care, there is also a form called blended-care. Blended-care means that there is a variety of online and offline care and contact moments. For example, a patient can have once each month a face-to-face contact moment with a specialized nurse and at the same time, they can follow an online intervention each week where they learn to manage their fatigue.</p>	
28. What do you think of blended-care?	<p><i>Additional questions:</i></p> <ul style="list-style-type: none"> <li>- Why do you think this?</li> <li>- Would this be something that works for you? Why?</li> </ul>

29. Do you currently have a health professional you prefer to speak with?	<i>Additional questions:</i> - If so, can you come here for all your questions?
30. What do you think of the idea that you can go to your preferred health professional who can answer your questions regarding managing fatigue after ABI?	<i>Additional questions:</i> - Why do you think that? - Is this something that would positively influence you during your fatigue management process? and why?
31. We talked a lot about your ABI, about coping with fatigue and the options related to eHealth. Do you have aspects you want to share with me about these topics that has not come to the fore until now?	

This were all the questions that I wanted to ask. As said before, the data of the interviews will be processed anonymously and will not be traceable to a single participant of this study. I would like to thank you for your participation. *Do you have any questions left at this point?* If any questions or comments come to mind later on, feel free to contact me via my email [e.tebraake@student.utwente.nl](mailto:e.tebraake@student.utwente.nl)

## Part 2. Health professionals

**Introduction:** The goal of this study is to investigate the opinions and perspectives about a stepped-care eHealth intervention for fatigue- management post Acquired Brain Injury (ABI). This study is targeted at the group of ABI survivors who did not undergo any kind of clinical rehabilitation. Because this study investigates both ABI survivors and Health Professionals, this study offers a broad perspective. The outcome of this study are specific recommendations for a fatigue-management intervention that can be shared with the practise. The interview will take about 60 minutes. The answers you give are confidential and will be processed anonymously. The answers you give will not be personal identifiable in the study. The data will not be accessed by third parties. Your participation is voluntary: therefore, you can withdraw at any time without any reason.

### Demographics

Age	
Gender	
Profession	
Years of working experience	

Although this study focusses on fatigue management, I would first like you to ask some general questions about the current health system for people with ABI.	
1. How do you experience the understanding of professionals in practise regarding the impact of ABI?	
Often, only patients with severe symptoms are eligible for rehabilitation and support services. Meaning that a large group with mild symptoms experiences limited access to the rehabilitation and support services.	
2. How do you experience the access to rehabilitation and support services for patients with ABI in practise?	<i>Additional questions (if poor efforts are mentioned)</i> - What does this mean for the ABI patient? - Are there any long-term physical consequences that you notice in practise because of this limited access? - Are there any long-term psychological consequences that you notice in practise because of this limited access?
3. Which aspects in general in the current health systems for patients with ABI are going well in practise?	

4. What do you miss in general in the current health system for patients with ABI?	
Some studies indicated that the large majority of ABI survivors remains at home without professional assistance.	
4. Do you feel like this is true when you take your practise into consideration?	Additional questions: - Do you have a view of the ABI survivors who remain at home?
5. If you look at your practise, do you think that the needs of ABI survivors regarding social and professional reintegration are fulfilled?	<i>Additional questions?</i> - Why do you think that? - Which needs are not fulfilled? - Why are these needs not fulfilled?
As you know, this study focusses on fatigue after ABI. It is known that fatigue after ABI is different than fatigue that is experienced by people without ABI.	
6. How often do you see fatigue related problems by patients with ABI in your practise?	<i>Additional questions:</i> - Is every patient with ABI fatigued? - What is the severity for fatigue then?
7. Do you notice any negative consequences of fatigue for patients with ABI?	<i>Additional questions:</i> - If so, which? - Do you notice any positive consequences of fatigue by patients with ABI?
8. Do you notice any changes in the physical and social activities due to fatigue of patients with ABI?	
9. Are you satisfied with the current fatigue management efforts in practise for people with ABI?	<i>Additional questions:</i> - Which aspects regarding fatigue management are going well in practise? - Which aspects regarding fatigue management are not going so well in practise?
10. What do you miss in the current health system for patients whom are experiencing fatigue?	
Until now, we mainly focused on the current health system. Now I want to ask some questions about the psychological process of fatigue management.	
11. Which aspects are important to include when coping with fatigue post ABI?	
12. What do you think will work for managing fatigue post ABI?	
13. What do you think will <b>not</b> work for managing fatigue post ABI?	
14. Are there aspects about fatigue management that are often forgotten in current fatigue management efforts?	<i>Additional questions:</i> - If so, which?
As you might know, limited interventions are available that focus on fatigue management post ABI. There are some interventions available. Fatigue after ABI is often separated in two dimensions: 'Mental fatigue' and 'Physical fatigue'. Mental fatigue is characterised by limited energy reserves to accomplish ordinary daily activities that requires alertness and retrieval of information stored in memory. Physical fatigue on the other hand, is characterised by a reduction in capacity to perform physical work as a function of prior physical effort. Some available interventions focus only on mental fatigue or only on physical fatigue. For example: Mindfulness-based stress reduction (mental) or specific activity schedules (physical).	
15. Do you know any fatigue management interventions specific for ABI survivors?	<i>Additional questions:</i> - Do you notice in this intervention a separation between mental and physical fatigue in practise? - How do you look at separating fatigue in mental and physical fatigue?

	<ul style="list-style-type: none"> <li>- Do you feel like the emotional aspect of fatigue is often forgotten?</li> </ul>
16. What do you think of educational approaches (psycho education) for managing fatigue for ABI survivors?	
17. What do you think of self-management approaches to manage fatigue for ABI survivors?	<p><i>For example:</i></p> <ul style="list-style-type: none"> <li>- Relaxation techniques</li> <li>- Keeping a diary</li> </ul>
<p>Zedlitz, Rietveld, Geurts, &amp; Fasotti (2012) designed a therapy called COGRAT that combines cognitive therapy (CO) with graded activity training (GRAT) and is developed to alleviate fatigue and fatigue related symptoms for patients with chronic stroke. The COGRAT was presented as a 12-week programme and consisted of CO with the emphasis of pacing and relaxation with a group size to a maximum of 4 patients. The GRAT protocol included walking on a treadmill, strength training, and homework assignments.</p>	
18. Are you familiar with this intervention?	<p><i>Additional questions:</i></p> <ul style="list-style-type: none"> <li>- What do you think about the COGRAT intervention?</li> <li>- Does this intervention miss certain aspects?</li> </ul>
19. Currently, the COGRAT intervention is only available at the clinical rehabilitation setting. What do you think of that?	<p><i>Additional questions:</i></p> <ul style="list-style-type: none"> <li>- Do you think this intervention should be available for all ABI survivors?</li> <li>- If so, how do you picture that?</li> </ul>
<p>As you might know there are different ways to provide eHealth care to patients. For example, you can make an app that will be the same for all patients, but there are also other options. Another option can be to provide a stepped-care intervention. This means that low intensity treatments are provided to most of the patients while they are closely monitored so that those who are not benefitting are quickly upgraded to higher intensity treatments. There is also blended-care, this means that there is a variety of online and offline care and contact moments.</p>	
20. What do you think of stepped-care?	
21. Do you have any experiences with stepped-care?	<p><i>Additional question:</i></p> <ul style="list-style-type: none"> <li>- Are these experiences positive or negative?</li> </ul>
22. What do you think of blended-care?	
23. Do you have any experiences with blended-care?	<p><i>Additional question:</i></p> <ul style="list-style-type: none"> <li>- Are these experiences positive or negative?</li> </ul>
24. What would be in your opinion the best solution to support management of fatigue for patients with ABI?	<p><i>Additional questions:</i></p> <ul style="list-style-type: none"> <li>- What do you think is needed in the current health system to achieve that solution?</li> </ul>
<p>A current approach is to organize care around the patient. This is called the patient-centred approach. Currently, patients visit different professionals for different problems and questions. Specific for fatigue management after ABI, it could be very interesting if patients can get help from their own preferred health professional to receive fatigue management efforts. To achieve this, a basic level of knowledge and skills about fatigue management should be available for all health professionals to achieve patient-centred care.</p>	
25. What is your opinion about a basic level of knowledge and skills about fatigue management available for all health professionals so that all patients with ABI who experience fatigue can be treated equally?	
26. How do you think we can manage to implement such basic level of knowledge and skills among professionals?	
<p>A way to achieve a basic level of knowledge is to provide training to a few persons of a health profession. In that way, there are some individuals from different disciplines where the ABI survivor can go to with possible questions and where the ABI survivor can receive guidance for the first step in fatigue-management.</p>	
27. What do you think of this idea?	
<p>In the final questions, I would like to ask you some questions about your preferences of an eHealth intervention for fatigue management. eHealth is the usage of information- and communication technology to support or improve the health of patients or the healthcare in general. Some examples of eHealth are telemonitoring or a watch that tracks your heart rate and health. eHealth can for example also be an intervention in form of an application which you can access via your mobile phone.</p>	

28. What sort of eHealth intervention would you prefer for managing fatigue for ABI survivors?	
29. Do you have any practical experience with eHealth?	<i>Additional questions:</i> <ul style="list-style-type: none"> <li>- If so, what were these experiences?</li> <li>- Where these experiences positive or negative?</li> </ul>
30. Would you, as health professional, like to be actively involved in the eHealth intervention?	<i>Additional questions:</i> <ul style="list-style-type: none"> <li>- If so, why would you like to be involved?</li> <li>- If so, how would you like to be involved?</li> <li>- Do you think a health professional should be involved in the eHealth intervention?</li> </ul>
31. If you look at your experiences in practise, what should be included in the eHealth intervention?	
32. If you look at your experiences in practise, what should <b>not</b> be included in the eHealth intervention?	
33. We talked a lot about care for patients with ABI, about coping with fatigue and the options to support patients related to eHealth and basic fatigue knowledge and skills. Do you have aspects you want to share with me about these topics that has not come to the fore until now?	

This were all the questions that I wanted to ask. As said before, the data of the interviews will be processed anonymously and will not be traceable to a single participant of this study. I would like to thank you for your participation. *Do you have any questions left at this point?* If any questions or comments come to mind later on, feel free to contact me via my email [e.tebraake@student.utwente.nl](mailto:e.tebraake@student.utwente.nl)

## Appendix 3: Coding scheme

### Part 1. ABI survivors

<i>Codes: ABI recovery process</i>	<i>Subcodes</i>	<i>Definition</i>
ABI related difficulties	Physical level	Experiences of ABI related difficulties on the physical level.
	Cognitive level	Experiences of ABI related difficulties on the cognitive level.
	Emotional level	Experiences of ABI related difficulties on the emotional level.
	Behavioural level	Experiences of ABI related difficulties on the behavioural level.
	Access to care	Experiences of ABI related difficulties due to access to care.
	Compassion and recognition	Experiences of ABI related difficulties due to the lack of compassion and recognition of health professionals.
	Other	Experiences of other ABI related difficulties
Unfulfilled needs	Educational approaches	Unfulfilled needs of the ABI survivor during their recovery process regarding educational approaches.
	Coping strategies	Unfulfilled needs of the ABI survivor during their recovery process regarding coping strategies.
	Access to care	Unfulfilled needs of the ABI survivor during their recovery process regarding access to care.
	Compassion and recognition	Unfulfilled needs of the ABI survivor during their recovery process regarding compassion and recognition of health professionals.
	Other	Other unfulfilled needs of the ABI survivors
Positives experiences	Access to care	Positive experiences regarding the access to care.
	Compassion and recognition	Positive experiences regarding the compassion and recognition from health professionals.
	Other	Other positive experiences during the recovery process.
<i>Codes: Fatigue (management)</i>	<i>Subcodes</i>	<i>Definition</i>
Central fatigue experiences	Mental fatigue	Experiences regarding mental fatigue.
	Physical fatigue	Experiences regarding physical fatigue.
	(No) separation	Experiences of (no) separation between the dimension of fatigue.
Consequences of fatigue	Physical activity	Consequences in physical activity due to fatigue.
	Social engagement & Leisure	Consequences in social engagement and leisure due to fatigue.
	Emotion processing	Consequences in emotion processing due to fatigue.
	Work reduction	Reduction of work due to fatigue.
	Invisibility of fatigue	Consequences due to the invisibility of fatigue.
	Other	Other consequences due to fatigue.
Self-management efforts	Educational approaches	Experiences with educational approaches as used self-management effort for fatigue.
	Relaxing activities	Experiences in relaxing activities as used self-management effort for fatigue.
	Emotion processing	Experiences in emotion processing as used self-management effort for fatigue.
	Physical activity	Experiences in physical activity as used self-management effort for fatigue.

	Coping and acceptance	Experiences in coping and acceptance as used self-management effort for fatigue.
	Other	Experiences in other activities used as self-management effort for fatigue.
Professional fatigue management support	Positive experiences	Positive experiences in professional fatigue management support.
	Negative experiences	Negative experiences in professional fatigue management support.
Social support	Positive experiences	Positive experiences in social support from informal networks for fatigue.
	Difficult experiences	Difficult experiences in social support from informal networks for fatigue.
Support needs	Professional involvement	Professional involvement as desired situation for fatigue management after ABI.
	Educational approaches	Educational approaches as desired situation for fatigue management after ABI.
	Other	Other desired situations for fatigue management after ABI.
<b><i>Codes: eHealth preferences</i></b>	<b><i>Subcodes</i></b>	<b><i>Definition</i></b>
eHealth experiences	Positive experiences	Positive experiences with eHealth.
	Negative experiences	Negative experiences with eHealth.
eHealth requirements	Desired eHealth elements	Desired aspects for fatigue management that should be included in an eHealth intervention.
	Undesired eHealth elements	Undesired aspects for fatigue management that should be excluded in an eHealth intervention.
	Time of usage	Opinions regarding the time to use the eHealth intervention.
	Frequency of use	Opinions regarding the frequency to use the eHealth intervention.
	Type of technological support	Opinions regarding the type of technological support of the eHealth intervention.
	Number of topics	Opinions regarding the number of topics that should be included in an eHealth intervention.
Ways to offer eHealth care	Stepped-care	Opinions about stepped-care eHealth care offer.
	Blended-care	Opinions about blended-care eHealth care offer.
	Patient-centred care	Opinions about patient-centred care eHealth care offer.

## Part 2. Health professionals

<b><i>Codes: Current Health System for ABI</i></b>	<b><i>Subcodes:</i></b>	<b><i>Definition:</i></b>
Barriers for ABI care	Time	Barriers related to time.
	Access to care	Barriers related to the (limited) access to rehabilitation care for ABI survivors.
	Follow-up	Barriers related to (the lack of) a follow up programme or services after the (clinical) rehabilitation.

	Compassion	Barriers related to (the lack of) compassion regarding the impact of ABI on the patients.
	Unfulfilled needs	Barriers related to unfulfilled needs of the ABI survivors.
	Motoric focus	Barriers due to the focus on the motoric health in hospitals.
	Knowledge	Barriers due to the lack of knowledge of health professionals regarding finding the connection with the right healthcare professional, the referral of the patient or familiarity with the current care possibilities.
	Other	Other barriers without specific category mentioned by health professionals.
Facilitating factors for ABI care	-	Facilitating factors for ABI survivors in the current health system.
<b>Codes: Fatigue (management)</b>	<b>Subcodes</b>	<b>Definition</b>
Central fatigue	Prevalence	Prevalence of fatigue related problems in practise.
	Mental fatigue	Experiences with mental fatigue in practise.
	Physical fatigue	Experiences with physical fatigue in practise.
	(No) separation	Opinions about separating mental and physical fatigue.
Consequences of fatigue	Social engagement & leisure	Experienced barriers in social engagement and/ or leisure due to fatigue by ABI survivors.
	Physical activity	Experienced barriers in physical activity due to fatigue by ABI survivors.
	Work reduction	Experienced reduction of work due to fatigue by ABI survivors.
	Emotion processing & self-regulation	Experience barriers in emotion processing due to fatigue by ABI survivors.
Healthcare options for fatigue	Facilitation options	Current facilitating healthcare options for fatigue after ABI.
	Hindering options	Current hindering healthcare options for fatigue after ABI.
Effectiveness of self-management strategies	Facilitating strategies	Opinions about facilitating self- management strategies for fatigue after ABI.
	Hindering strategies	Opinions about hindering self-management strategies for fatigue after ABI.
Fatigue management interventions	Emotion processing	Opinions about attention to the emotional aspect of fatigue.
	Educational approaches	Opinions about psycho-education as intervention for people with ABI.
	Self-management	Opinions about self-management intervention for people with ABI.
	COGRAT	Opinions about the COGRAT intervention for people with ABI.
<b>Codes: eHealth for ABI survivors</b>	<b>Subcodes</b>	<b>Definition</b>
eHealth experiences	Positive experiences	Positive experiences regarding eHealth.
	Negative Experiences	Negative experiences regarding eHealth.
Ways to offer eHealth care	Stepped-care	Opinions about stepped-care eHealth care offer for people with ABI.
	Blended-care	Opinions about blended-care eHealth care offer for people with ABI.
	Patient-centred care	Opinions about patient-centred care eHealth care offer for people with ABI.
eHealth requirements	Desired eHealth elements	Desired aspects for fatigue management that should be included in an eHealth intervention for people with ABI.

	Undesired eHealth elements	Undesired aspects for fatigue management that should be excluded in an eHealth intervention for people with ABI.
	Professional involvement	Opinions about professional involvement with the fatigue-management eHealth intervention.
	Type of technological support	Opinions about type of technological support for the fatigue-management eHealth intervention for people with ABI.