

# **Development of an ecological momentary assessment of fatigue after ABI using sequential exploratory design**

Thesis submitted in part fulfilment of the requirements of the award of Doctor of  
Philosophy

Faculty of Health and Life Sciences

Oxford Brookes University

Leisle Ezekiel

2020

## Abstract

**Background.** It is estimated that between 21 -77% people with acquired brain injury (ABI) experience problematic and persistent fatigue. Many struggle to resume their previous levels of activity and participation. Yet the relationship between fatigue and participation is unclear. Current approaches to assessing the impact of fatigue on participation fail to capture the variability of fatigue experiences or to evaluate the efficacy of fatigue interventions.

**Aim:** to develop and evaluate a smartphone ecological momentary assessment (smart EMA) of the impact of fatigue on participation in the context of daily situational factors.

**Methods.** A user-centred design approach guided the development of the smart EMA app and was underpinned by the biopsychosocial approach to disability. The concepts underpinning the app were generated through a systematic review of participation after stroke and narrative reviews of participation after ABI, together with a qualitative descriptive study of fatigue experiences after ABI. Interviews were conducted with people with ABI and the transcripts were analysed using the Frameworks method. Initial prototypes of the smart EMA were developed collaboratively with app developers, and people with ABI. The EMA consisted of self-reports of activity, energy and a psychomotor vigilance test. The app was evaluated using an iterative user-centred approach with Occupational Therapists and people with ABI, through talk aloud interviews, field testing, qualitative interviews and the system usability scale.

## Results

The systematic review of 82 studies investigating participation outcomes after stroke revealed multiple associations between biopsychosocial factors and participation but fatigue was infrequently investigated. The narrative reviews revealed conflicting evidence of the interplay between fatigue and participation and the need for ecological momentary assessments (EMA) of fatigue was established. 16 people with ABI were recruited to the qualitative study. Four themes were derived through analysis of qualitative interviews: experiencing fatigue in the context of everyday activities, struggling to make sense of fatigue, coping with fatigue, adjusting social participation in the context of fatigue. A model was developed proposing that the impact of fatigue on participation is mediated by coping strategies. The app was positively rated by 7 study participants with ABI, with a mean S.U.S. score of 86. 233 EMA surveys were completed during field testing. Key usability problems were related to the method of alerting participants to complete a survey. Visual inspection of the EMA data suggested within-person variation in temporal patterns of energy, fatigue, and activity, as well as individual differences in fatigue-activity interactions. A short PVT was found to be feasible as an objective indicator of fatigue.

**Conclusions:** these studies suggest coping and self-efficacy as intervention targets for mitigating the impact of fatigue on daily life. A smart EMA app to monitor fatigue and activity in ABI survivors is feasible, acceptable to users, and provides data about fatigue variability in the context of daily activities and environments. As such, the app has potential to ground the choice of self-management strategies in empirical evidence.

## Acknowledgments

Firstly, I would like to thank my supervisors Johnny Collett, Helen Dawes and Mary Boulton for their guidance, support, and enthusiasm throughout the last six years. Their consistent belief in me and their optimism about the research projects in this thesis was both energising and validating. I feel very fortunate to have such a generous and experienced supervisory team.

I am also immensely grateful for the ongoing support and camaraderie of the other PhD students at MORES and from my colleagues in the Occupational Therapy programme. Having the moral support and help of so many people through this process has made completing the thesis possible.

I would like to thank Jose Vegas Dominguez Veigas for his generosity with his time and expertise on writing the app code and his patience with me as a non-technical person. He helped to make this thesis possible.

I would also like to thank the brain injury support groups and ABI survivors who made these studies possible. I found the validation I received from ABI survivors, therapists, and carers about the importance of this project both reassuring and motivating.

Finally, I would like to thank my husband Eylan, and my daughters Esther and Zoe, for their patience, support, and sacrifice over the last few years and particularly over the last 6 months. They helped me keep perspective and gave me a reason to switch off. I hope they are as proud of me as I am of them.

## Declarations

I declare that unless otherwise stated, all work presented in this thesis is my own.

## Submitted abstracts

### *Publications*

**Factors Associated With Participation in Life Situations for Adults With Stroke: A Systematic Review.** Ezekiel, L., Collett, J., Mayo, N.E., Pang, L., Fields, L., Dawes, H. Archives Physical Medicine & Rehabilitation (2019), 100 (5):945-955. doi: 10.1016/j.apmr.2018.06.017. Epub 2018 Jul 5.

Objectives: To identify biopsychosocial factors associated with participation outcomes for adults with stroke and to investigate factors associated with participation at different time points poststroke.

Data sources: Medline, CINAHL, AMED, PsycINFO, and Web of Science were systematically searched using keywords stroke, participation, and outcomes and their synonyms on May 15, 2017.

Study selection: Observational studies reporting on biopsychosocial factors and participation outcomes for community-dwelling adults with stroke were selected. Studies were eligible for inclusion if participation outcomes were measured using indices that mapped to the participation domain of the International Classification of Functioning, Disability and Health (ICF). Intervention studies were excluded. A second reviewer checked all studies against eligibility criteria at each stage.

Data extraction: Data were extracted on any statistically determined association between biopsychosocial factors and participation outcomes.

Data synthesis: The proportion of studies reporting significant associations with variables was classified according to the ICF. The exact binomial test was used to determine the probability that the proportion of studies reporting significant associations was due to chance alone. Qualitative descriptive summaries of each study allowed consideration of interactions between variables and changes in participation over time points.

Conclusions: Although depressive symptoms, cognitive functioning, and mobility were found to have the strongest associations with participation, we found that other frequently occurring factors (such as fatigue and environmental factors) were less extensively considered. The diversity of outcome measures encountered within the review highlight the need for a consensus on a core set of outcome measures to evaluate long-term participation in life situations poststroke.

### **Experiences of fatigue in daily life of people with acquired brain injury: a qualitative study.**

Ezekiel, L., Fields, L., Collett, J., Dawes, H., Boulton, M. Disability and Rehabilitation (2020), pp. 1-9. doi: 10.1080/09638288.2020.1720318.

Purpose: To develop an in-depth understanding of how survivors of acquired brain injury (ABI) experience fatigue and how fatigue affects everyday life.

Materials and methods: We conducted semi-structured in-depth interviews with 16 adults with ABI fatigue, recruited from support groups in the south east UK. Interviews were analysed using the frameworks method.

Results: We developed four themes: experiencing fatigue in the context of everyday activities, struggling to make sense of fatigue, coping with fatigue, and adjusting social participation in the context of fatigue. Fatigue was comprised of mental, physical, generalised, and motivational fatigue. Balancing fatigue against participation in daily activities was influenced by coping strategies and

social support. Opportunities to socialize or participate in meaningful activities provided incentives for participants to push through their fatigue.

Conclusions: This study highlights complex interactions that potentially mitigate the impact of fatigue on everyday life. Educational and self-management approaches to fatigue need to account for different types of fatigue in the contexts of an individual's daily activity. Assessment of fatigue should capture in-the-moment experiences of different types of fatigue and activity. Social support and participation in meaningful activities may help individuals to break the negative cycle of fatigue and inactivity.

Implications for rehabilitation: assessment of fatigue after brain injury should capture the multidimensional nature of fatigue as well as contextual information about exacerbating activities and environments. Development of personalised coping strategies that account for perceived triggers of different subtypes of fatigue may help ABI survivors to broaden their activity and social participation. Social support and opportunities to participate in personally meaningful activities may help prevent or break a negative cycle of fatigue and inactivity for some ABI survivors.

Keywords: Brain injuries; coping; fatigue; self-management; social participation.

### *Presentations*

#### **Factors Associated with Participation in Life Situations for Adults With Stroke: A Systematic Review.**

**Oral presentation:** Royal College of Occupational Therapists national conference, Birmingham, June 2017.

**Ezekiel, L., Collett, J., Mayo, N.E., Pang, L., Fields, L., Dawes, H.**

## Abbreviations

ABI	Acquired brain injury
apps	applications
EMA	Ecological momentary assessment
EMI	Ecological momentary intervention.
FSS	Fatigue severity scale
FAI	Frenchay Activities Index
ICF	International classification of functioning, health, and disability.
mHealth	Mobile health
PVT	Psychomotor vigilance test.
SUS	System Usability Scale
TBI	Traumatic brain injury
UCD	User centred design

## Contents

Abstract .....	2
Acknowledgments.....	3
Declarations .....	4
Submitted abstracts .....	5
Abbreviations.....	7
List of Tables .....	10
List of Figures .....	11
Chapter 1: Introduction .....	12
1.1 Participation after acquired brain injury .....	12
1.2. Conceptualisation of participation within the ICF. ....	14
1.3 Fatigue after ABI. ....	17
1.4 Rationale for focusing on acquired brain injury. ....	22
1.5 Aims of the thesis.....	24
1.6. Structure of the thesis.....	26
Chapter 2: Factors associated with participation in life situations for adults with stroke: a systematic review .....	29
2.1 Chapter summary.....	29
2.2. Introduction .....	30
2.3 Methods.....	32
2.4. Results.....	35
2.5. Discussion .....	47
2. 6. Conclusion.....	53
Chapter 3 Narrative review of fatigue post acquired brain injury.....	55
3.1. Summary .....	55
3.2. Participation after acquired brain injury .....	55
3.4. Fatigue and participation after ABI .....	57
3.5. Defining and measuring fatigue after acquired brain injury.....	59
3.6. Factors associated with fatigue after ABI .....	67
3.7. Conclusion.....	68
Chapter 4: Experiences of fatigue in daily life of people with acquired brain injury; a qualitative study .....	69
4.1. Chapter summary.....	69
4.2. Research aims .....	70
4.3. Methods.....	70



4.4. Results.....	77
4.4.1. Characteristics of participants.....	77
4.5. Discussion .....	85
4.6. Conclusions and implications for further research and practice .....	91
Chapter 5. Smart ecological momentary assessment and user-centred design.....	93
5.1. Chapter summary.....	93
5.2. Introduction. ....	93
5.3. EMA and smart EMA .....	93
5.3. Approaches to the design of smart EMAs .....	105
5.5. The rationale for user-centred design in the development of smart EMA of fatigue.....	112
5.6. Conclusion.....	113
Chapter 6: Implementation of user-centred design in developing a prototype smart ecological momentary assessment of fatigue and activity .....	114
6.1. Summary .....	114
6.2. Implementation of user-centred design phase one: concept generation. ....	114
6.3. The rationale for EMA components .....	120
6.4. Content and testing of the first smart EMA working prototype (phase two).....	128
6.5. Conclusion.....	131
Chapter 7: Phase Three: A user-centred usability evaluation of the smart EMA application of fatigue and activity .....	133
7.1. Summary .....	133
7.2. Introduction .....	133
7.3. Methods.....	135
7.4. Results from stage one.....	142
7.5. Discussion of results from stage one.....	144
7.6. Results of stage two .....	147
7.7. Discussion .....	165
7.8. Conclusions .....	176
Chapter 8: General discussion and conclusions .....	178
8.1. Summary .....	178
8.2. Discussion of novel findings .....	180
8.3. Key Limitations.....	193
8.4. Future directions and recommendations .....	195
References. ....	197

## List of Tables

- 2.1. Outcomes measures mapped to Activity Participation domain of ICF.
- 2.2. Results of exact binomial test.
- 2.3 Biopsychosocial factors associated with participation outcomes at different time points in longitudinal studies.
- 3.1. Types of fatigue
- 4.1. Example of the charting stage of Frameworks method: excerpt of charted data within the ‘Contexts of fatigue experiences’ matrix.
- 4.2. Example of interpretation stage of Frameworks method: higher order abstraction of data analysis.
- 4.3. Demographic information of participants.
- 5.1 Summary of published EMA studies conducted in the ABI population.
- 5.2 Types of EMA sampling.
- 5.3. Phases of iterative user centred design process in mHealth.
- 6.1. ABI users’ needs for consideration in the development of the smart EMA.
- 7.0. Occupational Therapists participation in study.
- 7.1. Activity choices presented by smart EMA and codes for analysis.
- 7.2. ABI survivor’s demographic data.
- 7.3. Completion rates of EMA for each participant.
- 7.4. Participant 7 reported activities and NRS energy scores.
- 7.5. Participant 12 reported activities and NRS energy scores.
- 7.6. Sample of activity transition and AX3 data from participant 6.
- 7.7. Agreement between activity transitions detected by the phone sensors and physical activity recorded by AX3.
- 7.8 Complete record of activity transitions for participant 9.

7.9. Summary of sampled noise for each participant.

## List of Figures

1.1 Logic model of thesis. Adapted from O’Cathain et al (2019).

1.2 User centred design integrated into intervention development.

2.1. PRISMA flow diagram

2.2. Percentage of studies with the risk of bias for each domain.

4.1. Summary of participants' scores on domains of EQ-5D-5L.

5.1: Model of usability dimensions.

6.1 UCD approach applied to the development of a smart EMA of fatigue and activity after ABI.

6.2. A model explaining relationships between fatigue and participation.

6.3: User involvement in the development of the numeric rating scale for energy.

6.4: User involvement in the development of the activity question.

6.5. First prototype of app March 2018.

7.1.1. Flow of participant involvement in part 1 of the study.

7.1.2. Paper prototype of app screens.

7.1.3. Screenshots of app following changes made from feedback.

7.1.4. Summary of ratings for questions on the system usability scale.

7.1.5. Frequency of reporting different types of activity for participant 7.

7.1.6. Frequency of reporting different types of activity for participant 9.

7.1.7. NRS energy scores and mean reciprocal reaction times recorded at EMA for participant 7.

7.1.8. NRS energy scores and mean reciprocal reaction times recorded at EMA for participant 12.

7.1.9 Scatter plot of the number of lapses and NRS energy scores.

7.2. Scatter plot of mean reciprocal reaction times and NRS energy scores.

7.2.1. Box plot of reciprocal reaction times.

7.2.2. Box plot of the number of lapses on PVT.

## Chapter 1: Introduction

### 1.1 Participation after acquired brain injury

Acquired brain injury (ABI) is an umbrella term for non-progressive brain injuries, the most common cause being a vascular or traumatic event (Jolliffe *et al.*, 2018). ABI is a major cause of disability both in the UK and worldwide (Menon and Byrant, 2019). In 2017 in the UK alone, 348,453 people were admitted to hospital following an ABI, equivalent to 533 people per 100,000 of the population (Headway, 2019a).

The consequences of ABI are complex and may include impaired physical, cognitive, and emotional functioning. The exact constellation of impairments differs from one individual to the next but in the longer term, ABI often affects participation in daily life (Larsson *et al.* , 2013; Palstam, 2019; Wise *et al.*, 2010; Ponsford *et al.*, 2014).

Within this thesis, participation is defined (as by the ICF) as “involvement in a life situation” and is broadly conceptualised as involvement in activities or situations that fulfil social roles, as reflected by the domestic, interpersonal relationships, major life areas, community and civic life domains within the activity and participation chapter. Additionally, participation is conceptualised as a dynamic construct that includes the dimensions of performance, subjective experience, satisfaction, and choice (Cogan and Carlson, 2018; World Health Organisation, 2002, pp10).

Studies of long -term outcomes after ABI indicate that a significant proportion of survivors experience more restrictions in participation as compared to non-injured peers or in comparison to their pre-injury levels of participation (Goverover *et al.*, 2017; Skolarus *et al.*, 2014). Furthermore, there is also considerable evidence that the type of participation changes following ABI, with a shift away from high demand leisure, work, and social activities to more home-based and sedentary activities (Wise *et al.* , 2010; Wolf *et al.* , 2012; Jourdan *et al.* , 2016; Blomgren *et al.* , 2018).

Individual variation in the trajectory of participation after ABI has also been reported, where participation stays the same or improves for some but deteriorates for others (Jansen *et al.*, 2012). In contrast, Palstam & Sunnerhaden's (2019) study of participation five years post-stroke (n 261) found that over half of the respondents perceived their participation in daily life situations to be good to very good. Similarly, Larsson and colleagues' study of participation four years after TBI found that over 60% described their participation as good (Larsson *et al.*, 2013). However, both studies used the impact of participation on autonomy questionnaire (IPA) to capture self-reported satisfaction with choice and autonomy in five domains of participation (for example, autonomy indoors, social life and relationships) rather than the frequency of participation. Hence the seemingly contradictory findings of these studies may be explained by the concept of response shift, where individuals reappraise their perspective on participation (in this case, autonomy and choice) as part of an adaption process (Schwartz, 2010). Such a shift is well documented in several qualitative studies where ABI survivors change their perspectives on what satisfactory participation entails (Haggstrom and Lund, 2008; Woodman *et al.*, 2014; Schipper *et al.*, 2011).

The mechanisms that shape these differing trajectories of participation after ABI are not well understood (Törnbohm, Lundälv and Sunnerhagen, 2019). Furthermore, these studies exemplify a key challenge to establishing participation outcomes following ABI; what counts as a participation outcome? The subjective, complex, multi-dimensional nature of participation means it is difficult to define and measure (Cicerone, 2013; Cogan and Carlson, 2018; Wade and Halligan, 2017). There is also a myriad of participation measures, often reflecting different operationalisations of participation (Eyssen *et al.*, 2011; Tse *et al.*, 2013). Tse *et al.* mapped the content of five of the most frequently used participation measures (as identified by their systematic literature review) to the domains of the ICF and reported considerable variation in content across the measures. In addition, Tse identified that the reviewed measures focused on different dimensions of participation; for example, subjective perceptions of meaningful and satisfactory participation or more observable dimensions of the diversity, frequency or changes in participation. What defines and determines

satisfactory and sufficient participation varies from one person to the next and is contextualised by their life stage and experiences (Haggstrom and Lund, 2008; Dijkers, 2010). This is evidenced by the association of quality of life with perceptions of (or satisfaction with) participation rather than the actual frequency of participation (McLean *et al* , 2014; Johnston, Goverover and Dijkers, 2005).

## **1.2. Conceptualisation of participation within the ICF.**

The ICF classification of health, functioning and disability offers a partial solution to defining and measuring participation as it classifies a range of activities that contribute to participation. In the ICF participation is a dynamic concept shaped by the individual, their health, and their environmental contexts. It is defined as “participation in life situations”, where life situations are classified using a broad range of daily activities (World Health Organisation, 2002).

The ICF offers only a partial solution to defining participation because the classification does not delineate between activity and participation and does not consider the quality of participation, or the choice and opportunities open to an individual (Bickenbach, 2014). The ICF manual suggests several contradictory approaches to classifying participation; one where all activities contribute to participation and another where only the social and community-based activities contribute.

However, there is evidence to suggest that the activity and participation domains in the ICF overlap and cannot easily be separated. Jette, Tao and Haley (2007) completed an exploratory factor analysis of the ICF domains from the results of a cross-sectional survey of 272 patients from community rehabilitation services., using the Participation Measure for Post Acute Care (AM PAC). The AMPAC consists of 51 items from the nine domains within the activity and participation component of the ICF. Their analysis revealed five subdomains that cut across these 9 domains of activity and participation in the ICF; for example, the factor “mobility” had high loadings with items from both the mobility and the community/social/civic life domains of the ICF. The author's findings did not support their original proposition that activity and participation are separate domains but rather suggested a need to reconceptualise activity and participation within the ICF. However, the findings

of this study have limited generalisability because the use of a convenience sample threatens the external validity of the study. Still, the study echoes the concerns of other researchers as to the ontological coherence of the activity/participation domains within the ICF (Della Mea and Simoncello, 2012).

Others argue that the *purpose* of the activity defines it as an aspect of participation. Levasseur gives an example of how reading a newspaper (usually a solitary activity) supports social participation when it enables conversations and connections with others (Levasseur *et al.*, 2010). Yet capturing outcomes related to whether a person can get themselves dressed or cook a meal is not sufficient to understand the whole impact of brain injury. ABI rehabilitation research historically focused on survival, impairment or physical functioning outcomes (or example independence in self-care or functional mobility) but there is increasing recognition that independence in personal care does not necessarily mean a successful return to work or participation in social and leisure activities (Lees *et al.*, 2012; Johnston and Miklos, 2002; Wolf *et al.*, 2012; Blomgren *et al.*, 2019; Wilde *et al.*, 2012). Participation must be considered as more than independence in self-care and domestic activities. Participation captures an important outcome of rehabilitation after brain injury: the extent to which an individual participates in activities and social roles that are personally meaningful, that promote a sense of belonging and social connection, whilst living with physical, mental, or emotional limitations (Dijkers, 2010; Haggstrom and Lund, 2008; Cogan and Carlson, 2018). Hence the routine measurement of participation outcomes in ABI research and rehabilitation is recommended practice and participation outcomes are included in core sets of outcome measures after stroke and TBI (Salinas *et al.*, 2016; Wilde *et al.*, 2012).

Successful and satisfactory participation is widely viewed as the desired outcome of rehabilitation, particularly for those who experience a life-changing event such as an acquired brain injury (Cicerone, 2004; Engel-Yeger *et al.*, 2018; Goverover *et al.*, 2017). Yet the evidence of the efficacy of interventions for improving global participation outcomes after ABI is currently limited by too few

high quality RCTs, underpowered studies and small sample sizes (Graven, 2011; Brasure *et al.*, 2013; Lee, Heffron and Mirza, 2019). From four systematic reviews of interventions for participation outcomes, the evidence points to exercise or self-management components with the potential to benefit global participation outcomes (Obembe *et al.*, 2016; Graven, 2011; Brasure *et al.*, 2013; Lee, Heffron and Mirza, 2019). Obembe *et al.*'s (2016) meta-analysis of rehabilitation interventions found evidence of short term benefit of exercise (small to medium effect size) on participation outcomes but insufficient evidence to comment on long term benefits. However, Obembe did not define "exercise" in their review and included interventions focused on re-learning movement during self-care tasks, hence inflating the reported effect size. Lee, Heffron and Mirza (2019) suggested interventions promoting self-management may improve participation outcomes after stroke, but the heterogeneity of reviewed studies precluded a meta-analysis. Lee and colleagues reported that domain-specific interventions, such as those targeting leisure increased participation in that specific domain but not participation overall (Lee, Heffron and Mirza, 2019).

Comprehensive multidisciplinary rehabilitation programmes improve participation outcomes for some and may slow deterioration for others (Cicerone, 2013; Shany-Ur *et al.*, 2020) but often considerable time passes between the end of rehabilitation and the point at which participation levels stabilise, making it difficult to assess the contribution of rehabilitation to long term outcomes (Abrahamson, 2019; Pindus *et al.*, 2018). The reported changes to participation (with less social contact and physical activity) following brain injury need to be addressed, particularly as the long term health and well-being of the ABI population is a pressing public health concern (Corrigan *et al.*, 2014; Khan, Brayne and Prina, 2015). It is therefore essential to understand the mechanisms by which ABI affects participation, to provide targets for interventions and optimise participation outcomes.



### 1.3 Fatigue after ABI.

Fatigue after brain injury is often reported to negatively affect ABI survivor's participation in daily life situations. Estimates of the incidence of fatigue after ABI range from 21 -77% with evidence of problematic fatigue lasting more than 6 years post injury (Wylie and Flashman, 2017; Acciarresi, Bogousslavsky and Paciaroni, 2014; Ouellet and Morin, 2006). Qualitative studies of ABI survivors' experiences also suggest that excessive fatigue causes individuals to change their participation in daily activities and social events. For example, fatigue has been identified as a major barrier to engagement in physical activity and returning to employment (Nicholson *et al.*, 2014; White *et al.*, 2012; Andersen *et al.*, 2012; Jackson, Mercer and Singer, 2018). Törnbohm, Lundälv and Sunnerhagen (2019) qualitative study of 11 stroke survivor's participation several years after their stroke found that the study participants changed their daily routine and adapted their social life to help them cope with their fatigue. The study design employed several strategies that increased the trustworthiness of the findings. However, it is questionable whether the study reached data saturation with only 11 participants and a purposive sampling strategy. The participants were reported to be independent, and most had experienced mild stroke, so while it is notable that even those considered to have made a good recovery still experienced difficulties, the study findings do not reflect the experiences of those living with more substantial disability.

More recently, a survey of over 3000 ABI survivors in the UK revealed that 90% of respondents perceived fatigue to negatively affect their social life. 75 % of respondents were more than two years post brain injury (Headway, 2019b). It is unsurprising then that for some, fatigue is reported as the most debilitating aspect of their brain injury (Headway, 2019b). These qualitative findings suggest there is a pressing need to understand the relationship between fatigue and participation, to help inform fatigue interventions and the long term self-management of fatigue.

However, the relationship between fatigue and participation has not been substantiated in several large cohort studies and only one of three systematic reviews of participation after TBI identified

fatigue as a potential determinant of participation outcomes (Reistetter and Abreu, 2005; Son *et al.*, 2007; Sherer *et al.*, 2014). As with participation, fatigue is also a complex phenomenon with numerous definitions and considerable variation in how it is operationalised (to be discussed in chapter 3 ). For example, many fatigue measures are completed retrospectively and provide a summation of fatigue over a set time (Tyson and Brown, 2014). Yet retrospective completion increases the risk of recall bias as respondents focus on their most memorable experiences and this is further complicated by the daily variability of fatigue experiences (Stull *et al.* , 2009; Skogestad *et al.*, 2019). Hence current approaches to fatigue measurement lack sufficient granularity to determine interactions between fatigue and participation or to evaluate the effectiveness of fatigue management interventions (Skogestad *et al.*, 2019; Wylie and Flashman, 2017).

The relationship between fatigue and participation is also complicated by the associations of fatigue with depression, cognitive dysfunction and severity of injury, all of which potentially limit participation (Duncan *et al.*, 2015; Mollayeva, *et al.*, 2014; Ponchel *et al.*, 2015; Feigin *et al.*, 2012). Taken together, these points suggest that the relationship between fatigue and participation is complex, multifactorial and nonlinear. It is therefore unsurprising that the relationship is unsubstantiated by examining associations between fatigue and participation outcome measures.

This thesis will develop and explore a different approach to capturing the impact of fatigue on participation; one that captures fatigue in the context of daily situational factors, allows for the variability of fatigue over time and captures data at the individual level, rather than the group average. Such an approach has the potential for use as an intervention (to increase ABI survivors understanding of their fatigue and contribute to more effective self-management) and this has been taken into account in the development process. However, developing an intervention is beyond the scope of this thesis.

#### *1.4. Examining fatigue and participation through the biopsychosocial model of disability.*

Within this thesis, the biopsychosocial model (as operationalised in the ICF) is used to examine two complex, multifactorial and subjective concepts: participation and fatigue after acquired brain injury. The biopsychosocial model of disability is based on general systems theory and explains illness and disability as arising from multifactorial and non-linear relationships between biological, psychological and social factors (Engel, 1977). Moreover, in general systems theory, small changes in one part of the system may have significant effects on the whole system (Tramonti, Giorgi and Fanali, 2019). Hence, applying general systems theory to participation suggests that participation is potentially modifiable even with the presence of impaired body functions (Whiteneck, 2006). In addition, a biopsychosocial perspective suggests there may be reciprocal relationships between the biological, psychological and social factors affecting health and disability such that fatigue experiences shape participation and participation experiences shape fatigue, albeit in the context of impaired body functions and the psychological and social factors that influence recovery.

However, to date, there has been little research examining fatigue and participation after acquired brain injury using the biopsychosocial model. Ormstad and Eilertsen (2015) proposed a biopsychosocial model of fatigue and depression after stroke by combining literature from biomedical studies and qualitative studies (labelled as psychosocial). Wu et al (2015b) also developed a model of post-stroke fatigue following a review of stroke research. Although the biopsychosocial model was not explicitly named as an underpinning framework, Wu drew biological, psychological, and social factors from the literature to form an explanatory model of fatigue. However, neither of these models consider fatigue in the context of daily activity and participation, nor considers the environment to have a role in how fatigue after ABI manifests and is maintained. Both models offer a limited conceptualisation of social factors. These limitations arise as the models were based solely on previous research findings which are likely to be influenced by a biomedical approach and a reductionist focus on explanatory mechanisms (Tramonti, Giorgi and Fanali, 2019).

#### 1.4.1 Critique of the biomedical and biopsychosocial models

It has now been over 40 years since Engel first argued for the need to extend the biomedical model to account for psychological and social dimensions of health and illness (Engel, 1977). During that period the biopsychosocial model of illness has become one of the dominant models in western health care, particularly as it underpins the ICF (WHO, 2002; Wade and Halligan, 2017). However, whilst proponents of the biopsychosocial model recognise its influence in rehabilitation provision and the management of complex health conditions, they argue that the biomedical model dominates the funding and allocation of westernised healthcare services as these are often organised around diagnoses (Wade and Halligan, 2017).

The biomedical model explains illness as the consequence of disease (i.e.. signs and symptoms of illness arise from a biomedical abnormality) and health as an absence of disease (Engel, 1977).

Criticisms of the biomedical model are that it is reductionist as it assumes illness arises from a single underlying cause; that it perpetuates the dualism of mind and body and offers a mechanistic view of the body that is disease-focused, rather than person-centred (Wade and Halligan, 2017; Wade and Halligan, 2004; Engel, 1977). The focus of the biomedical model is to restore health and reduce impairment through the interventions of various health care professionals. Where there is an ongoing disability, the focus is on the individual learning to manage or adjust to their disability (World Health Organisation, 2002).

There is little doubt the biomedical model of illness led to technological advances that reduced mortality from a wide range of infectious diseases and illness (Stineman and Streim, 2010; Bolton and Gillet, 2019). Advances in the management of acute stroke exemplify this; the development of stroke care pathways and stroke-specific services, along with new diagnostics and treatments, have contributed to improved survival and recovery outcomes for those experiencing stroke (Seminog *et al.*, 2019). But there is a counter-argument that the biomedical model is an inadequate foundation for managing the complexity of long term conditions, where a person's social, psychological,

economic and environmental conditions affect both the presentation and course of their illness (Wade and Halligan, 2004; Longino & Murphy, 2020). In addition, there is now considerable evidence of social and environmental determinants of health and illness outcomes (Bolton and Gillet, 2019; Marmot, 2010; Marmot 2020). Recently this issue has come into sharp relief with the COVID-19 pandemic and the disproportionate rates of death and severe illness within black, Asian and minority ethnic communities (Marmot, 2020).

Whilst Wade & Halligan (2017) propose that the biopsychosocial model promotes holistic, person-centred health care, others are more scathing of the model, suggesting its adoption by healthcare professionals has the potential to harm because professionals resort to psychogenic explanations of disability when there are no clear biological markers (Geraghty and Esmail, 2016). This point was made about the experience of people with chronic fatigue syndrome but is particularly relevant when there is a symptom (such as fatigue) with no easily identifiable cause or mechanism. Ghaemi, in his critique of the biopsychosocial model also suggests that the model lacks scientific rigour, and unhelpfully blurs professional boundaries and responsibilities:

*“if everything causes everything, one cannot fail to be right whilst at the same time nothing formative is really being said”, Ghaemi (2011)pp 4*

However, there is nothing inherent in the biopsychosocial model to suggest equal weight is given to biological, psychological or social factors when explaining illness or disability (Longino & Murphy, 2020). Indeed, the degree to which these factors contribute to disability likely varies from one person to the next. Herein lies a key strength of the model; a biopsychosocial conceptualisation of illness and disability explains different experiences and outcomes in two people with a similar illness or injury (Wade and Halligan, 2017). Using the biopsychosocial model, one can predict that disability occurs in the apparent absence of biological abnormalities or, conversely, that disability may be relatively mild in the presence of extensive biological abnormalities (Wade & Halligan, 2004). Bolton and Gillet (2019) also suggest that the biopsychosocial model is most useful when it is applied to a

specific health condition within a particular stage of illness or recovery, rather than as a general model.

#### **1.4 Rationale for focusing on acquired brain injury.**

This thesis investigates fatigue and participation following acquired brain injury. Initially, the focus was on the stroke population, but then expanded to include the wider population of people with acquired brain injury. This shift arose because of the benefits of greater inclusivity when recruiting participants and the potential of a wider audience for the research findings. However, the shift is justified because the thesis takes a biopsychosocial perspective to examine fatigue and participation in life situations. Whilst the type of brain injury and its immediate biomedical consequences are paramount in the acute intervention phase, arguably it is the impairments arising from brain injury and the conditions of living that mitigate or perpetuate the impact of brain injury on participation.

Furthermore, there is commonality across types of acquired brain injury as all have the potential to cause impairment across many body functions. Similarly, there is variability of impairment within each specific type of brain injury. In addition, epidemiological shifts in both stroke and traumatic brain injury mean that historic age distinctions between these two populations are blurring. The number of people in their 40's and 50s presenting with stroke is increasing whilst there is also an increase in the number of older people presenting with TBI (Lawrence et al., 2016). A large prospective study (n 1571) of consecutive admissions of adults with TBI (as confirmed by CT scan) to a major trauma unit in Oslo found that 67% were over the age of 65 (Skaansar *et al.*, 2020). Hence there is likely to be increasing overlap in the personal, economic, and social factors contributing to disability (particularly those associated with ageing or long term unemployment) and there is considerable overlap between the long term consequences of stroke and traumatic brain injury (as discussed in chapter three).

Finally, fatigue after ABI is thought to be predominantly central fatigue, whether it is caused by stroke or TBI (as discussed in chapter three) and there are commonalities in both the experience and

impact of fatigue across different types of brain injury. Visser Keizer and colleagues developed a scale to capture fatigue, impact and coping of people in the chronic phase of acquired brain injury ( Visser-Keizer *et al.*, 2015). They reported on the fatigue profiles of 134 participants with ABI (stroke, TBI and other brain injuries) and found similar fatigue profiles across types of injury. They found a statistically significant difference between scores on the mental fatigue scale for those with TBI (compared to other types of injury). However, they also found that younger age was associated with higher mental fatigue scores and therefore may have been a confounding factor as those with TBI were younger than those with stroke.

The main limitation of taking a broader, more inclusive focus on ABI is the challenge it poses to searching and reviewing the literature. Published studies tend to be focused on stroke or traumatic brain injury, with few considering ABI as a whole. It becomes unmanageable to search the literature under every type of brain injury and so the literature referenced with this thesis reflects research on ABI, stroke, and traumatic brain injury.

### **1.51 Summary**

For many people, sustaining an acquired brain injury has a substantial effect on their participation. There are many consequences of ABI with the potential to influence participation outcomes. One such consequence is fatigue; ABI survivors report that debilitating fatigue limits their participation in a range of life situations. However, there is little research explaining the mechanisms by which fatigue affects participation. In addition, the evidence base for effective interventions is limited; the pathophysiology of fatigue is still poorly understood and there are multiple explanatory models of fatigue, each suggesting different intervention targets (De Doncker *et al.*, 2017; Wylie and Flashman, 2017). Clinical guidance recommends education and using coping strategies to manage fatigue, yet current approaches to fatigue assessment do not effectively capture people's experiences of fatigue or the daily conditions that exacerbate or alleviate their fatigue. Consequently, an alternative approach to monitoring participation and fatigue over time is necessary to effectively investigate

whether there is a relationship between fatigue and participation (and by extension, daily activities). A greater understanding of how fatigue affects participation after ABI is necessary to inform the development of more effective interventions for managing fatigue and optimising participation.

### 1.5 Aims of the thesis

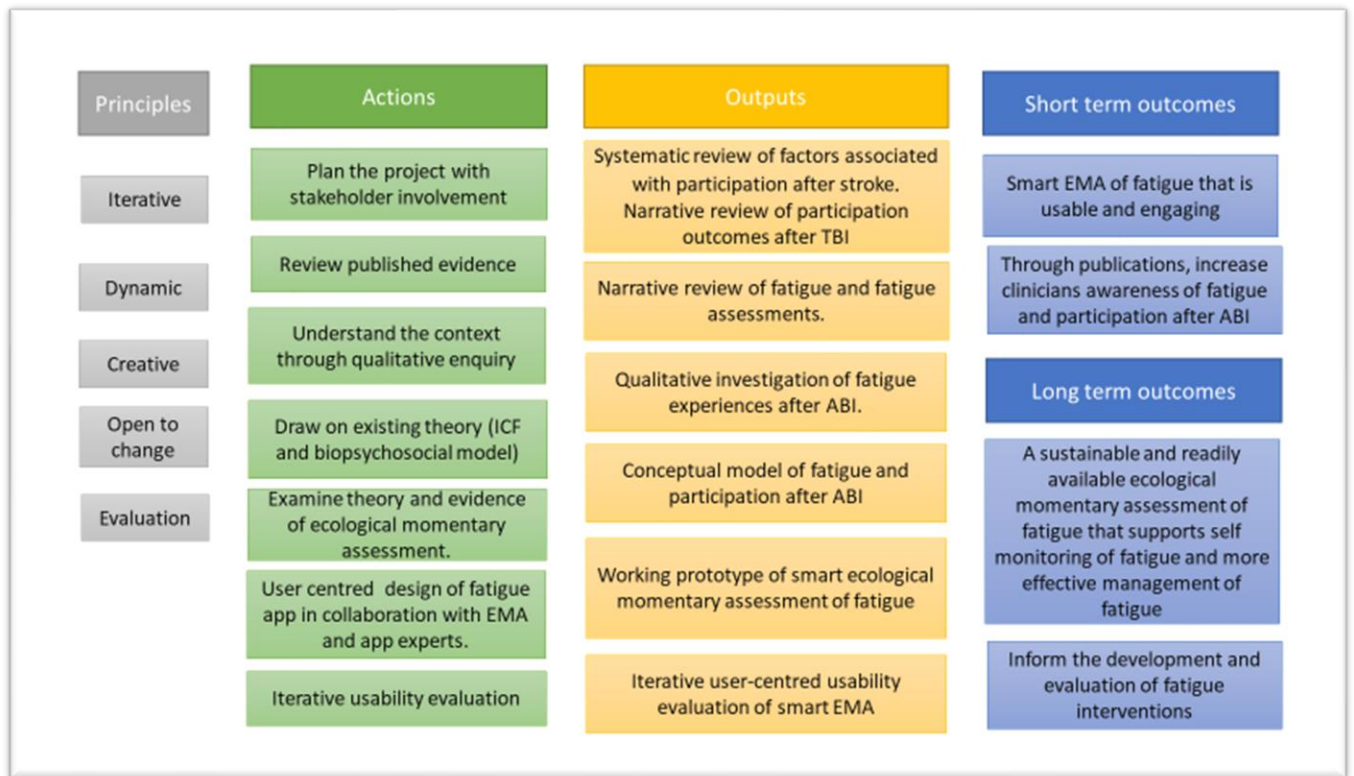
This PhD thesis aimed to develop a novel approach to monitoring fatigue alongside participation in ABI survivors through the application of user-centred design principles. The research objectives were:

1. To review published research literature for the factors affecting participation after ABI, evidence of the relationship between fatigue and participation.
2. To critically review methods of measuring fatigue and participation
3. To develop a conceptual model of the dimensions of fatigue after ABI and the mechanisms by which participation is affected, building on findings from the literature reviews and a qualitative investigation of fatigue
4. To develop an ecological momentary assessment of fatigue using a user-centred design approach
5. To establish the usability of an EMA of fatigue for people with acquired brain injury.

The following logic model describes the flow of the thesis and is presented below. O'Cathain et al's (2019) guide to developing interventions operationalises the Medical Research Councils (MRC) complex intervention framework but stresses that any intervention development must be iterative, dynamic, creative and open to change. It is for these reasons and because of the predominant role of technology in the intervention that the user-centred design (UCD) approach was implemented).



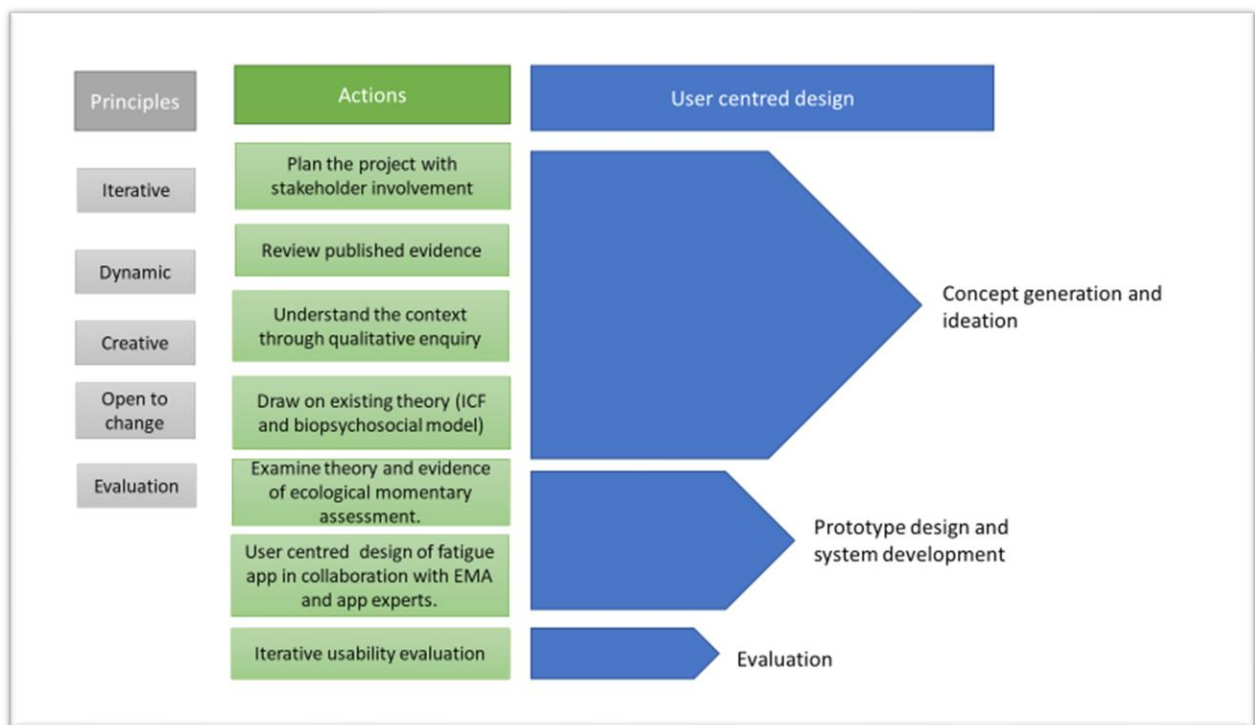
Figure 1.1 logic model of this thesis. Adapted from O’Cathain et al (2019).



UCD is a flexible, iterative, multidisciplinary approach that places information about the specified end-users needs, preferences and goals at the centre of the design process, thereby optimising the match between users’ needs and technology (Gulliksen *et al.*, 2003; Dopp *et al.*, 2019). It is founded on key principles of active user involvement at all stages of the design, and continuous iteration in response to user feedback and testing (Gulliksen *et al.*, 2003). UCD has four key phases: concept generation and ideation, prototype design and system development, evaluation and deployment and suggests a range of different activities within each phase (McCurdie et al 2012). However, the approach is not prescriptive and therefore fosters and supports innovation rather than constraining it. Whilst UCD originates from the field of human computer interaction it is increasingly used in mHealth intervention design and fits well with the MRC’s framework for complex intervention development (Korpershoek *et al.*, 2020; Farao *et al.*, 2020). Yardley et al. (2015b) also incorporate UCD into their person-centred design approach to developing complex interventions and this broader approach was considered as a framework to guide this project. However, the design phase

of the person-centred approach includes developing hypotheses of mechanisms for change, mapping of factors that shape behaviour and behaviour change techniques. As discussed in this introduction and the later chapters, there is currently insufficient evidence of mechanisms of fatigue and participation interactions to evidence hypothesis for change. Hence the need for an EMA of fatigue, and whilst a long term desired outcome of this PhD study is to support self-management of fatigue, the development of the EMA is the main focus of this thesis. Hence, UCD provided a discrete focus for the development of an EMA.

Figure 1.2 User-centred design integrated into intervention development.



### 1.6. Structure of the thesis

In chapter 2, the research literature is systematically reviewed to establish biopsychosocial factors associated with participation after stroke in community-dwelling adults. Participation after stroke was associated with a wide range of biopsychosocial factors and remained limited in the longer term. The review exposes complex interactions between multiple biopsychosocial factors, with depression, cognitive functioning, and mobility emerging as key factors. Associations between

fatigue and participation were statistically significant and moderate but were infrequently investigated. The review highlights the importance of fatigue, but also the need for further research into fatigue and participation after ABI. It also begins to highlight measurement issues currently holding back research in this area.

In Chapter Three, a narrative review of fatigue and participation after ABI synthesises what is currently known about post-ABI fatigue and its effect on an individual's behaviour and participation. The limitations of current approaches to measuring fatigue are discussed, further, particularly concerning how the use of retrospective measures limits understanding of fatigue and participation after ABI. The need for an in-depth exploration of ABI survivors' daily experiences of fatigue is identified and then reported in chapter four. The methods and results of a qualitative investigation of fatigue experiences after ABI are reported. Individual and daily variability in the severity of fatigue experienced was reported along with differential relationships between subtypes of fatigue and activity. Furthermore, individuals reported different coping strategies that appeared to mediate the impact of fatigue on participation. The study argues for the use of in-the-moment assessment of fatigue and activity within the context of daily life. An explanatory model of fatigue and participation after ABI is proposed. After highlighting the potential of using an in-the-moment assessment approach to measure fatigue alongside participation, the following chapters adopt a methodological framework suitable for developing healthcare technology.

Chapter five introduces the principles and practice of ecological momentary assessment (EMA) using a smartphone app. The chapter discusses challenges in EMA design and implementation of EMA in the ABI population and proposes the user-centred design approach to developing a smart EMA of fatigue and activity.

The implementation of an iterative user-centred design approach in the development of the smart EMA's detailed in chapter six and the choice of components included within the EMA is justified.

A user-centred evaluation of the smart EMA usability is reported in chapter seven. Occupational Therapists and ABI survivors participated in an iterative evaluation of their experiences of use. The smart EMA was found to be acceptable to participants with ABI but further development and testing are needed to address the validity of EMA components and to improve completion rates of EMA assessments.

Chapter eight concludes the thesis through a general discussion of the main findings and their implications, along with general limitations and recommendations for the next stages of measurement development and future research.

## Chapter 2: Factors associated with participation in life situations for adults with stroke: a systematic review

### 2.1 Chapter summary

This chapter reports on a systematic review of biopsychosocial factors associated with participation outcomes for adults with stroke and factors associated with participation at different time points post-stroke.

Observational studies reporting on biopsychosocial factors and participation outcomes for community-dwelling adults with stroke were selected. Studies were eligible for inclusion if participation outcomes were measured using indices that mapped to the participation domain of the ICF. Data were extracted on any statistically determined association between biopsychosocial factors and participation outcomes. Analysis of extracted data includes an exact binomial test (to determine the probability that the proportion of studies reporting significant associations was due to chance alone) and qualitative descriptive summaries of each study.

The analysis demonstrated that depressive symptoms, cognitive functioning, and mobility were found to have the strongest associations with participation. The relationship between fatigue and participation was infrequently investigated, despite being a prevalent symptom after stroke. Older age and low social support were also associated with poor participation outcomes. The wide range of factors associated with participation outcomes underscores the need to consider the interdependence of personal, environmental, and stroke-related impairments in shaping participation outcomes.

#### *2.1.1 Published paper relevant to this chapter*

Factors Associated With Participation in Life Situations for Adults With Stroke: A Systematic Review.

Ezekiel, L., Collett, J., Mayo, NE., Pang, L., Fields, L., Dawes, H. Archives Physical Medicine &

Rehabilitation (2019),100 (5):945-955. doi: 10.1016/j.apmr.2018.06.017. Epub 2018 Jul 5.

## 2.2. Introduction

Advances in the prevention and management of stroke mean that more people are surviving and living with the long-term consequences of stroke (Lakshminarayan et al., 2014). Moreover, the number of people experiencing stroke at a younger age is increasing (Bejot et al., 2014) resulting in a considerable lifetime impact of stroke, particularly around social, community, work, and leisure activities (Crichton et al., 2016; Blomgren et al., 2018). However, the extent to which participation is limited after stroke is unclear and study estimates sometimes fail to account for the complexity of participation outcomes. For example, a prospective cohort study (n 237) of younger stroke survivors by Blomgren et al. (2018) investigated stroke outcomes using the FAI at 7 years post-stroke. Just over half of those aged under 65 no longer participated in paid work and one fifth indicated that they do not go on social outings. Notably, 79 % of study participants at 7 years follow up had originally experienced a mild stroke and Blomgren also excluded data from participants who had experienced further strokes over the study period. Hence, the findings from this study indicate that even mild stroke has long term consequences for participation. Yet a longitudinal cohort study by Westerlind et al. investigated 5-year outcomes for stroke survivors of working age (n 174) who were in paid work at the time of their stroke (Westerlind, 2017) They reported that 75% of participants returned to work after the stroke. In the Westerlind study, the participants had experienced mild to moderate stroke, but the study authors used national records to establish return to work rates, rather than self-report. Whilst this approach had its limitations (it did not account for those who were self-employed), it is likely to reflect an underestimation of work status 6 years post-stroke, rather than an over-estimation. Both of these studies are of reasonable quality, with differing strengths and limitations but the Westerlind study demonstrates the necessity of considering participation outcomes in the context of ageing and premorbid circumstances. Therefore, participation outcomes after stroke must be investigated using a biopsychosocial approach.

Nevertheless, whilst the degree to which stroke affects participation is debated, the idea that stroke negatively affects participation is not, and satisfactory participation in daily activities and life roles is

an increasingly important long- term outcome of rehabilitation (Engel-Yeger et al., 2018; Palmstan, Sjodin, and Sunnerhaden, 2018). Furthermore, there is evidence of different trajectories of participation recovery, with participation levels increasing, stabilising, or declining (Singam et al., 2015). Early identification of those most at risk of poor or declining participation outcomes may be beneficial in shaping interventions to optimise participation or to prevent further deterioration.

Many overlapping terms are used to describe social and community participation with participation replacing terms such as integration or reintegration (Levasseur et al., 2010; McLean et al., 2014). The International Classification of Functioning (ICF) provides a taxonomy of activities and participation: where activities reflect performance at an individual level and participation in life situations reflects performance at a societal level (Atler, Malcolm and Greife, 2015; Butler et al., 2006; World Health Organization, 2001). For this review, participation was defined as “participation in life situations” and operationalised using the ICF chapters 6 (domestic life), 7 (interpersonal interactions and relationships),8 (major life areas) 9 (community social and civic life) (WHO, 2002b) (Perenboom and Chorus, 2003).

A broad range of personal, environmental, and stroke-related factors have been identified as potential barriers to resuming participation in life roles one year after stroke (Walsh et al., 2015) and there is considerable literature investigating different factors associated with or predicting participation, with each study having a specific focus. However, to date, this literature has not been synthesised. A comprehensive analysis of the available evidence is necessary to provide an aggregate view of biopsychosocial factors associated with participation after stroke and to identify those likely to experience poor or deteriorating participation.

Therefore, the aims of this study are:

- to identify biopsychosocial factors associated with or determining participation outcomes for adults with stroke

- to investigate associations with participation at different time points post-stroke.

## 2.3 Methods

### 2.3.1. Search strategy and Selection criteria

The systematic review that informed this chapter was registered with PROSPERO (registration CRD42015017909) (Ezekiel, Dawes and Collett, 2015) and is reported following PRISMA guidelines (Moher et al., 2009).

Studies involving stroke patients that met the following criteria were included in the review:

- community-dwelling stroke survivors (all strokes) aged 18 and over. Studies with mixed populations were included if 90% of participants had stroke
- observational studies
- investigated biopsychosocial factors associated with participation outcomes
- written in English.

Intervention studies were excluded.

Medline, CINAHL, AMED, PsychInfo and Web of Science on 1<sup>st</sup> January 2015 (updated on 17<sup>th</sup> May 2017) were systematically searched and the search was not limited by date; results dated back to 1946. Search keywords were 'stroke', 'participation', 'measures' and their associated synonyms and terms (Appendix A). The publications of the three most-cited journals from the eligible studies were hand-searched between May 2016 and May 2017. Additional studies were located through reference lists of eligible studies.

The primary outcome of interest was participation in life situations. An initial list of measures relevant to stroke was collated from literature that had evaluated psychometric properties and mapped participation instruments to the ICF (Noonan et al., 2009; Tse et al., 2013; Kessler and Egan, 2012; Salter et al., 2005).



Two reviewers then independently mapped the content of each measure to chapters six to nine of the activity and participation domain of the ICF (domestic life, interpersonal interactions, and relationships, major life areas, community, social, and civic life). Learning and applying knowledge, general tasks and demands, communication, self-care, and mobility were not included (WHO, 2013). This was to ensure that participation was the primary focus of each measure. Participation outcomes were included if fifty per cent or more of the questions in the measure mapped to chapters six to nine. Differences in reviewers' assessments were discussed until an agreement was reached.

A total of 24 measures were reviewed and 14 were eligible for inclusion (Table 1). Interrater agreement was very good (Cohen's kappa 0.81, 95% CI. 0.47-0.69). All included measures were standardized questionnaires. It is beyond the scope of this review to report on psychometric properties.

### ***2.3.2. Study selection process***

Figure 2.1 summarises the selection process. Search results were imported into EndNote and duplicated studies removed. A second reviewer (LF) independently reviewed all studies against eligibility criteria at each stage. Any disagreements were resolved through discussion between reviewers. Agreement was assessed using Cohen's kappa. Inter-rater agreement of eligibility by abstracts was moderate (kappa 0.65, 95% CI.,0.58 to 0.73) (McHugh, 2012). Inter-rater agreement of eligibility by full text was also moderate (kappa 0.58 95% CI. 0.47 to 0.69).

### ***2.3.3. Data extraction***

Study methods, participant details, type of outcome measure used, and study results were extracted into excel. Where studies were reported in more than one paper, data was extracted, pooled, and treated as one study. Data was collected on variables grouped according to ICF domains: contextual factors (age, gender, social status, socioeconomic factors and environmental factors), health condition (type of stroke, stroke severity, time since stroke and comorbidities), body function

impairments and activity limitations (World Health Organisation, 2002). Data on any statistically determined association reported with variables and participant outcome measures were extracted (as reported) from each study. The principal summary measures were Pearson and Spearman's correlations, standardized coefficients, variance and standard error, logistic odds ratios, analysis of variance, p values and confidence intervals.

#### ***2.3.4. Risk of bias in individual studies***

The risk of bias was assessed using the quality assessment tool for observational and cross-sectional studies (NHLBI, 2014a; NHLBI, 2014b) (Appendix B). This tool was developed by research methodologists and informed by concepts and assessment tools from a wider range of organisations, including the Cochrane Collaboration and NHS Centre for Reviews and Dissemination (NHLBI, 2014a). The tool provides a rating for low, fair, or high risk of bias. A second researcher reviewed (LP) ten per cent of the risk of bias assessments, interrater agreement of risk of bias was moderate (kappa 0.56, 95% CI 0.02-1). All eligible studies were included in the review but the quality of the study was considered in the analysis. and informed the interpretation of the findings, particularly where studies reported anomalous results.

#### ***2.3.5. Analysis***

Variables investigated were grouped (by LE) according to the ICF classification (Cieza et al., 2005): contextual factors (personal or environmental factors), health condition (the type of stroke, time since stroke), stroke-related impairments in body functions and structures (e.g. cognitive deficits, movement deficits) and activity limitations (i.e. limitations in mobility or daily activities) (World Health Organization, 2001). For example, Fugl Meyer assessment of lower limb function was labelled as "control of voluntary movement" from the ICF chapter "neuromusculoskeletal and movement functions", whereas the six-meter timed walk test was labelled as "walking and moving" from the ICF chapter "mobility". As the presence of depressive symptoms was determined by depression

scales, it was mapped to “emotional functions” within the ICF chapter “mental functions”, rather than assuming the presence of depression as a health condition (Cieza et al., 2005).

For each study, statistical data for reported biopsychosocial factors were categorised as relationship/no relationship by considering whether results were statistically significant (according to the studies reported p values or confidence intervals). In longitudinal studies with multiple data time points, each association was counted once. The probability that the observed proportion of studies reporting associations deviated from the expected proportion by chance alone (assuming that there was no association and no publication bias) was calculated using the stattrek binomial probability calculator (Cooper, Hedges and Valetine, 2009). The expected proportion of studies finding an association with  $p < 0.05$ , was determined to be 0.05 (Greenland and O'Rourke, 2008). To provide context for interpretation of the binomial test, the number of sufficiently powered studies (power of 0.8, with alpha at 0.05) to detect a weak association (correlation of 0.2) was reported. The power calculation was completed using the Clinical and Translational Science Units online calculator and the equation:  $N = [(Z\alpha + Z\beta)/C]^2 + 3$  (Hulley *et al.*, 2013) pp79.

Factors that were investigated once only were not included in the binomial test analysis (Appendix C).

The studies were summarised in table form and the results of each study were examined for descriptions of interactions between biopsychosocial factors (Popay et al., 2006). Findings from cohort studies were summarized by time points to provide a descriptive summary of how factors associated with participation outcomes changed over time.

## 2.4. Results

In total, 92 papers (reporting on 82 studies) were eligible for inclusion (figure 2.1). Thirty-three of the studies in the review were cross-sectional and collected data from participants who were from three months to 31 years post-stroke. Forty-two were prospective cohort studies and seven were

retrospective cohort studies. Of the cohort studies, 11 studies assessed participants' outcomes at multiple time points, ranging from three months (Mercer et al., 2009) to six years post-stroke (Singam et al., 2015). The total number of study participants was 11,815. Studies included people from 18 to 99 years old and stroke severity from minor to severe, residing at home or in a care facility (Appendix D). Fourteen participation measures assessed aspects of participation in life situations (Table 1.1). Studies employed a range of statistical analyses including correlation, univariate, and multivariate regression analysis.

Figure 2.1. PRISMA flow diagram

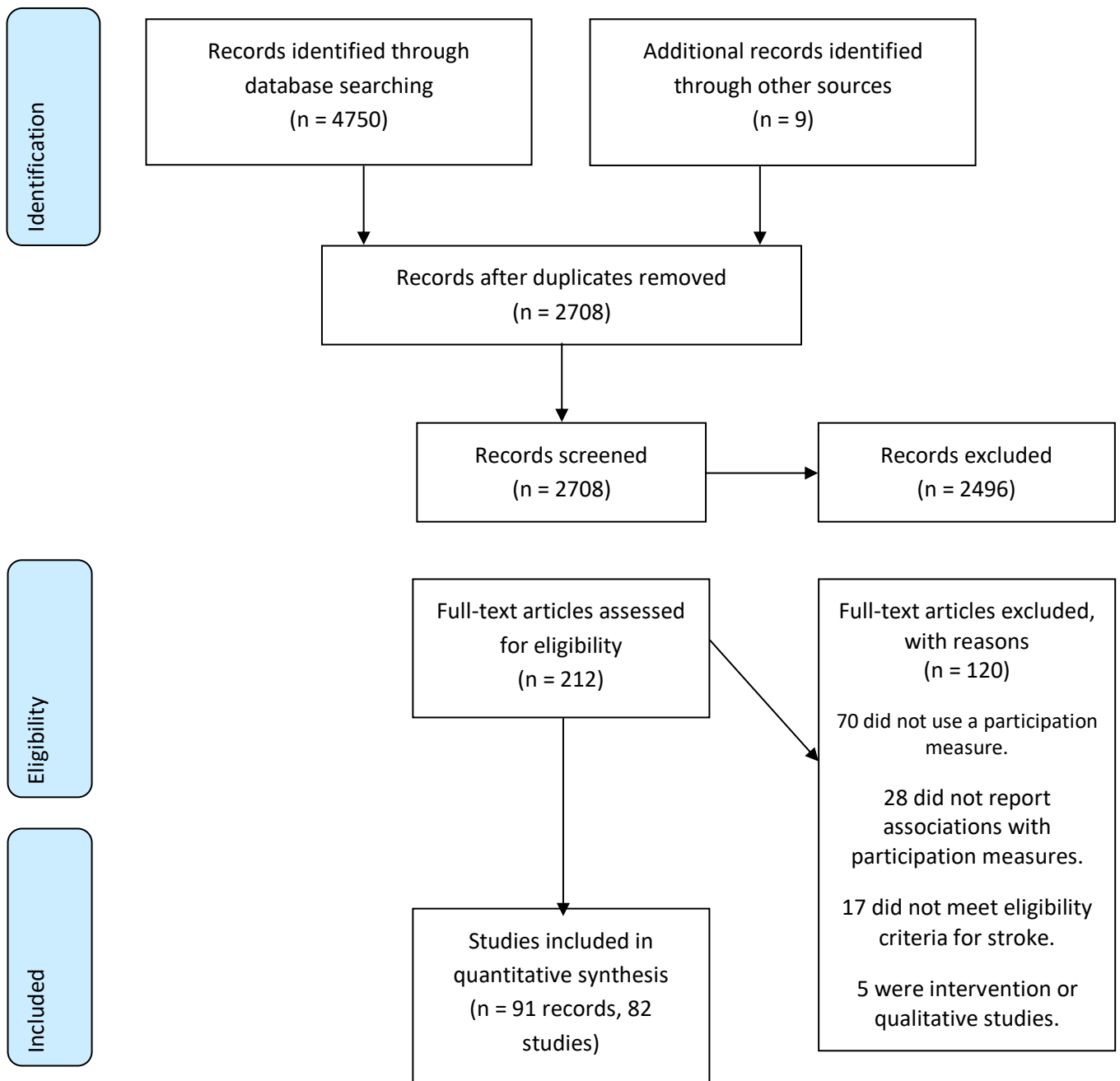


Table 2.1: Outcomes measures mapped to the activity participation domain of ICF

Outcome measures	Activity and Participation chapters ICF								
	Learning & knowledge	General tasks	Communication	Mobility	Self-care	Domestic life	Interpersonal relationships	Major life areas	Community, social and civic life
Activity Card Sort (ACS) <sup>*</sup> (Baum and Edwards, 2001)	✓		✓	✓	✓	✓	✓	✓	✓
Community Integration questionnaire (Corrigan and Deming, 1995)		✓		✓		✓	✓	✓	✓
Frenchay Activities Index (Schuling et al., 1993)				✓		✓		✓	✓
IMPACT-S (participation subscale)(Post et al., 2008)					✓	✓	✓	✓	✓
Impact on Participation &Autonomy Questionnaire (IPAQ)(Cardol et al., 2001)					✓	✓	✓	✓	✓
LIFE-H (assessment of life habits) (Noreau et al., 2004)			✓	✓	✓	✓	✓	✓	✓
London Handicap Scale(Harwood, Gompertz and Ebrahim, 1994)			✓	✓	✓	✓	✓	✓	✓
PAR- Pro (Ostir et al., 2006)				✓		✓	✓	✓	✓
Re-integration to normal living index (Wood-Dauphinee et al., 1988)							✓	✓	✓
Short Form 36 (social role functioning subscale only) (Ware and Sherbourne, 1992)									✓

Sickness Impact Profile (psychosocial subscale only) (Bergner et al., 1981)			✓	✓	✓				
Stroke Impact Scale (social subscale) (Duncan et al., 1999)						✓	✓	✓	✓
Sydney psychosocial scale reintegration(Tate et al., 1999)			✓	✓	✓		✓	✓	
Utrecht scale for the evaluation of rehabilitation – participation (USER-P)(Post et al., 2012)			✓	✓		✓	✓	✓	✓

\* Includes constructs outside of activity and participation

#### 2.4.1. Analysis of factors associated with participation outcomes

Participation outcomes were associated with sociodemographic factors, health conditions, body function impairments and activity limitations. Type of stroke was the only factor where the proportion of studies finding associations with participation was likely to be a chance occurrence. The direction of the associations was mostly consistent across the studies with sex being the only exception. Poorer participation outcomes were associated with older age, increased stroke severity, more comorbidity, a greater degree of stroke-related impairment, and more activity limitations (Table 2.2).

Table 2.2: Results of the exact binomial test

Associations with biopsychosocial factors and participation in all studies compared to those found in sufficiently powered studies ( $n > 194$  for a correlation size of 0.2). Effect sizes are categorised by Cohens rule of thumb were  $d = 0.2$  small, 0.5 medium, 0.8 large or  $r < 0.3$  small,  $0.31 < r < 0.5$  medium,  $r > 0.5$  large (Rosenthal and Rosnow, 1984). NR (not reported).

	Total number of studies.	No. of studies with a significant association	Binomial test, significance at $p < 0.05$	Association found in (n) studies with sufficient power*.	Effect size	No association found in (n) studies with sufficient power	Effect size
<b>Contextual Factors</b>							
Age	58	33	$p < 0.001$	9	small – medium	3	small
Gender	35	10	$p < 0.001$	2	small	2	NR
years of education	22	8	$p < 0.001$	3	small	3	Small
Employment	9	3	$p = 0.001$	2	small	0	
<b>Environmental factors</b>							
Social support	7	4	$p < 0.001$	0		0	
<b>Health condition</b>							
comorbidities	11	7	$p < 0.001$	2	small	2	small
Type of stroke (haemorrhagic or ischemic)	14	2	$p = 0.12$	2	small	2	NR
Stroke severity	22	21	$p < 0.001$	7	medium-large	2	NR
Number of strokes	5	3	$p = 0.001$	3	small-large	1	NR
Time since stroke	13	4	$p = 0.003$	0		1	NR
<b>Body functions.</b>							
Impairment in movement related functions	14	14	$p < 0.001$	3	small-large	0	
Involuntary movement reaction functions: balance	6	6	$p < 0.001$	0		0	
Impairment in movement related functions: arm	7	5	$p < 0.001$	1	NR	1	NR
Impairment in specific mental functions (cognition)	30	24	$p < 0.001$	6	medium-large	2	NR



	Total number of studies.	No. of studies with a significant association	Binomial test, significance at p< 0.05	Association found in (n) studies with sufficient power*.	Effect size	No association found in (n)studies with sufficient power	Effect size
Mental functions of language (aphasia)	10	9	p<0.001	2	small - medium	1	NR
pain	7	6	p<0.001	2	small	0	
Depressive symptoms	47	41	p< 0.001	11	small-large.	1	small
Anxiety	6	4	p<0.001	1	NR	0	
Impairment in / energy or drive functions	6	5	p<0.001	1	medium	0	
Urinary continence	5	4	p<0.001	1	large	1	
<b>Activity limitations</b>							
Handling stress (coping)	2	1	p=0.007	0		0	
Driving	3	2	p=0.007	0		0	
Limitations in activities of daily living	44	36	p<0.001	13	medium-large	1	small
Mobility	21	21	p<0.001	3	large	0	

### Contextual Factors

Older age was associated with worse participation outcomes. Whilst there was inconsistency in study results, we found a small effect size for associations between age and participation in sufficiently powered studies with a fair to low risk of bias.

Associations between gender and participation outcomes were also inconsistent. Ten studies reported significant associations, with women being at greater risk of poor participation outcomes than men. However, the effect size was small ( $r = 0.1 - 0.27$ ) (Gum, Snyder and Duncan, 2006; Schepers et al., 2005) and two adequately powered studies found no association between the person's gender and participation (Lo et al., 2008; Carod-Artal et al., 2009). One study reported

better participation outcomes for women (Egan et al., 2015) and one study reported a differential effect of marriage on participation according to sex (Clarke et al., 1999).

#### Environmental factors

The most frequently investigated aspect of the environment was social support (as measured by standardised and non-standardised questionnaires). Social support included both the individuals' access to support and their perceived quality of and satisfaction with, social support. Four studies found positive associations between social support and participation. These studies were underpowered but reported small to medium effect sizes ( $r = 0.21 - 0.41$ ) (Desrosiers et al., 2002; Gottlieb et al., 2001).

Only one of the eligible studies evaluated relationships between aspects of the wider environment and participation outcomes. Rochette et al (2001) measured the perceived influence of environmental factors using the measure of the quality of the environment (MQE) (Fougeyrollas et al., 1999) and found perceived barriers in the environment to be moderately associated ( $r = 0.42$ ,  $p = 0.002$ ) with scores on LIFE-H (where higher scores indicate worse participation) (Rochette, Desrosiers and Noreau, 2001).

#### Stroke factors

Stroke severity and an increased number of comorbidities were consistently, and moderately associated with worse participation outcomes. The type of stroke (ischaemic or haemorrhagic) was not found to be associated.

#### Stroke related impairments

Cognitive functioning and the presence of depressive symptoms were the factors most frequently investigated. Most studies investigating depressive symptoms found significant associations with participation outcomes; the effect size range from small to large. One sufficiently powered study did not find an association with depressive symptoms (as measured by the Centre for Epidemiological Studies Depression Scale (Radloff, 1977)) but did find a significant association between positive affect and better participation outcomes (Berges, Seale and Ostir, 2012). Depressive symptoms were

determined through the administration of depression scales, for example, the Geriatric Depression Scale (Yesavage et al., 1982). Mean scores on the depression scales reflected the presence of mild depressive symptoms with only two studies reporting mean scores indicating moderate to severe depression (Feigin et al., 2010; Cooper et al., 2015).

Cognitive functioning was determined through cognitive screening tools and assessment of specific cognitive functions. Most studies found significant relationships of impaired cognitive functions with participation, with effect sizes ranging from small to large.

Movement related functions and balance were consistently associated with poorer participation outcomes. Associations between hand and arm function and participation tended to be weaker than associations with impaired lower limb function or balance.

Nine out of ten studies reported significant associations between aphasia and participation outcomes. Effect sizes range from small to large.

Fatigue and pain were less frequently investigated but were consistently significantly associated with poorer participation outcomes. Five out of six studies reported moderate associations between fatigue and participation outcomes.

#### [Activity limitations](#)

Limitations in activities of daily living and mobility were strongly associated with poor participation with studies reporting medium to large effect sizes. Only one investigated the frequency of falls and found a moderate association between participation outcomes and the number of falls or fear of falling (Liu et al., 2015). Two studies investigated associations between coping styles and participation with mixed results but both studies were underpowered and the risk of bias was unclear and high.

#### *2.4.2. Factors associated with participation at different time points post-stroke*

Participation scores for most stroke survivors were stable at one year or more post-stroke (Blomer et al., 2015; Patel et al., 2006; Gall et al., 2009). There seems to be an improvement in participation outcomes when comparing mean participation scores at three months to six months (Sturm et al., 2002) but little variation in participation scores overall from 1 year on (Patel et al., 2006; Desrosiers et al., 2006; Blomer et al., 2015). However, this does not reflect changes in participation at an individual level. Jansen et al found that participation deteriorated for 11% and increased for 12% of participants (Jansen et al., 2012). Lo et al also reported that 17.8% of participant's participation scores deteriorated from three months to one year post-stroke (Lo et al., 2008). Whilst Egan found improvement in participation scores over time but only for participants with higher incomes (Egan et al., 2015). Deterioration in participation scores was associated with older age two studies (Lo et al., 2008; Singam et al., 2015). Participation outcomes remained significantly different from matched controls (Chahal, Barker-Collo and Feigin, 2011) (Naess et al., 2006) and poor participation outcomes at one year were strongly associated with poor outcomes three years post-stroke (Jansen et al., 2012).

Seven studies compared biopsychosocial factors associated at different time points after stroke (time points from three months to three years). No single factor was consistently associated with participation at all time points (Table 2.3).

Table 2.3 Biopsychosocial factors associated with participation outcomes at different time points in longitudinal studies

Factors associated with participation at time points post-stroke					
	<3 months	4-6months	7-11 months	12-23 months	>24 months
(Clarke et al., 1999)	Stroke severity, depressive symptoms, cognition, limitations in adls			Stroke severity, depressive symptoms, cognition, limitations in adls, gender	
(Egan et al., 2015)		Mobility, female, low income	Mobility, female, low income, emotional well being	Mobility, female, emotional well being	Female, emotional well being
(Harwood et al., 1997)				Depressive symptoms, stroke severity, limitations in adls, age, gender	Depressive symptoms, stroke severity, limitations in adls,
(Mercer et al., 2009)	Motor function	Not significant			
(Patel et al., 2006)				Depressive symptoms, mobility, pain	Depressive symptoms, mobility, energy functions
(Sturm et al., 2002)	Limitations in adls			Limitations in adls	
(Tse et al., 2017)	Limitations in adls, cognition, depressions, mobility	Limitations in adls.			

### 2.4.3. Descriptive analysis findings

From the narrative descriptive analysis, the presence of cognitive impairments was reported as an independent predictor of participation but was also found to predict depression and was associated with limitations in activities of daily living (Desrosiers et al., 2008; Carter et al., 2000; Blomer et al.,

2015). Depression and fatigue were reported as independent predictors of participation outcomes in one study (Naess et al., 2006).

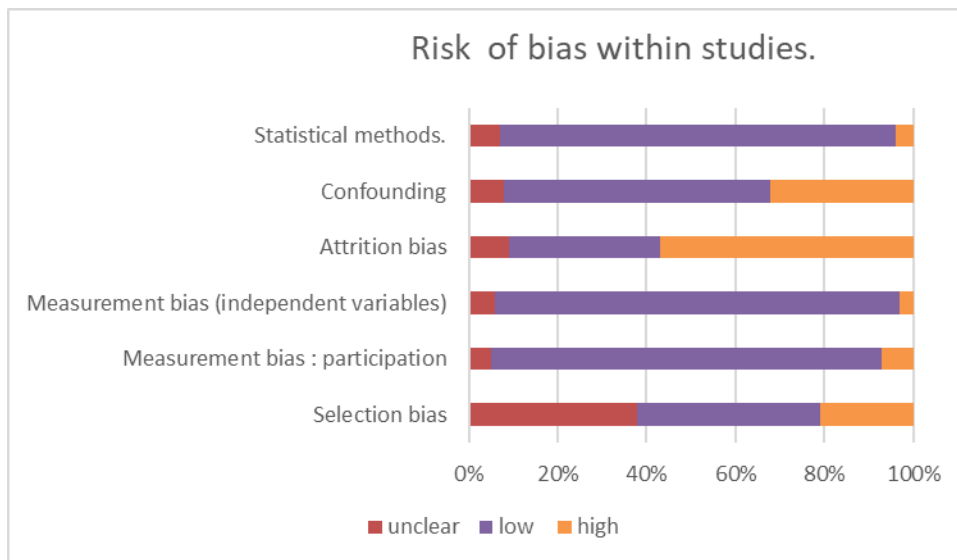
Four studies reported associations with subdomains of participation and found depression to be strongly associated with social functioning domains (Fallahpour et al., 2011; Naess et al., 2006). In addition, two studies examined predictors of frequency of participation, perceived restrictions, or satisfaction with participation (as measured on the USER-P). Depression, physical and cognitive functioning predicted scores on all three dimensions, whilst frequency of participation was additionally associated with age, education level and fatigue (van der Zee et al., 2013; Blomer et al., 2015).

One study reported that participation outcomes at six months post-stroke predicted emotional wellbeing up to two years post-stroke (Egan et al., 2014).

#### ***2.4.4. Risk of bias within studies***

Forty-six studies were assessed as being low to fair for risk of bias, 35 at high risk of bias and 11 studies where the risk of bias was unclear. The main sources of bias were selection bias and attrition bias (figure 2.2). Death and deterioration in health were the main causes of attrition in longitudinal studies with 57 % of studies losing 20% or more participants (NHLBI, 2014b).

Figure 2.2. Percentage of studies with risk of bias for each domain.



## 2.5. Discussion

As far as can be determined, this is the first comprehensive synthesis of research exploring factors associated with participation outcomes after stroke. This study found that participation in life situations was associated with a wide range of biopsychosocial factors and remained limited in the longer term after stroke with most improvement occurring in the first six months. Furthermore, this review exposes the biomedical focus of research in stroke outcomes where associations between participation and factors other than body functions are rarely considered.

The initial gains in participation after stroke may be explained by the recovery of body functions but the review found that participation outcomes stabilised for most stroke survivors after six months post-stroke (Patel et al., 2006; Blomer et al., 2015; Desrosiers et al., 2006; Jansen et al., 2012; van Mierlo et al., 2016). However older age was associated with worsening participation outcomes over time (Lo et al., 2008). The relative stability of participation outcomes may be explained by qualitative literature on life after stroke. Wood et al (2010) reveals how stroke survivors adjust their lives to match changes in their abilities once their recovery from stroke has slowed (Wood, Connelly and Maly, 2010). Furthermore, Salter (2008) describes a process of relinquishing roles and

meaningful activities because of a loss of ability and this is likely to be reflected in participation outcomes (Salter et al., 2008). However, the stability of participation from one year post-stroke could also be affected by long term stroke survivors being younger with less severe stroke (Desrosiers et al., 2006). Over half of the cohort studies in this review were at risk of attrition bias, with death and worsening health being cited as the main reasons for high attrition rates.

The studies included in the review tended to reflect a biomedical focus with relatively few studies investigating environmental factors. Nevertheless, social support was found to be positively associated with participation after stroke. Other studies report satisfactory social support to be protective of well-being and health-related quality of life (Northcott et al., 2016) and may enable a successful return to social and community activities (Walsh et al., 2015). Jellema et al conducted a systematic review on the role of environmental factors in stroke survivor's resumption of daily activities, with a narrative synthesis of eligible qualitative and quantitative studies. They found that social support was necessary to both create opportunities and to enable individual's engagement in meaningful daily activities. In addition, shared responsibilities with family members and friends encouraged individuals to resume activities (Jellema et al., 2016). Taken together, these findings suggest that knowledge of an individual's available social support, along with considering the presence of other factors such as older age and comorbidities may help identify those at greater risk of poor participation outcomes.

There was insufficient evidence to draw conclusions about associations between other environmental factors and participation considered in the review: for example, type of residence, whether the person lives alone, quality of physical and social environments and societal attitudes. This finding reflects a historical focus on the recovery of body functions and personal care activities within stroke research with little consideration given to environmental influences on participation (Wolf et al., 2012). Meaningful and reliable measurement of environmental barriers is difficult because of the complexity and amount of possible environmental barriers encountered in daily life



but also because what qualifies as a barrier varies from one individual to the next (Heinemann et al., 2015). Further research utilising valid environmental measures is needed to improve understanding of how the environment enables or restricts stroke survivors' participation.

Of the other contextual factors investigated, age and sex were most likely to be associated with participation. In line with others' findings, this review found that participation outcomes for older stroke survivors were worse than those for sociodemographic and comorbidity matched peers (Skolarus et al., 2014; Desrosiers et al., 2005). The relationship between age and participation is complex, with older people experiencing more comorbidities and activity limitations before their stroke, as well as increased likelihood of severe stroke (Bentsen et al., 2014). Although sex was less consistently associated with participation in the studies reviewed, there was a small effect size for women to experience worse participation outcomes than men. However, this finding can be explained by sex differences in stroke severity and survival. Dehendorff et al. (2015) found that women experience more severe stroke and have better survival rates than men (Dehendorff, Andersen and Olsen, 2015).

All the investigated impairments in body functions were associated with participation, with depressive symptoms and cognitive impairment being most frequently investigated and consistently associated. In addition, two studies provided evidence of a reciprocal relationship between depression and participation, underscoring the importance of participation outcomes for wellbeing (White et al., 2014; Egan et al., 2014).

The review also identified factors that are possibly influential but were underrepresented in the literature. Post-stroke fatigue is common and has a reported incidence of between 35% and 92%, yet fatigue was investigated by only six studies within this review (Duncan, Wu and Mead, 2012).

Although fatigue is associated with depression, Naess et al (2006) and Van der Zee et al (2013) reported fatigue as an independent predictor of participation outcomes (Ponchel et al., 2015).

Taken together, these findings suggest that further investigation is needed to explore the role of fatigue in participation outcomes.

Limitations in mobility and activities of daily living were both consistently associated with poor participation outcomes. This finding may be due in part to overlapping constructs within activity and participation measures, despite the review only including participation measures with a focus on domestic, social and community life. However, limitations in mobility and activities of daily living are also indicative of stroke severity (Glymour et al., 2007) and whilst rehabilitation after stroke focuses on optimising independence in these areas, over half of stroke survivors are left with long term limitations (Stroke Association, 2016). This review's findings indicate that stroke survivors who experience ongoing limitations in their mobility and daily activities may need additional intervention to optimise their participation once their recovery of body functions has stabilised.

The findings of this review suggest that clusters of difficulties (such as depressive symptoms, cognitive dysfunction, poor mobility and lack of social support) are detrimental to participation outcomes rather than any single impairment. Many stroke survivors experience multiple impairments, and it is likely that interactions between impairments further compound the impact on participation by limiting the individual's ability to adjust and compensate for their difficulties (Törnbohm et al., 2017; Naess, Lunde and Brogger, 2012). Woodman et al.'s meta-synthesis of participation after stroke highlights the importance of adaptive processes such as cognitive reappraisal, problem-solving and self-management skills in shaping participation after stroke (Woodman et al., 2014). Yet problems such as depression, cognitive dysfunction and fatigue potentially disrupt successful adaptation and the processes that contribute to self-efficacy after stroke (Muina-Lopez and Guidon, 2013; Lewin, Jöbges and Werheid 2013). Constructs related to positive adaptation (such as coping styles, resilience and self-efficacy) were rarely considered in the reviewed papers, highlighting the need for further research in this area.

The wide range of biopsychosocial factors associated with participation in this review is illustrative of the ICF framework and suggests the need for interactionist perspectives to researching participation after stroke, examining the interdependence of personal, environmental and stroke-related impairments (Bartlett et al., 2006). Participation is conceptualised as emerging from the dynamic, non-linear and multiple interactions between the health condition, the person and their given context and is therefore theoretically modifiable and achievable even in the presence of long term limitations (Mallinson and Hammel, 2010; Whiteneck, 2006).

### *2.5.1. Measuring participation outcomes*

Defining and measuring participation continues to be problematic with a lack of consensus as to the operationalisation of participation (Dijkers, 2010) and blurring of participation and activity within the ICF (Whiteneck, 2010). Older participation measures frequently include constructs outside of the activity and participation domain, as they are not underpinned by the ICF framework (Tse et al., 2013). Furthermore, measures included in this review captured different aspects of participation such as participation restriction, frequency or satisfaction (Eyssen et al., 2011). The included measures all relied on self-report which compounds issues of unreliability (Dijkers, 2010) and is particularly problematic for this group because of the frequency of language, vision and cognitive deficits.

Consequently, the results of this review have been interpreted cautiously, particularly where findings are less consistent across the studies or where factors have been infrequently investigated. Nevertheless, these findings suggest that factors such as depressive symptoms, cognitive functioning and limitations in mobility are associated with poor participation outcomes. Further research is needed to explore potential causative relationships between these factors and participation and to investigate the contribution of pervasive symptoms (such as fatigue) on participation.

Participation in life situations is widely recognised as an important long term outcome of stroke rehabilitation, yet participation outcomes remain underutilised in intervention studies (Teasell et al.,

2012; Veras et al., 2017; Sivan et al., 2011). Whilst the measurement of participation outcomes remains limited, more routine and judicious use of participation outcome measures and wider use of the ICF is necessary to develop causative explanatory models of participation after stroke.

### *Limitations*

The broad scope of this review is both a strength and a limitation. Whilst primary research has focused on selected key areas, this review enabled examination of a wide range of factors to explore associations and potential risks for poor participation after stroke. Nevertheless, the heterogeneity of participation measures and inconsistency in the reporting of statistical findings meant meta-analysis was not viable. Therefore, proportions of studies with significant associations were determined (Cooper, Hedges and Valetine, 2009). This approach is limited as it gives higher relative weighting to small studies and does not account for publication bias (Cooper, Hedges and Valetine, 2009). Consequently, the number of insufficiently powered studies were reported to aid the interpretation of the analysis.

There are inherent difficulties with synthesising results from observational studies. Foremost is the increased risk of confounding variables and selection bias arising from the lack of randomisation (Viswanathan et al., 2013). Cross-sectional studies, in particular, are at increased risk of bias as it is difficult to establish temporal relationships between exposure (in this case stroke-related factors) and participation outcomes (Carlson and Morrison, 2009).

Selection and attrition bias means that the studies in this review reflect outcomes for those with mild to moderate stroke, particularly as one out of four stroke survivors die within a year after stroke (Stroke Association, 2016). Further targeted research is needed to establish participation outcomes and restrictions for those living with more severe stroke and disability.

Interrater agreements for eligibility and risk of bias judgements were moderate and reflect the diversity of methodologies and participation outcome measures used by studies included in the

review. However, differences between the two reviewers were resolved through discussion without the need for recourse.

Problems with defining and operationalising participation in life situations are well-documented (Dijkers, 2010; Woodman et al., 2014) and the lack of a clear delineation between activity and participation has already been discussed. Furthermore, the psychometric properties of commonly used participation measures within stroke research are limited (Salter et al., 2013) thereby introducing measurement bias in the review findings. Associations between biopsychosocial factors and participation outcomes were examined whilst recognising that the participation measures reflected different aspects of participation. Hence participation outcomes were viewed in the broadest terms and did not delineate between satisfaction with participation or restrictions in participation.

## **2. 6. Conclusion**

In summary, this review suggests that multiple factors impact participation outcomes and underscores that stroke survivors may experience participation restrictions long term, particularly when they have impairments across a range of body functions. As such, interventions to improve participation outcomes should be person-centred, deliver gains across a range of body functions and activities, and focus on the resolution of community participation restrictions (Graven, 2011; Engel-Yeger et al., 2018). Further research is necessary to investigate coping, resilience and self-efficacy in moderating the impact of stroke-related impairments on participation, and the potential for self-management programmes to improve participation outcomes (Cicerone and Azulay, 2007; Lee, Heffron and Mirza, 2019).

The review identified that older people with more severe stroke and stroke-related impairments are most at risk of poor participation. There is little change in participation outcomes from one year post-stroke for most stroke survivors and variability as to the factors associated with participation at

different time points after stroke. The presence of depressive symptoms, problems in cognitive functioning, mobility and activity limitations were most frequently and consistently associated with poor participation outcomes. Fatigue was also associated with participation outcomes but infrequently investigated, given the prevalence of post-stroke fatigue. Further research is needed to investigate the role of fatigue in participation outcomes.

Evidence of interrelationships between multiple factors suggests that an interactionist approach to participation research is necessary to develop explanatory models of participation after stroke. The results of this review also reflect a biomedical focus of research in this area, and further research is needed to understand the potential role of environmental factors in mitigating poor participation outcomes.

The considerable variability in how participation is operationalized is a barrier to measuring this important outcome after stroke interventions. With this in mind, a consensus is needed on defining and measuring participation outcomes relevant to stroke survivors, along with wider use of participation outcomes in research to build a body of evidence for effective interventions.

## Chapter 3 Narrative review of fatigue post acquired brain injury

### 3.1. Summary

Having established that fatigue is one of several factors affecting participation after stroke, this chapter will discuss what is known about participation after acquired brain injury (with a focus on causes other than stroke) and explore the influence of problematic fatigue on participation outcomes. The disparity in research findings is discussed in more detail and related to challenges in defining and measuring fatigue. Approaches to fatigue measurement are evaluated and an alternative approach to investigating fatigue is suggested, one which examines individual variability in fatigue and participation experiences.

### 3.2. Participation after acquired brain injury

Participation after acquired brain injury follows similar trajectories to those for stroke survivors, with most improvement occurring in the first year post-injury (Ruet et al., 2019). Poor participation outcomes after ABI are associated with older age, the severity of injury, cognitive and emotional functioning and poor social support (Son et al., 2016; Reistetter and Abreu, 2005). Changes in types of activities and level of participation have been reported long term following traumatic brain injury, with survivors experiencing lower levels of participation when compared both to pre-injury levels and to non-injured controls (Goverover *et al.*, 2017; Migliorini *et al.*, 2016). Most improvement in participation seems to occur during the first year but continued positive changes in participation have been demonstrated up to 20 years post-injury (Andelic et al., 2018; Brands et al., 2014). However, the trajectory of participation is variable and those with more severe injury or older age are at risk of their participation levels deteriorating over time (Ezekiel *et al.*, 2019; Willemse-van Son *et al.*, 2007). A large (n1947) longitudinal study of participation outcomes after TBI found that the group average participation score was stable from one year post-TBI, but those over 60 years old experienced worsening participation over time (Erler et al., 2018). Other studies similarly report associations between age and participation outcomes, with older people with TBI experiencing

greater participation restrictions than younger people with TBI (Corrigan *et al.*, 2014; Ritchie *et al.*, 2014). Thus as with the stroke population, age may be a factor affecting participation following TBI.

Whilst there are different trajectories for global participation levels, some aspects of participation are more vulnerable to disruption than others, with complex social and work activities being affected more than those that occur in the home (Jourdan *et al.*, 2016; Wise *et al.*, 2010).

As discussed in the previous chapter, there is a considerable body of research investigating predictors or determinants of participation outcomes after ABI, but these tend to be focused either on traumatic brain injury or stroke. Several systematic reviews have synthesised research studies of factors affecting participation after traumatic brain injury. Reistetter *et al* (2005) and Son *et al* (2007) conducted systematic reviews of determinants of participation in adults with TBI and completed a narrative synthesis of eligible studies. Both reviews reported associations between participation outcomes and severity of brain injury, older age, premorbid employment, substance abuse and disability (activity limitations). Additionally, Reistetter *et al* reported associations between participation and cognitive or emotional functioning. However, the relative importance of each factor in its effect on participation cannot be determined from these reviews. Reistetter only described and summarised the findings of eligible studies, whilst Son used vote counting to indicate the predominance of associations. This approach means that the results from each study are equally weighted and does not consider the effect of sample size (Bushman and Wang, 2009).

Sherer *et al.* (2014) extended our understanding of participation after ABI by focusing on modifiable factors associated with participation outcomes. In their systematic review, they investigated relationships between self-reported traits or environmental barriers, and participation. They were unable to identify the predictors of global participation outcomes due to the heterogeneity of outcomes measures used in the studies reviewed. However, they noted that self-reported pain, fatigue and well-being were predictive of employment outcomes (where employment was categorised as a domain of participation) (Sherer *et al.*, 2014).



More recently published longitudinal studies have reported associations between participation outcomes and social support, perceived self- efficacy or coping styles. The effect of perceived self- efficacy and coping styles on participation outcomes was small with each accounting for less than 5% of the variance in participation scores, and neither were independent predictors of participation (Brands et al., 2014; Ditchman et al., 2016).

In summary, when examining the literature relating to participation outcomes after ABI, multiple health, personal and environmental factors are associated with participation after ABI, with no single factor predominating. Fatigue is rarely considered in these studies, despite its prevalence after ABI. This is not to say that fatigue is likely to be the single predominant factor affecting participation but understanding the role it plays in limiting activities and restricting participation is fundamental to effective self-management strategies.

#### **3.4. Fatigue and participation after ABI**

Fatigue is frequently reported as a barrier to ABI survivors' engagement in social, work leisure and physical activities (Andersen et al., 2012; Jackson, Mercer and Singer, 2018; Nicholson et al., 2014; White et al., 2012). Several qualitative studies found that those living with fatigue post brain injury tended to avoid physical and social activities in response to their fatigue and consequently replaced these more demanding activities with sedentary and home-based activities (Eilertsen, Ormstad and Kirkevold, 2013; Theadom et al., 2016). This means that physical activity levels for ABI survivors tend to be lower than those recommended by physical activity guidelines, particularly with regards to moderate or vigorous activity (Jackson, Mercer and Singer, 2018; Duncan et al., 2015). 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 (Piercy et al., 2019; Durcan and Bell, 2015).

In direct contrast to ABI survivor's reports about their fatigue and participation, several cohort studies were unable to demonstrate significant relationships between fatigue and participation in

daily activities or fatigue and physical activity (Bushnik, Englander and Wright, 2008; van de Port et al., 2007; Cantor et al., 2008; Norlander et al., 2016; Crosby et al., 2012; Elf et al., 2016). Elf et al. (2016) measured fatigue (Fatigue Severity Scale, FSS) and daily activity (Frenchay Activities Index, FAI) of 102 stroke survivors six years post-stroke. Within this study, associations between FSS scores and FAI total score or domain scores were not statistically significant. Elf hypothesised that the lack of association might be a result of stroke survivors adapting their activities to cope with fatigue (Elf *et al.*, 2016).

Cantor and colleagues study of 223 TBI survivors also found no significant association between scores on the fatigue severity scale and the frequency of participation in home and community activities (Cantor et al., 2008). Fatigue was associated with all domains of the SF36, suggesting that fatigue affected the quality of activity and participation experiences rather than the amount. Cantor et al suggested that fatigue impacts ABI survivor's perception and satisfaction of their engagement in more complex daily activities and events, rather than the frequency of activities.

More recently, Blomgren et al reported weak associations between fatigue impact and activity (as measured by the FAI) seven years post-stroke. However, after multivariate regression analysis, fatigue was not an independent predictor of FAI once depression and cognitive dysfunction were controlled for (Blomgren et al., 2018).

In the studies cited above, the FAI was most frequently used to measure participation. However, FAI captures the frequency of activities and the overall score is weighted towards domestic activities (Turnbull et al., 2000). It is possible, therefore, that the choice of participation measure obscures the relationship between fatigue as it may not capture the types of activities most affected by fatigue (Elf *et al.*, 2016; (Stallinga et al., 2014). Fatigue may affect dimensions of participation other than frequency of activity, for example, satisfaction with participation, or the diversity and balance of activities contributing towards participation (van de Port et al., 2007). The studies also evaluated average participation and fatigue scores and so are not indicative of the variability of ABI survivors

experiences, despite evidence of different trajectories of participation after ABI (van der Krieke et al., 2015). In addition, there are considerable challenges to measuring fatigue and these also confound efforts to establish whether and how ABI fatigue affects participation outcomes (Wylie and Flashman, 2017).

### **3.5. Defining and measuring fatigue after acquired brain injury**

As a clinical symptom, fatigue is a complex multidimensional phenomenon that overlaps with lay concepts of tiredness and with the symptoms of depression, sleep dysfunction and muscle weakness (De Doncker et al., 2017) (Mollaveva *et al.*, 2014; Zwarts, Bleijenberg and van Engelen, 2008).

Fatigue is a normal experience in everyday life, however, fatigue after ABI is persistent, unpleasant, and disruptive and ABI survivors report that it bears little resemblance to their pre-injury experiences of fatigue (Thomas et al., 2019).

Whilst our understanding of the pathophysiology of fatigue has progressed, the exact mechanisms of fatigue are still to be determined (De Doncker et al., 2017; Wylie and Flashman, 2017). In addition, the evidence of effective interventions for fatigue is limited with insufficient evidence to recommend any single intervention (Wu et al., 2015a; Marshall et al., 2015; Hinkle et al., 2017). Several authors have attributed the difficulty in establishing effective interventions to limitations in how fatigue is defined and measured, not just after brain injury but also in other neurological conditions (Skogestad et al., 2019; Kisala et al., 2019; Wylie and Flashman, 2017; Hubbard, Golla and Lausberg, 2020).

#### **3.5.1. Defining fatigue**

Currently, there is no definition for fatigue after acquired brain injury and there is a lack of consensus for theoretical definitions of both post-stroke fatigue and post TBI fatigue (Cantor, Gordon and Gumber, 2013; De Doncker et al., 2017). Within the research literature fatigue, there are numerous definitions of fatigue reflecting either the subjective experience of fatigue or physiological mechanisms (De Doncker et al., 2017). Definitions of fatigue describing subjective

experiences include feelings of weariness, exhaustion, lethargy, inertia, lack of physical or mental energy or aversion of effort, fatigue out of proportion to effort or not necessarily associated with activity, and fatigue that interferes in day to day functioning (Barker-Collo, Feigin and Dudley, 2007; Barbour and Mead, 2012; Bay and Xie, 2009; De Doncker et al., 2017). Cantor et al (2014) further conceptualise fatigue as encompassing “psychological, motivational, situational, physical, and activity-related components” and define it as a:

*“subjective awareness of a negative balance between available energy and the mental and physical requirements of activities” (Cantor et al., 2014).*

Cantors conceptualisation extends the definition of fatigue by placing it within the context of daily life and linking fatigue with the demands of daily activities. In this definition, fatigue emerges from dynamic interactions between the individual, their actions, and their environments.

Mechanistic definitions of fatigue separate into different subtypes: exertion or chronic fatigue (Tseng et al., 2010), physical, mental (cognitive) or psychological fatigue (Staub and Bogousslavsky, 2001), and central or peripheral fatigue (Chaudhuri and O Behan, 2004) (see Table 3.1). Fatigue is also categorised according to the associated health condition, as there is evidence to suggest that cancer-related fatigue is different to that experienced after ABI, which is, in turn, thought to be different to fatigue arising from multiple sclerosis (Lukoschek et al., 2015; Butt et al., 2013). Fatigue also consists of subjective experiences (the perception and sensation of being fatigued) and objective signs (i.e. a measurable reduction in performance) (Kluger, Krupp and Enoka, 2013).

Central fatigue is a term increasingly used to described fatigue after ABI, with “central” denoting a central nervous system origin (Chaudhuri and O Behan, 2004; Leavitt, 2010; Cantor, Gordon and Gumber, 2013; Feigin et al., 2012; Acciarresi, Bogousslavsky and Paciaroni, 2014). Chaudhuri and Behan define central fatigue as

*“the failure to initiate and/or sustain attentional tasks (‘mental fatigue’) and physical activities (‘physical fatigue’) requiring self-motivation (as opposed to external stimulation)” (Chaudhuri and Behan, 2000).*

Central fatigue is characterised by feelings of exhaustion, increased perception of effort and difficulty with sustained motivation (Chaudhuri and O Behan, 2004). The concept of central fatigue accounts for both the experience of fatigue and for fluctuations in fatigue severity arising from different levels of stimulation or effort, as well as fatigability. Consequently, this definition of fatigue is useful when considering fatigue after brain injury because it encapsulates multiple dimensions of fatigue and captures a range of fatigue-related behaviours (Leavitt and DeLuca, 2010).

**Table 3.1. Types of fatigue**

Type	Definition
Fatigability	<i>“the magnitude or rate of change in a performance criterion relative to a reference value over a given time of task performance or measure of mechanical output”</i> (Kluger, Krupp and Enoka, 2013, pp.411).
Chronic fatigue	<i>“a state of weariness unrelated to previous levels of exertion and is associated with pathological factors”</i> (Tseng et al., 2010).
Exertion fatigue	<i>“Exertion fatigue is acute in nature, with rapid onset, short duration, and short recovery period, and is commonly experienced after exertion of physical power or use of mental effort”</i> (Tseng et al., 2010).
Central fatigue	<i>“the failure to initiate and/or sustain attentional tasks (‘mental fatigue’) and physical activities (‘physical fatigue’) requiring self-motivation (as opposed to external stimulation)”</i> (Chaudhuri & Bevan, 2000, pp35).
Peripheral fatigue	<i>“the inability to sustain a specified force or work rate is limited to exercise or physical activity and there is little loss of endurance in mental tasks”</i> . (Chaudhuri & Bevan, 2000, pp34).
Cognitive (mental) fatigue	<i>“A transient increase in mental exhaustion resulting from prolonged periods of cognitive activity. Cognitive fatigue can be described as feelings of mild to extreme mental exhaustion which can last anywhere from several hours to days and is often felt as a rebound effect after mental exertion”</i> (Wylie and Flashman, 2017).
Psychological fatigue	<i>“Lack of interest or poor motivation”</i> (Staub and Bogouslavsky, 2001)

### 3.5.2. Measuring fatigue.

This diversity of terms used to classify fatigue within the research literature confounds the measurement of fatigue and the evaluation of fatigue interventions, making it difficult to draw

conclusions about ABI fatigue (Wylie and Flashman, 2017; Acciarresi, Bogousslavsky and Paciaroni, 2014; Nadarajah and Goh, 2015; Kisala et al., 2019). Currently, fatigue is measured through subjective reports of the frequency, severity, or impact of fatigue (Beaulieu Bonneau et al, Wylie et al 2017). Objective assessment of central fatigue (particularly mental fatigue) outside of laboratory conditions has not yet been established because of the disparity between subjective reports of fatigue and objective markers of fatigue (Beaulieu-Bonneau and Ouellet, 2017; Ashman et al., 2008).

### Subjective measures of fatigue

There are a plethora of subjective fatigue measures available to researchers, with considerable variation in constructs captured by each fatigue measure (Wylie and Flashman, 2017). Many of the fatigue measures used with the ABI population have been developed for use in health conditions other than brain injury and may not reflect ABI specific features of fatigue or distinguish between the impact of fatigue on daily functioning, as opposed to that of cognitive and physical dysfunction (Mead et al., 2007; Visser-Keizer et al., 2015; Mills et al., 2012).

The limitations of fatigue measures are illustrated by Skogestad et al.'s systematic review of Patient Reported Outcome Measures (PROMS) used in studies of post-stroke fatigue. They completed a qualitative content analysis of the most used fatigue measures in the research literature (11 PROMS) and recorded 83 items across four dimensions of fatigue: fatigue severity, interference, characteristics, and management. They reported little overlap in the dimensions measured by the PROMS and questioned the content validity of the three most reported measures (fatigue severity scale, SF36 vitality scale and the VAS-F). On the whole, measures conflated other stroke-related impairments with fatigue symptoms and did not capture the variability or trajectory of fatigue, or factors that exacerbate fatigue. The authors conclude that the limitations of current approaches to fatigue measurement are such that they impede the progress of fatigue research (Skogestad and Lerdal, 2019).

Whilst Skogestad et al. considered the constructs measured by fatigue PROMs, they did not consider another important dimension of fatigue: that is the difference between fatigue experienced in-the-moment (state fatigue) and the tendency to be fatigued (trait fatigue) (Wylie and Flashman, 2017). Wylie and Flashman argue that measures of trait fatigue (where the respondent is asked to recall their fatigue experiences over a designated period) are flawed because the response is likely to represent a confluence of fatigue, depression and cognitive dysfunction, rather than fatigue alone. Attempts to summarise fatigue experiences over time may also result in individuals reporting beliefs about their symptoms, rather than the experience of symptoms (Van den Bergh and Walentynowicz, 2016; Broderick et al., 2008). Additionally, retrospective measures of fatigue are subject to recall bias, with responses shaped by the respondent's current emotional state (Heron and Smyth, 2010). Whereas self-reports of state fatigue are more likely to reflect fatigue alone and be more closely related to fatigue-related behaviour (for example, whether to continue with an activity or whether to stop and rest) (Wylie and Flashman, 2017).

Because of these issues, measures of state fatigue potentially provide a detailed picture of how fatigue severity fluctuates, but they are situational, that is they capture fatigue in real-time in whatever context the measurement is taken (Wylie and Flashman, 2017; Tseng, Gajewski and Kluding, 2010). Repeated measurement of state fatigue over time is advantageous in capturing the variability of fatigue but also in linking state fatigue to daily life situations, thereby enabling the investigation of fatigue and fatigue-related behaviour. Hence, whilst measures of state fatigue do not directly tell us about levels of participation, their use may reveal connections between fatigue and daily activity choices which then contribute to participation, as illustrated in a recent study by Lenaert et al (2020).

Lenaert et al. sampled self-reports of state fatigue and activity of 26 stroke survivors over six days, using ecological momentary assessment (Lenaert et al., 2020). Lenaert found that levels of physical activity and perceived effort predicted greater fatigue both at the time of assessment and up to four

hours later. Group average ratings of fatigue were highest when participants were resting and lowest when engaging in physical activity, indicating that state fatigue influences activity choices. Perceived effort and low enjoyment were associated with increased fatigue at the same time point, suggesting that increased fatigue affects the participant's disposition towards the activity. The type of activity engaged in did not predict fatigue scores two hours later. Increased perceived effort predicted fatigue scores for up to four hours, but no variables predicted fatigue at four hours or more. These findings suggest subtle interactions between fatigue and activity, but these seem to be short-lived. Lenaert did not explore fatigue as a predictor of activity and this relationship is a necessary part of evaluating the effect of fatigue on activity and participation.

When examining individual responses and patterns of fatigue, Lenaert found differential responses to physical activity, where respondents reported higher or lower levels of state fatigue after self-reports of physical activity ("I have been physically active since the last beep"). Lenaert suggests that this demonstrates a need for individualised approaches to fatigue assessment and intervention. However, it is unclear as to how participants defined their physical activity, and this may have biased the results. A more objective measure of physical activity is needed to clarify the relationship between physical activity and state fatigue.

Whilst this study has its limitations (the relatively short sampling period, non-probability sampling and small sample size), it illustrates the benefit of repeated measures of subjective states and activity (using an intraindividual approach to analysis) in establishing the relationship between fatigue and activity after ABI.

#### Self-monitoring of fatigue

With regards to assessing the impact of fatigue in clinical settings, paper-based activity diaries are used to assist ABI survivors in monitoring their fatigue experiences of patients in daily life (Mohr, 2010). Activity diaries may provide a distorted picture of fatigue experiences as they often rely on retrospective accounts of activities and fatigue responses (Huguet et al., 2015) and cognitive or



memory deficits after ABI potentially limit the frequency and accuracy of reporting. For example, Vanroy and colleagues compared data from self and proxy completed activity diaries with data from accelerometers for 15 stroke survivors during their inpatient stay. They found poor correlations between accelerometer data and diary data, and between activity diaries (completed by the patient compared to those completed by observers). The data from activity diaries indicated greater levels of activity than that recorded by the accelerometers, whilst stroke survivors reported lower levels of engagement in light physical activities than their observers. Vanroy and colleagues suggest that light activity is more short-lived and less memorable than sedentary or moderate activities (Vanroy, 2014). However, the sample size for this study was small and represented inpatients experiences, thereby affecting the wider generalisability of the results. Nevertheless, it seems likely that the use of activities diaries in community settings would further exacerbate the inaccuracy of activity diary data because of the complexity of daily life.

Self-monitoring of symptoms using mobile apps is a growing area of mHealth but to the best of this author's knowledge, none have been developed for monitoring fatigue after brain injury (Birkhoff and Smeltzer, 2017). Hence the use of an ecological momentary assessment app in clinical settings and daily life may have therapeutic benefit as it provides more detailed and accurate information about individuals state fatigue in the context of their daily activities and environments (Lenaert *et al.*, 2020).

#### Objective measures of fatigue

As noted in the previous section, objective, measurable signs of post-ABI fatigue are yet to be established, particularly for mental fatigue (Leavitt, 2010; Kuppawamy, 2017). Leavitt *et al.* (2010) suggest that attempts to measure mental fatigue rest on the assumption that fatigue results in an observable deterioration in performance over time (i.e. fatigability) and that this deterioration is associated with subjective reports of fatigue. However, evidence suggests that subjective fatigue is associated with poorer performance overall, particularly with regards to response times and

vigilance (Ashman et al., 2008; Belmont, Agar and Azouvi, 2009; Sinclair et al., 2013; Pearce et al., 2016).

Ashman et al (2008) investigated the hypothesis that a decline in performance was associated with state and trait measures of fatigue. They measured fatigue in 204 participants with TBI and 77 non injured controls, following repeated administration of a cognitive test battery. Whilst there was no association between changes in performance and state fatigue, they noted that both state and trait fatigue were associated with response speeds on two reaction time tests. (Ziino and Ponsford, 2006) and (Sinclair et al., 2013) also investigated vigilance and fatigue in TBI survivors and similarly reported associations between state fatigue and slower response times over the whole task or fatigue and increased variability of performance than that of non-injured controls. Decremental performance was not associated with fatigue, although Ziino examined the results of a subgroup of participants (those reporting high levels of fatigue) and found that reaction times increased towards the end of the reaction time test (Ziino and Ponsford, 2006). In addition, Ziino reported no association between response speed and scores on the fatigue severity scale.

Whilst these studies indicate an association between response times and state fatigue, it is unclear whether slow response times and, by implication, slow processing speeds are a result of mental fatigue or whether slow processing times contribute to mental fatigue. Significantly slower information processing speeds after ABI have been widely reported in the literature (Mathias and Wheaton, 2007; Ponchel et al., 2015).

It is important to note that the literature about fatigue and reaction times in the ABI population is not conclusive. (Kuppuswamy et al., 2015) reported no association between reaction times and trait fatigue (as measured by the fatigue severity scale) in 41 stroke survivors but state fatigue was not measured and this could explain their discrepant results.

Nevertheless, these studies suggest the potential for a simple reaction time test (such as the psychomotor vigilance test) to be used as an objective measure of state fatigue after ABI, assuming that state fatigue and fatiguability are separate constructs.

### 3.6. Factors associated with fatigue after ABI

Adding to the complexity of measuring ABI fatigue, is the association of fatigue with other sequelae of brain injury and the challenge of distinguishing fatigue from conditions with overlapping symptoms, such as depression or cognitive dysfunction (Cantor et al., 2008);(Johansson, Berglund and Ronnback, 2009). Furthermore, there is considerable overlap of factors associated with participation after ABI and factors associated with fatigue. Three reviews summarise the research evidence of associations with fatigue after stroke and fatigue after TBI. Cantor et al undertook a qualitative literature review of TBI fatigue and reported depression, pain, cognitive, emotional and physical functioning and sleep disorders to be strongly associated with fatigue (Cantor, Gordon and Gumber, 2013). However, the review was not conducted systematically as it was intended to provide an overview of fatigue. Hence it presents an incomplete picture of factors associated with fatigue. Mollayeva et al.'s more rigorous systematic review of the literature presented a narrative description of 22 studies and found depression, sleep disturbance, anxiety and poor physical and mental health to be associated with fatigue. But, as there was no further synthesis of the data, the review does not indicate which of these factors has the largest effect size on fatigue (Mollayeva *et al.*, 2014).

Ponchel et al's systematic review of factors associated with fatigue after stroke similarly summarise associations found in the literature. Whilst they reported mixed results in associations between fatigue and age, coping styles, attention and processing speeds, sleep disorders, or lack of social support, the evidence supporting associations between fatigue and depression, anxiety or greater dependency was more conclusive (Ponchel et al., 2015). These reviews indicate that there are several biological and contextual factors associated with fatigue and that no single factor causes fatigue.

Together these studies highlight the complexity of fatigue and its impact on participation and the necessity of considering fatigue alongside other consequences of brain injury.

### 3.7. Conclusion

Participation in life situations is a complex multidimensional concept that is variably affected by acquired brain injury. Fatigue emerges as a common consequence of ABI that has the potential to disrupt satisfactory participation. However, fatigue is also a multidimensional construct that is poorly defined, thereby posing challenges to its effective measurement and, in turn, hindering the evaluation of fatigue interventions.

Current clinical guidance to address problematic and persistent fatigue after ABI recommends educational and self-management approaches to managing fatigue with activity scheduling as a recommended component of self-management strategies (Marshall et al., 2015; Intercollegiate Stroke Working Party, 2017) but, as discussed in this chapter, current approaches to understanding an individual's daily experience of fatigue and activity are limited. The relationship between fatigue and participation is unclear, as is the effect of fatigue on performance. The most widely used approaches to the measurement of fatigue focus on trait fatigue but this approach fails to account for intraindividual variations in fatigue experiences. However, distinguishing state fatigue from trait fatigue, and repeated measurement of state fatigue in the context of daily activities, offers opportunities to investigate the daily dynamics of fatigue and activity after ABI. The addition of an objective marker of fatigue (such as a simple reaction time test) offers opportunities to examine the relationship between subjective fatigue, performance, and activity in the context of daily life.

It is therefore vital to explore how living with fatigue shapes ABI survivors' participation in everyday activities as well as the strategies used to cope with fatigue in everyday life. A more in-depth understanding of the way ABI survivors' perceive and manage their fatigue is also required to inform the development of a more effective measurement approach, such as momentary assessment of fatigue. Consequently, the next chapter presents the findings of a descriptive qualitative investigation into experiences of fatigue in daily life for people with ABI.

## Chapter 4: Experiences of fatigue in daily life of people with acquired brain injury; a qualitative study

### 4.1. Chapter summary

This chapter reports on a descriptive qualitative study investigating fatigue after acquired brain injury. The study aimed to develop an in-depth understanding of how survivors of acquired brain injury (ABI) experience fatigue and how fatigue affects everyday life. Semi-structured in-depth interviews were conducted with 16 adults with ABI fatigue, recruited from support groups in South East England. Interviews were analysed using the Framework method. Four themes were developed: experiencing fatigue in the context of everyday activities, struggling to make sense of fatigue, coping with fatigue, adjusting social participation in the context of fatigue. Fatigue was comprised of mental, physical, generalised and motivational fatigue. Balancing fatigue against participation in daily activities was influenced by coping strategies and social support. Opportunities to socialize or participate in meaningful activities provided incentives for participants to push through their fatigue.

This study highlights the complex interactions that potentially mitigate the impact of fatigue on everyday life. Educational and self-management approaches to fatigue need to account for different types of fatigue in the contexts of an individual's daily activity. The findings indicate a role for in-the-moment assessment of fatigue that capture experiences of different types of fatigue and activity.

#### 4.1.1. Published paper relevant to this chapter.

Experiences of fatigue in daily life of people with acquired brain injury: a qualitative study. Ezekiel, L., Fields, L., Collett, J., Dawes, H., Boulton, M. *Disability and Rehabilitation* (2020), pp. 1-9. doi: 10.1080/09638288.2020.1720318.

### 4.2 Introduction

As discussed in the previous chapter, several qualitative studies have taken the phenomenon of fatigue after acquired brain injury as their main focus (Flinn and Stube, 2010; Kirkevold *et al.*, 2012; White *et al.*, 2012; Thomas *et al.*, 2019; Barbour and Mead, 2012). These studies reported fatigue as

different from that experienced pre-injury, disruptive to daily life and difficult to cope with because of uncertainty around when they would become fatigued, the intensity of the fatigue and the overall trajectory of fatigue (Eilertsen, Ormstad, and Kirkevold, 2013; Theadom *et al.*, 2016; White *et al.*, 2012; Thomas *et al.*, 2019). Processes of coping and adjustment to living with fatigue have also been explored (Theadom *et al.*, 2016; White *et al.*, 2012; Flynn and Stube, 2010; Kirkevold *et al.*, 2012). However, only Barbour and Mead explicitly investigated participant perceptions of what makes fatigue worse or what helps alleviate fatigue. Our study was conducted in the early stages of recovery and focused on the inpatient environment. With this exception, there has been very little in-depth exploration of the specific contexts of how and when fatigue is experienced, particularly around how everyday tasks, environments and social contexts interact with fatigue experiences. A better understand of the contexts and manifestation of fatigue is essential for guiding choices around which constructs to include in a momentary assessment of fatigue and daily situational factors.

Reflexivity on the part of qualitative researchers is important in understanding and addressing their prior assumptions and in ensuring the trustworthiness of the study's findings. As none of the qualitative studies referred to above include researcher reflexivity, it is not clear how the researcher's prior assumptions shaped the interview schedules, analysis and subsequent findings. This absence of reflexivity, therefore, calls into question the trustworthiness of the studies' findings (Probst, 2021; Tong, Sainsbury and Craig, 2007).

#### **4.2. Research aims**

This study aimed to develop an in-depth understanding of how ABI survivors experience and cope with fatigue, and how fatigue affects their everyday lives.

#### **4.3. Methods**

The study was approved by the Oxford Brookes University Research Ethics Committee (150954).

#### 4.3.1. Study Design

The study design was a descriptive qualitative study (within the constructivist paradigm) of participants' experiences of fatigue after acquired brain injury. In the constructivist paradigm, knowledge is constructed by individuals as they make sense of their experiences. This means there are multiple social constructions of meaning and knowledge that can only be known through understanding individuals' lived experiences (Schwandt, 1998). Hence semi-structured interviews were used to elicit participant's accounts of their fatigue and the causes and consequences they attribute to fatigue.

Qualitative descriptive design was chosen as the approach for this study because it best matched the research aims: that is, to provide detailed descriptive accounts of participants experiences of fatigue (Kim, Sefcik and Bradway, 2017). With this approach, the researcher's analysis stays close to the surface of the data rather than aiming for complex abstraction of data and generation of theory (Sandelowski 2000). Interpretation of data occurs, but at a lower inference than approaches such as ground theory or phenomenology (Sandelowski 2000). With qualitative descriptive design, the phenomenon under study is presented from the participant's view and in the participant's language (Neergaard *et al.*, 2009; Colorafi and Evans, 2016). Hence it is a suitable approach for generating data to guide the development of an assessment tool (Neergaard *et al.*, 2009).

Qualitative descriptive design is not wedded to a specific sampling strategy or method of analysis, and so allows flexibility for the researcher to make pragmatic decisions about the choice of methods (Colorafi and Evans, 2016). For example, the Framework Method was chosen for the analysis strategy because the process of analysis is documented in detail, it enables the researcher to manage large amounts of data through the use of summary matrices, and the research team had prior experience of using the Framework Method, making it a resource-efficient choice.

#### *4.3.2 Reflexivity- the research team and research assumptions.*

Sandelowski (2010) described qualitative descriptive design as the least theoretical of qualitative approaches as it is not tied to one theoretical framework. It is therefore essential that researchers are transparent regarding their underpinning assumptions.

The author (LE) alone had contact with participants and conducted all interviews. LE is a lecturer in occupational therapy with an MRes in Social Research and previous experience of qualitative interviewing and of working with people with brain injury. MB is a Professor in Health Sociology and experienced in the use of Framework as a method of analysis. LF is a research assistant, studying for a BSc in Occupational Therapy.

LE's prior assumptions were shaped by the tenets of occupational therapy, the biopsychosocial model of disability and general systems theory. These assumptions are that health and functioning arise from interactions between environmental, physical, behavioural, psychological, and social factors; that an individual's daily activities and participation contribute to their sense of self, their social relationships and their long term health and well-being (Wilcock, 1999). But the activities and opportunities available to an individual depend not only on their abilities but also on their physical, social and cultural environments. Hence relationships between person, what they do (their occupations) and their environments are transactional (Law *et al.*, 1996; Noreau and Boschén, 2010). These assumptions shaped the qualitative study through the questions asked and through the analytical process. For example, when a participant talked about work being tiring, the interviewer was curious as to how work was tiring.

*“And you talked a bit about the way that work sort of made you tired. What was it that was most tiring about work?”*



### ***4.3.3 Researcher position***

LE conducted the interviews either at the participants home or in a quiet room at their day centre. Using a familiar and comfortable space aimed to help participants feel at ease. Whilst LE's research position was outside that of the participant's experiences, her familiarity with rehabilitation settings and recovery post-ABI supported a deeper understanding of participants experiences. LEs experience as a therapist and her working-class roots mean she is adept at helping others feel at ease and successfully adapts her communication across social classes and backgrounds. These experiences and skills facilitated rich conversations with the study participants.

### ***4.3.4. Recruitment of study participants***

Participants were recruited from five stroke and head injury support groups across three counties in England using a purposive sampling strategy to capture people with a broad range of fatigue experiences after brain injury. We aimed to recruit adults of working age or retired, with different types of acquired brain injury, at varying times post brain injury. Individuals were eligible to participate in the study if they were aged 18 or over, reported problematic fatigue following acquired brain injury, able to give informed consent, and able to communicate sufficiently to participate in an interview.

Individuals were excluded if they had a diagnosis of another health condition that is known to cause fatigue, were taking medication where significant fatigue was listed as a side effect, unable to give informed consent, or unable to communicate sufficiently to participate in an interview. Participants were recruited between December 2015 and April 2017.

### ***4.3.5. Data collection***

Written informed consent was obtained from each participant before data collection. Semi-structured interviews were conducted, and questionnaires completed either at the persons home or in a private space at the relevant day service. LE interviewed all participants using a flexible semi-

structured interview guide (Rubin and Rubin, 2012). The semi-structured interview guide was developed following consultation with ABI survivors to address the research question and objectives. It consisted of open questions and prompts organised around three key topics: experiences and manifestations of fatigue, the impact of fatigue on daily routines and activities, and adapting to living with fatigue (Appendix E). Participants were asked to describe the circumstances in which they noticed feeling fatigue, their perceptions of what triggered or exacerbated their fatigue, or what helped to prevent or reduce fatigue. Interviews lasted between 15 and 90 minutes and were audio-recorded and then transcribed by LE and LF.

Participants also completed three questionnaires: a short demographic questionnaire which included participant's gender, age, length of time since brain injury, and type of injury, home circumstances and employment status; the FSS (Krupp *et al.*, 1989); and the EQ5D-5L health questionnaire (Herdman *et al.*, 2011) Appendix F).

The FSS measures the degree to which fatigue interferes in everyday life (Lerdal and Kottorp, 2011). It has good psychometric properties (Whitehead, 2009) and is suitable for use with people with acquired brain injury (Ziino and Ponsford, 2005; Valko *et al.*, 2008). The FSS consists of nine questions and is scored on a seven-point Likert. A mean score of four or more indicates fatigue severity above that expected in healthy populations (Valko *et al.*, 2008).

The EQ-5D-5L is a health-related quality of life questionnaire which measures perceived health overall and problem severity across five domains (mobility, self-care, usual activities, pain/discomfort and anxiety/depression.) The EQ-5D-5L is scored on a five-point Likert scale with where 5 indicates no problem and 1 indicates a severe problem. It has been validated for use with people with long term health conditions, including stroke (Janssen *et al.*, 2013).

Interviews were analysed concurrently with recruitment. After 16 interviews, LE reviewed the data to establish whether data saturation had been achieved and the research objectives met. As no new codes had been added for the final three interviews, the decision was taken to end recruitment.

#### **4.3.6. Data Analysis**

Interview transcripts were analysed using the Framework Method (Ritchie *et al.*, 2013) and data were managed in NVIVO. The Framework Method is a type of thematic analysis that involves the reduction of interview data into matrices and enables the researcher to analyse data within and across participants (Ritchie *et al.*, 2013). It is a rigorous and systemic approach to data analysis that involves five stages: familiarisation with the data, identifying an analytical framework to code the data, indexing (applying codes), charting (summarising interview data under themes), mapping and interpretation (Ritchie *et al.*, 2013). The Framework method is a suitable approach for research where the analysis may be both inductive and deductive (Gale *et al.*, 2013).

Interviews were transcribed by LE and LF and then checked for accuracy against the audio recording. LE and MB independently coded the first five interviews and then compared and discussed coding. Through this discussion, codes were grouped into categories (broad categories and sub-categories) and these categories formed the initial analytical framework. The framework categories were also informed by the topics within the interview guide. The framework was piloted on the first three interviews and then further refined through peer debriefing with MB. LE then applied the revised analytical framework to all interviews and any new codes arising from subsequent interviews were added to the framework. Once the final analytical framework had been applied to each interview, LE created five matrices, one for each broad category. The broad categories were experiences and effects of brain injury, contexts in which fatigue was experienced, how fatigue was experienced, responses to being fatigued, the effects of fatigue on daily life. Each matrix consisted of columns of subcategories and rows which corresponded to each interview. For each interview, all data within each subcategory were charted into the corresponding cell of the matrix (see Table 4.1). This process

reduces the data and allows the researchers to look for patterns in the data and analyse the data across and within cases.

During the process, LE looked for patterns in how fatigue was experienced over time, configurations of contexts that shaped the impact of fatigue on daily life, types of activity or features of activity that were perceived as tiring, and patterns in the manifestation of fatigue.

For each matrix, LE then examined the charted data and identified dimensions of the data which were then grouped into broader themes (Table 4.2).

Table 4.1. Example of the charting stage of Frameworks method: excerpt of charted data within the 'Contexts of fatigue experiences' matrix

<b>Subthemes</b>	<b>Interview transcript:</b> participant 8: age 20-29, traumatic brain injury, more than 5 years post-injury
Perceived causes of fatigue.	Walking with balance problems makes him tired. Travelling to Headway on buses as well. Being in " <i>really noisy places</i> " is tiring. Using the laptop to do tasks for the charity
Contexts where fatigue is not experienced	Not discussed
Fatiguing Cognitive activities	Using the laptop, trying to remember how to do things is tiring. Working on the checkout at the supermarket. " <i>I get really tired and then my concentration my focus starts to dip.</i> "
Fatiguing physical activities	Walking tires him out so he uses buses a lot. " <i>I can't really afford not doing that cause it's my only way of getting about</i> ". Doesn't do a lot of sport because that tires him out also.
Experiences of fatigue at work.	Working at the checkout at a local supermarket. Got really tired and found concentration difficulty. Struggles to keep focus and not be distracted.

Table 4.2. Example of the interpretation stage of Frameworks method: higher-order abstraction of data analysis

Interview	Charting of interview in subtheme: perceived causes of fatigue	Elements	Dimensions	Theme
Participant 8	Walking with balance problems makes him tired	balance affects fatigue	Interaction between impairment and fatigue.	Struggling to make sense of fatigue

	Travelling to Headway on buses as well.	Travelling on public transport.	Being in public places.	Fatigue in the context of everyday activities.
	Being in "really noisy places" is tiring.	Noisy environments.	Physical activity	
	Using the laptop to do tasks for charity work.	Using the computer.	Environment – noise	
	"Doing too much or too much at once, yeah I get quite tired".	Doing too much at once	Cognitive activities	
			Overexertion	Struggling to make sense of fatigue

#### 4.3.7. Trustworthiness

Peer review of the qualitative data analysis, an audit trail and a reflexive diary was used to ensure that the analysis was true to the interview data. For peer review, LE discussed the analysis and decision making in detail with MB throughout the analytical process. LF audited the analytical process by tracking themes back through each stage of the analysis to the interview transcripts and examined how representative the themes were of the original data. LF noted areas where she questioned the analytical process and these prompted discussion with LE and re-examination of the analysis.

## 4.4. Results

### 4.4.1. Characteristics of participants

Seventeen people agreed to participate in the study; one interview was not usable due to technical issues. Participants ranged from 28 to 79 years old and time since ABI ranged from six months to 28 years. Ten participants had experienced stroke, two both stroke and traumatic brain injury, and four had experienced traumatic brain injury (see Table 4.3). Results from the EQ-5D-5L show that participants experienced problems across a range of daily functions (figure 4.1). Four participants

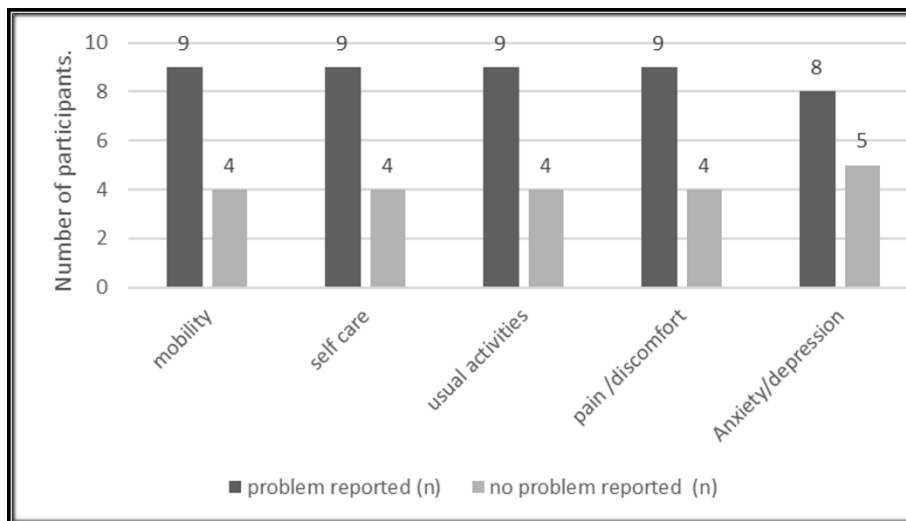
were still receiving physiotherapy or occupational therapy. Only two participants described being advised on how to manage their fatigue.

Table 4.3. Demographic information of participants

Participant	Age	Gender (male /female)	Time since ABI	Type of ABI	Lives alone (Y/N)	Works status	Mean score of fatigue severity scale*
1	72	F	Six months	stroke	n	retired	6.9
2	48	F	11 months	stroke	n	unable to work	6
3	76	M	28months	stroke	n	retired	6
4	66	M	5 years	stroke	n	retired	8
5	79	F	4 years	stroke	n	retired	4.8
6	55	M	24 years	TBI	y	retired	4.2
7	64	F	4 years	stroke	n	Self employed	missing data
8	28	M	16 years	TBI	n	unable to work	6
9	66	M	4 years	stroke	n	retired	7.8
10	60	M	28 years	stroke	y	unable to work	3.7
11	71	M	19 years	TBI	n	unable to work	5.2
12	37	M	8 years	TBI	n	employed	3.7
13	55	M	5 years	TBI and SAH	y	Unable to work	5.2
14	60	F	4 years	stroke	n	retired	5.1
15	59	M	11 years	stroke	y	retired	6.2
16	52	M	5 years	stroke and TBI	y	Unable to work.	6.4

\*Score of 4 or more indicates problematic fatigue.

Figure 4.1. Summary of participants scores on domains of EQ-5D-5L



4.4.2. Interview themes. Four major themes were derived from the analysis of the interview data.

These were: experiencing fatigue in the context of everyday activities, struggling to make sense of fatigue, coping with fatigue, adjusting social participation in the context of fatigue.

#### Theme 1: experiencing fatigue in the context of everyday activities

Most participants reported that what they did (activities) and where they did them (environments) shaped their experience of fatigue. Specific features of activities and environments that worsened or lessened their fatigue were identified. Only one participant was unable to do so because he identified fatigue as "always there" (Participant 10).

For many of the participants, everyday physical activities (for example, a short walk or light gardening task) now seemed to exacerbate fatigue.

*"But just getting dressed, I am worn out, simple tasks.... which everyone just takes for granted". (Participant 1, female, aged 71, stroke).*

Participants also felt fatigued during sedentary activities such as using the computer, reading, writing or completing administrative tasks. All these tasks led to mental fatigue as they involved

focused attention, information processing or multitasking. Coping with distractions and being interrupted whilst concentrating also worsened fatigue.

*"Umm distractions. I worked in an office upstairs on my own, and everyone else was downstairs. I'd start doing one particular job, part of a job, I'd get a phone call and so it's coming away and dealing with that. And I would have to really concentrate to think to go back to what I was doing. And then it's constant".* (Participant 2, female, aged 48, stroke).

In contrast, two participants described how physical exercise helped them to cope with their fatigue.

Participant 13 found that exercise tired him physically and this helped with his mental fatigue.

Another felt energised after exercise. Several participants also identified restorative activities such as listening to relaxation track or browsing on their computer.

*"But I was getting home [from the gym] and thinking oh I must do this; I must do that. More of an incentive to do something. It must be something to do with the exercise. Because even though I was tired I had more get up and go in me".* (Participant 13, male, 55, TBI).

Features in their environment such as artificial lighting, background noise and crowds also made fatigue worse. Participants were fatigued by the effort of concentrating as they struggled to follow a conversation when background music was playing.

*"I really don't like going shopping because there are too many people coming at me in all directions. I just can't cope with watching everyone. With crowds I can't cope with all the different sounds and voices, trying to listen to everyone. I just can't manage it anymore and it whacks me out."* (Participant 4, male, aged 66, stroke).

A few participants identified environments that offered temporary relief from fatigue because they felt relaxed or understood by others, as in the case of attending a stroke support group. Whilst others discussed participating in activities, they found restorative, such as listening to a relaxation track or browsing on their computer.

*"So the swimming pools are warm and then you've got beds you can sit on and have a cup of tea and cake. There's something also about the fact that it's relaxing".* (Participant 2, female, aged 48, stroke).

## Theme 2 Struggling to make sense of fatigue

Participants often struggled to make sense of their experiences as fatigue was both predictable and at times unpredictable, with variability in severity and the type of fatigue experienced. Many



participants were able to identify triggers that usually worsened their fatigue and often attributed their fatigue to “overdoing it”. Fatigue affected participant’s physical and cognitive performance as well as their social interactions with others.

The severity of fatigue fluctuated over a day or sometimes over several days. Many participants experienced fatigue in the middle of an activity or social event, whereas others described a sense of fatigue building over the week. One participant used a battery-powered toy analogy to explain how his fatigue seemed to build up over several days but each day his energy level dropped lower than before until finally, he had no energy left.

*“It starts off, pretty good. And you’ve got the power, but you gradually use up your power. And as each day’s amount of power you get dips, and you recharge, by sleeping. Dip. Like that. And it goes down and away. And then I’ll end up, having a day in bed”.* Participant 16, male, aged 52, stroke and TBI).

Others perceived fatigue to be sudden and overwhelming, forcing them to stop and rest.

*“You are running at 90 mile an hour and all of a sudden something’s there and you just bang and you are on the floor. Just everything drains. It’s like turning a tap on in your ankle and feeling everything draining out of you slowly. So by the end of it there is literally nothing left.* (Participant 2, female, aged 48, stroke).

Several participants were able to distinguish between mental or physical fatigue, whereas others experienced fatigue that was all-encompassing and difficult to describe. Several participants described difficulty motivating themselves and found they procrastinated more. They described “not wanting to do anything” or needing to marshal their mental resources when faced with a demanding task. At times this experience was complicated by the person’s disability as everyday tasks became more effortful.

*“I just can’t be bothered, you know? I’d rather sit and watch some pointless thing on the TV than actually get up and do anything. And I think a lot of it is because to do anything is difficult. It’s not as easy one-handed. But there’s a lot of one-handed people about and they manage. It’s Just this feeling of I can’t be bothered really. I’d rather sit here”* (Participant 5, female, aged 79, stroke).

When feeling fatigued, participants noticed changes in their thought processes, communication and movement. These changes were sometimes related to impairments that had resulted from their

brain injury. For example, participant 16 noticed how the hemiparetic side of his body weakened as he fatigued.

*“The more tired I get, the more I lean to the right. Like, when I’m sat down, relaxing, I start going over to the right. But, when I’m fatigued, I really go over and like, I can’t sit upright”* (Participant 16, male, aged 52, stroke and TBI).

Participants also found that fatigue negatively affected their ability to concentrate, process information or multi-task.

*“Well I think, I think it’s possibly the fact that I do stop communicating. And er I keep on walking down the road with my wife, when she talks to me I can’t concentrate on the two things, walking and talking. So that’s, I know I am getting tired and need a rest.”* (Participant 4, male, aged 66, stroke).

Other participants found fatigue affected their mood and they became irritable or were frustrated. Sometimes irritability was the first sign of fatigue.

*“I suppose it most probably manifests its self initially in annoyance. Which maybe accounts for some of the anger. Annoyance that I am feeling tired, annoyance that I can’t do as much as I had done previously.. its frustration that’s it’s happening to me again and then thinking ok that I’ve got to give in to it because my body is telling me that I am tired. And I must be tired even if it’s not physically its mentally.”* (Participant 9, male, 66, stroke).

### Theme 3: coping with fatigue.

Participants employed a wide range of strategies to cope with fatigue including both proactive strategies directed at minimising future fatigue and reactive strategies directed at recovering from fatigue.

#### *Proactive strategies*

Participants used proactive strategies to reduce the impact of fatigue on daily life by balancing the demands made on them against their available physical and mental resources. However, effective use of proactive strategies depended on the person’s ability to predict how effortful they might find an activity or event to be. This was sometimes hampered by memory impairments and by the fluctuating nature of fatigue which meant that achieving a satisfactory balance between activity and fatigue was an ongoing challenge.

*“I’m sort of, four and a half years in, and I’m still learning really to try and balance the tired- the fatigue, and what I want to do. And, what I want to do, right, is higher the fatigue levels [allow].” (Participant 16, male, aged 52, stroke and TBI).*

Proactive strategies involved planning and prioritising their activities, avoiding fatiguing situations, pacing themselves, and planning rests or short daytime "naps".

*“I try to pace myself, it doesn’t always work, having never done it before. But if you listen to your body then yes, I do have to take breaks during the day.” (Participant 14, female, aged 60, stroke).*

One participant stressed the importance of rest, hydration, and diet in maximizing his energy levels (Participant 12, male, 37, TBI).

### *Reactive strategies*

All participants used rest or sleep to recover from their fatigue. Resting could mean sitting quietly for half an hour, or resting in bed for a whole day, depending on the severity of the fatigue. Some participants also identified restorative activities such as listening to a relaxation track or browsing on their computer.

In situations where fatigue had become overwhelming, participants tended to use sleep to recover. For some, a short nap would suffice, whereas others needed to sleep for several hours. Participant 3 described the difference between “nipping it in the bud” and “hitting a brick wall”: with the former, she required a short rest and with the latter, she would need to lie down and sleep.

*“If I have washed the floor perhaps, I will come and have a sit-down and perhaps get the laptop out just go on the laptop and just go on eBay or something like that. And I am there for half an hour and will help me get my mind back in. You know it’s not really doing anything just window shopping.” (Participant 4, male, aged 66, stroke).*

Participants who used sleep as their main reactive strategy seemed to have less control over their fatigue. They described a lack of predictable routine as they slept during the day and were awake for extended periods at night. They then found themselves out of step with the outside world.

*“But now, I seem to have my days and nights mixed up. Sort of um, sleep all day and sort of have broken sleep at night. Which isn’t a surprise. I’d already had seven or eight hours sleep in the day.” (Participant 10, male, aged 60, stroke).*

### *Continuing despite fatigue*

For many of the participants, living with fatigue also meant knowing when to accept their fatigue and when to “push through” it. Participants described “keeping going for a few hours” but would then need to “wave the flag” to recover (participant 16, male, 52, stroke and TBI). Participants pushed through their fatigue for different reasons. Sometimes it was necessary because they wanted to attend a social event important to them, or because there was something they had to do and they didn’t want to disappoint friends or family. At other times, they simply did not want to give in to their fatigue.

*“I’m not going to not do something because I going to get tired. I would rather go for a walk for an hour, um and yes come home and need to lie down for an hour than sit here and not do anything” (Participant 2, female, aged 48, stroke).*

Other participants acknowledged that having “something to do” or the presence of another person, helped them to push through their fatigue but those who were alone, without any planned meaningful activities or events, could find this more difficult.

*“I spend a lot of time, too much time in bed because I ain't going anywhere. I just lie in bed. I've got the TV and computer next to me. If I get up, all I do is go and sit on the settee, so I think what's the point?” (Participant 13, male, age 55, stroke).*

### *Theme 4: adjusting social participation in the context of fatigue.*

Both fatigue and coping with fatigue had significant impacts on social participation. Participants described a process of balancing the risk of fatigue against doing what they needed or wanted to do. Their need to rest or sleep when fatigued was also factored into the process as participants cleared their schedule so they could rest before and after an event. This required them to make stark choices about how they spent their time.

Socialising with others was particularly affected by fatigue, often because participants found social settings tiring as they struggled to focus on and follow conversations.

*“We don't do a lot of socialising now. I can't take the noise; my brain can't filter the noise. Erm, we don't go to the cinema anymore. Again, I can't take the noise. Um I can't take*

*crowds – is a great problem for me. ... it's a battle. But we just grin and bear it. And bite the bullet and just get on with it." (Participant 14, female, aged.60, stroke).*

Some participants found ways around difficulties in socialising. They met friends at home or scheduled social events to earlier in the day. Others limited their contact with family members and found ways to exit the situation when they were tired. Participants with younger grandchildren all commented on how fatigue limited both what they could do with their grandchildren and how much time they could spend with them.

*"And I get, like with my little grandchildren, I get a great deal of pleasure out of them... But, after about two, two and a half hours, I need to be away from them, so I go and sit in the other room. Um, they can't understand it, of course, bless them. But they um, you know it's just too much, to take it all in".(Participant 11, male, 71, brain injury).*

Poignantly, participants found they were no longer able to take part in activities previously shared with family members and friends. This was exemplified by participant 2, talking about her daughter.

*"for many years I've worked backstage at every show they've (daughter and friends) ever done. No way I could handle all that [now] ... I would love to go back to the cinema, I and my daughter were always at the pictures. There's not a film that I know that I could go and watch on the big screen with the noise." (Participant 2, female, aged 48, stroke).*

Three participants felt that their fatigue prevented them from going back to work. Another participant was able to work part-time but found it made a significant impact on his life outside work. Participant 12 maintained his part-time job by following a set routine of early nights and by limiting his participation in other activities. To place this in context, he described needing eleven hours of sleep at night and to rest at midday so he could work for three hours a day as a cleaner.

*"Before I used to be a right lad around town, with my friends. We used to often be out late at night. But I can't do that anymore, I have to manage myself, just managing your sleep early ... About half past nine (evening) ". (Participant 12, male, aged 37, brain injury).*

#### 4.5. Discussion

This study explored the experiences of people living and coping with fatigue after an acquired brain injury, in the context of their daily lives. ABI fatigue was found to consist of subtypes of fatigue that were differentially associated with specific activities, events or environments. This study also

extends previous research on coping with fatigue by examining how strategies used to manage fatigue and incentives to overcome fatigue related to an individual's perception of coping.

#### *4.5.1. Subtypes of fatigue experienced in the context of daily activities*

In line with other studies, this study reports how fatigue after ABI substantially affects an individual's participation in leisure, community, social and work activities (Flinn and Stube, 2010; Theadom et al., 2016; Palstam, Törnbohm and Sunnerhagen, 2018). However, this study also demonstrates how the experience of fatigue among ABI survivors may be comprised of several different types of fatigue: mental, physical, generalised and motivational fatigue (i.e. a decline in the willingness to exert further effort) (Muller and Apps, 2019). The experience of physical and mental fatigue seems to be distinct from generalised fatigue or motivational fatigue. Physical and mental fatigue were both attributed to specific contexts. Physical fatigue was attributed to physical activity whereas mental fatigue was associated with activities or environments that taxed cognitive processes such as information processing (for example finding their way in a busy supermarket), dual- or multitasking (such as holding a conversation whilst getting dressed) and focused attention, as is often needed in a social setting. This suggests that different types of fatigue may affect different areas of participation and that the composition of overall fatigue may vary from one individual to another.

Several cohort studies have also reported the presence of these different types of fatigue after brain injury, as measured by multidimensional fatigue scales (Visser-Keizer *et al.*, 2015; Beaulieu-Bonneau and Ouellet, 2017; Ouellet and Morin, 2006). These studies reported varied results as to which type of fatigue, physical or mental fatigue, was most prominent whilst motivational fatigue was reported as less pronounced than other types of fatigue.

The attribution of excessive fatigue to specific activities or situations (for example socialising, physical exertion or coping with noisy environments) has been reported in previous qualitative studies (Flinn and Stube, 2010; White *et al.*, 2012; Kirkevold *et al.*, 2012). However, as discussed in chapter 4, a causal relationship between daily activity and fatigue has not yet been established in

quantitative studies. It has been previously argued that fatigue changes how an individual participates in daily activities rather than the frequency of activity and hence the effect of fatigue would not be shown by comparing fatigue scores against measures of daily activity (Cantor et al., 2008).

In this current study, several ABI survivors changed social activities to avoid exacerbating fatigue, either by meeting friends at home or by avoiding the activity completely. This is in line with a study by (Törnbohm, Lundälv and Sunnerhagen, 2019), who interviewed eleven stroke survivors about their experiences of participation seven years post-stroke. Fatigue and lack of energy were reported as barriers to socialising, with stroke survivors managing their fatigue by limiting social contact and engaging in solitary activities either before or after the social event. These findings are supportive of the assertion that state fatigue is closely related to behaviour and by extension, activity choices (Wylie and Flashman, 2017). This is important because the assumption that what individuals do affects their fatigue underpins many fatigue management strategies (Barker-Collo, Feigin and Dudley, 2007). Hence assessing fatigue and activity as they occur throughout the day may help to establish the nature of the relationship between fatigue and activity and to understand which fatigue management strategies are most effective at minimising fatigue whilst supporting social participation.

Taken together, these findings suggest that it may be more helpful to view fatigue as an umbrella term that includes subtypes of fatigue, recognising that each sub-type may have different symptoms and consequences for participation in daily life (Cantor, Gordon and Gumber, 2013) and may require different intervention approaches (Ormstad and Eilertsen, 2015). The findings also underscore the importance of considering state fatigue when assessing the impact of fatigue on daily life.

#### ***4.5.2. Balancing fatigue and participation in daily life***

Participants in this study were engaged in an ongoing process of balancing their fatigue against their participation in daily activities and the efficacy of this process formed a continuum. At one end of

the continuum, participants were mostly satisfied with the balance they achieved and felt their fatigue was under control. At the other end, participants felt their fatigue dominated their life and they struggled to cope. The types of strategies used to overcome fatigue and the specific incentives for wanting to do so may influence how well controlled an individual perceives their fatigue to be.

### Strategies to manage fatigue

In line with other qualitative studies of living with fatigue, this study found that strategies such as daytime sleep, resting, avoidance of triggers and pacing were frequently used to mitigate the impact of fatigue (Eilertsen, Ormstad and Kirkevold, 2013; Theadom *et al.*, 2016; White *et al.*, 2012). Energy levels were also considered alongside fatigue as participants used strategies to manage their energy, either by pacing or by engaging in restorative activities. The concept of energy as a resource also appears in White *et al.* (2012) and Theadom *et al.*'s (2016) qualitative studies of fatigue, although it is unclear whether the concept originated from the participants or the authors.

It was notable that participants who perceived themselves as unable to cope with fatigue relied predominantly on reactive and avoidance strategies, reported less structure in their daily routine, described limited social participation and often lived alone. This finding challenges Eilertsen, Ormstad and Kirkevold (2013) who suggested that difficulties coping with fatigue arose because strategies such as rest and sleep were not sanctioned socially and were therefore resisted. However, rather than resisting sleep, participants in this study were often overwhelmed by their need to sleep, which then limited their engagement in everyday activities (Theadom *et al.*, 2016).

However, the current study could not determine whether the severity of fatigue drives participant's reliance on reactive strategies (particularly daytime sleep), whether negative coping strategies contribute to the severity of fatigue or whether other factors (such as social isolation, lack of meaningful roles or the complexity of disability experienced) contribute to a negative cycle of fatigue and overuse of reactive strategies. Avoidant and emotion-focused coping styles have also been



associated with greater subjective fatigue after ABI in studies but the direction of the relationship is unclear (Ponchel *et al.*, 2015).

Nor is it clear whether lower levels of activity and social participation are a result or consequence of reliance on reactive coping strategies. However, social support and social contact have been linked to coping styles, so it seems likely that the relationship between social participation and coping strategies is reciprocal (Rochette *et al.*, 2006; Buono *et al.*, 2015). Further research is needed to understand these different patterns of response to fatigue and to determine whether levels of activity and participation are potentially useful targets for therapeutic interventions for fatigue (Beaulieu-Bonneau and Ouellet, 2017).

#### Incentives to overcome fatigue.

For many of the participants, opportunities to take part in activities or events that were enjoyable, rewarding or involved another person, sometimes provided incentives to push through fatigue, to keep active around the home or to participate in an event that would otherwise be too daunting. Kirkevold *et al.* (2012) also described how being mentally and physically active was used to transform and overcome fatigue after stroke.

These findings highlight how living with others is beneficial in maintaining activity levels and social participation as it provides reasons for individuals to overcome fatigue. However, living with others also complicates the management of fatigue as ABI survivors strive to be a productive member of the household, whilst hiding their fatigue. Eilertsen, Ormstad and Kirkevold (2013) described how stroke survivors were distressed by high expectations of family members, with one study reporting that a third of family members or significant others viewed the person as lazy (Norrie *et al.*, 2010). Both authors suggest that the behaviours and beliefs of significant others are detrimental to those struggling with fatigue. Several participants in the current study worried about being a burden to their family or partner and so tried to do as much as they could to relieve the burden.

However, it seems likely that pushing through fatigue is an important part of learning to manage fatigue in the longer term and the cumulative effect of increasing activity levels may help to reduce levels of fatigue (Beaulieu-Bonneau and Ouellet, 2017). An effective balance between activity and fatigue is often difficult to achieve, with ABI survivors fluctuating between doing too much or too little (Kirkevold et al., 2012). Hence ABI survivors and those that support them would benefit from education about how best to manage their fatigue whilst gradually increasing their activity levels. Further research is needed to establish whether interventions focused on education, strategy use, and utilising social support would reduce the long-term impact of fatigue of participation.

#### **4.5.3. Strengths and Limitations**

A key strength of this study was the diversity within the participant group with regards to the type of brain injury and the length of time since brain injury. This enabled examination of a broad range of experiences and may have relevance to a wider section of the brain injury population.

Strategies such as an audit trail, peer review and a reflective journal were also employed to support the analysis process and credibility of the findings.

However, whilst this study's sample was diverse in several aspects, there were no participants from black and minority ethnic backgrounds. There is evidence to suggest cultural differences in how fatigue is understood and so these findings can only be generalised to ABI survivors of similar cultural backgrounds (Karasz and McKinley, 2007).

This study's participants also experienced other health conditions and were taking a wide range of medications, some of which might exacerbate fatigue. However, this is reflective of clinical practice in that comorbidities are frequent after ABI (Chan *et al.*, 2017a; Fischer *et al.*, 2006) and fatigue is unlikely to be the sole difficulty.

#### 4.6. Conclusions and implications for further research and practice

This study adds to our understanding of fatigue experienced by individuals with ABI by highlighting the complex interactions between types of fatigue, coping strategies, everyday activities, and environments. As such the findings suggest potential areas for health professionals to consider when supporting individuals with ABI to manage their fatigue.

Understanding different types of fatigue and how these are exacerbated by activities and environments are necessary when advising on self-management strategies, particularly in relation to balancing fatigue with daily activity. Feeling unmotivated as part of the fatigue experience is important to consider when educating ABI survivors and carers about managing fatigue, as it helps to explain behaviour that might be construed as laziness, particularly if individuals fluctuate in what they feel able to do.

The role of sleep both as a proactive and reactive strategy also needs to be considered with regard to an individual's quality of sleep at night and the impact on everyday activities (Theadom et al., 2016). ABI survivors may need guidance on how to develop strategies that can be more easily applied in social settings. Furthermore, the use of personalised and nuanced coping strategies may help ABI survivors to participate in a wider range of daily activities and to increase their physical activity levels. Additionally, recognising the importance of participation in meaningful activities and access to social support may help individuals in breaking the negative cycle of fatigue and inactivity.

These findings reinforce the view that fatigue is a multidimensional concept, and that fatigue assessment should reflect the daily variability of fatigue and the contexts in which it occurs. There is now a need to move beyond the current limitations of fatigue scales and paper diaries and develop alternative approaches. In-the-moment assessment of fatigue within the context of daily life may be more beneficial in guiding self-management strategies, serve to increase ABI survivors' self-knowledge of fatigue patterns and triggers through self-monitoring of fatigue, and thereby facilitate faster and more effective adjustment to living with fatigue (White et al., 2012). Furthermore, in-the-

moment assessment of fatigue may help to understand the differences between those who manage their fatigue effectively and those to struggle to gain control of fatigue.

## Chapter 5. Smart ecological momentary assessment and user-centred design

### 5.1. Chapter summary

The previous chapter highlighted the need for more granularity in the measurement of fatigue and participation. This chapter introduces the EMA method for measuring subjective and objective fatigue and provides an overview of ecological momentary assessment (EMA), including the benefits and challenges of using and designing EMAs. A systematic search of three databases for EMA studies conducted in the ABI population was conducted, followed by a brief review of EMA methodology. In the absence of specific guidance on the development of smart EMA's, this chapter argues for the relevance of the user-centred design approach to developing smart EMAs. The chapter ends with the rationale for adopting a user-centred design approach to developing a smart EMA of fatigue after brain injury.

### 5.2. Introduction.

The previously discussed literature reviews of participation after ABI highlight the complexity of participation outcomes. Whilst multiple factors come together to shape participation outcomes, the nature of the relationship (how fatigue and participation interact) is unknown. Findings from the qualitative study of fatigue after ABI reinforce the within-person and between-person variability of fatigue severity and suggest daily situation factors (such as coping behaviours, activities, and environments) contribute to the experience of fatigue. Taken together with the limitations of more traditional approaches to capturing the severity and impact of fatigue on daily life (as discussed in chapter three), these points support the case for using repeated momentary assessment to gain a more nuanced and individualised understanding of fatigue and the circumstances in which fatigue occurs.

### 5.3. EMA and smart EMA

Ecological momentary assessment (EMA) is a “collection of assessments of subjects’ current or recent states, sampled repeatedly over time, in their natural environments” (Shiffman, Stone and

Hufford, 2008). EMA is also known as the experience sampling method or ambulatory assessment (Lenaert *et al.*, 2017). The essential features of EMA are repeated in-the-moment assessments conducted in the context of everyday life, rather than the specific method or technology used (Shiffman, Stone, and Hufford, 2008). EMA provides opportunities to explore experiences in the context of time, how the persons state changes over time, daily fluctuations, and potential relationships with daily situational factors (van de Ven *et al.*, 2017; Trull and Ebner-Priemer, 2009). EMA data may be analysed at the group level (between individuals) and at the individual level. Intraindividual analysis is particularly relevant when investigating phenomena that are highly variable, both over time and by the individual (van der Krieke *et al.*, 2015).

There has been considerable growth in the use of smartphones to deliver EMA in recent years, propelled by the widespread adoption of smartphones amongst the general population (van de Ven *et al.*, 2017; Cornet and Holden, 2018). Smartphone applications provide opportunities for passive data collection via smartphone sensors, can send and receive data and are capable of processing data. There is also growing interest in the potential use of EMAs as therapeutic tools for self-monitoring of health-related symptoms and behaviours (Heron and Smyth, 2010; van Os *et al.*, 2017; van de Ven *et al.*, 2017).

For these reasons, a smartphone application (app) was chosen to deliver an EMA of fatigue and activity. The focus of this chapter is the development of an EMA delivered through a smartphone app (also known as a smart EMA) (van de Ven *et al.*, 2017). The longer-term aim of developing a smart EMA is to support ABI survivors in monitoring their fatigue in the context of daily life.

### **5.3.1. Benefits of smart EMA.**

Since the first smartphone was launched in the UK in 2008, smartphones have become ubiquitous and are now owned by over 95% of adults under the age of 55 and 55 % of adults aged between 55 and 65 (O'Dea, 2019). Smartphones have been most quickly adopted by younger people but, more recently, there has been a rise in smartphone use of older adults with one in five people aged over

75 in the UK using smartphones (Ofcom, 2019). There is also evidence of increased uptake of smartphones by ABI survivors, with the increased use of smartphone calendars and apps to support daily living (Jamieson *et al.*, 2017; Wong *et al.*, 2017).

Self-tracking of health and lifestyle behaviours using apps and wearable technology has become widespread in developed countries (Maltseva and Lutz, 2017). This concept of using smartphone apps to collect lifestyle data means that smart EMA is now potentially accessible to a wider range of the population (Heron and Smyth, 2010). Smartphone use is also now pervasive in daily life as an increasing range of applications makes smartphones the most used digital device (Lee *et al.*, 2019). Hence smartphones provide a familiar way of delivering EMA and this increases the ecological validity of smart EMAs (Heron and Smyth, 2010).

It is important to note the difference between smart EMA and self-tracking. Self-tracking involves individuals collecting data about their health and behaviour, often with the goal of improving aspects of their life (Maltseva and Lutz, 2017; Almalki, Gray and Sanchez, 2015). Whilst self-tracking is generally comprised of continuous data collected from wearable or phone sensors, it may also include users' self-reports of their subjective states or complex behaviours (Maltseva and Lutz, 2017). Self-reporting in this context typically involves data being entered by the individual as and when they choose and consequently may be biased and unrepresentative of the individual's whole experience (Moskowitz and Young, 2006). Smart EMA's address some of the drawbacks of self-report by using sampling strategies to ensure more comprehensive coverage of the individual's experiences, and by using specific events to trigger a self-report. As assessments are conducted "in the moment", the biases associated with retrospective recall (such as the tendency to recall more memorable events or to be influenced by mood states) are reduced (Heron and Smyth, 2010; Beute, de Kort and Ijsselsteijn, 2016; Trull and Ebner-Priemer, 2009).

In addition, increased sophistication of smartphone technology and the integration of multiple sensors allows for EMAs to passively collect data on behaviour or environmental contexts; for

example, physical activity (using the accelerometer) or environmental data (for example noise levels through the phone's microphone), thus reducing the assessment burden on the user (Cornet and Holden, 2018). Hence smart EMAs have the potential to provide rich data about the within-day dynamics and contexts shaping an individual's experiences. This focus on data at the individual level may potentially reveal different patterns of experience which would be lost in group-level data analysis (Zheng *et al.*, 2013).

Finally, smart EMAs can be integrated into smart ecological momentary interventions (smart EMI) and used to support the delivery of bespoke behaviour change interventions and "just in time" interventions (Cornet and Holden, 2018; Kim *et al.*, 2019). Whilst several authors promote the therapeutic use of smart EMAs and EMI's in healthcare, it is an emerging area of practice in the field of ABI (van Os *et al.*, 2017; Heron and Smyth, 2010; Christopher, Alsaffarini and Jamjoom, 2019). A recent systematic review of mHealth apps for people with TBI reported relatively few apps available on iOS and Android platforms. Of 53 apps reviewed, only nine involved symptom tracking and management, with most being focused on sport-related concussion (Christopher, Alsaffarini and Jamjoom, 2019). The authors also reviewed studies evaluating the efficacy of mHealth interventions and found the evidence to be limited in both the number of studies and in study design, with case series being the most frequently used methodology. Further research is needed in the design and development of mHealth apps for use by ABI survivors and in evaluating the efficacy of interventions delivered via mHealth apps.

### ***5.3.3. Methodological challenges in the design of EMA for use in the ABI population***

The use of EMA to investigate the consequences of ABI is a relatively new area of research (Lenaert *et al.* 2017; Lassalle-Lagadec *et al.*, 2012). A systematic search of three databases (Medline, CINAHL and PsychInfo) completed in January 2020 resulted in 11 published EMA studies conducted with ABI survivors and one protocol. A further search on google scholar resulted in one newly published study.



These studies are summarised in Table 5.1 and will be used to illustrate the specific challenges of designing effective smart EMA's for use with ABI survivors.

There are currently no best practice guidelines to inform the design of EMAs, both in content and the scheduling of assessments (Soyster and Fisher, 2019). This means that the choice of assessment is dependent on the researcher's judgement or is informed by examining previous EMA studies.

However, it is essential that the components of an EMA capture the person's state at that moment, rather than a summary of retrospective experiences, and therefore the inclusion of most validated paper-based measures is precluded (Soyster and Fisher, 2019; Degroote *et al.*, 2020). This also makes it difficult to establish the validity of EMA constructs and data, as there may be little to compare the data with (Degroote *et al.*, 2020).

One strategy to increase the validity of EMA's is to build them around several single construct questions (such as visual analogue scales) rather than integrating multi construct questionnaires or bipolar scales. Single construct questions are advantageous because they are less prone to bias and less cognitively demanding (Beute, de Kort and Ijsselsteijn, 2016; Trull and Ebner-Priemer, 2009).

The choice of single construct questions should be guided by the research aims and by relevant evidence or theory that explains the dynamics of the phenomenon under investigation (Shiffman, Stone and Hufford, 2008). Soyster and colleagues also suggest identifying constructs through consultation with representatives from the target population, or healthcare professional with relevant expertise (Soyster and Fisher, 2019).

The use of single construct questions is the most frequent approach taken in EMA studies in the ABI population (see Table 5.1). A systematic search of three databases (Medline, Cinahl and PsychInfo) conducted on 21<sup>st</sup> January 2020 resulted in 14 articles reported EMA studies in the ABI population. Nine of the studies reviewed referred to previous EMA studies, a theoretical framework or adapted questions from validated questionnaires. Two studies did not offer any rationale for their chosen EMA constructs (Lassalle-Lagadec *et al.*, 2012; Lenaert *et al.*, 2020). Only one study described

consulting with health professionals and patients to inform the content of their EMA (Smith *et al.*, 2012).

When designing EMA components to capture complex phenomena (such as fatigue and participation), there are myriad of available constructs. Yet the EMA components should be parsimonious to optimise the balance of data collection and participant burden. The methods of choice described above are limited as adapting questions from standardised questionnaires means their established psychometric properties can no longer be assumed. When considering questions from previous studies, the researcher should consider how the constructs were chosen and whether they were informed by research evidence or theory (Soyster and Fisher, 2019). Consulting with “experts” in the area being assessed may help narrow the choice of questions down to those that are most pertinent to the area being investigated, thereby bolstering face validity.

As noted previously, establishing the validity of constructs measured with EMAs is problematic. Within the reviewed ABI EMA studies, several authors did not consider the validity of the EMA’s (Pacella *et al.*, 2018; Jean *et al.*, 2013). The most reported strategy was investigating the concordant validity of constructs (within the EMA) with standardised measures. However, the results were mixed, illustrating differences between measures of state and trait fatigue (Johnson *et al* 2009; (Mazure *et al.*, 2014; Juengst *et al.*, 2019; Johnson *et al.*,2009) also examined the intercorrelation of EMA components to assess the convergent validity of constructs and this may be a useful approach when constructs are expected to relate to each other. Whilst several studies delivered EMA on a smartphone, none of them utilised smartphone sensors. Yet data from smartphone sensors offer an alternative strategy for establishing the validity of relevant EMA constructs (Dubad *et al.*, 2018). Heron and Smyth (2010) also suggest combining self - reports with objective measures where possible. Only Johnson and colleagues (2009) included an objective measure in the EMA: they used a short working memory test, the results of which were predicted by participant’s mini-mental state examination scores.

Table 5.1 Summary of published EMA studies conducted in the ABI population

Reference	Focus of EMA	Health condition	n	Device	Duration of use	Number of alerts	Type of signal	Content of EMA
(Johnson <i>et al.</i> , 2009)	Activities, environment, social interactions, cognitive symptoms, stress, and emotional states.	stroke	48	PDA	7	4x daily	Signal contingent – random stratified	Single construct questions and a working memory test.
(Fitzgerald-DeJean, Rubin and Carson, 2012)	Psycho-emotional variables and communication	Chronic stroke	1	PDA	5 days per week for 6 weeks	4x daily	Signal contingent – random stratified	Positive-negative response scales.
(Smith <i>et al.</i> , 2012)	Pilot study feasibility of EMA – a two-part study using fixed and random alert schedules.	PTSD after TBI	27	PDA	Not reported	Once-daily	a. Random signal contingent b. time contingent	Questions adapted from existing standardised questionnaires
(Jean <i>et al.</i> , 2013)	Behavioural risk factors for depression	Stroke 3 month post	36	PDA	1 week	5x daily	Signal contingent – random stratified	Single construct questions.
(Lassalle-Lagadec <i>et al.</i> , 2012)	Relationships between daily life events and mood	stroke	15	PDA	7 days	5x daily	Signal contingent – random stratified	Single construct questions
(Lassalle-Lagadec <i>et al.</i> , 2013)	Associations between mood and cerebral atrophy	Stroke (acute)	12	PDA	7 days	5x daily	Signal contingent – random stratified	Single construct questions
(Mazure <i>et al.</i> , 2014)	Gender differences in mood reactivity	Stroke (acute)	43	PDA	7 days	5 x daily	Signal contingent – random stratified	Single construct questions
(Juengst <i>et al.</i> , 2015) (Juengst <i>et al.</i> , 2019)	Assessment of mood-related symptoms	TBI	20	Smart phone app	8 weeks	2-4 times per day	Signal contingent in 3-hour block	Existing standardised questionnaires and one single construct question.
(Villain <i>et al.</i> , 2017)	Evaluate social contacts, activities, depression symptoms and behaviour	Stroke (acute phase)	34	PDA	1 or 7 days	5x daily	Signal contingent – random stratified	Single construct questions
(Vansimaey <i>et al.</i> , 2017) protocol	Psychological health (depression, anxiety), coping	Minor stroke	40	Smart phone app	1 week repeat	4x daily	Signal contingent sent within	Single construct questions,

Reference	Focus of EMA	Health condition	n	Device	Duration of use	Number of alerts	Type of signal	Content of EMA
	strategies and quality of life				ed 3 times		2-hour blocks.	some adapted from standardised questionnaires.
(Pacella <i>et al.</i> , 2018)	Investigating the trajectory of post-concussion syndrome	Mild TBI		Text message via phone	14 days	3x daily	Time contingent	Single construct questions
(Lenaert <i>et al.</i> , 2017)	To assess the feasibility of high-density EMA using psymate device	TBI and stroke	17	Touch screen device	6 days	10x daily	Signal contingent - semi-random	Single construct questions
(Lenaert <i>et al.</i> , 2020)	EMA study of fatigue and activity after stroke during rehabilitation	stroke	30	Psymate app on a smart phone	6 days	10 x daily	Signal contingent – random stratified	Single construct questions

The protocol for sampling momentary experiences also needs careful consideration, particularly how assessments are triggered and the density of sampling. The sampling protocol aims to gather a representative range of the participant's everyday experiences and is therefore informed by the aims of the research, the dynamics of the experiences being assessed, and the time burden on participants (Shiffman, Stone and Hufford, 2008). Time burden is especially important to consider when constructing EMA of fatigue experiences because of the risk of causing distress or increasing fatigue. Additionally, if the EMA schedule is experienced as too disruptive, it affects completion rates and hence threatens the ecological validity of the study (Ram *et al.*, 2017).

There are multiple approaches to sampling, as outlined in Table 5.2. It is essential to minimise the overall burden of completing the EMA's on participants as this is likely to affect EMA completion rates. Hence the sampling protocol is often a compromise between the number of EMAs prompted

and the length of time taken to complete the assessments. The overall schedule should be acceptable to participants, but be sufficient to address the research aims, without draining the smartphone battery (Vansimaey *et al.*, 2017; Harari *et al.*, 2016).

Table 5.2 Types of EMA sampling (Fisher and March, 2012; Soyster and Fisher, 2019; Lathia *et al.*, 2013)

Type of sampling	Definition and examples
Signal contingent sampling	A fixed number of alerts sent per day but are generated randomly within specified parameters to avoid clustering in a narrow block of time.
Time contingent	The alert is sent at fixed time points.
Event contingent	An alert is triggered by a specified event, often triggered by phone sensors. For example, an alert is sent when the user changes location or activity levels. An event contingent report may be generated by the participant as they experience a specified event.
Continuous sampling	Describes automatic sampling completed by passive sensors or wearable devices. For example physical activity or heart rate.
Context sampling	Data from smartphone sensors are sampled at the time of the EMA to augment momentary assessments with contextual information.

Historically, event contingent sampling has depended on the participant completing an assessment when they experience a specified event (Shiffman, Stone and Hufford, 2008). However, momentary assessments can now be triggered by changes in data passively collected from smartphone sensors (Harari *et al.*, 2016). This type of event contingent sampling is advantageous because it means the momentary assessment and the experience or behaviour both occur in a very short space of time and the assessment is truly in the moment. Dunton and colleagues demonstrated the feasibility of using activity recognition data from smartphone sensors to augment EMA (Dunton, Dzubur and Intille, 2016). They investigated the physical activity levels of teenagers using a smart EMA and compared sensor data with physical activity data recorded on a waist-worn accelerometer, whilst asking participants the location of their phone. They acknowledged that phone sensors were less accurate than the accelerometer (particularly when capturing moderate physical activity), possibly

because participants did not carry their phones during exercise. Nevertheless, participants completed more of the sensor (event) contingent EMA's than the random signal contingent EMAs (85% completion rate versus 79% completion rate). The authors suggested that participants were more likely to be with their phone when notified of a sensor contingent EMA and therefore more likely to respond.

However, Dunton's findings also demonstrate a key drawback to the use of event contingent sampling. Non randomised sampling may lead to systematic bias in the data collected as the specified experiences are likely to be over-represented (Lathia et al., 2013). Furthermore, defining the algorithm to trigger an event contingent assessment is complex and needs careful consideration as it may result in too many or too few momentary assessments (Shiffman, Stone and Hufford, 2008).

In contrast, signal contingent sampling captures a range of experiences throughout the day but is more likely to miss infrequent experiences (Shiffman, Stone and Hufford, 2008). Time contingent sampling may be used to capture specific events, for example, subjective states on waking or before going to bed (Burke *et al.*, 2017). Combining different methods of sampling potentially resolve these issues but also allows researchers to investigate temporal relationships between events and subjective states (Shiffman, Stone and Hufford, 2008). In addition, context sampling may be used to prevent a momentary assessment from being triggered when it would be unsafe for the participant to respond (van de Ven *et al.*, 2017).

Within the ABI EMA studies, the protocols for signalling schedule were relatively simple, with most opting for signal contingent sampling. The number of signals sent ranged from one to ten assessments per day and completion rates ranged from 65% and 100% (Lenaert *et al.*, 2020 (Fitzgerald-DeJean, Rubin and Carson, 2012). Fitzgerald -DeJean and colleagues reported a 100% completion rate but with only one participant, their results are not generalisable. In contrast, Lenaert's study included a schedule of 10 alerts per day for six days and reported an EMA

completion rate of 65% after excluding two participants who completed less than 30% of the EMA's. Each EMA was estimated to take two minutes to complete. Leneart et al. (2020) demonstrated that higher density signal schedules are possible, but this may come at the cost of a reduced completion rate. Augmenting EMA with data from smartphone sensors and designing the EMA for greater user engagement offer solutions for reducing assessment burden whilst maintaining adequate sampling of experience.

Smith et al. (2012) compared the results of a random signal contingent protocol against a fixed signal contingent protocol (both scheduled for once daily) and found higher completion rates with the fixed signal. Study participants found the random signal too intrusive, but this may have been an artefact of using only one signal daily and using a personal digital assistant (PDA) to deliver the EMA. Participants had to carry an extra device with them and be on the alert for the single signal, which possibly added an extra burden on the user (Smith *et al.*, 2012).

Multiple daily data collections points involved in EMA also raises the possibility of assessment reactivity, where repeated EMA affects participants behaviour and experiences (Timmer, Hickson and Launer, 2017). Only Lenaert et al.'s (2017) study evaluated participants perceptions of assessment reactivity, through the administration of a questionnaire post data collection.

Participants did not report any influence of the EMA on their daily activities or daily mood. However, the result is questionable due to the possibility of both recall bias and social desirability bias.

There is currently insufficient evidence to determine the impact of assessment reactivity to fatigue measures in the ABI population (Lenaert *et al.*, 2017; Juengst *et al.*, 2015). However, assessment reactivity has been investigated in EMA studies of addiction and chronic pain, with mixed results. Schrimsher and Filtz (2011) review of assessment reactivity in alcohol studies demonstrated that alcohol consumption reduced as a result of repeated assessments. The authors concluded that EMA acts as an intervention because the individual's attention is focused on the phenomena under investigation, thereby enhancing their self-efficacy (Schrimsher and Filtz, 2011). In contrast, a study

by Stone and colleagues investigated assessment reactivity in participants with chronic pain and found no significant effects of repeated assessments on pain scores when compared to those of a control group (Stone *et al.*, 2003). Shiffman and colleagues opinion piece about EMAs suggests that assessment reactivity occurs when the individual is alerted to a behaviour and there is still an opportunity to change the behaviour (Shiffman, Stone and Hufford, 2008). Hence assessment reactivity may differ depending on the focus of the momentary assessment and potentially, whether the assessment captures behaviour or a subjective state. In the absence of definitive evidence of assessment reactivity, Heron & Smyth (2010) suggest mitigating the potential of reactivity by matching the density of an EMA schedule to the likely frequency of symptom or experience under investigation.

Finally, smart EMAs raise specific ethical concerns about participant privacy and data security (Heron and Smyth, 2010). Continuous sampling of phone sensor data is unobtrusive yet provides information about the user's activities, location and communications. It is therefore vital that data collection methods in EMA studies are transparent and participants fully understand (and have consented to) any passive data collection (Harari *et al.*, 2016). Privacy is best protected by collecting the minimum data necessary and by using behavioural inference data (i.e., extracting and abstracting information) as opposed to streaming raw data from the phone (Arora, Yttri and Nilse, 2014; Harari *et al.*, 2016). Also, the collection, transmission and storage of smart EMA data is complex and requires data to be encrypted, de-identified and password-protected to ensure continual data security at all stages of the study (Harari *et al.*, 2016).

In summary, this brief review of previous EMA studies conducted in the ABI population emphasises the importance of designing effective sampling protocols and incorporating strategies to assess the validity of EMA components and minimising assessment reactivity. The inclusion of objective data (for example augmentation of EMA with sensor data) and consultation with ABI survivors and experts in the design of EMA emerge as possible approaches to optimising EMA.



### 5.3. Approaches to the design of smart EMAs

Smart EMA is recognised as part of the broader field of mHealth (van Os *et al.*, 2017) and, within this literature, it is widely accepted that participant involvement in the design of mHealth products is essential for the successful adoption of the product by the target population (Matthew-Maich, Harris and Markle-Reid, 2016; Yardley *et al.*, 2015b; LeRouge and Wickramasinghe, 2013). User-centred design, in particular, has been suggested as an essential approach to increasing the acceptability of mHealth products (Matthew-Maich, Harris and Markle-Reid, 2016). However, as noted previously, decisions on the content and timing of EMAs have traditionally been made by the researcher and driven by theory or previous research (Soyster and Fisher, 2019).

#### 5.4.1. User-centred design

The user-centred design approach (UCD) evolved from the field of human computer interaction and was informed by cognitive psychology and participatory research (Lyon and Koerner, 2016). The approach was first comprehensively described by Don Norman in his book “The design of everyday things” (Norman 1988). Norman was a cognitive psychologist and a usability engineer who believed that understanding how individuals interact with an object was essential to improving their experience of using the object (that is the *usability* of the product). UCD is now widely used in the field of human computer interaction and across government and industry sectors (Dopp *et al.*, 2019). It has more recently appeared in healthcare development, particularly within eHealth and mHealth (Ghazali, Arrifin and Ridha, 2014).

UCD is a multidisciplinary approach that places information about the specified end-users needs, preferences and goals at the centre of the design process (Gulliksen *et al.*, 2003; Dopp *et al.*, 2019). It is founded on key principles of active user involvement at all stages of the design, and continuous iteration in response to user feedback and testing (Gulliksen *et al.*, 2003).

UCD consists of four broad phases: concept generation, design and development, evaluation, deployment (see Table 5.3) (McCurdie *et al.*, 2012). Projects might start at any of the first three

phases, depending on the nature of the project (BSI, 2019a). Each phase is suggestive of a range of activities, but these are not necessarily prescriptive. Factors affecting the usability of the end product are considered throughout the development process with a formative evaluation of usability shaping the next round of development.

The flexibility of UCD means it can be widely applied across diverse projects, but key aspects (such as active user involvement) are open to interpretation (Iivari, Isomaki and Pekkola, 2010; Yardley *et al.*, 2015a). Whilst effective active involvement of users is seen as increasing usability and acceptability of the final product, there is a lack of clarity as to the degree and manner of user involvement (McCurdie *et al.*, 2012; Dopp *et al.*, 2019).

Table 5.3. Phases of the iterative user-centred design process in mHealth (McCurdie *et al.*, 2012)

Phase	Suggested activities
1. <b>Concept generation and ideation.</b>	Ethnography Focus groups Surveys Interviews Task analysis Create user profiles Analyse user environments
2. Prototype design and system development	Design concepts Software simulations Working prototypes Development
3. Evaluation	Usability testing Walkthroughs Field studies
4. Deployment	

#### 5.4.2. Active user involvement in user-centred design

The British Standards Institute (BSI) recommends that “*User involvement should be active, whether by participating in design, acting as a source of relevant data or evaluating solutions.*” (BSI, 2019a).

Within mHealth, the extent of user participation varies widely from consultation with users (users as reactive informers) to users as co-creators and co-designers (participatory approaches) (Moore *et*

*al.*, 2019). The degree of user involvement is influenced by factors such as user availability, cost, time constraints and design team expertise and is accompanied by several challenges (Kujala, 2003).

Firstly, users (participants) may be difficult to recruit when they are not already part of an established group or if they are scattered across different geographical locations (Muller and Druin, 2007). Participatory approaches to design may also be time-consuming for the individuals involved (Holone, 2013). Eyles *et al.*'s review of participatory approaches in mHealth design found that the time between the initial formative phase to the end of pilot testing was between 12 and 15 months (Eyles *et al.*, 2016). Such long periods of involvement mean it may be difficult to locate participants who are willing and able to sustain their commitment to the project, particularly for those living with health conditions and disabilities (Daly, Armstrong and Martin, 2016). One solution is to involve therapists or carers as they may be able to supplement the views of users with health conditions (Chammas and Mont'Alvao, 2015). Additionally, those participating in UCD may not be representative of all potential users, particularly where there is diversity in the context of how a product is to be used (BSI, 2019). Participants may also have contradictory views which must then be carefully negotiated to prevent participants from feeling disappointed or disempowered (Oswal, 2014).

In mHealth, codesign between the design team and participants is further complicated by the necessity for the final product to be evidence-based, effective, safe to use, and to meet the regulatory requirements of a medical device in the UK (Marcilly, Peute and Beuscart-Zephir, 2016). Hence, the reasons for and extent of, user participation in the design project needs to be clearly defined at the beginning of the project. Whilst these limitations may forestall the implementation of a truly democratic and equitable participatory approach, it is possible to approach user involvement with an attitude of genuine collaboration rather than tokenism, even when user participation is limited. In recent mHealth studies, concepts such as "user-driven" or "user-centred research and design" have emerged, demonstrating an increased emphasis on active user involvement but

stopping short of a participatory design approach (LeRouge *et al.*, 2019; Srinivas *et al.*, 2019; Triberti and Barelo, 2016; Bahja and Bahka, 2018). These concepts are particularly important in the development of smart EMAs, where the focus and purpose of the EMA are informed by research but user involvement is necessary to promote user engagement and assessment completion (Soyster and Fisher, 2019). Furthermore, user-centred design is essential to optimising the *usability* of a smart EMA, particularly if the app is to be used for self-monitoring (Hartson, Andre and Williges 2009). Iterative usability evaluation is an essential component of user-centred design (McCurdie *et al.*, 2012).

#### **5.4.3. Usability evaluation of smartphone health apps**

The usability of any mHealth application is central to its success for two key reasons. Firstly, usability issues contribute to low levels of user engagement and limited uptake in the longer term (Torous *et al.*, 2018; Peiris and Mohr, 2018). Secondly, poor usability poses a threat to the effectiveness of mHealth interventions as it is difficult to disentangle the impact of the intervention from the technology (Ologeanu-Taddei, 2020).

Whilst there may be initial interest in an app, this often rapidly reduces. Market analysis of app downloads and use in 2019 indicated that only 21% of health apps were still used seven days after installation and this figure fell to 15% after 30 days (Adjust, 2019). A large observational study of user engagement with an asthma health app found that of 40,683 initial downloads, only 7593 people enrolled. Less than half of those enrolled completed more than 5 daily or weekly surveys over six months (Chan *et al.*, 2017b). This study demonstrates the size of the difficulty in retaining active users of the app but offers a limited explanation as to why this happened as there was no qualitative investigation of user's perspectives of the app. However, the study's quantitative analysis suggested that those who were older with more problematic asthma were more likely to use the app. Thus one possible interpretation of this study's findings is that perceived usefulness and

whether app users can achieve their personal goals by using the app are key drivers in overall app use and acceptability.

A Europe wide poll of health app use by 4000 members of the public, reported that 10% identified difficulty using the app as their main reason for discontinuing (Incisive Health International, 2017). Additionally, Vaghefi and colleagues conducted a longitudinal qualitative study of 17 healthy adults regarding their continued use of mHealth apps to achieve health-related goals over 14 days (Vaghefi and Tulu, 2019). The study participants identified ease of use (simple interfaces, navigation, and data entry mechanisms) as influencing their decision to continue with the app. Furthermore, for participants with low motivation to reach their goals, ease of use supported their engagement with the app, albeit at a more limited level. Whilst the study participants are not necessarily reflective of those living with health conditions, the study suggests that app usability is influential in the decision to use and continue to use a mHealth app.

Usability is a key construct informing the development and evaluation of mHealth technology (Inal, 2020). Usability is defined as:

*“the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use”* p3 (BSI, 2017).

However, the construct of usability was built on the assumption that users are focused on one task, as when using desktop applications or static technology (Harrison, Flood and Duce, 2013). In this instance, industry standards conceptualise usability as having three key dimensions: efficiency, effectiveness and satisfaction (BSI, 2017). It is now widely recognised that mobile applications and mobile technology require a broader conceptualisation of usability (Coursaris and Kim, 2011; Heo *et al.*, 2009; Harrison, Flood and Duce, 2013; Baharuddin, Dalbir and Razali, 2013). When using a mobile application, the individual is more likely to be dual-tasking (for example walking whilst using the phone) and to use the app in a broad range of environments (Harrison, Flood and Duce, 2013). For

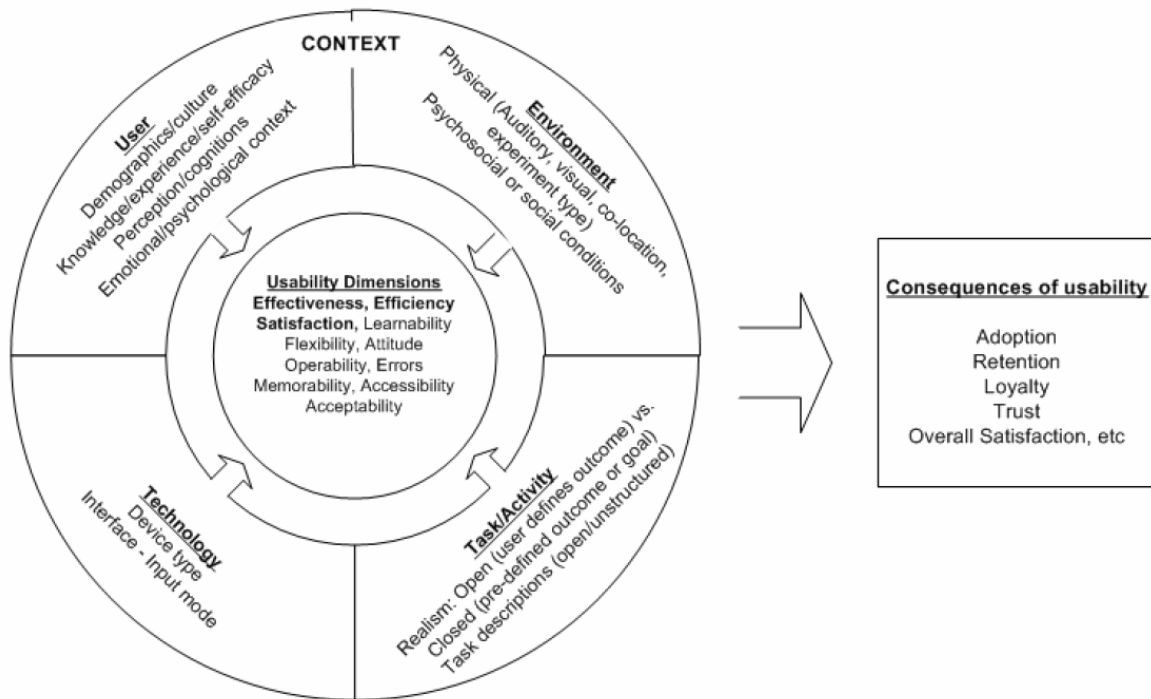
these reasons, any evaluation of a mobile app should include typical contexts of use, such as multi-tasking and different locations (Coursaris and Kim, 2011; Harrison, Flood and Duce, 2013).

Several authors have reviewed current practice in usability evaluation of mobile technology and mobile applications, particularly concerning the conceptualisation of usability. Coursaris and Kim (2011) developed a model of usability of mobile technology that considered several contexts of use. These were: the *person performing a task* using mobile *technology* (ie what type of device is used) in a range of *environments* (see figure 5.1). Through their analysis of usability studies, published over 10 years, they identified 13 key dimensions of usability, including the standard dimensions of effectiveness, efficiency and satisfaction. The added dimensions were learnability, flexibility, attitude, operability, accessibility, operation errors, memorability, usefulness, playfulness, and acceptability. The framework was further tested by Baharuddin et al (2013), again through a critical review of usability studies published between 2010 and 2012. In this review, dimensions of usability had shifted to include aesthetics, simplicity, attractiveness and intuitiveness. Baharuddin did not explain the change in usability dimensions but it seems likely that an increased focus on the usefulness and attractiveness of mobile applications reflects the increased availability of mobile apps to the general public.

Harrison and colleagues developed a different usability framework for mobile apps and tested the framework through a literature review of usability studies. Harrison's unique contribution was that of cognitive load as a dimension of usability. Harrison defines cognitive load as the cognitive processing needed to complete a task and argues that dual tasking is integral to using mobile apps. By implication, overly complex tasks within a mobile app negatively affect usability because the increased cognitive load required is detrimental to the individual's performance whilst using the app (Harrison, Flood and Duce, 2013). The concept of cognitive load is particularly relevant when considering ABI survivors experiences of using mobile apps because they are more likely to have

attention deficits or difficulty dual-tasking, for example using the phone app whilst walking (Plummer *et al.*, 2013; Sinclair *et al.*, 2013).

Figure 5.1: Model of usability dimensions (Coursaris and Kim, 2011)<sup>1</sup>



A key limitation of these usability frameworks is that they describe practice within usability studies rather than seek to establish dimensions of usability from a users perspective. Nevertheless, these expanded conceptualisations of usability have implications for how usability is evaluated as many of these dimensions are best understood through examining the whole of the user's experience (Heo *et al.*, 2009). Furthermore, effective usability evaluation involves evaluating use during everyday contexts, whilst considering the particular needs of the target user group.

<sup>1</sup> Copyright © 2010-2011, Usability Professionals' Association and the authors. Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. URL: <http://www.usabilityprofessionals.org>

## 5.5. The rationale for user-centred design in the development of smart EMA of fatigue

The development of a smart EMA by ABI survivors as an aid to self-monitoring of fatigue and activity is a novel approach (Leneart *et al.*, 2020). User-centred design involving ABI survivors has not been used to develop EMAs for this population. As discussed previously, there are few EMA studies of fatigue after ABI. In the studies reviewed, none of the EMA constructs were selected in consultation with ABI survivors and thus are likely to reflect the research teams' perspectives of fatigue after ABI.

In addition, user engagement with the EMA is potentially optimised if the users' needs are central to the design and content of EMA and the EMA is perceived to be useful (Duque *et al.*, 2019). This is particularly pertinent in the design of the assessment schedule, types of signal, frequency, and timing. A low density of assessment signals may fail to capture the variability of experiences, whereas a high density of signals is likely to be intrusive and affect user compliance (Shiffman, Stone and Hufford, 2008)

Finally, people with ABI may have physical or cognitive limitations that affect their use of the app and smartphone. In a survey of smartphone use by people with brain injury ( $n = 29$ ), simplicity of use was rated as the most important feature of the smartphone (Wong *et al.*, 2017). Barriers to smartphone use were identified as difficulty navigating the phone, poor vision and forgetting how to use the phone. These limitations may also affect their experience of the cognitive load, learnability and memorability of an app. Together with the timing and frequency of EMA alerts, there is considerable potential for a smart EMA to place an excessive burden on the user and negatively affect their use of the app (Birkhoff and Smeltzer, 2017). It is therefore essential that the design of a smart EMA considers the usability of the application with regard to the specific needs and characteristics of the user group. Ultimately, meaningful personalisation of the app is also necessary to optimise individual engagement.



## 5.6. Conclusion.

The sophistication of smartphone technology and its increased use in daily life provide opportunities for the use of EMA, both for research purposes and as tools to support self-monitoring and self-management of long term health conditions. There are relatively few studies examining the use of EMA in the brain injury population but those that have, demonstrate the feasibility of this approach.

However, there is no specific guidance on the development of smart EMA's and in the EMA studies reviewed, most researchers based their designs around previous EMA studies, standardised retrospective questionnaires, and theoretical frameworks. Yet within the broader field of mHealth, the benefits of user involvement in the design and development process are widely accepted.

Hence, this chapter argued for the relevance of a user-centred design approach to developing smart EMAs. A discussion of the concept of usability as part of an iterative user-centred design approach underscored the necessity of examining dimensions of usability associated with a mobile app, in the context of daily life, from the perspective of the person using the app.

The remainder of this thesis presents the development of the content and scheduling of a smart EMA app through the application of user-centred research and design, from concept generation to evaluation.

## **Chapter 6: Implementation of user-centred design in developing a prototype smart ecological momentary assessment of fatigue and activity**

### **6.1. Summary**

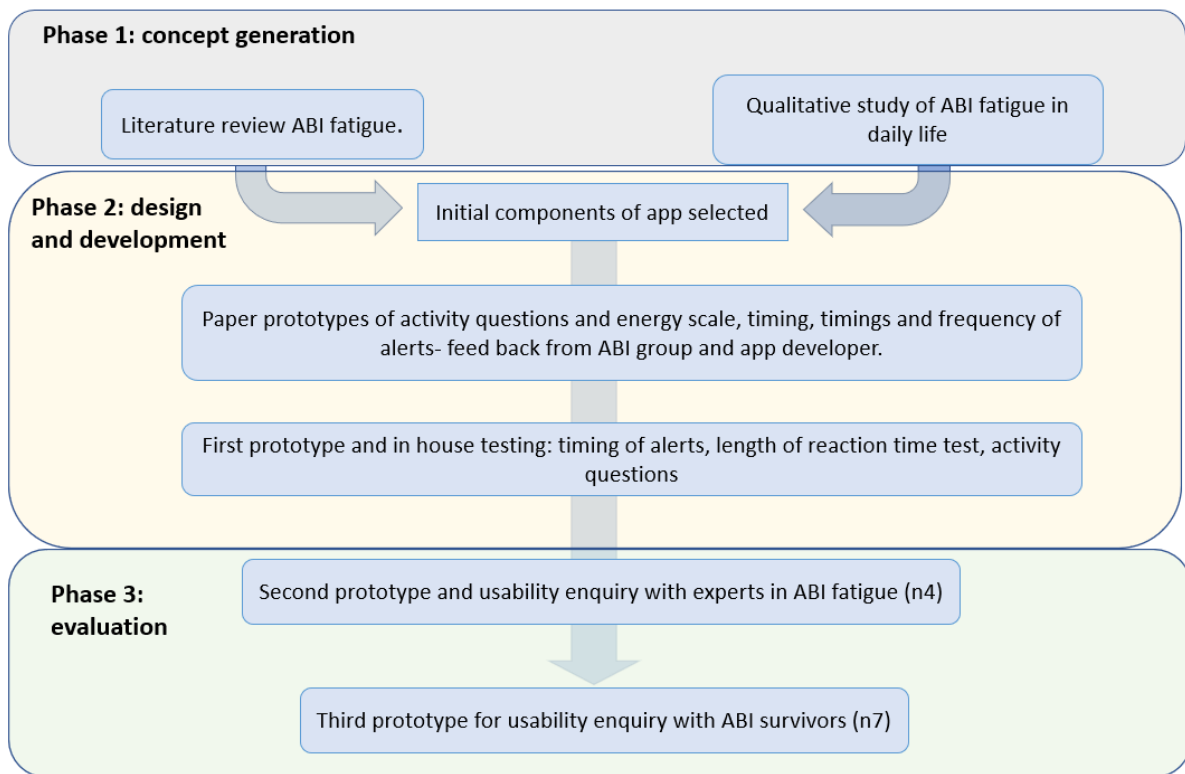
This chapter describes reports on concept generation (phase one) and prototype design and development (phase two) of the user-centred design of a smart ecological momentary assessment of fatigue. It starts by discussing how findings from the qualitative study of ABI survivor's experiences of fatigue in daily life contributed to the choice of EMA components. Phase two then describes ABI survivors contribution to the development process and discusses the rationale for the chosen components of the smart EMA, the signalling schedule, as well as aspects of design pertinent to users with ABI. In particular, the argument for shifting the focus to subjective reports of energy rather than fatigue is presented. The first round of in-house testing is also described.

### **6.2. Implementation of user-centred design phase one: concept generation.**

As discussed in chapter 5, the user-centred design is an iterative approach that consists broadly of four phases (McCurdie *et al.*, 2012; Kubler *et al.*, 2014). The key aim of phase one, concept generation, is to develop an in-depth understanding of potential user's needs, regarding the purpose of the smart EMA app and interactions with the app. This understanding was developed through the qualitative study of ABI survivors' experiences of fatigue (reported in chapter 4), consultation with members of the public who had experienced ABI and by utilising both the authors and other therapists' clinical experience. Figure 6.1 provides an overview of the applied user-centred design process.

The app was developed in collaboration with Professor Tomas Ward and Jose Vegas, Dublin City University. Jose Vegas wrote the code for the app, managed data security, advised on interface design and technical solutions to the researcher's and user's requirements of the app.

Figure 6.1 UCD approach applied to the development of a smart EMA of fatigue and activity after ABI



### 6.2.1. Public and patient involvement (PPI)

At the inception of the project (June 2015), LE met with a group of brain injury survivors and carers (n 9) at a local day service to explore their views on the concept of using a smartphone to track fatigue. Three key points were raised at this meeting.

Firstly, fatigue was reported to be a significant problem for many of the people at the meeting and was often unpredictable. The group agreed that an app to help them to make sense of fatigue and predict fatigue would be useful. One person kept described how they kept a daily diary of their fatigue to understand and manage their fatigue more effectively.

Secondly, the early signs of fatigue were sometimes missed by the person with ABI but noticed by friends and family. Individuals commented that an early warning of fatigue would help them cope with fatigue as they could take action before being overwhelmed by fatigue. This points to the app including an objective marker of fatigue.

Finally, most of those present at the meetings reported using their used smartphones in daily life and the idea of using a smartphone to track fatigue was acceptable to them.

This initial meeting indicated that the proposal to use a smartphone app to assess fatigue in daily life was of interest to people with ABI who experienced fatigue.

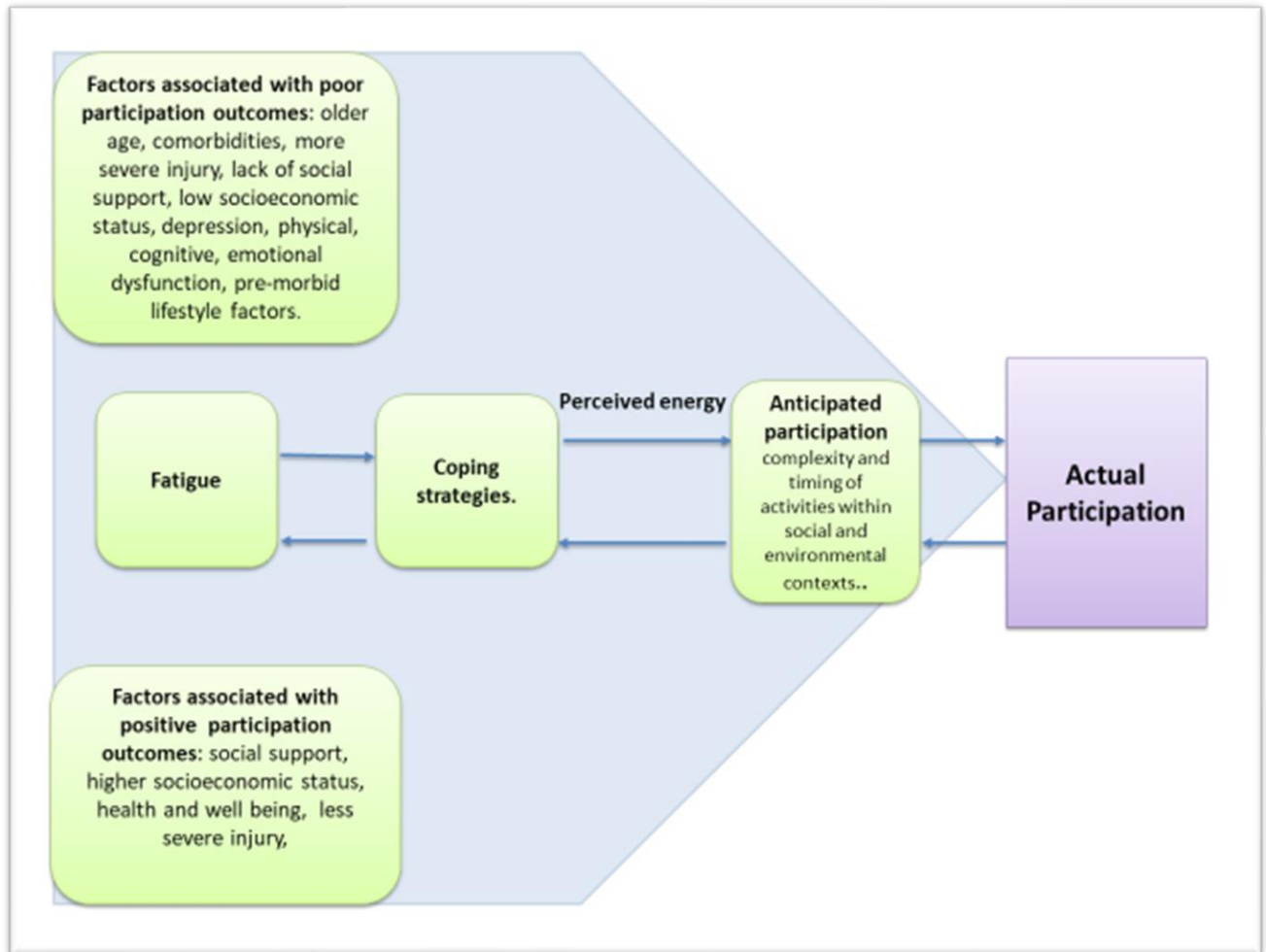
Further formative work was then needed to identify which constructs were necessary to effectively track fatigue in daily life (Martin-Hammond *et al.*, 2016). An initial narrative review of fatigue after ABI (chapter 3) revealed that little was known about the daily experiences and manifestations of fatigue after acquired brain injury. Hence, findings from the qualitative study (reported in chapter 4) informed the constructs and contexts captured by the smart EMA.

### **6.2.2. *The contribution of research study findings to the smart EMA***

As discussed in chapter 5, EMA is used to explore relationships between variables related to the phenomena under study and how these change over time. The content and structure of an EMA should be grounded in research evidence whilst reflecting the needs and experiences of those completing the EMA's. To this end, the findings of the systematic and narrative reviews together with the qualitative investigation of fatigue informed the choice of EMA components.

The proposed relationship between fatigue and participation is illustrated in figure 6.2. The impact of fatigue on participation is viewed within the contexts of other factors associated with participation but is mediated by the strategies used to managed fatigue and the individual's perceived resources (mental or physical energy). Beliefs about their anticipated experience of participation (the type and timing of activity, barriers or enablers of social and physical environments) are also influential in the individual's decision to participate, whereas the experience of participation provides feedback about the success of coping strategies and participatory choices. Findings from the qualitative study also highlight that fatigue experiences fluctuate both within a given situation and over a day or several days.

Figure 6.2. A model explaining relationships between fatigue and participation in the context of factors associated with participation outcomes



The model suggests many potential constructs that could be investigated by EMA. These include different types of fatigue (mental fatigue, physical fatigue, motivational fatigue), coping strategies such as sleep (amount, timing and quality of sleep), daily activities, and specific environmental factors that were perceived to exacerbate or trigger fatigue (for example, noise levels or location). However, when choosing constructs for inclusion in the EMA, the researcher was cognisant of the EMA schedule being overly burdensome and the risk of low completion rates (Vansimaey *et al.*, 2017). Hence the number of constructs included in the EMA were limited and the choice of construct was informed by the qualitative research findings and user involvement. The initial constructs considered in the app development were:

- Subjective reports of different types of fatigue.
- Subjective report of energy levels.
- An objective indicator of fatigue.
- Physical activity
- Types of daily activity users engage in.
- Timing and duration of sleep.
- Environmental information such as location or noise levels.

#### **6.2.4. User Involvement in the development process**

Potential users of the app were primarily identified as people who had a brain injury and experienced problematic fatigue. However, Occupational Therapists specialising in brain injury were also identified as potential users of the app, albeit with their patients. Fatigue management interventions are a routine aspect of occupational therapy practice and, although EMAs are not routinely used in clinical practice, there is growing recognition of the potential benefits of using EMAs as a clinical assessment tool (Jean *et al.*, 2013; Sibon *et al.*, 2012; Timmer, Hickson and Launer, 2017).

For the initial development of the app, user involvement consisted of two strands. Firstly, an early prototype of the EMA was presented to a support group for people with brain injury in February 2017. From this group, seven people volunteered to consult on the app development via email. Email consultations ran monthly from February 2017 to March 2018 with updates on progress made and information and questions about aspects of the smart EMA design. For the rest of the thesis, people involved in the user centre design process will be referred to as users.

During the development phase, users gave feedback and made suggestions about the self-rating of energy, the activity questions, the design of the battery rating scale, and the timing and number of alerts during each day.

### 6.2.5. Understanding user's needs

An essential component of phase one of user-centred design is understanding users' needs, both in the purpose of the app but also as they interact with the app interface (McCurdie *et al.*, 2012; Chammas and Mont'Alvao, 2015). LE, through personal clinical experience and informal discussion with therapists and ABI survivors, advised the developer about possible areas of difficulty when using the app and the implications for app design (see Table 6.1).

Table 6.1: ABI users' needs for consideration in the development of a smart EMA

Possible areas of difficulty	Presentation	Implications for smart EMA design.
<b>Vision</b>	Loss of part of visual field (may be left, or right or a bit of both) or double vision. About 60% of stroke survivors will have a visual deficit (Rowe <i>et al.</i> , 2019). May also have chaotic visual search patterns so it is harder for them to find information (Turton <i>et al.</i> , 2015).	Place information centrally on the screen. Keep visual information on each screen to a minimum.
<b>Information processing skills</b>	Difficulty processing visual information and impaired visual cognition. This means that people are less able to mentally manipulate visual information (Rabinowitz and Levin, 2014).	Keep written information to a minimum, remove extraneous stimuli/ information from the screen. Simplicity is key. Information needs to be presented slowly and in small chunks.
<b>Visual attention</b>	May have difficulty attending to /finding visual information (Robertson and Schmitter-Edgecombe, 2017).	Consider the use of colour and text size on the screen. Use signifiers to direct the required action. Highlight changes or signify new page by a change in screen colour. Keep information to a minimum and flag anything important.
<b>Difficulties with abstract thinking and complex problem-solving.</b>	Can be very literal, concrete in their thinking - so won't necessarily make connections and will take information at face value.	Consider wording for instructions. Installation and deletion of the app should be as simple as possible.

<b>Attention deficits</b>	Difficulty focusing attention and sustaining attention. Easily distracted and may then lose track of what they were doing (Robertson and Schmitter-Edgecombe, 2017).	Minimise the number of screens available and limit navigation backwards and forwards between screens
<b>Memory problems</b>	Working memory may be affected which affects the person's ability to learn a new task and process information, holding on to information to make sense of it (Robertson and Schmitter-Edgecombe, 2017).	Simple instructions and avoid relying on memory to use the app or locate options.
<b>Organisational skills</b>	May have difficulties with more complex routines and planning (Robertson and Schmitter-Edgecombe, 2017).	Minimise the impact of the app on phone battery life to avoid having to charge the phone more than the person usually does.

### 6.3. The rationale for EMA components

Following discussions with the app developer, pragmatic decisions were made about the components of the EMA. For example, Jose Vegas advised that the phone sensors are not able to detect whether the user is asleep, it could only approximate periods of sleep through the on/off time of the phone. The app would need pairing with a wearable device to monitor sleep patterns. Whilst pairing the app with a wearable device is desirable in the longer term, it was beyond the size and scope of the current project.

As discussed in chapters three and four, fatigue is a complex multidimensional construct that has several subtypes. However, in the qualitative study, participant's ability to label their fatigue as one type or another was mixed. It was for this reason (and to maintain the simplicity of the app) that questions about types of fatigue were not included in the EMA design. The final components of the smart EMA consisted of a subjective report of state energy, a psychomotor vigilance test (as an objective marker of mental fatigue) and a question about the activity participants were engaged in at the time of the EMA alert. Noise levels and physical activity levels were considered as potential triggers to alert participants to complete an assessment. The rationale for choosing these components is presented next.



### 6.3.1. From subjective fatigue to subjective energy

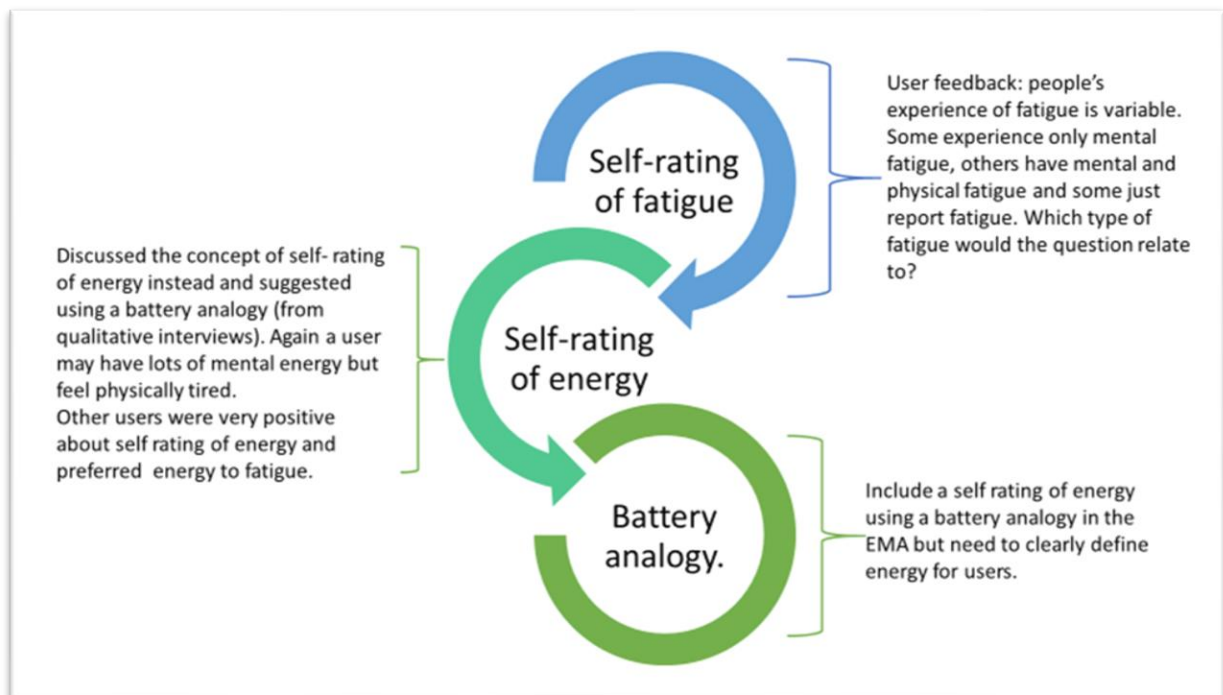
Whilst the principal aim of the EMA was to assist individuals in self-monitoring their fatigue in the context of their daily activities, the decision was taken to include a self-report of state energy in the EMA as opposed to a self-report of state fatigue. Energy is defined as:

*“the subjective feeling of having the capacity to complete mental or physical activities”*(Puetz, 2012).

Within the ICF, the perception of energy is classified within the broader dimension of global mental functions (World Health Organisation, 2017).

This shift was prompted by the findings of the qualitative study where participants used the concept of energy (as a resource) to reflect the impact of fatigue on daily life. For example, participants talked about having enough energy to do what they wanted to do and taking steps to restore their energy levels when fatigued. Users were also supportive of the concept of energy and the analogy of a battery to represent energy draining or being full of energy (see figure 6.3). Whilst the battery analogy originated from the qualitative interviews, it is also a concept used within occupational therapy practice and fatigue management (Malley, 2017). Within the fatigue literature, a lack of energy is considered a defining feature of fatigue after ABI (Lynch *et al.*, 2007; Theadom *et al.*, 2016; Wylie and Flashman, 2017; Ormstad and Eilertsen, 2015).

Figure 6.3: User involvement in the development of the numeric rating scale for energy



Arguably, this shift from fatigue to energy represents a strengths-based approach to managing fatigue as individuals seek to direct their energy into their chosen daily activities. It also aligns with the use of EMA to self-monitor the impact of fatigue, to enable more effective self-management. The concept of conserving energy to manage fatigue is used by occupational therapists across a range of health conditions (Blikman *et al.*, 2013; Vincent *et al.*, 2013; Pearson *et al.*, 2018) and there is moderate evidence that implementing energy conservation principles reduces the impact of fatigue on daily life in other health conditions (Blikman *et al.*, 2013; Bennett *et al.*, 2016). Hence capturing individuals' perceptions of energy levels across the day potentially was seen as being more informative when considering strategies to manage the impact of fatigue on daily activities.

Additionally, this focus on energy attempts to mitigate the potentially detrimental effect on the user of repeatedly focusing on fatigue, as the risk of reactivity to repeated assessments of fatigue is currently unknown. Hence focusing individuals on their energy levels across the day is potentially a more empowering and positive experience.

However, it is important to note that whilst fatigue and energy are closely related constructs, they may not be opposites of the same construct (Loy, Cameron and O'Connor, 2018). Energy appears an item in several standardised questionnaires (for example the SF36 or profile of mood states) but there is little consistency in how energy is conceptualised within these measures (O'Connor, 2004). For example, in the SF36, energy and fatigue are opposite poles of a single construct whilst in the profile of mood states, they are separate constructs (fatigue and vigour) (Ware and Sherbourne, 1992; Bourgeois, 2010; Loy, Cameron and O'Connor, 2018). Several studies report associations between self-reports of energy and fatigue in other health conditions (So *et al.*, 2015; Braley, Chervin and Segal, 2012; Hornsby, Naylor and Bess, 2016) but a narrative review by Loy and colleagues suggest that fatigue and energy are independent constructs and may even reflect different physiological processes. Loy suggests it is, therefore, possible to be energetic and fatigued at the same time and provides several examples from non-brain injury studies demonstrating the independence of these two constructs (Loy, Cameron and O'Connor, 2018).

For the smart EMA of fatigue, it is assumed that fatigue is experienced when energy levels are low, reflecting the hypothesis that fatigue is triggered when energy resources are low (Loy, Cameron and O'Connor, 2018). This assumption will need further investigation once the smart EMA reaches the validation stage of development.

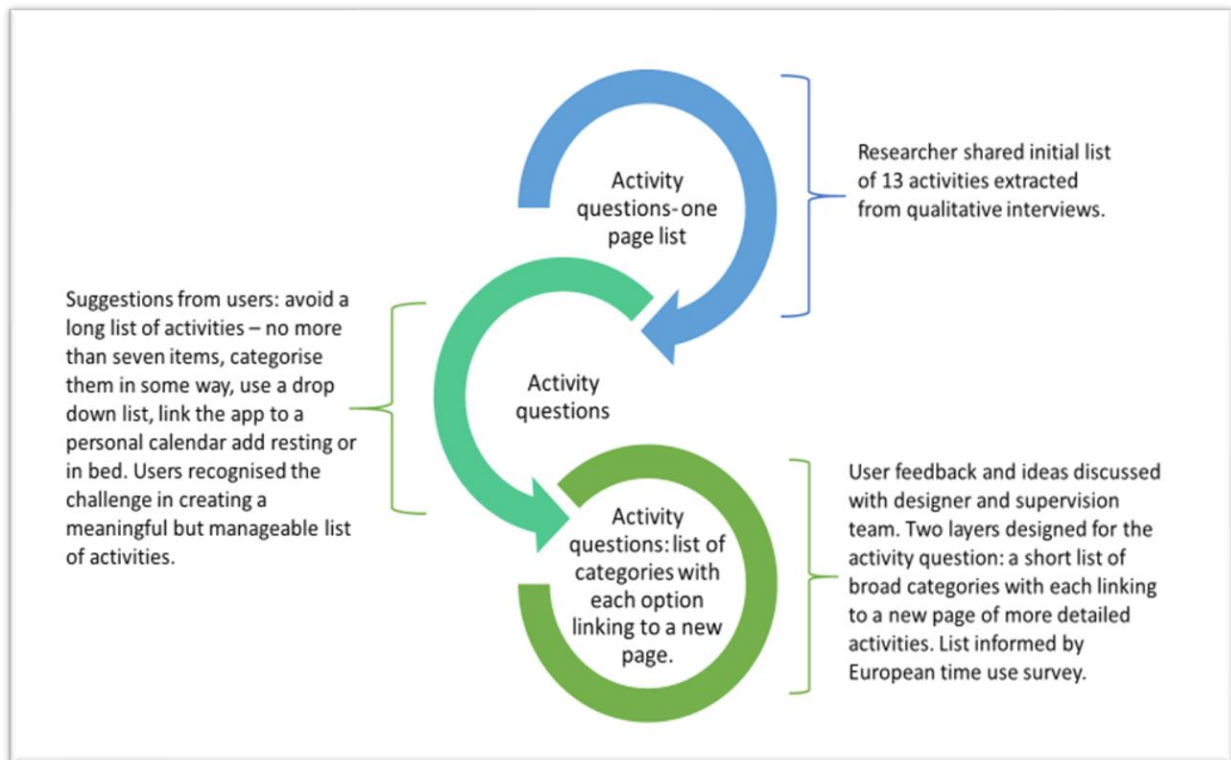
The self-report of energy was constructed around an 11 point numeric rating scale (NRS), with 0 indicating drained of energy and 10 being full of energy. An 11 point NRS was chosen rather than a visual analogue scale for several reasons linked to usability. Firstly, numeric rating scales require less interpretation and are less prone to error for people with cognitive or visual impairments (Price, Curless and Rodgers, 1999; Hjermstad, 2011). Converting the VAS to the relatively small screen size of a mobile phone is also problematic and would require the user to change phone orientation whilst using the app, potentially affecting app usability. Delgado *et al* (2018) suggested that the size of the VAS on a mobile phone and the method of scoring (specifically, using a finger on a touch screen)

affects the precision of measurement. They compared the scores of 98 individuals on three versions of a visual analogue scale of pain: a visual analogue scale delivered on a laptop, a touch screen mobile phone and a paper version. The study found poor agreement between the paper version of the VAS and the mobile phone version, although the difference in scores did not reach their pre-determined threshold for a minimal clinically significant difference. Delgado et al noted that participants were allowed to repeatedly change their score on the mobile VAS until they were satisfied, in an attempt to compensate for the method of input (Delgado *et al.*, 2018). However, for a smart EMA, the input needs to be simple and easy with a relatively low cognitive load, otherwise, it might affect usability. Finally, on a more pragmatic note, the app developer advised that the software coding for a VAS on a mobile phone is more complex than that of a numeric rating scale and would delay the development of the smart EMA.

### **6.3.2. Development of the activity question**

The initial EMA included a single question “Which of these were you doing just now? Please choose one”, followed by a list of eight types of activity. The list of activity types was constructed using data from the qualitative interviews as to the types of activities people found to reduce or exacerbate fatigue. Developing an inclusive list to fit on a smartphone screen whilst maintaining readability was challenging. The app developer suggested seven items to avoid having to scroll down the page but the initial prototype had nine options to maintain sufficient detail about the user's activity. See figure 6.4 for user feedback and the development of the activity question.

Figure 6.4: User involvement in the development of the activity question



In the first two rounds of testing, the 9 item list was used. This was changed to the expanded activity list during the usability study and will be discussed in the next chapter.

### 6.3.3. Psychomotor vigilance test

In early PPI discussions, both carers and those with ABI reported reduced awareness of fatigue, with ABI survivors noticing fatigue once they felt overwhelmed. Early detection of fatigue was perceived to be useful in managing fatigue more effectively. As discussed previously in chapter 3, establishing objective markers of fatigue after ABI has been elusive but several studies point to the psychomotor vigilance test as a potential assessment of objective fatigue. Heron and Smyth (2010) also recommend combining objective and subjective measures in EMAs (where possible), to reduce the impact of demand characteristics. This is important when considering the potential integration of the smart EMA into smart intervention or to capture changes following an intervention. For these reasons, an adapted psychomotor vigilance test (PVT) was integrated into the app as an objective marker of fatigue.

The psychomotor vigilance test (PVT) is a simple reaction time test as it requires only a reaction to a stimulus, rather than a choice or decision (as in the go-no-go test where the user reacts to stimuli according to colour). The stimuli are presented repeatedly (between 2 and 10-second intervals), over extended periods and the person touches the screen as soon as they see the stimulus (Dinges and Powell, 1986; Grant et al., 2017). The PVT measures response speeds (information processing speeds) and lapses in vigilance due to fatigue or sleep loss (Lee *et al.*, 2010; Basner *et al.*, 2018). It is widely used to investigate the effects of sleep loss in healthy individuals but has been suggested as an objective proxy for fatigue in individuals with health conditions (Basner and Dinges, 2011) Sinclair et al; (Price *et al.*, 2017; Lee *et al.*, 2010). In addition, Hoermann, Uken and Voss (2012) reported that variability of performance on the PVT (number of lapses) is associated with subjective state fatigue in healthy adults. Additionally, the PVT has minimal practice effects from repeated administration making the PVT particularly suitable for EMA (Basner *et al.*, 2018).

The original PVT lasts for 10 minutes and delivers a visual stimulus via a handheld device, to which the participant responds by pressing a button. Whilst the 10 minute PVT is the gold standard for assessing the impact of sleep loss in laboratory conditions, it is not practical for use in real-world settings (Roach, Dawson and Lamond, 2006). Several studies have investigated the validity of shorter psychomotor vigilance tests. (Loh S, 2004) compared reaction times and lapses in the first 2 and 5 minutes of a 10-minute test to the full 10-minute test in relation to the effects of sleep loss in healthy participants. They found the sensitivity of the test to detect the effect of sleep loss increased with the length of the test but changes in reaction times were evident in the 2-minute test. Basner et al developed a 3-minute PVT-Brief. They reported a 21% reduction in sensitivity of the test to loss of vigilance due to sleep loss. However, they suggested that the loss of sensitivity was outweighed by the benefit of a shorter test (Basner, Mollicone and Dinges, 2011). Basner et al (2012) also developed an adaptive duration PVT, using an algorithm to predict overall performance on a 10-minute test based on the participant's initial performance. The number of lapses or false starts was used to calculate the probability of the participant's performance being high, medium or low. Those

presenting with false starts and lapses early in the test were highly probable to be poor performers overall. The adaptive duration PVT reduced the length of the test to an average of 6.5 minutes, with tests ending at under one minute for those with poor performance (Basner and Dinges, 2012). Price *et al.* (2016) also investigated associations between cognitive tests (including a short PVT of 20 stimuli) delivered via smartphone and fatigue. Only the short PVT test was significantly associated with self-reported fatigue in healthy participants (Price *et al.*, 2016). Price *et al.* suggested the PVT was potentially useful in tracking state fatigue in daily life.

The PVT has also been adapted for use on a smartphone, but using a smartphone has implications for the sensitivity and reliability of the test (Basner, Mollicone and Dinges, 2011; Kay *et al.*, 2013; Grant *et al.*, 2017). Grant *et al.* (2017) compared a 3-minute smartphone psychomotor vigilance test to the standard 10 minute PVT in laboratory conditions. The 3-minute smartphone PVT was found to be a reliable indicator of the effects of sleep loss but was less sensitive than the 10 minute PVT. The study standardised the administration of the smartphone PVT by mounting the smartphone, which does not reflect how smartphones are used in daily life (Grant *et al.*, 2017). Differences in how the smartphone is held may affect both reaction times and the number of lapses. Kay *et al.* (2013) explored different methods of user input in a smartphone PVT and found reaction times varied according to the method of input. Arsintescu and colleagues also reported significantly shorter reaction times and more lapses when the phone screen was landscape and participants used their thumb to respond, rather than their index finger (Arsintescu, Mulligan and Flynn-Evans, 2017). Furthermore, reaction times on a touch screen are affected by device latency (that is the time taken for the app to register the screen being touched) and this varies across different smartphones (Arsintescu *et al.*, 2019).

Steps to reduce the impact of these limitations include standardisation of instructions on how to complete the PVT on a smartphone and changes in the PVT to increase the test sensitivity (Grant *et al.*, 2017). For example, Basner *et al.* 2011 reduced the inter-stimulus interval (1-4 seconds) and

lowered the threshold for lapses to 355ms for their three-minute PVT-Brief (Basner, Mollicone and Dinges, 2011). These limitations of a short PVT test delivered on a smartphone are recognised and hence the PVT will be used to track within-person changes in performance over time, rather than compare performance across individuals.

Taken together, these studies provide evidence to support the concept of using a shortened PVT to objectively track state fatigue in daily life using a smartphone. The evidence is far from conclusive but integrating the PVT into a smart EMA offers opportunities for future exploration of the relationship between PVT scores and state fatigue or state energy for people with ABI.

#### **6.3.4. Sensor augmented EMA**

Data from the qualitative study suggested that contextual environmental data is useful to consider when investigating situational fatigue because contexts such as location, noise level and types of activity were perceived as triggering or exacerbating fatigue. Physical activity, noise and location may all be detected by smartphone sensors and potentially used to trigger event contingent alerts and collect data about subjective state energy, activity and reaction times whilst in fatiguing situations. Location data was not included in this version of the app because of ethical concerns around privacy.

#### **6.4. Content and testing of the first smart EMA working prototype (phase two)**

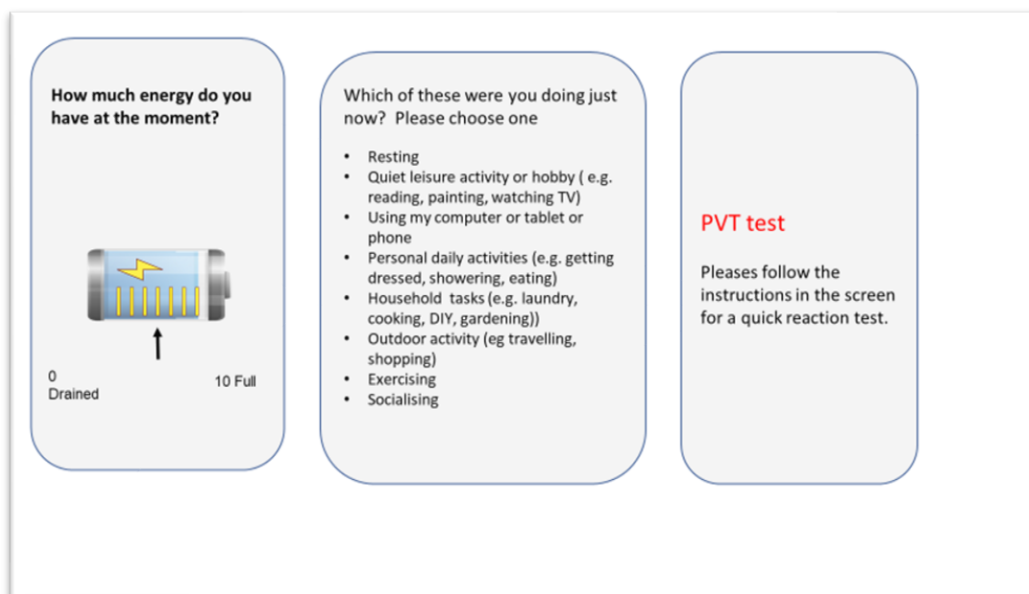
The initial version of the fatigue smart EMA consisted of three components for the assessments: a numeric rating scale (NRS) of self-reported energy, an activity question and an adapted PVT. The app also sampled data on physical activity and noise levels from passive sensors in the phone (see figure 6.5 for the initial prototype).

The reaction time test integrated into the app is based on the psychomotor vigilance test but is adapted for use on a smartphone. The smartphone reaction time test was freely available as open-source software and permitted integration with other apps. The app presents the user with a blank



screen and then asks them to touch the screen as soon as a number appears. The number counts up in milliseconds and gives the user information about their reaction speed. Response times less than 100 ms are interpreted as anticipation errors and the user gets a “too early” notice. Response times of 350ms or greater are interpreted as a lapse in concentration. The stimulus is presented twenty times, with 5 stimuli presented in each 30-second block, excluding response times of less than 100ms.

Figure 6.5. An initial prototype of app March 2018



#### 6.4.1. EMA signal schedule

With regards to the EMA assessment schedule, the initially suggested time window of alerts was between 9 am and 8 pm. Users reported that 8 pm was an acceptable time for the alerts to stop but 9 am was too early for some. The time contingent alerts were therefore set at 10 am and 8 pm, similar to those used in an EMA study of fatigue in people with multiple sclerosis (Powell et al., 2017). Time contingent alerts set in the morning and evening provide a daily baseline of energy levels that is helpful to track how energy changes over each day.

Users were asked their views on how many alerts per day would be acceptable. Between four and six alerts were seen as manageable but one user suggested scheduling an extra two because people are likely to miss alerts throughout the day. The final schedule consisted of eight alerts in total, with the option for users to additionally self-trigger assessments.

#### EMA augmentation with phone sensors

As discussed in chapter 4, data from smartphone sensors may be used to augment EMA and provide contextual information about the user's activity or environment. Data from phone sensors may also be used to define event contingent signals. In this EMA, data from the phone's microphone (and from the phone's accelerometer and GPS) provide information about ambient noise levels and the user's transition from one physical activity state to another.

Ambient noise was sampled every 15 minutes with each sample lasting 30 seconds, subject to whether sampling is affected by the phone being on stand-by when inactive. For physical activity transition, a Google application interface (api) for activity recognition was used which creates behavioural inference data from GPS and accelerometer data on the phone. The app detects transitions from being still, to moving on foot to moving in a vehicle. 0 denotes entering an activity and 1 denotes leaving an activity. Hence the app provides information about physical activity transitions, timestamp of the transition, and how long the activity lasts.

The app asks Google to update on transitions every minute but sampling is dependent on strategies used by the phone to conserve battery life, for example, whether the phone goes to sleep when inactive. These strategies vary from phone to phone.

#### *6.4.2. The first round of prototype testing*

The prototype was tested in-house with five people in the MORES research group in July 2018. The app was installed on five phones for one week to assess for installation issues, whether the EMA alerted users as expected, for the developer to check for bugs in the app software, and to view the

data returned by the app (Burke *et al.*, 2017). The EMA schedule was a combination of time contingent and event contingent alerts, with an event defined as the background noise of greater than 75 decibels or an activity transition and alerts scheduled at 10 am and 8 pm. The app was installed and tested on three makes of android phone (all with android version 6) to assess compatibility across different makes and models of smartphones.

The app was successfully installed on a range of smartphones. The app required users to sign in with a Gmail account and give permission for the app to access the phone camera and microphone. Users were asked to report any error or warning messages and on their experience of the alerts. From this initial test, the app did not alert users as expected, particularly with event contingent alerts. The app developer (Jose Vegas) advised that event contingent alerting increased the risk of bias in the data, particularly as there was insufficient information to accurately define the events (for example, what noise level should trigger an alert) (Lathia *et al.*, 2013). The EMA schedule was therefore changed to time and stratified random signal contingent alerts but continued to sample noise and activity transitions as previously described. The random alerts were stratified from 11 am to 7 pm, with a minimum of 60 minutes between alerts. Noise and activity transitions were sampled to inform the threshold for events to trigger an alert.

After the first round of testing, the app was refined, changes made to the EMA schedule and the app reinstalled and tested again on two phones. The alerts worked as expected and the app was determined to be ready for usability evaluation.

## 6.5. Conclusion

This chapters described the implementation of an iterative user-centred design approach to developing a smart EMA of fatigue and activity. Findings from the narrative literature review, qualitative interviews and discussion with users informed the selection and design of the EMA components and aspects of the EMA schedule. A prototype was developed and tested in-house. Testing revealed the event contingent alerts were not effective and the schedule was changed to

include random stratified signal contingent alerts. Following a further round of testing, the smart EMA was ready for usability evaluation. The next chapter discusses phase three: an iterative usability evaluation of the smart EMA.

## Chapter 7: Phase Three: A user-centred usability evaluation of the smart EMA application of fatigue and activity

### 7.1. Summary

This chapter describes the methods used to formatively evaluate the usability of the smart EMA application (app) and to investigate ABI survivors experience of using the app in the course of their daily lives. A two-stage approach was taken. Firstly, the app was tested by Occupational Therapists with expertise in acquired brain injury and ABI fatigue. The therapists completed a think-aloud evaluation of the app and then 2 therapists went on to trial the app for 6 days. Changes were made to the app as a result of this initial evaluation and the app was tested by 7 ABI survivors who used the app for 6 days. The results of the evaluation are presented, and recommendations made for the future development of the smart EMA.

### 7.2. Introduction

As discussed in chapter five, usability evaluation describes a broad range of activities designed to assess the efficiency and effectiveness of a product as well as subjective experiences of using the said product (Tao *et al.*, 2016). There are two approaches to usability evaluation in mHealth: expert-based methods or user-centred methods (Zapata *et al.*, 2015; Jaspers, 2009). Expert-based methods include cognitive walkthroughs and usability heuristic evaluation where designers or usability experts evaluate efficiency and ease of use (Yen and Bakken, 2012). User-centred evaluation focuses on the user's satisfaction and experience and includes methods such as think-aloud, interviews and questionnaires (Jaspers, 2009). In their systematic review, Zapata *et al.* (2015) reviewed 22 usability studies of mHealth apps to determine current approaches to usability evaluation. They found considerable variation in approaches but identified questionnaires, interviews, think-aloud method and logs (record of app use) as the most frequently used methods of evaluation (Zapata *et al.*, 2015). However, evidence and guidance on effective usability evaluation in mHealth is still in its infancy and is limited by the interdisciplinary nature of mHealth research and the fast pace of

technological developments (Agarwal *et al.*, 2016). Traditional research models are a poor fit for this rapidly changing field and current guidance on user evaluation stems from industry and the field of human computer interactions rather than healthcare (Mohr *et al.*, 2017).

Expert-based methods and user-centred evaluation are not mutually exclusive, rather they usually occur at different points in the development process (BSI, 2016). User-centred evaluation starts in the early stages of the project and provides feedback on the strengths and weaknesses of the design, from the user's perspective (BSI, 2019b). Evaluation findings are implemented iteratively to improve the design and optimise the user's experience of using the final product. User-centred methods also allow investigation experiences of use in daily life, in different environments, as opposed to laboratory-based testing. Testing in naturalistic environments is particularly important when evaluating the use of a mobile app.

User-centred evaluation is now the main approach to the evaluation of mHealth products but is a relatively new area of practice in the development of ecological momentary assessments (Jaspers, 2009; Inal, Guribye and Nordgreen 2020; Zapata *et al.*, 2015; Soyster and Fisher, 2019). This is likely to be because EMAs are viewed primarily as research tools and the concept of EMA as a self-monitoring tool or integrate into smart EMI is also relatively new (Kim *et al.*, 2019).

However, user-centred evaluation is not without its limitations. Zapata *et al.* noted that studies often used multiple but similar methods to evaluate usability, with the methods being prone to similar limitations. For example, combining interviews and surveys of user's experiences both rely on retrospective recall of the experience and are subject to bias. Hence it is important to use a range of methods for usability evaluation and to consider what each method brings to the evaluation process. For this study, user-centred evaluation was the chosen approach because the smart EMA is in the early stages of development and user feedback from testing in the field is essential to understand the limitations and strengths of the app design. Evaluation by ABI survivors using the app in daily life allows investigation into the specific challenges arising from interactions between the demand of the

app on the user and the characteristics of users that are a consequence of ABI. Different methods of evaluating usability were implemented, including the think aloud method, a questionnaire and interviews.

The primary aim of this study was to evaluate the usability of the smart EMA. A secondary aim was to investigate the feasibility of using a smart EMA to track activity and fatigue in daily life.

The objectives of the study were:

- To identify design inconsistencies and usability problem areas within the app interface and content areas.
- To investigate user satisfaction with the app in the context of their daily life.
- To evaluate the effectiveness of using smartphone sensors to inform event contingent alerts.
- To investigate user perspectives of the EMA and reaction time test when using the app in daily life.
- To examine the data collected through the smart EMA and consider its potential usefulness in supporting self-management of fatigue.

The study was approved by Oxford Brookes University Ethics committee (UREC: no 181198).

### **7.3. Methods**

In phase three of the user-centred design approach to developing the smart EMA, formative evaluation of the smart EMA was conducted in two stages and included data from occupational therapists and people with acquired brain injury. A sample size between 10 to 15 participants was deemed sufficient to find 95 to 97% of usability problems (Faulkner, 2003).

In stage one, a working prototype of the app was tested with Occupational Therapists who were experienced in working with people with brain injury and fatigue. As a profession, occupational therapy is concerned with how an individual's abilities and impairments affect their performance of

daily activities in everyday environments. Therapists who work with ABI survivors develop specialist knowledge of the consequences of brain injury and its impact on performance. Enabling ABI survivors to manage fatigue in daily life is also within the scope of occupational therapy practice. Hence Occupational Therapists are potentially well placed to advise on potential the needs of ABU survivors when using a smart EMA. The decision to start the evaluation process with therapists was taken to address common usability problems before testing with ABI survivors.

In stage two, the app was refined and then field-tested with ABI survivors who had experienced problematic fatigue. ABI survivors trialled the app for six days and wore an accelerometer to allow comparison with activity transition data collected from the phone sensors.

### ***7.3.1. Recruitment***

Occupational Therapists were recruited from the Royal College of Occupational Therapists specialist section in neurological practice. Therapists were eligible to participate if they had current experience of working with or caring for people with ABI and were able to use android smartphones. All interviews and discussions with therapists were conducted virtually. Consent was taken before participating in the study.

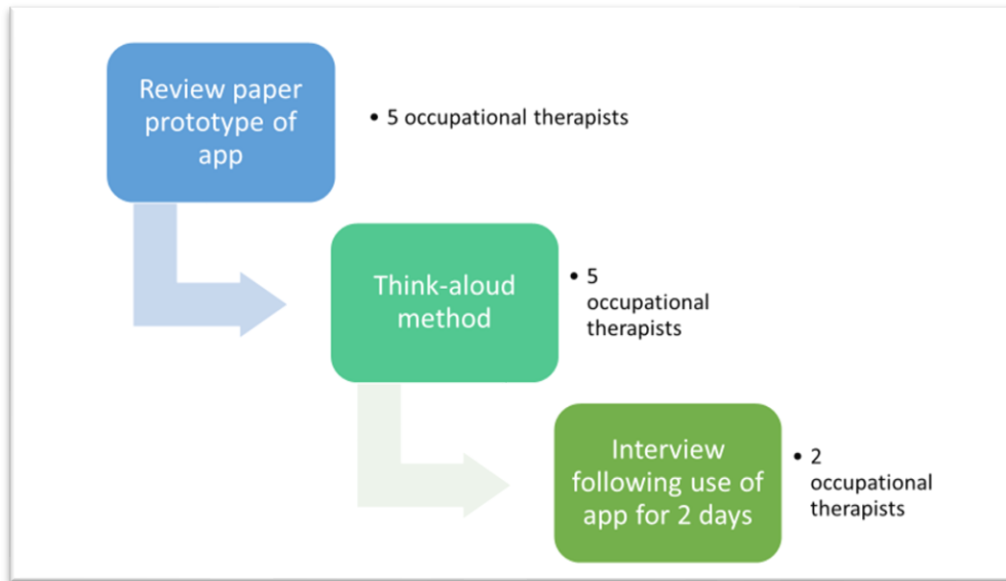
ABI survivors were recruited through online advertising with Oxford Headway and the Arni Institute. Members of the initial advisory group who had expressed interest in testing the app were also invited to participate. To be eligible to participate in the study, all participants must have experienced ABI and fatigue, be able to use an android smartphone in daily life, be able to give informed consent and communicate sufficiently in English to follow instructions and participate in an interview.

### ***7.3.2. Stage one: data collection***

Five therapists consented to review the paper prototype of the app and participate in a think-aloud. Two participants also agreed to test the app during their daily lives. See figure 7.1.1.

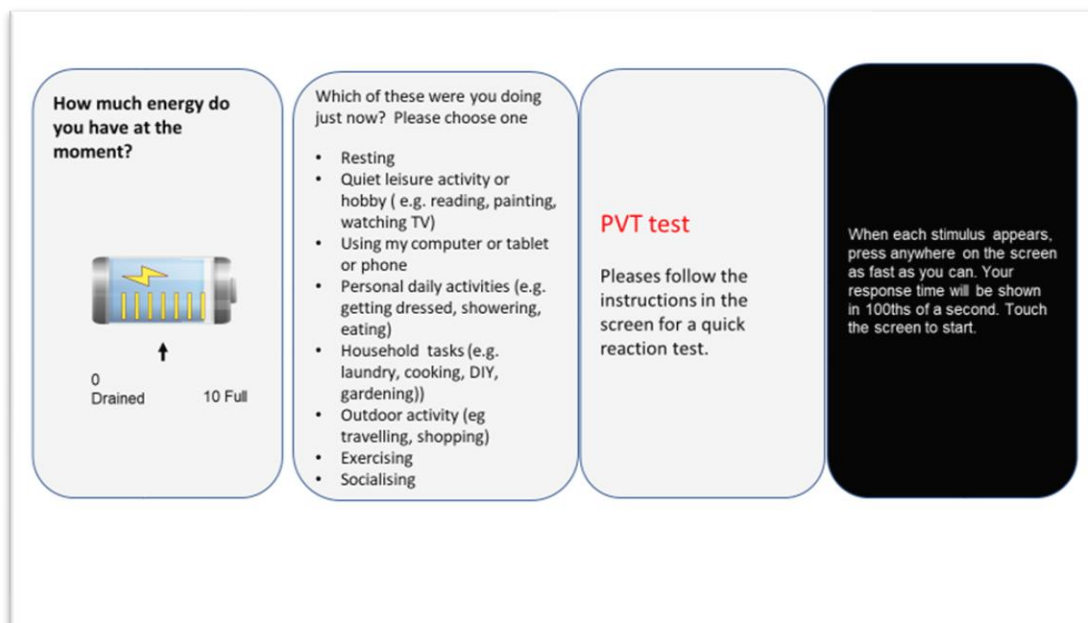


Figure 7.1.1. The flow of participant involvement in part 1 of the study



Therapists were initially asked to review paper prototypes of the app screens (figure 7.1.2) and to comment on the design and clarity of instructions. The researcher made notes of the feedback given by therapists after they reviewed the paper prototypes.

Figure 7.1.2. Paper prototype of app screens



The therapists engaged in a think-aloud method as they completed the EMA of fatigue, activity question and the reaction time test. Before participating in the think-aloud, participants viewed a short video demonstration. Then as they used the app for the first time, they were asked to verbalise their thoughts, feelings and what they saw. Minimal prompts were given and then only in response to a direct question from the participant. The think-aloud's were audio-recorded and later transcribed.

The think-aloud method is used to gain insight into how an individual interacts with the application and to identify factors that affect usability (Jaspers, 2009). The method originated in cognitive psychology and is assumed to reflect participants immediate cognitive processing of a given task, rather than their delayed interpretation and explanation of what happened (Charters, 2003). However, within usability evaluation, the focus of the think-aloud is the user's interactions with the product being tested, rather than eliciting users' cognitive and problem-solving processes. The user becomes the expert as they interact with the product and uncover usability issues (Boren and Ramey, 2000). The user is instructed to state what they are thinking and experiencing as they navigate and use the application their speech is audio recorded and later transcribed for analysis (Jaspers, 2009). The researcher may encourage the participant or assist with any difficulties but otherwise minimises their interruption (Boren and Ramey, 2000).

Two therapists agreed to test the app over two days, after which they were interviewed about their experience. The interviews were audio-recorded and later transcribed. The smart EMA was then refined following feedback from the therapists in readiness for the next stage of evaluation.

#### ***7.3.4. Stage two data collection***

After obtaining informed consent, participants with ABI were sent written instructions on using the app, and an accelerometer (Axivity AX3) to wear on their non-dominant hand. The AX3 is a wrist-worn data logger that has a 3-axis accelerometer, flash-based onboard memory and a real-time

quartz clock which makes it suitable for collecting longitudinal movement data. The AX3 was set up to capture triaxial acceleration data over six days, 100Hz with a dynamic range of  $\pm 8g$ .

Participants met with the researcher using video conferencing and were supported to install the app on their phone. Participants who did not have access to an android phone were loaned an android phone for one week, with the app installed. During the initial contact, participants were shown how to use the app and completed a short demographic questionnaire (Appendix F).

Each participant using the app was allocated a unique identifier by the app and their data was streamed over an encrypted channel to a secure server on Firebase (Google's mobile platform). Hence the data returned by the app was de-identified. The smart EMA collected time-stamped data which included ratings on the numeric rating scale of energy, answers to a question "what have you been doing for the last 10 minutes?", reaction times for a short reaction time test (reaction time to a stimulus randomly presented 20 times), how the alert was triggered (either by the individual or by the app) and whether the EMA was skipped and for what reason, (participants could choose to skip the EMA and were asked to indicate whether they were too tired or whether they didn't have time to respond). The reaction time test presented 20 stimuli each time, excluding false starts (less than 100ms) and late responses (greater than 1000ms). The app also returned data on activity transitions (as analysed by the Google application interface) and sampled ambient noise levels for 30 seconds at 15-minute intervals.

Participants were asked to complete and return the system usability scale questionnaire (SUS) once they finished the agreed period of testing (Appendix G). The SUS provides a global view of perceived usability and is not platform-specific, so it can be used to evaluate mobile apps (Zapata *et al.*, 2015; Brooke, 1996; Lewis, 2018). It is a 10 item questionnaire that has high internal consistency and satisfactory reliability (coefficient alpha of 0.91) (Bangor, Kortum and Miller, 2008). The scale is scored out of 100, with 68 being an average score (68 is the 50th percentile). Scores of 80 or higher

indicate acceptable usability but should be interpreted cautiously in small studies as the scale is skewed to higher scores (Bangor, Kortum and Miller, 2008).

Participants were contacted six to seven days after installing the app and were interviewed about their experience of using the EMA using a semi-structured interview guide (see Appendix H). All interviews were audio-recorded and later transcribed. After completing, participants who used their phone for the study were shown how to uninstall the app.

### *7.3.5. Methods of analysis of stage one and two data*

The think-aloud procedure and interview transcripts were analysed separately using inductive content analysis (Vaismoradi, Turunen and Bondas, 2013). Inductive content analysis involves familiarisation with the data, open coding of interview transcripts and grouping codes together into broader, descriptive categories (Elo and Kyngas, 2007). The researcher analyses the manifest content of interviews by staying close to what participants say rather than exploring underlying meanings (Bengtsson, 2016). The researcher assumes a factist perspective to the data, where the data is assumed to be a truthful representation of an individual's experiences. Hence content analysis is a suitable approach for reporting descriptions of common issues encountered in the interview data (Vaismoradi, Turunen and Bondas, 2013).

The coding of interviews was informed by the research objectives and dimensions of usability (as discussed in chapter 5) but the researcher also developed codes that reflected novel concepts within the interviews.

The SUS was summarised using descriptive statistics (mean and standard deviation). Data from the app was analysed to determine the percentage of EMAs completed. The app recorded when alerts were created, started and whether they were actively skipped by the user. It did not record how many alerts were sent but not responded to. Hence completion rates were calculated for full days only, assuming that eight alerts were sent each day.

Data from each participant (NRS energy scores, reciprocal reaction time test) were plotted in Microsoft Excel to allow exploratory visual inspection of potential intraindividual patterns of fatigue and activity over time. Mean and standard deviation of group NRS scores and individual mean scores were calculated. NRS energy scores and the number of lapses were plotted on scatterplots to examine an individual's performance on the reaction time test and their self-rating of energy. The number of different types of activity recorded in the activity question was plotted in doughnut charts, again to visually inspect the data and explore the potential usefulness of the data collected by the app.

For reaction time tests, outliers were removed from the data. Outliers were defined as a response time of over 3000ms (as these indicate an error) and those of under 100ms (as this indicates a false start) (Basner and Dinges, 2011). As each reaction time test recorded reaction times to 20 stimuli, the mean of reciprocal reaction times for each test was calculated and the number of lapses counted. Basner and Dinges (2011) study of 73 health individual's reaction times after sleep loss found that the response speed (reciprocal reaction time) and the number of lapses were most sensitive in detecting fatigue due to sleep loss and recommended these as primary outcomes for reaction time tests. Reaction times of greater than 355ms were considered a lapse.

The AX3 data were downloaded and analysed in 60-second epochs using OMGUI software, v1.0.0.37. The programme then calculated whether an epoch was spent in sedentary, light, moderate and vigorous activity by applying 'cut-points' that correspond to different intensities of activities (Esliger et al., 2011). Non-wear time in 30-minute epochs was also calculated using the OMGUI software algorithm. A period was classified as non-wear time if the standard deviation was less than 3mg for two of the three axes or if the value range was less the 50mg for two of the three axes (Jackson, 2020).

Agreement between activity transitions as recorded by the app and activity levels as recorded by AX3 was investigated using agreement Tables and calculating kappa for each user. Activity

transitions were recorded as 0 (still), 3 (on foot), 7 (in a vehicle) with timestamps for entering and leaving the activity. The mode of levels of physical activity as recorded by the AX3 was categorised as still or moving to allow comparison with the activity recorded by phone sensors. The category “in a vehicle” was excluded from the analysis as it did not fit into either category (being still or the person is moving). The timestamp transitions for being still or moving were compared to physical activity recorded by the AX3 (sedentary or moving) for periods of recorded wear time of the AX3.

Sampled levels of noise in decibels were summarised for each participant and the number of potential event contingent alerts recorded where noise levels above 45 decibels were detected.

#### 7.4. Results from stage one

Five Occupational Therapists participated in the initial evaluation of the app. All therapists worked with ABI survivors and had clinical experience of fatigue management interventions. See Table 7 for details of their involvement in the study.

Table 7. Occupational Therapists participation in the study

Participant	Feedback on prototypes	Completed think-aloud	Used the app in daily life
1	✓	✓	
2	✓	✓	
3	✓	✓	✓
4	✓	✓	
5	✓	✓	✓

##### 7.4.1. Feedback from therapists on prototypes

Of the five therapists that reviewed the prototypes, four commented positively on the numeric rating scale of energy and the visual analogy of a battery to represent a loss of energy or increased fatigue. They reported using similar analogies when educating ABI survivors about managing fatigue and believed patients found it helpful. One participant reported that the battery would be better upright as it made more sense of the visual image of draining or being full. They all commented on the need for the marks on the battery to range from 0-10 as this would be more familiar and

potentially less confusing for patients (therapists reported asking patients to rate their subjective state out of ten). Therapists expressed different views about self-rating energy as opposed to fatigue. Participant 5 stated that energy was better understood by her patients but questioned whether energy related to physical or mental energy.

With regards to the activity question, therapists commented on the categories being too broad and that items were missing (such as work) whilst others needed to be defined (for example rest).

Therapists reported that use of the word “test” might be anxiety provoking for some and that they did not know what PVT meant. One participant thought the change in screen colour was helpful to focus the user’s attention whilst another questioned the accessibility of white text on a black background.

#### *7.4.2. Results of the think-aloud method and therapist interviews*

Three key themes were derived from the think-aloud interviews: visual cues were helpful, knowing what to do next and working through uncertainty.

##### *Visual cues were helpful*

Participants found the use of colour to reinforce concepts within the app or to signal a change in screen helpful. For example, participant 2 when using the numeric rating scale of energy stated: “I understand that full is green that sort of implies a lot of energy”.

##### *Knowing what to do next*

All four participants found it easy to navigate from one component of the EMA to the next component. The instructions were perceived to be clear and no errors were made in navigation.

Participant 4: “now I know that I can see “next” is highlighted so I need to go to the next page”.

## Working through uncertainty

Participants experienced two sources of uncertainty in the EMA. The first arose in the activity question. In this version of the app, there were 12 options to choose from in response to the question “which of these were you doing just now?” One participant was unsure initially of which category to use.

*Participant 1: “Which one of these were you doing just now choose one. Ah well. I was almost doing a cross between 2 & 3. Quiet leisure activity -using a Tablet. I was in fact sitting here but reading a book on my iPad. So ah, I was reading but I guess I was on my Tablet so I am going to say “on my Tablet”.*

The second source of uncertainty was the reaction time test. Two participants did not recognise the numbers scrolling up as “the stimulus” and became confused about when to start and what to do.

*Participant 5: “I thought I was waiting to touch something coming at me on the screen. I don't know whether I am but it seems to be just 100s of a second that came up on the screen. So was I supposed to touch or was I supposed to wait?”*

The other two participants started the reaction time test correctly but were unsure of how long the test would last for and this caused uncertainty as time progressed. There was also no feedback at this point and the app closed, leaving the participants “mystified”.

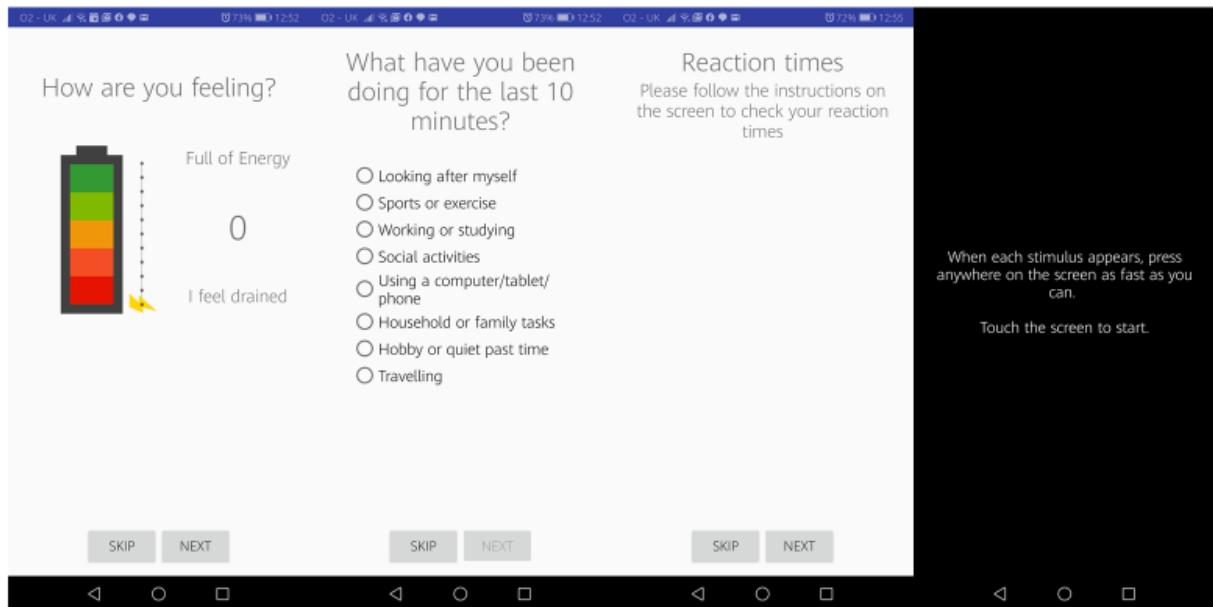
*Participant 4 “So I seem to have done quite a few now and I am wondering how many there will be”.*

## 7.5. Discussion of results from stage one

Feedback was discussed with Jose Vegas and areas for change were categorised and prioritised. Key changes were focused on addressing feedback about the NRS of energy and the activity question, as illustrated in figure 7.1.3. The battery for the NRS of energy changed to an upright position and was placed centrally on the screen. The scale became an 11 point scale (0-10) and was more closely aligned to with the battery.



Figure 7.1.3. Screenshots of app following changes made from feedback



The choice of answers for the activity question was expanded using eight branching categories based on the activity groups used with the harmonised European time use guidelines (Eurostat, 2019). Users are asked to consider which broad category their current activity related to and then select a more specific activity from the following screen. Several activities appeared in two categories, thereby reducing the need to memorise where activities appeared. For example, walking appeared both in the “travelling” category and the “sports and exercise” category. Each activity was allocated a code to allow for analysis of the data as reported by the app (see Table 7.1). The order of activities presented changed randomly each time on each screen, to encourage the participant to consciously choose a response, rather than respond automatically.

Table 7.1. Activity choices presented by smart EMA and codes for analysis

Screen 1	Screen 2
Looking after myself: 1	Getting washed or dressed: 1 Eating: 2 Sleeping: 3 Taking time out to rest: 4 Unwell in bed: 5

Screen 1	Screen 2
Household or family tasks: 2	Cooking: 6 Cleaning house or car: 7 Gardening: 8 Childcare: 9 Caring for another adult: 10 Financial or administrative tasks: 11 Shopping: 12 Laundry: 13 House repairs: 14
Working or studying: 3	Working from home: 15 Working at your workplace: 16 In a lesson: 17 Studying: 18
Travelling: 4	Driving: 19 Passenger in a car: 20 Using public transport: 21 Cycling: 22 Walking: 23
Social activities: 5	Socialising at home: 24 Talking on the telephone: 25 Visiting friends or family: 26 Out with others for a meal or drinks: 27 At the cinema or theatre: 28 Watching live sport or music: 29
Using a computer/Tablet/phone: 6	Playing a game: 30 Watching videos: 31 Checking emails: 32 Browsing the internet: 33 Reading: 34 Listening to music/radio: 35
Sports or exercise: 7	Walking: 23 Jogging/running: 36 Cycling: 22 Ball game: 37 Yoga/Pilates: 38 Fitness class: 39 Swimming: 40
Hobby or quiet past time: 8	Watching television: 41 Reading: 42 Listening to music/radio: 35 Playing a musical instrument: 43 Art or craft work: 44

Finally, the instructions for the reaction time test were changed and an instruction manual developed to support an initial app use tutorial and serve as a quick reference guide as participants adjusted to using the app (Appendix I).

## 7.6. Results of stage two

Seven people with acquired brain injury agreed to take part in the study (see Table 7.2 for participant details). Four participants had experienced stroke and three had a traumatic brain injury. Ages ranged from 37-73. Only two participants were able to use their phone for the study. Four participants owned an iPhone, and one participant was unable to install the app on to their phone. This meant that those using the study phone carried two phones with them for the duration of the study. All participants reported using their phone to make calls and receive messages and using the calendar as their diary. Daily app use was more variable, ranging from no use of other apps to using apps for entertainment and to assist in daily life.

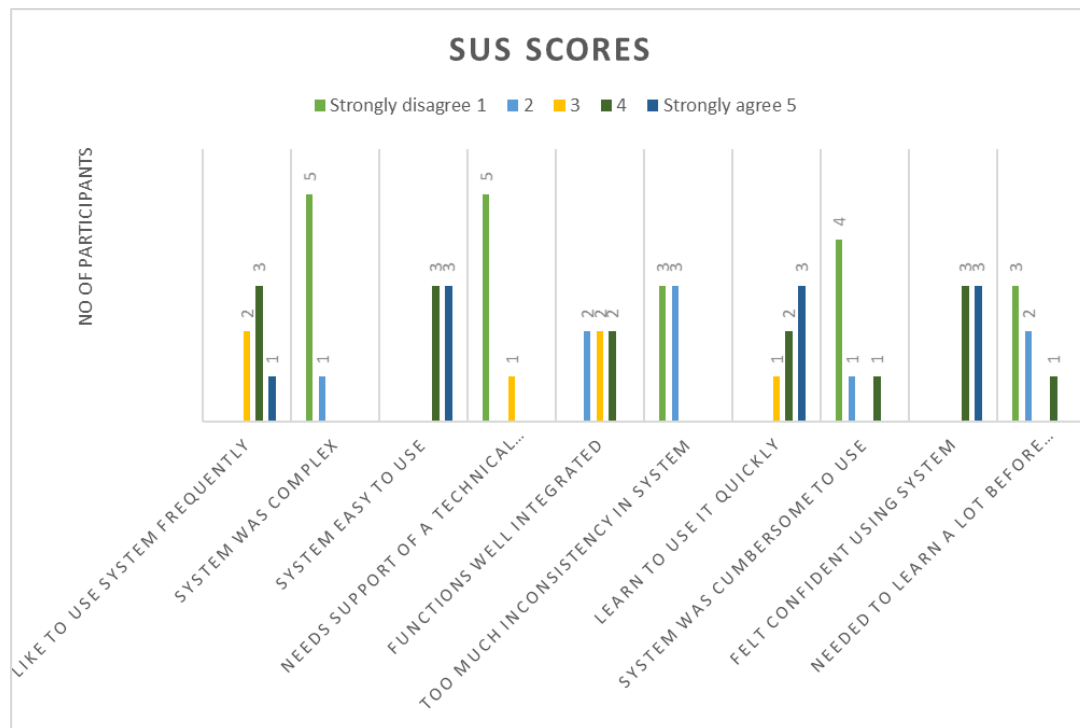
Table 7.2. Summary description of participants with ABI.

Participant id	Age	Gender	Time since brain injury	Type of phone (own or study phone)	Usual app use on phones.
6	61	Man	6 years	Study phone (Moto 3)	Uses apps to assist in daily life and for entertainment purposes.
7	61	Man	9 years	Study phone (Moto 3)	Uses apps for entertainment purposes only
8	37	Woman	2 years	Study phone (Moto 3)*	Uses apps to assist in daily life.
9	72	Man	2 years	Own phone Samsung Galaxy	Uses apps to assist in daily life.
10	47	Man	32 years	Study phone (Moto 3)	Does not use apps to assist in daily life or entertainment purposes.
11	51	Man	3 years	Own phone Samsung	Uses apps to assist in daily life and for entertainment purposes.
12	73	Woman	2 years	Study phone (Moto 3)	Uses apps to assist in daily life

\*Participant initially attempted to use own phone (Samsung) but was unable to configure the phone's permissions to allow installation of the app.

Six participants completed the system usability scale and the mean total score was 82.5 (maximum score of 100), range 62.5 -92.5, with only one participant scoring less than 68. See figure 7.1.4.

Figure 7.1.4. Summary of ratings for questions on the system usability scale.



The percentage of EMAs completed ranged from 2% to 98% and the mean completion rate of random and fixed alerts was 37% (table 7.3). The mean number of surveys completed per participant was 33, a total of 233 surveys were completed for the whole study. Participant 9 reported syncing his phone with his Tablet and responded to alerts on both devices, hence the completion rate could not be calculated for this individual. Participants were able to self-trigger an EMA and tended to self-report rather than respond to a trigger. For example, participant 10 completed only 5% of app surveys but self-reported 27 times over 6 days. With regards to fixed alerts, the response rate was poor with five out of seven participants responding to less than 50% of the alerts. Data from qualitative interviews revealed that several participants were unable to hear the phone notification to complete an EMA and carrying a second phone to use in the study likely contributed to the low completion rates.

Table 7.3. Completion rates of EMA for each participant

id	No. of full days	max no of alerts sent.	No. of responses	No. Completed EMAs	No. EMAs skipped	No. of responses to fixed time alerts	No. self-triggered EMAs	% alert responded to.
6	6	48	22	19	3	3	9	21
7	6	48	48	48	0	11	1	98
8	6	48	22	22	0	2	11	23
9	7	Unable to determine *	80	78	2	23	9	Unable to determine *
10	6	48	30	28	2	0	27	2
11	5	40	9	9	0	1	7	5
12	5	40	29	29	0	7	0	72

### 7.6.1. Findings from the content analysis of interviews with ABI survivors

Content of the interview transcripts was coded and grouped into three main categories: participant's perspectives on using the app, barriers to using the app, perspectives on future developments.

#### Participant's perspectives on using the app.

Participant's comments about the app were generally positive. They liked the discreteness of the app in that they could delay it or ignore it if it alerted at an inconvenient time. They also reported that the app was easy to learn and easy to use.

Participant 12 *"In the beginning, I was a bit apprehensive but once you have done it a few times, it was almost second nature and it wasn't a big deal"* (woman aged 72).

Participant 7: *"it's well balanced and not complicated, which I think is very important for those of us that are struggling with fatigue."* (man, aged 71).

Two participants reflected on how using the app changed their behaviour. Participant 6 noticed the impact of his sleeping patterns on his daily energy levels and decided to change his approach towards managing his sleep. Participant 7 explained that he started to think differently about his fatigue and questioned whether he needed to rest or whether he had enough energy to do something else.

Participant 7: *“Well it just made me do it more often than I normally do whereas- but in a normal day, I wouldn’t have been thinking ‘are my energy levels at above five or below five’. I would just be thinking ‘well I’m feeling alright or I’m not’ or ‘it’s about time I went out and have a rest’ or something like that. So I suppose what it did was made me think about how much- how I felt not just ‘oh it’s time to go and have a rest.’*

The frequency of alerts was reported to be manageable, but two participants found the fixed alert times didn’t match their lifestyle and would have liked the option to change the times. For example, participant 8 was a mother of young children who were up at 6.30 am each day. She reported that the app measured how she felt after the school run, rather than when she got up.

The numeric rating scale of energy was reported as a positive feature of the app by most of the participants. They found the analogy of a battery and changing energy levels related to their experience of fatigue. Participant 6 described how the energy related to his experience of fatigue.

Participant 6 *“ I’ve had a good night’s sleep, I would have a lot of energy. Then if it goes down, my personal battery goes down late in the afternoon and I sleep for a couple of hours. There’ll be a short period when I wake up, that it’ll be much better that it just drains quicker so, I like that. I do like that. It’s really good,”* (6, man, aged 61)

Several participants commented that thinking about energy rather than fatigue was more positive.

The concept of energy was perceived to be “more encapsulating” than fatigue and prompted participants to consider energy as a resource.

Participant 11: *I think generally I was thinking about how tired I was at the time and I would also consider how about how much I had to do for the rest of the day and whether I would have enough energy to get through all of that”* (11, man, aged 51).

Several participants related their energy levels directly to how fatigued they felt.

Participant 12: *“Well, I related it very much to the energy was almost, when you had low energy, yes you were fatigued, in my mind.”* (12, woman aged 72).

Participants experience in answering the activity question was more variable, with some reported the activity categories to be too restrictive, whilst others thought the categories were comprehensive. One participant struggled to categorise activities that served two purposes. He felt that the way his brain injury affected his thinking made answering this question more difficult, particularly if no category directly matched his activity.

Participant 6: *"I think the thing is gym work, I think. Cause that's kind of like socialising for me. I get everything compartmentalised is what I'm trying to say so a bit more specific like the gym, yeah I would've ticked that one then"* (6, man, 61).

Participant 8 also experienced difficulties deciding which category an activity came under but also felt that some categories were too broad to reflect her experience.

Participant 8: *"Or if you were doing things that both fit under cleaning or childcare but actually were very different. So I just thought, it covers a multitude of sins, doesn't it childcare?"* (8, woman, aged 37).

The activity question did not have a "back button" so participants could not return to the previous question or change their mind. This was viewed differently amongst the participants. Participant 7 thought it was helpful to stop him from "getting stuck in a loop" whilst trying to decide what to choose. Whereas other participants were "stuck" on the wrong sub-category of activities.

Participant 11: *"if there was a way of improving it so that you wouldn't get stuck. It was the sub options that were particularly...So if I clicked on working from home for instance and there was a sub-option, the sub-option,...it wouldn't capture exactly what I was doing but it would mean i wouldn't have to click on the wrong answer".* (11, man, aged 51).

Participant 9 commented that there weren't enough stroke-specific activities.

Participant 9: *"I think just when I have been doing exercise. I do arm and hand exercise in a seating position. The only thing that was there was a fitness class and it's not really a fitness class but that was the nearest thing on the list".* (9, man, aged 72).

With regards to the reaction time test, participants described completing the test both as a game and as a potential "chore". Two participants reported that the length of the test was just about acceptable for a short period but that they would not have tolerated a longer test. Participant 12 suggested either shortening the reaction time test or completing it less frequently.

Participant 12: *"Well I think, there were 20 of them weren't there? Well in all honesty, by the time I had done it each time, I got to about 15ish and I would think I am fed up of this, I've had enough of this."*

Others became competitive and tried to beat their score. Several perceived their reaction times to be faster when they felt alert or noticed that they were less able to concentrate on the test.

Participant 8: *I guess it was just quite illuminating how many different seconds there is between when you feel energised or when you feel sleepy or how that doiness does affect your concentration*

### Barriers to using the app

Participants identified two barriers to using the app. The first was having two mobile phones, for those who used the study phone. One participant found carrying two phones “confusing” (participant 6), whilst several others kept their phone in a bag and were aware of missing alerts (participants 8, 10, 11). This may explain the low completion rates for these four participants.

The sound notification was the other key barrier to using the app. Participants phones vibrated to indicate it was time to complete an assessment and this was missed by several participants.

Participant 12 *“I think I missed a few. I don’t think it buzzed as strongly as it might have”.*

### Perspectives on future developments

Participants were asked about what they would change with the app or what feedback they would like to see. Participants were interested in the apps’ potential to predict their fatigue or to notify them of when to rest. Others wanted to capture their experiences over time to see how their fatigue changed, whilst two participants wanted to know how they compared to others living with fatigue.

Participant 6. *“it’d be great if I could just put great in the morning and then watch it (the battery) slide down and say, “oh, right .. should I have a nap now?”*

Others suggested it would be helpful to capture information about their sleep and night and daytime naps.

In terms of improvements for the app, participants wanted greater personalisation so that they could change the alert to make it more audible or persistent, adjust fixed time alerts to match people’s routines or amend activity categories and better reflect individual’s lifestyles.



### 7.6.2. Analysis of data collected by the smart EMA app

The following section reports on the data collected by the app and by the phone sensors and provides an initial exploration of the feasibility of using the app data to monitor fatigue and activity.

#### Activity pie charts

Responses to the activity question provided information about the type of activity engaged in and how many times the activity was reported by each participant. Figures 7.1.5 and 7.1.6 are examples of participant's responses to the activity question. These participants completed the most EMA's of the sample and are comparable but participant 9 reports less variety of activities and has a greater proportion of sedentary activity than participant 7. Participant 9's most frequently reported activity was watching television, whereas participant 7's most reported activity was socialising at home. (See Appendix J for summarised data for participant 6, 8,10,11 and 12).

Figure 7.1.5. Frequency of reporting different types of activity for participant 7

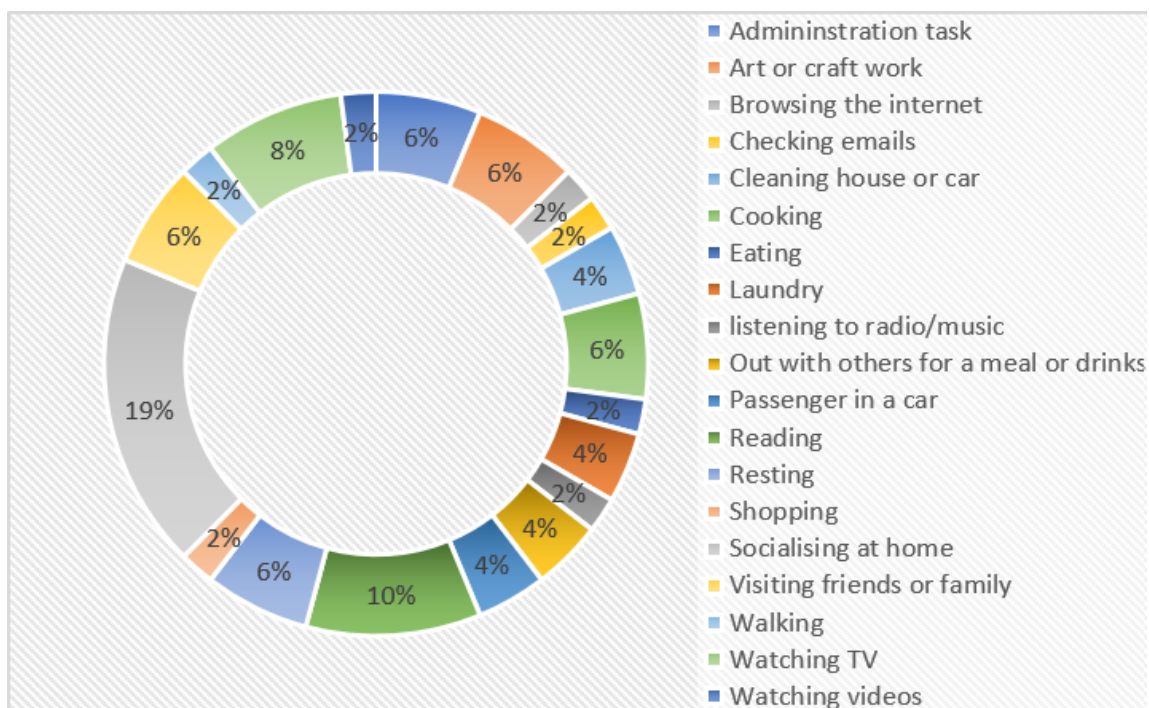
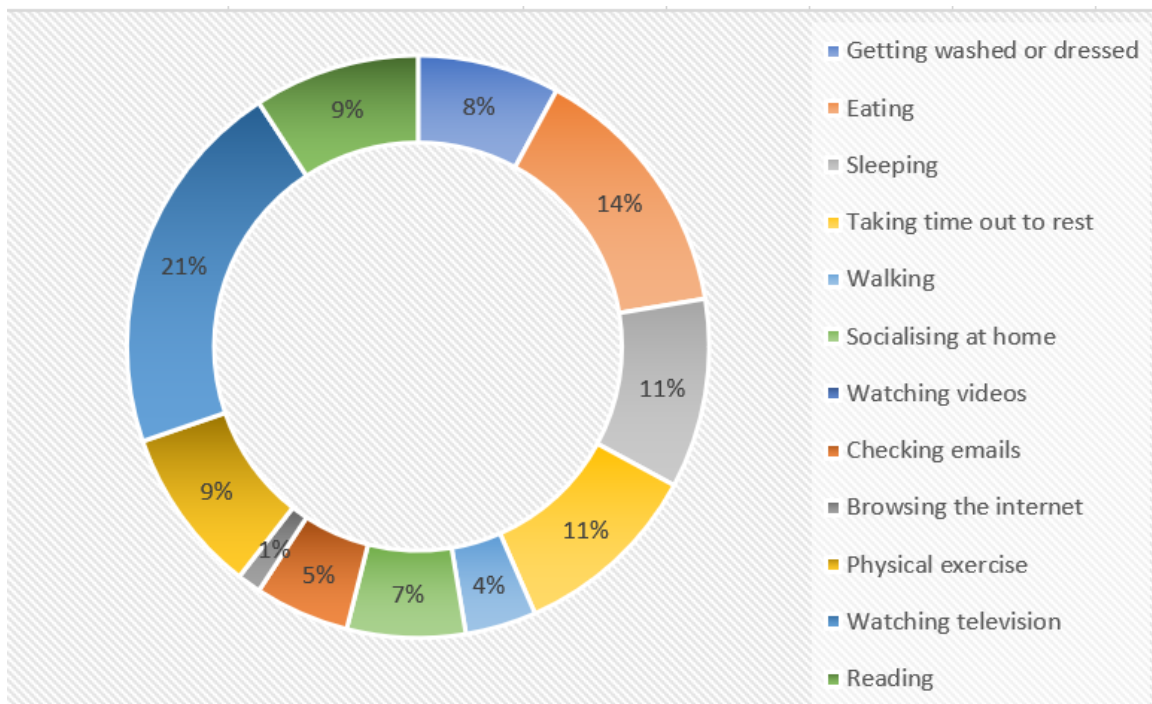


Figure 7.1.6. Frequency of reporting different types of activity for participant 9

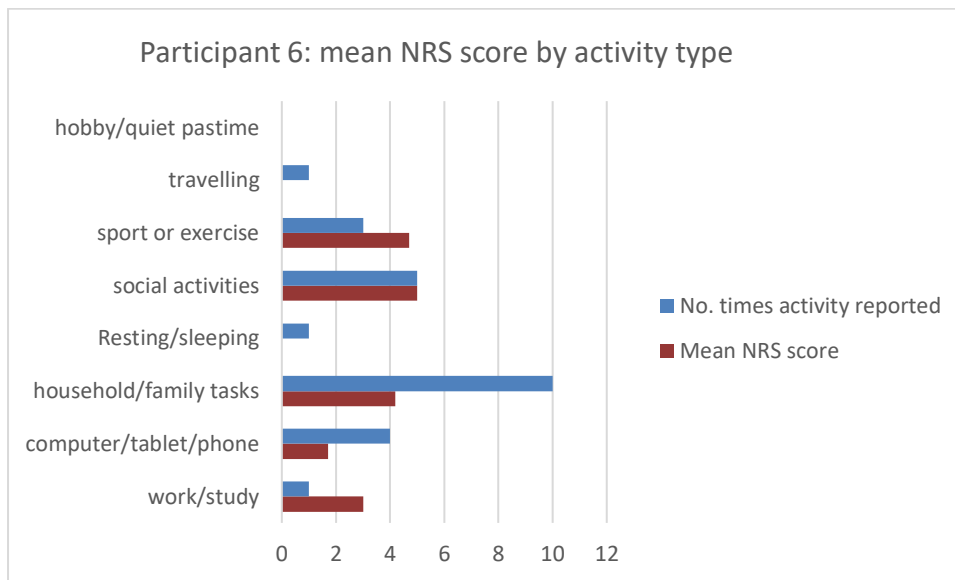


#### Activity and NRS scores

The mean of NRS energy scores of all participants was 5.1 with a standard deviation of 1.8, range of 0 to 10. Individual mean NRS scores ranged from 3.6 to 6.4.

Visual inspection of mean NRS scores by activity type points to varying patterns of energy scores and activity by participant. For example, participant 6 rated his energy as 4 or higher for exercise, socialising or household tasks but reported lower energy when travelling, resting, working or using his phone or computer.

Figure 7.1.7 Mean NRS score by activity type for participant 6



Whereas participant 12 rated her energy as 5 or more during quiet past times, household tasks or using her computer or phone, but reported low energy when socialising, exercising and travelling.

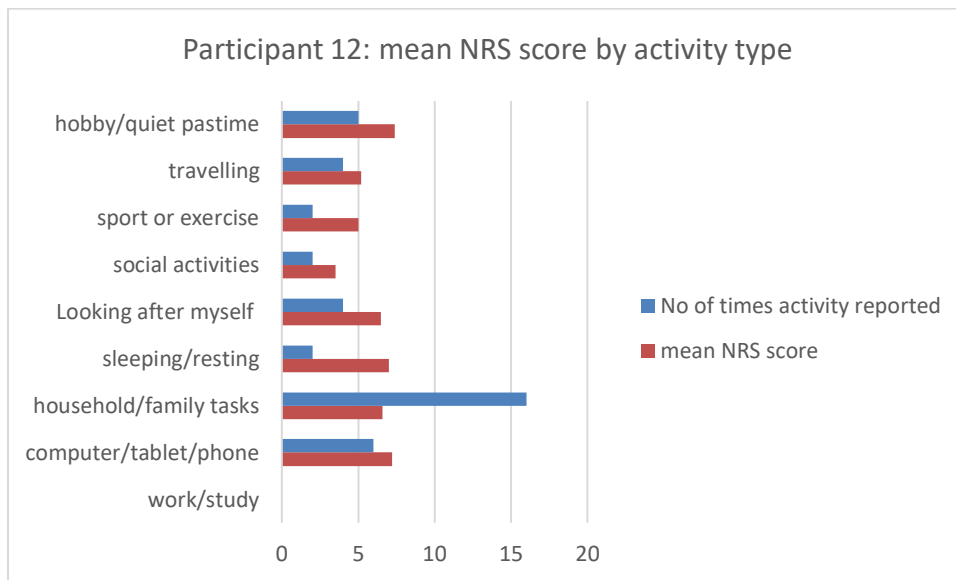
Participant 9 indicated very little fluctuation in his reported energy levels so there was no discernible relationship between his energy levels and activity type.

These patterns may be explained as participants tackling more demanding tasks (whether they are physically or mentally demanding) when their energy levels are relatively high (as in participant 6).

Or participants using quieter activities to restore their energy (as in participant 12). Different

patterns may also be explained by participants experiencing different time lags between activity and fatigue, with some experiencing increased fatigue during the activity while for others, fatigue builds more slowly over time.

Figure 7.1.8 Mean NRS score by activity type for participant 12.



#### Reaction time test and numeric rating scale of energy

The group mean of reciprocal reaction times was 2.6 (SD 0.81). Visual inspection of the NRS energy and mean reciprocal reaction times revealed variation in patterns of scores and reaction times amongst participants. For example, with participants 6, 7, 8 and 12, mean reciprocal reaction times tended to follow NRS energy scores (see figure 7.1.7 and 7.1.8). As the rating of energy levels increased, reciprocal reaction times increased (i.e. reaction times were faster). When inspecting NRS energy scores, participant 7 and 8 reported higher energy levels at the beginning of the day, with scores reducing as the day progressed, whereas participant 6 and 12 reported daily variation in their energy levels but with no discernible pattern. Both participant 7 and 12's daily mean NR scores tended to decline following social activity. Participant 12's decline was concurrent with social activity whilst participant 7's score declined the following day (see Tables 7.4 and 7.5). See Appendix K for reported activities and mean NRS scores for participants.

Figure 7.1.7. NRS energy scores and mean reciprocal reaction times recorded at EMA for participant

7

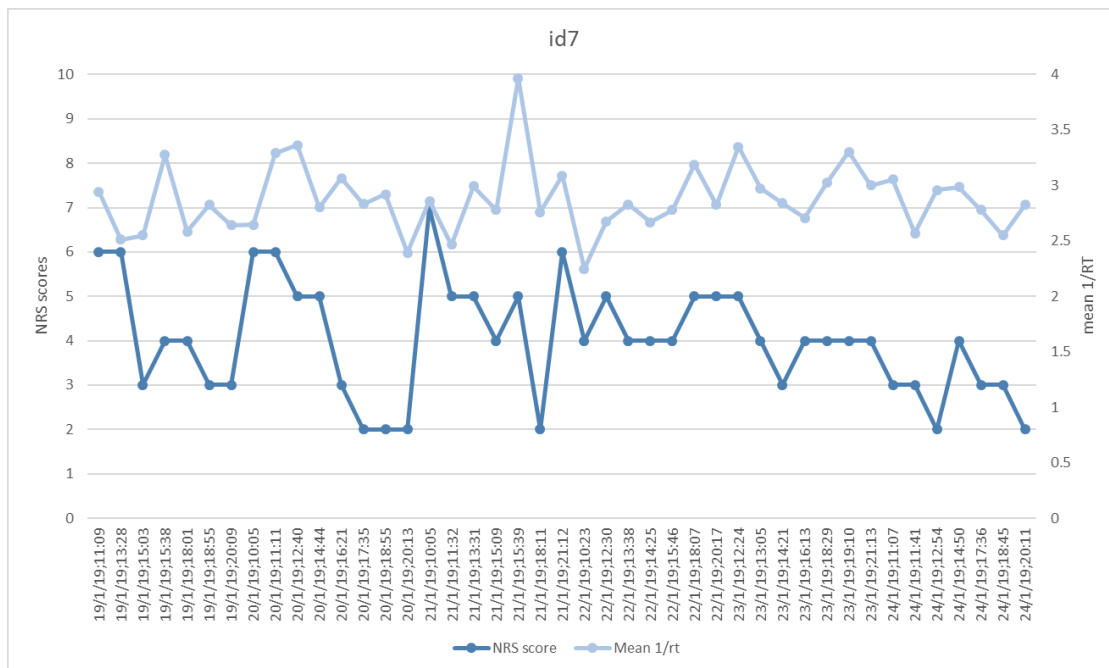
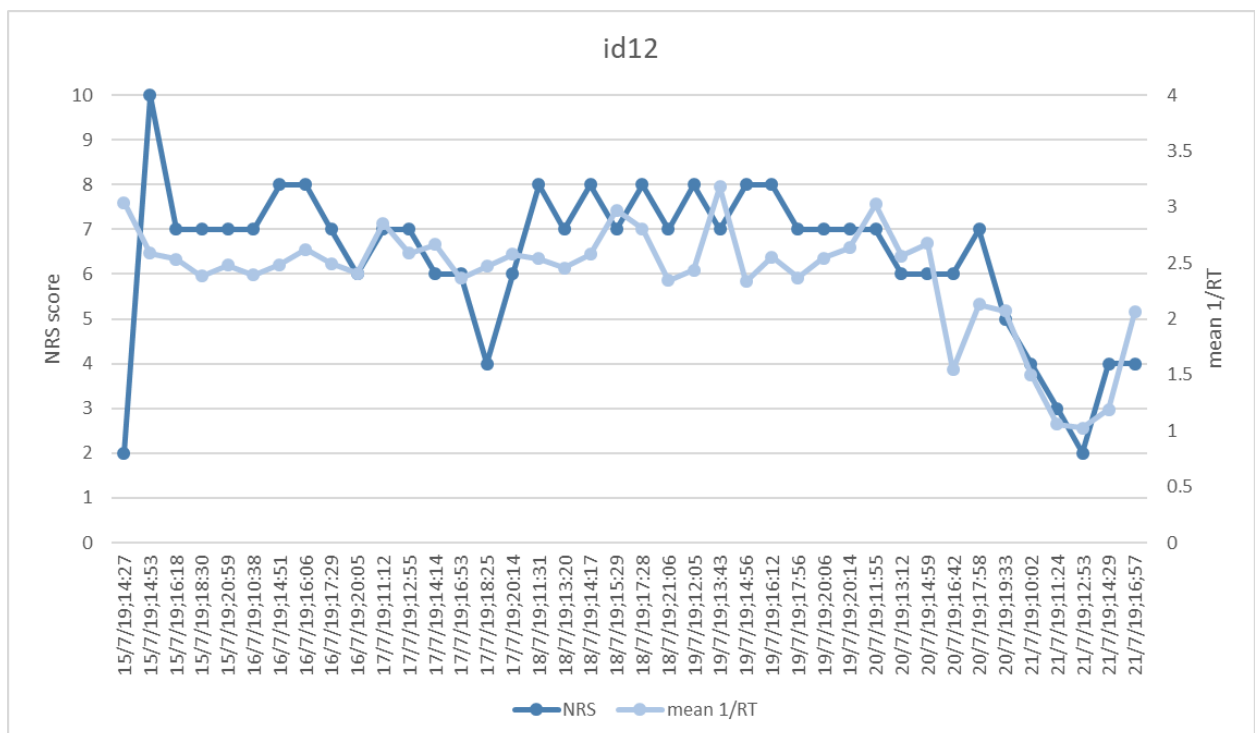


Figure 7.1.8. NRS energy scores and mean reciprocal reaction times recorded at EMA for participant

12.



Participant 11 only completed 11 EMAs over five days and there was insufficient data to indicate any

trends. Participant 9 reported limited variation in energy levels over time (with a mean score of 5

and SD of 0.8) but with no discernible pattern. There was, however, variability in his reaction time scores, but this did not follow his NRS energy scores.

Table 7.4. Participant 7 reported activities and NRS energy scores

<b>Date</b>	<b>Reported activities</b>	<b>NRS energy score.</b>	<b>Daily mean NRS score</b>
19-Feb	Administration task	6	4.38
	Browsing the internet	6	
	Out with others for a meal or drinks	6	
	Visiting friends or family	3	
	Resting	4	
	Visiting friends or family	4	
	Art or craft work	3	
	Watching TV	3	
20-Feb	Checking emails	6	3.88
	Administration task	6	
	Laundry	5	
	Shopping	5	
	Reading	3	
	Socialising at home	2	
	Reading	2	
	Watching TV	2	
21-Feb	Administration task	7	4.62
	Cleaning house or car	5	
	Art or craft work	5	
	Passenger in a car	4	
	Visiting friends or family	5	
	Passenger in a car	3	
	Cooking	2	
	Art or craft work	6	
22-Feb	Laundry	4	4.25
	Walking	5	
	Cooking	4	
	Socialising at home	4	
	Socialising at home	4	
	Socialising at home	3	
	Socialising at home	5	
	Watching videos	5	
23-Feb	Socialising at home	5	4.14
	Socialising at home	5	
	Socialising at home	4	
	Resting	3	
	Socialising at home	4	
	Watching TV	4	

	Cooking	4	3.11
24-Feb	Watching TV	4	
	Cleaning house or car	4	
	listening to radio/music	3	
	Out with others for a meal or drinks	3	
	Reading	2	
	Reading	4	
	Reading	3	
	Eating	3	
	Resting	2	

Table 7.5. Participant 12 reported activities and NRS energy scores

Date	Reported activity	NRS energy score	Daily mean NRS energy score
15-Aug	Checking emails	7	6.67
	Walking	2	
	Resting	10	
	Cooking	7	
	Financial or administrative tasks	7	
	Watching television	7	
16-Aug	checking emails	7	7.2
	Shopping	8	
	Checking emails	8	
	Watching television	7	
	Financial or administrative tasks	6	
17-Aug	Laundry	7	6.0
	Laundry	7	
	Checking emails	6	
	Driving	6	
	Resting	4	
	Financial or administrative tasks	6	
18-Aug	Listening to radio/music	8	7.5
	Washed and dressed	7	
	Financial or administrative tasks	8	
	Checking emails	7	
	Browsing internet	8	
	Watching television	7	
19-Aug	Cooking	8	
	Financial or administrative tasks	7	
	Watching television	8	
	Yoga/pilates	8	
	Cooking	7	

	Financial or administrative tasks	7	7.43
	Eating	7	
20-Aug	Eating	7	6.17
	Laundry	6	
	Passenger in car	6	
	Shopping	6	
	Passenger in car	7	
	Eating	5	
21-Aug	Out with others for meals/drinks	4	3.4
	Out with others for meals/drinks	3	
	Passenger in car	2	
	Financial or administrative tasks	4	
	Laundry	4	

Trend lines plotted on scatter plots of the number of lapses and NRS energy scores indicate weak negative linear associations with two or more outliers present for two participants (8 and 12) (figure 7.1.9). Increasing the sensitivity of the reaction time test by counting all times greater than 355ms as a lapse created a ceiling effect for participant 6 as most of his reaction times were greater than 355ms (figure 7.1.9). The scatter plot of mean reciprocal reaction times and NRS energy scores indicated weak to moderate positive linear associations for all but participant 9 (figure 7.2). Box plots of reciprocal reaction times and lapse count indicated that the reciprocal reaction time data were less variable, but outliers were present for several participants (figure 7.2.1 and 7.2.2).



Figure 7.1.9 Scatter plot of the number of lapses and NRS energy scores

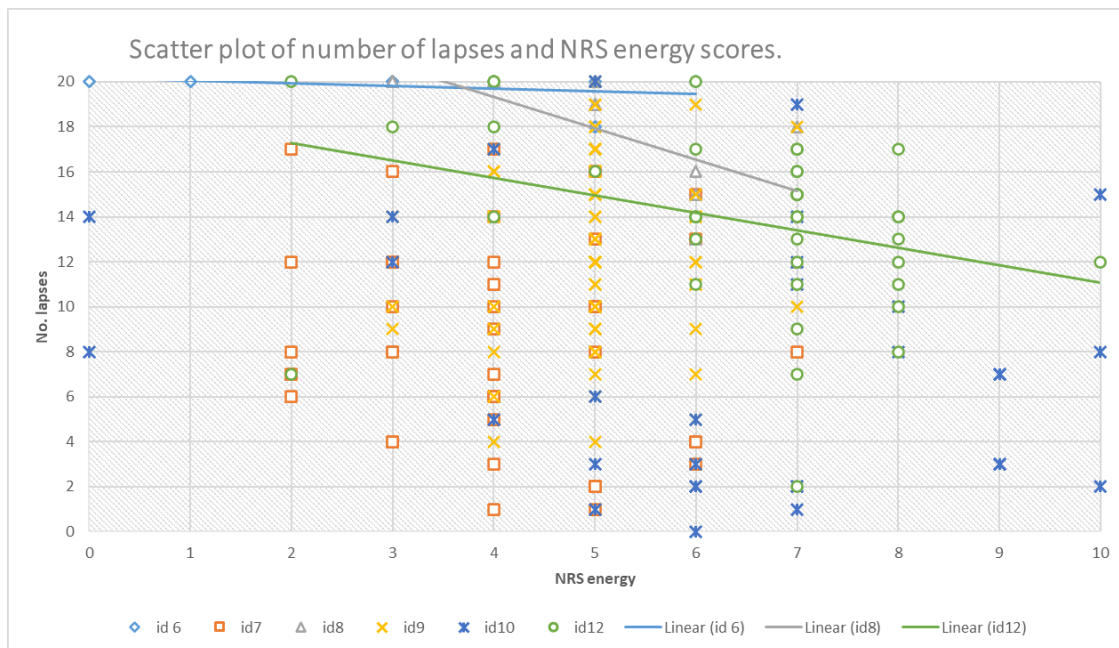


Figure 7.2. Scatter plot of mean reciprocal reaction times and NRS energy scores

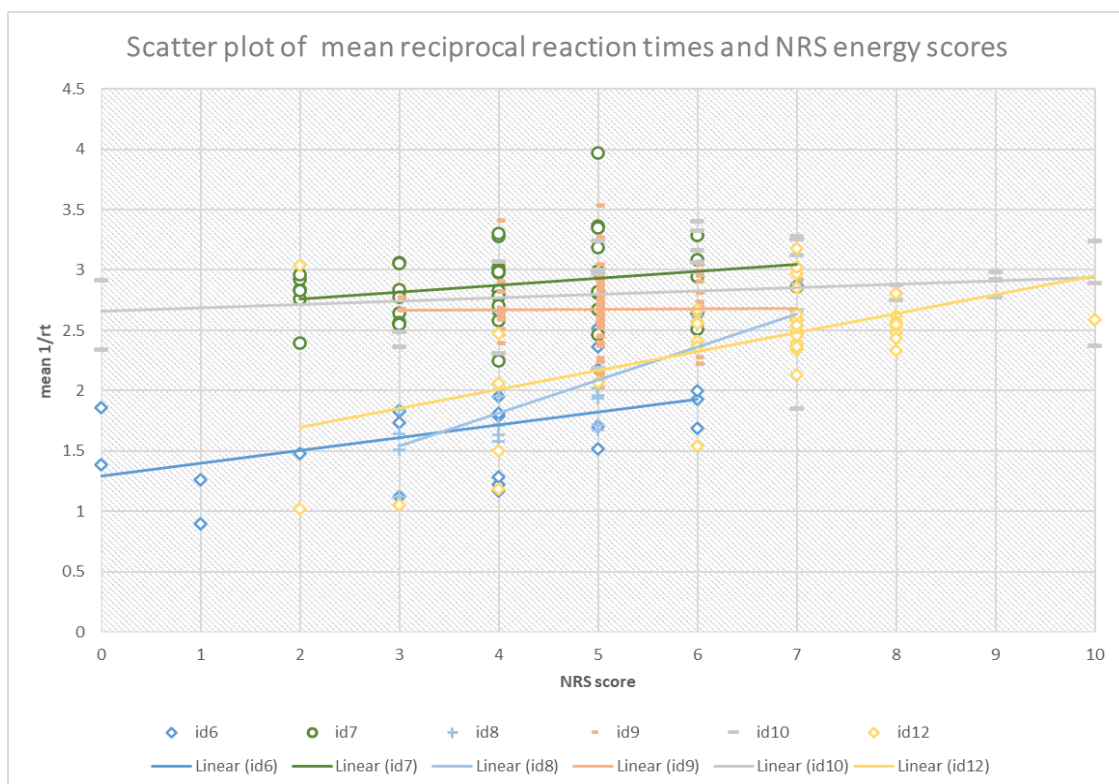


Figure 7.2.1. Box plot of reciprocal reaction times

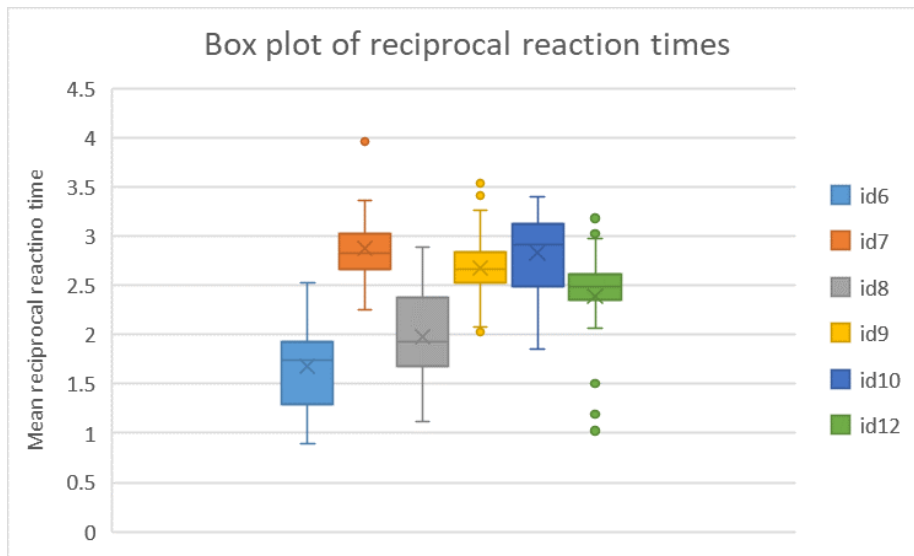
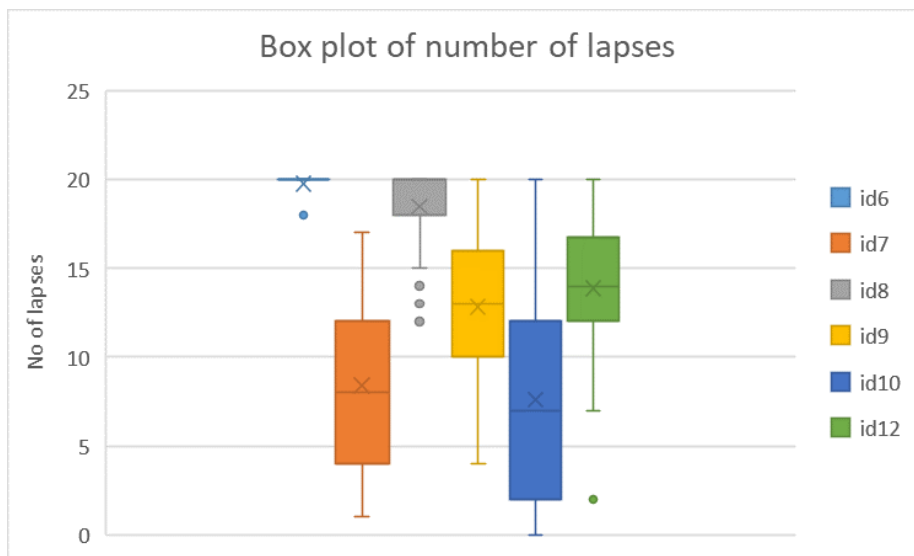


Figure 7.2.2. Box plot of number of lapses on PVT



### 7.6.3. Comparison of app data (activity transitions) and physical activity data from AX3

The wear time of the AX3 ranged from 63% to 100% during the hours the EMA sampled (10 am to 8 pm), with five participants wearing the AX3 for 90% of the time or more.

Kappa statistics for agreement between activity transitions recorded by the phone sensors and activity levels recorded by the AX3 for participants 6, 7 and 8. Table 7.6 demonstrates how activity transitions were recorded and compared to physical activity data.

Table 7.6. Sample of activity transition and AX3 data from participant 6

Date	Time	Activity type recorded by app	Transition	Mode physical activity recorded by AX3.
06/03/2019	06:49:09	still	enter	
06/03/2019	09:49:27	still	exit	light
06/03/2019	09:49:27	vehicle	enter	
06/03/2019	10:01:59	vehicle	exit	Not included
06/03/2019	10:01:59	on foot	enter	
06/03/2019	10:08:07	on foot	exit	light
06/03/2019	10:08:07	still	enter	
06/03/2019	10:36:03	still	exit	sedentary
06/03/2019	10:36:03	on foot	enter	
06/03/2019	10:40:29	on foot	exit	sedentary
06/03/2019	10:40:29	still	enter	
06/03/2019	10:41:39	still	exit	sedentary

For participants 6 and 7, kappa statistic indicated fair agreement but for participant 8, kappa was not statistically significant (Landis and Koch, 1977). See Table 7.7.

Table 7.7. Agreement between activity transitions detected by the phone sensors and physical activity recorded by AX3

<b>Participant 6</b>		<b>AX3</b>			Kappa = 0.412, SE 0.13 95% confidence interval 0.156 to 0.667
		still	movement	total	
<b>phone transition</b>	still	20	9	29	
	movement	5	14	19	
total		25	23	48	
<b>Participant 7</b>		<b>AX3 data</b>			Kappa 0.315 SE of kappa = 0.096 95% confidence interval: 0.128 to 0.503
		still	movement	total	
<b>Phone transition</b>	still	33	13	46	
	movement	20	30	50	
total		53	43	96	

Participant 8		AX3 data			
Phone transition		Still	Movement	total	Kappa= 0.120 SE of kappa = 0.166 95% confidence interval: from - 0.205 to 0.445
	still	4	9	13	
	movement	2	9	11	
	total	6	18	24	

There was an error in the activity transition data file for participant 10 and could not be analysed.

For participants 9, 11 and 12, the activity transitions recorded by the phone sensors indicated long periods where the phone was stationary and so unlikely to reflect the participant's movements (see Table 7.8). For example, participant 12's activity was recorded either as still or in a vehicle.

Table 7.8 Complete record of activity transitions for participant 9

Date	Time	Activity type recorded by the app	Transition
21/05/2019	20:19:12	still	leave
21/05/2019	20:19:12.	on foot	enter
21/05/2019	20:20:24	on foot	leave
21/05/2019	20:20:24.	still	enter
23/05/2019	12:14:16.	still	leave
23/05/2019	12:14:16.	on foot	enter
23/05/2019	12:16:23.	on foot	leave
23/05/2019	12:16:23.	still	enter

#### 7.6.4. Sampling of noise data

The sampled noise for each participant is summarised in Table 7.9. The level of noise detected by the phone sensors is low, ranging from silence to a noise level equivalent to conversational speech (Berger, Neitzel and Kladden, 2010). Participants 8, 10 and 11 all reported keeping their phone in a bag and this would have limited the phone sensors detection of noise. At the notional 45 decibel threshold, too many EMAs would have been triggered, whilst a threshold of 55 decibels would have triggered only 5 EMA's in total (for just two participants). However, 55 decibels is equivalent to the

sound of light traffic in the background or normal speech at a distance of 1m, so, surprisingly, the detected noise levels were so low.

Table 7.9. Summary of sampled noise for each participant

Participant	Number of time decibels exceeded 45, between 10am and 8pm	Total number of noise samples	Range of recorded noise levels in decibels
6	0	590	6-35
7	21	509	45-57
8	21	423	0-57
9	14	1221	10-52
10	1	878	0-50
11	0	695	11-42
12	3	429	0-56

## 7.7. Discussion

This study offers some important insights into the usability of a smart EMA in the context of daily life. The smart EMA was positively evaluated by participants who reported high levels of satisfaction with the app and found it simple to use and easy to learn. Additionally, the smart EMA was perceived to be useful in that it related to participants experience of fatigue in their everyday life and captured their participation in daily activities, as well as variations in reaction times and self-reported energy. The construct of energy was perceived to be useful in understanding participant's resources to engage in daily activities.

Data from the app suggested individual differences in the variability of self-reported energy and reaction times. The activity question also illustrated the types and frequency of activity engaged in whilst using the app. This data is potentially useful in capturing baseline levels of energy and activity to inform strategy use and capture changes over time.

However, several factors adversely affected the usability of the app from the participants perspective, and these were mostly linked to how the user was notified of an alert (thereby affecting the completion rate of EMA's) and the cognitive load of the activity question (affecting the accuracy

of responses). Participants using two phones also affected the study outcomes, particularly the effective use of passive sensor data to augment the smart EMA.

### *7.7.1. Usability of the smart EMA*

Participant's satisfaction with the smart EMA (as rated by the SUS) was high with a mean score of 82.5. This score is interpreted as good satisfaction with the usability of the app and places it in the top 90-05 percentile of rankings of mean SUS scores (Sauro and Lewis, 2011). Bangor and colleagues reviewed their database of over 200 usability studies and found that scores of 80 and over indicated good to excellent perceived usability (Bangor, Kortum and Miller, 2008). A high mean SUS score does not assure the success of the smart EMA but it is a positive indicator of potential success, whereas low SUS scores indicate serious usability problems which are likely to limit the use and acceptability of the app (Bangor, Kortum and Miller, 2008). However the SUS score was obtained from a small sample and therefore should be interpreted with caution. Tullis and Stetson (2004) compared scores on different system usability scales for user ratings of two web sites and found that, with a small sample size, the SUS was more accurate in distinguishing between the two websites than other scales. However, with a sample size of 6, only 35% of users scores on the SUS distinguished between the two websites (Tullis and Stetson, 2004). Hence, the SUS scores reported in this study should be interpreted with caution. Whilst participant's perceived usability of the smart EMA is promising in this initial round of development, further evaluation is needed once the smart EMA has been refined.

Qualitative content analysis of participants interviews indicated that they found the app simple to use, easy to learn and potentially useful in learning about their patterns of fatigue in the context of daily life whilst not exacerbating fatigue. Simplicity and learnability are both considered to be key dimensions of usability (Baharuddin, Dalbir and Razali, 2013) but are particularly important when considering use by people with acquired brain injury and fatigue. A qualitative study by Engstrom and colleagues explored thirteen ABI survivor's experience of using everyday technology, including

the use of mobile phones. Their participants reported increased difficulty in learning how to use new technology after their brain injury and particularly noted difficulty following instructions (Engström, Lexell and Lund, 2010). Participants fatigued whilst using technology and this became a barrier to engaging with technology. Whilst this study did not focus on the use of mobile phone applications and the results are of limited generalisability, the results indicate that ease of use and simple instructions need greater consideration when evaluating usability for people with ABI, as they potentially reduce the cognitive load associated with use. In the current study, the simplicity of instructions, design interface and linear progression through the app, were key to increasing the perceived usability of the smart EMA.

Several participants commented on how the app potentially increased their understanding of fatigue and activity patterns or might help monitor their progress, particularly if feedback became available. The anticipated usefulness of the app most likely contributed to the number of EMAs completed even though the phone notification was difficult to hear. This finding is in line with Ancker et al.'s qualitative study of individuals perspectives on tracking their health data using diaries (Ancker *et al.*, 2015). They interviewed 22 people living with multiple long- term health conditions and found participants kept personal health data to help them make sense of their symptoms or to track their progress. However, Ancker noted that participants became disillusioned with tracking if they could not connect their behaviour and their health data. The participants in Ancker's study mostly used paper diaries to track their symptoms rather than a mobile app. Nevertheless, the findings suggest that the usefulness of information collected is a key motivator for individuals tracking their health condition. With the smart EMA, participants connected the concept of energy recharging or draining from a battery to their experiences. It seems likely that this resonance contributed to their perceived usefulness of the app.

### 7.7.2. Ways in which the smart EMA may support fatigue management

Data from the qualitative interviews and intraindividual analysis of EMA response data revealed the potential for the smart EMA to assist both clinician-supported and self-supported management of fatigue, to identify patterns of activity, fatigue and capturing changes over time.

From the qualitative interviews, participants noticed connections between their behaviour and their energy levels or reaction times which then prompted them to reflect on their experiences and consider how they manage their fatigue. Repeatedly logging activities and scoring energy levels is a form of self-monitoring, which is an established behaviour change strategy used within mHealth (Mohr *et al.*, 2014; Shiffman, Stone and Hufford, 2008). As discussed in chapter 5, there is evidence that repeated EMA affects an individual's behaviour by increasing awareness and promoting self-efficacy but this has not been investigated in the ABI population (Schrimsher and Filtz, 2011). Yet changes in executive function, memory and self-awareness after ABI, may be detrimental to retrospectively tracking symptoms and experience. This was highlighted in chapter 4, where participants discussed their difficulty in keeping track and making sense of their fatigue experiences (Ezekiel *et al.*, 2020). This usability evaluation study suggests a potential for self-monitoring of fatigue (using a smart EMA) to positively influence self-management strategies but further research is needed to investigate how self-monitoring affects fatigue after ABI.

On the other hand, evidence of reactivity to the EMA is a threat to the ecological validity of the EMA as it no longer reflects everyday life, rather it reflects daily life *whilst* completing the EMA (Ram *et al.*, 2017). Hence the findings of EMA may not be generalisable across time when participants are no longer completing EMA's.

Inspection of individual's energy scores and activity patterns revealed considerable variability of experience amongst the participants. Visual inspection of mean NRS scores by activity type pointed to participants engaging differentially in activity types according to whether their energy was high or low. Participants were also grouped into three categories according to their NRS energy scores:



those whose energy scores reduced as each day progressed, those whose energy scores fluctuated throughout the day, and one participant (9) whose ratings indicated little fluctuation in his perceived energy levels. Furthermore, low NRS energy scores appeared to be concurrent with (possibly) demanding activities for some participants but were delayed in others. Lenaert et al.'s (2020) EMA study of fatigue in 26 stroke survivors found that fatigue was higher during effortful activities and was related to the type of activity, with "resting" predicting higher fatigue scores. (Lenaert et al., 2020). However, Lenaert et al's analysis was conducted at the group level, not at the individual level and so did not report on different participants' patterns of activity and fatigue, although they noted evidence of variance within the sample.

These findings indicate that a combined approach of greater detail about types of activity along with ratings of participants disposition towards activity would provide a more nuanced understanding of the relationship between activity and fatigue. Nevertheless, the usability evaluation suggests the potential utility of the app in assessing individuals' experiences of energy, activity and fatigue in daily life and support further development of the app.

Juengst et al. (2019) also reported significant within-person variability in reporting of symptoms (including fatigue) after TBI. Using ecological momentary assessment, they found that variability of symptoms could be categorised as high or low, where high variability was associated with increased symptom severity and being female. However, participants reported their momentary fatigue on alternate days rather than throughout each day and therefore the study did not capture fluctuation of fatigue throughout each day (Juengst et al., 2019). Findings from the qualitative study reported in chapter 4 also suggested individual differed in the variability of their fatigue experiences (Ezekiel et al, 2020). Of the remaining EMA studies in the ABI population identified in chapter 5, only Juengst completed within-person data analysis.

Intraindividual analysis of EMA data analysis enables the use of EMA as a tool to support self-management. Using EMA data for therapeutic purposes is suggested by several authors but with a

focus on self-management of mental health conditions (Heron and Smyth, 2010; van de Ven et al., 2017; van Os et al., 2017). Kramer and colleagues illustrated the efficacy of personalised feedback from EMA (as an adjunct to anti-depressants) in significantly reducing depressive symptoms in adults with depression, through a randomised control trial with three arms (n =109). Those in the intervention arm of the trial met with a researcher weekly and received feedback from their EMA data about their ratings of positive affect in the context of daily activities and events. Participants in the intervention arm had a statistically and clinically significant reduction in their scores on the Hamilton depression rating scale at six months follow up, as compared to those in the other arms of the trial. The authors suggest that EMA and the use of personalised feedback increased participants awareness of how patterns of behaviour contributed to positive affect, thereby resulting in behaviour change. In this usability study, the finding of different patterns of energy and activity is suggestive of similar potential with the smart EMA of fatigue: that is to increase participant's awareness of fluctuating energy in the context of daily activities (Kramer et al., 2014).

Visual inspection of reaction time scores and self-rated energy scores point towards an association between the two, with reaction times increasing as energy scores decrease. This finding is in line with those reported by Sinclair et al (2013). Sinclair and colleagues found that self-reported fatigue was associated with slower reaction times for participants with TBI as compared to those without fatigue or non-injured controls. In Sinclair's study, 20 participants with TBI completed a 10 minute PVT test in laboratory conditions and hence enabling standardisation of the PVT test. In this usability study, participants were instructed on how to complete the PVT test but the conditions in which the test was administered were not standardised and this may have contributed to the variability of reaction time results. The reaction time test was also shorter than recommended in several validation studies and this might reduce the effect size of fatigue on reaction times (Roach, Dawson and Lamond, 2006).

Nevertheless, the number of tests completed and qualitative interviews with participants indicate that in situ assessment of reaction times (for a short duration) is feasible in the ABI population, although there may be a trade-off between the length of the reaction time test and how often it is completed. Further research is needed to establish whether a longer PVT completed less frequently would be acceptable to users but more reliably detect effects of fatigue.

### *7.7.3. Factors limiting the effectiveness of smart EMA*

Data from qualitative interviews and the low completion rates of fixed and random alerts suggest two features that limited the effectiveness of the smart EMA: an inability to personalise the app (for example, to change the phone notification or alter the times of fixed alerts) and the design of the activity question. Participants sometimes selected the wrong activity and were unable to correct their choice.

Participant feedback about the phone notifications was mixed, with some appreciating the discreteness of the alert, whilst others found it to be too quiet and hence missed the alerts. Similarly, participants either reported the timing of fixed alerts to be acceptable or felt they did not match their daily routine. Allowing personalisation of the smart EMA would resolve these difficulties and allow the app to be tailored to individual's needs and lifestyles and possibly increase the completion rate of signal contingent alerts. In an integrative review of mHealth apps, Birkhoff and Smeltzer (2017) reported that personalisation increased the perceived usefulness of apps and so contributed to user engagement and usability (Birkhoff and Smeltzer, 2017). It seems likely that enabling participants to adjust the smart EMA may increase their completion of the fixed and random signal contingent EMAs and increase the efficacy of the smart EMA.

In this usability study, the efficacy of the EMA was negatively affected by the low completion rate of signal contingent alerts and the high numbers of self-reports. This resulted in a lack of randomisation of EMA sampling and possible over-representation (for example) of instances when the participant felt fatigued. For the smart EMA to be effective, it needs to sample enough experiences throughout

the day to capture how fatigue and energy fluctuate and a representative range of activities. However, there is no universal minimum completion rate for EMA's to be considered effective. The sampling densities and types of triggers used within EMA studies vary widely as sampling density should be balanced with the time taken to complete the EMA and the overall duration of the study (Shiffman, Stone and Hufford, 2008). In addition, the use of self-reports and event contingent sampling means there is no pre-determined number of daily EMAs to be completed and therefore completion rates are not applicable. Nevertheless, several systematic reviews of EMA studies report completion rates ranging from 56-96% (Ono et al., 2019; Degroote et al., 2020; Colombo et al., 2019). With a completion rate of 37%, it is clear that steps need to be taken to improve the efficacy of the app.

From the qualitative data, the activity question, branching of responses and lack of a "back button" increased the cognitive load of using the app and limited the accuracy of the data collected. The process of determining which primary activity they were engaged in, and then choosing the correct broad category to find their activity, was reported to be difficult at times and led to selecting the wrong activity. In addition, there was no link to return to the previous screen to correct the mistake. However, one participant commented that the lack of a "back button" was helpful to avoid becoming "lost" whilst using the app. Kettlewell's stakeholder evaluation of a smartphone app developed for people with ABI similarly reported on the impact of user's cognitive problems on app usability. In particular, difficulty switching between screens on the app was identified as a barrier to use (Kettlewell et al., 2018). Thus, it is likely that the activity question in the smart EMA of fatigue challenges cognitive functions that are often impaired after brain injury, as exemplified by participant 6s comment "I'm not very flexible in my thinking". The question and responses, therefore, need revising to be more intuitive but allowing users to move backwards and forwards between the branching screens may not be helpful.

Data from the phone sensors to detect noise and activity transitions was ineffective due to participant's varying approaches to phone use and by carrying two phones. Whilst there has been considerable research investigating the accuracy of activity recognition by phone sensors, the studies depend on users carrying the phone on their person (Case et al., 2015; Coskun, Incel and Ozgovde, 2015; Voicu et al., 2019). For example, (Capela et al., 2016) examined activity data collected using a smartphone with stroke survivors but the phone was strapped to participants waists. This does not reflect the real-life use of smartphones. Redmayne (2017) surveyed 197 women (aged 15 -40) about the location of their phone during use and non-use. Over 80 % of respondents reported keeping the phone either in a bag or elsewhere off their body when not actively using the phone (Redmayne, 2017). Dunton and colleagues also reported lower rates of moderate physical activity as detected by phone sensors than those compared to a waist-worn accelerometer (Dunton, Dzibur and Intille, 2016). In the current study, participants reported keeping the phone in a bag when they were out of the house (thereby affecting the detectable noise levels) whilst data from other participants recorded long periods of inactivity, suggesting the phone had been kept in one place rather than carried on the person. These findings do not preclude using phone sensors to augment the EMA but suggest further analysis is needed to develop an effective algorithm for sensor-based event contingent sampling.

#### ***7.7.4. Strengths and Limitations***

There were several notable strengths of this usability evaluation study. Firstly, evaluating the app in two rounds (with therapists first) enabled iterative development of the app with the result that the app was more functional when tested by people with ABI. This two-stage approach made better use of ABI survivors' expertise and enabled them to focus on the experience and content of the EMA, rather than more obvious usability issues. Furthermore, repeated usability testing with small sample sizes (between 4 and 8) is recommended practice for finding and correcting serious usability problems (Molich, 2010)

Field testing of the app with ABI survivors also provided insights into the perceived usefulness of the app and the potential burden of the EMA schedule. When evaluating smart EMAs, field testing is essential to understand the impact of responding to the EMA in different circumstances (Harrison *et al.*, 2013).

Finally, the study used multiple methods to evaluate usability, with a focus on ease of use, learnability, satisfaction, and perceived utility of the app. Using multiple and varied methods means that the strengths of one method compensates for the weaknesses of another method. For example, the SUS and post-experience interview may both be subject to recall bias, whilst the think-aloud method evaluates real-time use of the app, thereby increasing the robustness of the usability evaluation (Jaspers, 2009).

Whilst this evaluation identified several usability issues, the lack of objective measures of usability means that the frequency with which those issues occurred and their impact on the use of the app was not established. Including an automated evaluation tool would enable tracking of participants interactions with the activity question and help to describe how often participants struggled with the question and which categories were problematic (Kluth, Krempels and Samsel, 2014)

A key limitation of the study design is the absence of measures to establish the validity or accuracy of data collected by the app. Data from AX3 enabled the evaluation of physical activity transition data and highlighted limitations of the phone sensor data. However, the accuracy of responses to the activity question data or validity of the self-rating of energy was not established in this study.

Establishing the validity of EMA components is problematic as traditional questionnaires (used to establish convergent validity) are not suitable for administration as repeated momentary assessments (Degroote *et al.*, 2020). (Powell *et al.*, 2017) used a self-rating of energy from a previously validated questionnaire to establish the convergent validity of an EMA of momentary fatigue. However, the authors did not acknowledge any threats to the validity of the energy question

from the altered administration of the original question. Whilst they demonstrated strong negative associations between ratings of fatigue and energy, this only demonstrates intercorrelation rather than convergent validity, if the construct validity of the adapted question is in doubt.

Finally, offering participant's use of a study phone meant the recruitment process was more inclusive but negatively affected the EMA completion rate as participants then carried two phones with them. Installing the app onto participants own phones is likely to increase ecological validity because the participant's phone use is closer to their usual behaviour (Harari et al., 2016). However, using participant's phones means there is a lack of standardisation of sensor data and touch screen response times for the reaction time test, thereby preventing the comparison of EMA results between participants.

#### ***7.7.5. Recommendations***

This usability evaluation identified several ways in which the smart EMA needs further development. Firstly, the app needs to support personalisation to resolve the issues identified with notifications. Tailoring of the fixed time alerts to match users' lifestyles is also needed to optimise the completion rates of fixed alerts. The app also needs to record when there is no response to an alert, to facilitate the calculation of completion rates and evaluate the efficacy of the app.

Further research is also needed to establish the functionality of using noise levels for sensor-based event sampling. It is possible that using noise levels (decibels) alone is too unpredictable to define an event for sampling. However, combining data from multiple phone sensor (for example noise levels and behavioural inference data from GPS) may be more successful at sampling events where the participant is in a highly fatiguing environment.

Several additions to the EMA questions are recommended, to determine the validity of data collected and to provide a more nuanced picture of a user's daily experiences and to better capture participation. A self-rating of fatigue or tiredness would enable exploration of associations between

state energy and state fatigue. Further research is necessary to determine the length and frequency of the reaction time component of the smart EMA, as well as its validity as an objective marker of fatigue.

It would be beneficial to understand users disposition to the sampled activity, for example, whether they perceive the activity to be enjoyable or effortful (Lenaert et al., 2020). Furthermore, adding a social dimension to the EMA would provide further information about the user's social participation. Finally, pairing the app with a wearable sensor would also more reliably capture data on physical activity and These additions may be beneficial to self-management of fatigue, as discussed previously in the qualitative study of fatigue experiences (Ezekiel et al., 2020).

Provision of individualised feedback also needs to be incorporated into the app. Participants suggested types of feedback that would be useful but further user involvement is necessary to ensure that the feedback format is accessible and useful to end-users.

After implementing the recommendations, the smart EMA will need a further round of usability evaluation with people with ABI before being ready for use in research.

## **7.8. Conclusions**

This chapters reported on an iterative user-centred enquiry into the usability of a smart EMA of fatigue and activity. The results indicate that the app's simplicity, ease of use and perceived usefulness contribute to its usability, whereas an inability to personalise the app was reported to affect the effectiveness of the app. Furthermore, the study highlights the need to consider a participant's habits in how they carry the phone and whether they routinely keep the phone near to them or on their person. Individuals phone use behaviours limit the feasibility of using phone sensor data for event contingent EMA's. Further refinement and development of the smart EMA is recommended to increase both its usability and usefulness in contributing to self-management of fatigue.



Visual inspection of the app data suggests intraindividual variation in temporal patterns of energy, fatigue and activity and possible associations between reaction times and self-rated energy.

However, further research is needed to establish the accuracy and validity of EMA components before investigating these associations in a larger sample.

Whilst a main strength of the study was its user-centred approach to evaluating usability, the lack of objective measures of usability means the frequency and size of each usability problem cannot be determined, nor the extent to which each problem threatens the eventual use of the app.

Nonetheless, the findings of this study serve to highlight the benefits of user-centred usability evaluation in the development of smart EMA's and in optimising the acceptance of the smart EMA by end-users.

## Chapter 8: General discussion and conclusions

### 8.1. Summary

The primary aim of this thesis was to develop an innovative approach to monitoring fatigue and participation in ABI survivors using readily available technology, with a longer-term aim of supporting self-management of fatigue. Within a framework of intervention development, the thesis objectives were (1) To review published research literature for the factors affecting participation after ABI and evidence of the relationship between fatigue and participation, (2) to critically review methods of measuring fatigue and participation, (3) to develop a conceptual model of the dimensions of fatigue after ABI and the mechanisms by which participation is affected, (4) to develop an ecological momentary assessment of fatigue and (5) to establish the usability of an EMA fatigue for people with acquired brain injury.

These objectives were achieved as discussed below.

The systematic review of factors associated with participation after stroke in community-dwelling adults in chapter 2 synthesised findings from over 80 studies. The review emphasised the complexity of biopsychosocial factors associated with participation outcomes after stroke even though the studies reviewed reflected a largely biomedical focus. Fatigue was one of the factors investigated but was rarely considered in studies, considering the predominance of problematic fatigue after ABI.

The narrative review of fatigue in chapter three explored diverse definitions of fatigue and underlined the challenge of operationalising and measuring fatigue. Overall, retrospective measures of fatigue and participation failed to account for the variability of experience and hence continue to limit our understanding of interactions between fatigue and participation after ABI.

Having highlighted the need for better understanding and measurement of fatigue, an in-depth exploration of ABI survivors' daily experiences of fatigue was reported in chapter four. Experiences

of fatigue varied by individual and over time, with differential interactions between subtypes of fatigue (for example, physical or mental fatigue) and activity. Participants described making sense of the triggers and consequences of their fatigue and negotiating their daily activities whilst trying to manage their fatigue. This study highlights the importance of considering a participant's fatigue within their ecological context and provides evidence supporting the need for the development of an in-the-moment assessment of fatigue and activity to be used in the context of daily life.

After establishing the potential for using ecological momentary assessment, the principles and practice of EMA were introduced in chapter 5. The case for adopting a user-centred design approach to developing a smart EMA for use with ABI survivors was also presented.

In chapter 6, the results from the literature reviews of participation after ABI and the qualitative investigation of fatigue were integrated to propose an explanatory model of fatigue and participation after ABI. The model proposed that individuals' decisions to engage in activity were influenced by comparing their perceived available resources with the demands of the activity or situation. Whilst coping strategies mediated the effect of fatigue on energy levels and activity, participation occurred in the context of biopsychosocial factors that either supported or restricted participation. The explanatory model proposed many potential constructs for inclusion in an EMA, hence the final components were chosen as a result of discussion with ABI survivors (through PPI), by reviewing the evidence and by consideration of what was feasible for the size of the project. This was in line with the first phase of the user-centred design approach: concept generation. The rationale was presented for a shift from monitoring self-ratings of fatigue to self-ratings of energy and the integration of an adapted PVT.

In chapter seven, a user-centred evaluation of the smart EMA usability was conducted and found the smart EMA to be acceptable to participants with ABI. A need for further development and testing was identified to establish the validity of EMA components and to improve the completion rates of

EMA assessments. The potential usefulness of data collected by the smart EMA was discussed in relation to understanding intraindividual relationships between fatigue and activity.

This final chapter will provide an overview of the main findings of this thesis and their implications for research and practice. Limitations of the thesis will also be considered, and possible future directions of the research discussed.

## **8.2. Discussion of novel findings**

This thesis makes important contributions to our understanding of the complexity of participation and fatigue after ABI. A new conceptual model is presented; one which explains how fatigue shapes activity and participation after ABI and provides the basis for arguing that coping styles and perceived self-efficacy are key constructs that moderate the impact of fatigue on participation. Study three points to the feasibility of using an EMA of fatigue and activity with ABI survivors and suggests that smart EMA may usefully contribute to self-monitoring of fatigue and, by extension, promote more effective self-management. Analysis of the EMA data also adds to evidence of different individual trajectories of fatigue and different responses to activity and fatigue by delineating different patterns, whereas previous studies only flagged that such differences exist (Lenaert *et al.*, 2020; Juengst *et al.*, 2019).

### **8.2.1. Participation after ABI**

The systematic review in chapter 2 emphasised the complexity of issues affecting participation after ABI and highlighted the challenges in measuring participation outcomes. Reviewing the research literature through the lens of the ICF and the biopsychosocial model revealed how research focused predominantly on biomedical factors or non-modifiable person factors such as age and sex. Environmental factors such as social, physical, economic and policy factors were rarely considered, despite evidence that those living with long term health conditions and disability are amongst the poorest in the UK and globally (Banks, Kuper and Polack, 2020; Tinson *et al.*, 2016).

For ABI survivors living with long term disability, their continuous interaction with environmental and social factors may protect them or place them at greater risk of poor participation outcomes (Bolton and Gillet, 2019). Yet personal and environmental factors are either insufficiently classified (there is no taxonomy of person factors in the ICF) or are so fragmented that effective measurement becomes problematic (Whiteneck, 2009; Cerniauskaite *et al.*, 2011). However, if the ICF is to fulfil the World Health Organisation's original intention of providing "*a scientific basis for understanding and studying health and health-related states, outcomes and determinants*" (World Health Organization, 2001), then understanding the role of personal and environmental factors in determining participation is essential (Geyh *et al.*, 2011).

Personal and environmental factors set the scene for participation, not just in terms of what people do, but also as to the opportunities and choices available to them (Badley, 2008). This is especially important when considering participation after ABI where personal factors such as age, race, gender, and socioeconomic status potentially intersect to shape participation outcomes. The reviews in this thesis underscore the need to incorporate environmental factors when researching participation outcomes after ABI, alongside implementing an evidence and theory informed taxonomy of personal factors (Ezekiel *et al.*, 2019).

But the author recognises that adding yet more factors adds to the difficulty of capturing participation outcomes, even if the outcome is focused participation restrictions or the frequency of participation. Yet, qualitative studies of participation for people with a long term health condition reveal the importance of the what, where, when, how often and with whom aspects of participation, alongside autonomy, choice and being accepted by others (Haggstrom and Lund, 2008; Schipper *et al.*, 2011; Jellema *et al.*, 2016). It is for these reasons that some argue participation cannot be measured whilst others argue that participation cannot be measured using traditional methods, such as retrospective questionnaires (Wade and Halligan, 2017; Dijkers, 2010). Smart EMA offers a solution to capturing participation outcomes because they allow passive data collection via phone

sensors to be combined with self-reports of participation experiences. EMA supports exploration of the ecology of participation experiences, whilst capturing frequencies of activity types and the individual's disposition towards their participation. Seekins, Ipsen and Arnold (2007) conducted a study examining the feasibility of EMA of participation using a personal digital device. The EMA included measures of place, activity, social contact, environmental barriers, fulfilment, community connectedness and the effect of transient health states (such as mood or fatigue). Five participants received six prompts per day for a total of seven weeks during nine months, generating over a thousand data points. With a completion rate ranging from 42-92%, the study demonstrated the feasibility of EMA in capturing participation outcomes and the resulting data enabled investigation of participation dynamics with social, environmental and personal factors, at a group level and an individual level.

Despite the promising results of Seekin's feasibility study, EMA has not been widely adopted for the measurement of participation outcomes and this is likely due to the increased cost and complexity of EMA as compared to using a participation questionnaire. However, the increased availability and usefulness of smartphones and wearables has resulted in renewed interest in digital tools to capture outcomes, particularly for evaluating intervention studies (McCarthy, Ballinger and Lewis, 2020; Taylor *et al.*, 2020).

### ***8.2.2. An explanatory model of fatigue and participation after ABI***

To the best of the author's knowledge, this is the first time an explanatory model of fatigue and participation after ABI fatigue has been proposed. Whilst there are no other models explaining fatigue and participation after ABI, there are currently four models focused on fatigue, either after stroke, TBI or ABI. Two models were developed from reviews of research literature (Wu *et al.*, 2015 b; Ormstad and Eilertsen, 2015), one from a cross-sectional study of 72 people with TBI (Ponsford, Schonberger and Rajaratnam, 2015) and one based on clinical expertise and an adapted model of

fatigue for people with multiple sclerosis (Malley, Wheatcroft and Gracey, 2014 ). None of the models explicitly consider fatigue in the context of participation.

In common with the model proposed in this thesis, the models developed by Wu et al , Ormstadd et al and Malley all frame psychosocial and behavioural factors as predisposing or perpetuating fatigue, to a greater or lesser extent. Wu et al and Malley et al also consider the role of coping strategies in maintaining or alleviating fatigue. In contrast, Ormstad proposes that *acknowledgement* of fatigue from others is key to the stroke survivor's ability to cope with fatigue and to avoid reinforcing fatigue. This hypothesis came from their meta-synthesis of qualitative studies of post-stroke fatigue, although it is unclear how the authors arrived at that conclusion (Eilertsen, Ormstad and Kirkevold, 2013). In the qualitative study in this thesis, social contact and expectations from others motivated individuals to test the limits of their fatigue and positively reinforced their use of adaptive coping strategies, but participants recognised that others could also complicate their efforts to manage fatigue. Hence, social contacts were instrumental in how ABI survivors coped with fatigue but not necessarily because others acknowledged their fatigue.

Wu et al.'s (2015b) model distinguishes between early fatigue and late-onset fatigue and argues that each has different mechanisms, with psychological, behavioural and social factors perpetuating late-onset fatigue. However, the evidence for early and late-onset fatigue is not conclusive. Duncan et al's (2014) year-long prospective cohort study of post-stroke fatigue (n 136) reported that fatigue either resolved at 6 months, continued or (for a minority) appeared at 12months. More recently, Kjeverdu et al. (2020) conducted an 18-month prospective study of 115 stroke survivors and failed to find similar trajectories of fatigue. Instead, they reported that fatigue severity was stable across the study period, although there appeared to be three classifications of fatigue trajectory (low, medium and high fatigue). These anomalous results may be explained by the adoption of different methodological approaches to determining the presence of fatigue and to incomplete data. Duncan reported data from all participants, even though there was incomplete data for participants at each

time point, whereas Kjeverdu reported on participants who provided data at all four-time points but had a very low attrition rate (4%). Hence Duncan's study findings are more likely to reflect non-response bias. Christensen et al. (2008) also reported that fatigue was present over 2 years and noted that only a minority of their participants (9%) developed fatigue three months or more post stroke. So, whilst it may be clinically useful to distinguish between pathological mechanisms of fatigue and the biopsychosocial factors that contribute to the long term experience of fatigue, there is limited evidence that late-onset fatigue is secondary to the consequences of stroke. Instead, it may be that the impact of fatigue (particularly mild fatigue) is not fully appreciated by the individual until they attempt to resume their previous lifestyle and activities (Kirkevold *et al*, 2012; Theadom *et al.*,2016).

Malley, Wheatcroft and Gracey's (2014) model of fatigue after ABI explains how an individual's response to fatigue increases or decreases their overall vulnerability to fatigue. The model is adapted from a conceptual map of physical and psychosocial influences on fatigue and the relationship between fatigue and activity for people with multiple sclerosis (Harrison, 2007). Whilst the model adaptation was informed by clinical practice and research literature, it has yet to be empirically tested. Within the model, coping strategies are categorised as helpful or unhelpful, which is in agreement with the findings of the qualitative study in this thesis. However, the relationship between fatigue, activity and participation is not explicitly portrayed, rather activity is a trigger for fatigue. Additionally, the model fails to capture the social and environmental factors that contribute to fatigue experiences (Ezekiel *et al.*, 2020).

Finally, Ponsford, Schonberger and Rajaratnam (2015) hypothesised relationships between vigilance, fatigue, depression, anxiety and daytime sleepiness using data from a cross-sectional study of 72 people with moderate to severe TBI. The model was tested, revised, and retested using structural equation modelling. The final model had a good fit, with significant relationships between fatigue, depression and vigilance (attention). The model was interpreted as evidence of a cycle between



fatigue, depression and attention, where ongoing fatigue triggered depression, which in turn negatively reduced attention and further exacerbated fatigue. The authors noted that the variables entered into the model do not comprehensively reflect the experiences of fatigue after ABI and suggested that personal and environmental factors, as well as coping styles, should be considered in future research.

The model present in this thesis draws on findings from systematic and narrative reviews, and the qualitative investigation of fatigue experiences after ABI. In the model the impact of different types of fatigue on participation is mediated by coping strategies; perceived resources for action (conceptualised as energy) are matched by the perceived demands of taking part in an activity or situation, within a given context. A range of coping strategies was identified in the qualitative study and coping strategies were labelled as reactive (including avoidant behaviours) or proactive strategies.

Within the model, avoidant and reactive coping strategies disrupt the individual's participation in life situations as they “short circuit” the feedback loop between participation and fatigue. Reactive and proactive strategies reflect a dual coping process of reactivity (that is the immediate response to being fatigued) and action regulation (how the individual directs their energy and manages their fatigue)(Skinner and Zimmer-Gembeck, 2007). Satisfactory and sufficient participation depends (in part) on the individual’s ability to effectively balance these dual processes of coping but in turn reinforces the individual’s self -efficacy beliefs about coping with their fatigue (Liepold and Mathiowetz, 2005). It is therefore hypothesised that there is a positive coping cycle, where strategies leading to greater participation reinforce self-efficacy beliefs and adaptive coping, thereby reducing the severity and impact of fatigue (Mollayeva *et al.*, 2014). But overuse of reactive and avoidant coping strategies perpetuates the negative cycle of fatigue as the resulting inactivity and loss of social contact contribute to poor participation and low self-efficacy. This hypothesis explains the finding in the qualitative study where participants perceived reactive and avoidant coping

strategies as “not coping” and where reliance on these strategies was linked to limited social contact and a lack of daily routine.

This hypothesis is supported by other research evidence. A recently published EMA study by Neff et al. (2020) demonstrated statistically significant associations between fatigue and social contact, both in the moment and at the next time point. For their 48 participants with mild stroke, higher average fatigue (individuals average fatigue scores over the 2-week study) was associated with low self-ratings of social confidence and satisfaction with the interaction. Momentary fatigue predicted low confidence and satisfaction ratings at the next time point (approximately two hours later) in their between-person analysis but not the within-person analysis. High ratings of self-confidence and satisfaction with social interactions also predicted lower momentary fatigue at the next time point in their between-person analysis. The findings of this study suggest that fatigue disrupts the individuals’ social interactions during the interaction, may continue to affect later social interactions, but also, that more satisfactory social interactions lead to lower fatigue scores at a later point. Neff et al suggest the impact of momentary fatigue on social interactions as a therapeutic target.

However, Neff does not explain the different findings of the within-person analysis and the between-person analysis, nor do they consider how the time of day might affect a person’s fatigue.

The lack of agreement in significant associations at the within-person and between person-level indicates there may be a hidden but confounding variable mediating the relationships between fatigue and social interactions (Falkenström, Solomonov and Rubel, 2020; Leckie, 2013). It is therefore possible that time of day may be a source of unexplained variability. In addition, the study has a small sample size which, together with multi-level modelling, increases the risk of a type 1 error (Austin and Leckie, 2018) . Hence whilst the findings of this study support the model of fatigue and participation presented in this thesis, the evidence is far from conclusive.

With regards to fatigue and coping styles after ABI, there has been relatively little research examining the relationship between them (Ponchel et al., 2015; Aarnes, Stubberud and Lerdal, 2019;

Wu, *et al.* 2014). Emotion-focused and avoidance coping tend to be associated with fatigue after stroke, with researchers suggesting these may be effective strategies in the earlier days of recovery but less so longer-term (Jaracz, Mielcarek and Kozubski, 2007; Wei *et al.*, 2016). In the wider literature on coping in the ABI population, emotion-focused and avoidant coping styles tend to be associated with negative outcomes such as depression, anxiety and poor quality of life (Brands *et al.*, 2014, Tielemans *et al.*, 2015; Kendall and Terry, 2008).

Several studies have established relationships between coping styles and self-efficacy after ABI (Tielemans *et al.*, 2015, Brands *et al.*, 2014; Scheenen *et al.*, 2017). Scheenen and colleagues reported small to moderate associations between self-efficacy and coping styles in their study of 409 consecutive TBI patients, with high self-efficacy relating to more active coping styles. Similarly, Tielemans *et al.* reported high active coping to be associated with high self-efficacy in their cross-sectional study of 112 stroke survivors. Proactive coping was associated with fewer perceived participation restrictions but self-efficacy was not associated with participation outcomes (Tielemans *et al.*, 2015). Both studies measured general self-efficacy and so may not reflect domain specific self-efficacy related to managing the impact of ABI symptoms on participation.

Brands *et al.* (2014) investigated relationships between TBI self-efficacy and coping and also reported that high self-efficacy was associated with active coping styles. In addition, they established that the relationship between coping and study outcomes (participation and quality of life) was mediated by self-efficacy. High emotion-focused scores on an adapted CISS, were associated with low quality of life scores but this was mediated by self-efficacy. Whilst participants who used more emotion-focused coping had worse outcomes than those who used task-focused coping, those with high self-efficacy and high passive coping fared better than those with low self-efficacy and high passive coping. These studies demonstrate the necessity of considering coping along with self-efficacy, albeit concerning quality of life outcomes. It seems likely that coping and self-efficacy also play a role in mitigating the impact of fatigue on daily life.

Self-efficacy is defined as the person's confidence in their ability to successfully apply strategies and positively influence their experience (Dumont et al., 2004). As discussed in chapter 4, several study participants reported difficulty managing their fatigue because they found it to be unpredictable (both over time and in different environments and situations) and because they struggled to keep track and make sense of their fatigue. Others worried about what would happen if they pushed their fatigue further. It is suggested that these experiences reflect low self-efficacy.

In his theory of self-efficacy, Bandura identified four processes that contribute to self-efficacy: mastery of experience, vicarious experience, verbal persuasion, and physiological states (Bandura 1997). Mastery of experiences refers to an individual's confidence in their ability to successfully meet activity and environmental demands (Dumont *et al.*, 2004). Efficacy expectations influence the individual's choice of activity, coping strategies, and persistence in the face of adversity (Bandura, 1997). The findings from the qualitative study reported in chapter 4 evidence ways in which these processes are disrupted and hence contribute to low perceived self-efficacy of fatigue and activity (Ezekiel *et al.*, 2020).

Firstly, even mild cognitive dysfunction has the potential to impede individual's abilities to recall and learn from their experiences, as well as to make connections between their experience of fatigue and their experience of activity (Lewin, Jobges and Werheid, 2013; Ezekiel *et al.*, 2020). In the qualitative study reported in chapter 4, several participants discussed how memory difficulties affected their ability to understand triggers and patterns of fatigue.

Secondly, fatigue is an unpleasant physiological experience that leads to withdrawal behaviour and may even directly affect self-efficacy because of a chronic lack of mastery over bodily experiences (Stephan *et al.*, 2016). Again, in the qualitative study, participants repeatedly described situations where they withdrew because of overwhelming fatigue, thus disrupting their experience of success through a negative physiological state.

Thirdly, the social isolation and lack of social support experienced by some ABI survivors mean that active encouragement from others to experiment with strategies and activities may be limited (Ezekiel *et al.*, 2020). In chapter 4, several participants described their limited social contact with others and the need for support or encouragement from others. Re-engagement in participation requires stepwise experimentation and experiences of success, for which social support is essential (Jellema *et al.*, 2016).

Whilst far from conclusive, Banduras theory of self-efficacy taken together with the research evidence and findings presented in this thesis support the conclusion that perceived self-efficacy of managing fatigue, and coping strategies used to engage in daily activities is instrumental in explaining the relationship between fatigue and participation outcomes, suggesting that self-efficacy and coping styles need to be explicitly addressed within fatigue management programmes. In addition, because self-efficacy is thought to be domain-specific (Brands *et al.*, 2014), self-efficacy interventions should focus on building ABI survivor's confidence in their ability to participate in daily life whilst effectively managing their fatigue.

Self-management approaches are currently used to address the impact of fatigue after ABI but are not without their limitations. Current clinical guidance advises clinicians to provide education about fatigue, and advice on strategies such as activity pacing and, activity scheduling (Marshall *et al.*, 2015; Intercollegiate Stroke Working Party, 2017). Whilst evidence supporting the effectiveness of fatigue management approaches is limited by a lack of large, randomised control trials, reducing trait fatigue can be beneficial (Shuman-Paretsky, Gumber and Dams-O'Connor, 2017; Stubberud *et al.*, 2019). Additionally, the effect of fatigue management approaches on activity and participation has not yet been established because few studies examine participation as an outcome (Zedlitz *et al.*, 2012; Johansson, Bjuhr and Rönnbäck, 2012; Lu, Krellman and Dijkers, 2016; Raina *et al.*, 2016). Clarke and colleagues conducted a randomised pilot trial of a fatigue management programme (16 stroke survivors) and reported improvements in social functioning scores (as a domain of SF36)

approached significance for the intervention arm (Clarke, Barker-Collo and Feigin, 2012). However, the study was underpowered to find a statistically significant effect. Considering the challenges in measuring fatigue discussed in this thesis and the possibility of response shift in self-reports of fatigue (Andrykowski, Donovan and Jacobsen, 2009), changes in activity and participation must be recognised as an essential outcome in fatigue management research.

The mechanisms by which fatigue management programmes potentially affect fatigue after ABI have not yet been established. Zedlitz et al.(2015) compared cognitive behavioural intervention against combined cognitive behavioural and graded exercise programmes and reported statistically significant reductions in trait fatigue scores for both interventions. Only the combined intervention group had a clinically meaningful reduction in their fatigue severity. However, the study was underpowered, there was no intention to treat analysis (despite an attrition rate of 18%) and attrition varied between the two groups, introducing the possibility of attrition bias. Zedlitz et al. (2012) also acknowledged that the absence of a sham control group means it is difficult to determine which aspects of the interventions were effective.

In addition, there is limited discussion of theoretical frameworks underpinning the development of fatigue management programmes. Psychoeducation and cognitive behavioural and problem-solving interventions are central to several fatigue management programmes but (unlike condition specific self-management programmes) there is no overt consideration of behaviour change theories such as self-efficacy (Clarke, Barker-Collo and Feigin, 2012; Raina *et al.*, 2016; Zedlitz *et al.*, 2012). Stubberud and colleagues observed that participants with low self-efficacy benefited least from their fatigue management programme and called for a greater focus on building self-efficacy (Stubberud *et al.*, 2019). A survey of 55 stroke survivors also found low self-efficacy was associated with higher fatigue scores for stroke survivors (Muina-Lopez and Guidon, 2013). Together, these studies suggest that high perceived self-efficacy of fatigue and activity may be important contributors to managing

fatigue effectively in the longer term and may be instrumental in reducing the impact of fatigue on participation.

### ***8.2.3. Smart EMA of fatigue and activity***

The smart EMA developed as part of this PhD study is novel because it was informed by ABI survivor's experiences of fatigue and then developed in collaboration with people with ABI. It also combines subjective reports of energy, activity, and response times to a short PVT, as an objective marker of fatigue. All of these constructs have appeared elsewhere in the literature, but this is the first time that they have been combined in an EMA. This means that (subject to validation) the EMA captures rich data that allows investigation of the relationships between state energy, objective fatigue and activity in the context of daily life and the variability of fatigue experiences. The EMA has the potential to contribute to our understanding of different trajectories of fatigue and activity and help to differentiate between those that successfully self-manage their fatigue in the context of their daily activities and those that struggle to gain control.

Inspection of data returned by the smart EMA reveals novel findings of individual differences in relationships between fatigue and activity after ABI. Activity and fatigue appeared to occur concurrently for some or was delayed in others. Participants engaged in a quiet activity when energy was low, pointing to the possible influence of fatigue when deciding what to do. Whereas others reported higher energy levels during quiet activities, pointing to the role that quiet activities play in restoring energy levels and potentially indicate different recovery rates between individuals. Lenaert *et al's* (2020) EMA study of fatigue after stroke also found that momentary fatigue varied when participants were physically active or resting and doing nothing, but not by the other activity types (self-care, household tasks, working or travelling). However, reported perceived effort predicted later fatigue. It seems likely that the way activity was categorised lacked sufficient granularity to unpick more nuanced relationships between fatigue and activity. Whereas the EMA in this thesis provides more detail about types of activity, particularly separating resting from quiet pastimes and

technology use. Understanding how ABI survivors use different activities to rest or recover from fatigue (as reported in chapter 4 where some participants described using quiet and sedentary activities as an opportunity to rest) is necessary for developing effective fatigue management strategies. Furthermore, it is essential to understand how using digital technology interacts with fatigue because the average adult in the UK spends over three hours a day online and because digital technology is a key access point to many essential services (OfCom, 2020).

In addition to variable relationships between fatigue and activity, three trajectories of energy were noted where participants energy levels fluctuated across the day, declined as the day progressed or were relatively stable but consistently low. Juengst et al. (2019) also reported daily variations in fatigue symptoms, although they only surveyed their participants once a day. Leneart et al (2020) noted considerable individual differences in relationships between fatigue and activity, indicating the need for person-centred approaches to fatigue interventions. The preliminary but novel findings view from the EMA usability study support Lenaerts view that interventions should account for individual differences in the relationship between fatigue and activity.

The long term aim for the smart EMA of fatigue and activity is for its eventual use as a self-monitoring tool. The information returned by the app has the potential to help to build self-efficacy as it enables individuals to base their appraisal of anticipated participation on empirical evidence, rather than by recall of events. It may also contribute to their efficacy expectations regarding their coping strategies (Dobkin, 2016). Additionally, because the EMA includes an objective marker of fatigue, it has the potential to act as an early warning of fatigue. Both in the PPI and the qualitative study of fatigue in chapter 4, ABI survivors commented on how others notice fatigue before the individual notices it for themselves. An early warning of fatigue may allow people to implement strategies to reduce fatigue before it becomes too severe.

The use of smart EMA's with the acquired brain injury population is an exciting emerging area of research that has the potential to address several limitations of current research approaches to



investigating fatigue and participation. The advantages of EMAs over more traditional outcome measures were discussed in chapters 3 and 5: well-constructed EMA's have greater ecological validity, are less susceptible to recall bias and capture fluctuations in subjective states. Additionally, smart EMA's are also suited to research examining relationships between variables at an individual level, rather than at the group level (Conner et al., 2009). This is advantageous because it allows investigation of difference, for example, different trajectories of participation, different fatigue reactions to activity and different responses to fatigue interventions.

Many of the studies investigating interventions to improve participation or reduce fatigue have been limited by their sample size or attrition rate and it is generally accepted that conducting large RCTs in rehabilitation research is very difficult (Mayo et al., 2016). However, EMAs provide multiple data points over time and can, therefore, provide a large amount of data from a small number of participants (Smith and Little, 2018). Thus, integrating EMA with intervention studies focused on fatigue and participation provides opportunities to examine differences in how participants respond to the intervention, as well as to collect information on participant's activity and subjective states, as they happen. Taken together, these features suggest that EMA may be more effective than traditional outcome measures in capturing change following fatigue management or participation focused interventions. Smart EMA is likely to be a useful addition to interventions investigating the efficacy of fatigue interventions.

### **8.3. Key Limitations**

In addition to specific limitations reported in individual chapters, key limitations of the thesis as a whole will now be considered.

At the inception of this PhD study, the vision was for an assessment or tool, delivered using readily available and accessible technology, to track fatigue experiences after ABI. This was a novel approach which meant the development of the smart EMA did not "fit" methodological or conceptual frameworks for digital interventions. For example, Yardley's person-based approach

influenced the decision to conduct a qualitative study to elicit ABI survivors' experiences of fatigue and to adopt a user-centred design (Yardley *et al.*, 2015) while the concept of digital self-monitoring as a behaviour change strategy arose from Mohr's behavioural intervention technology model (Yardley *et al.*, 2015b; Mohr *et al.*, 2014). These frameworks were influential in the development of the thesis but were too extensive to adopt completely, as their focus is on the development of behaviour change interventions. Hence the approach taken was broadly informed by intervention development guidance, using an iterative approach and combining research evidence with user involvement (O'Cathain *et al.*, 2019).

Using a framework to guide research is beneficial in that it provides a systematic process to follow and effectively integrates theory and research practice (Mohr *et al.*, 2014). The absence of such a framework in this thesis means that the methods used may not have captured the data sufficiently comprehensively to develop and test the smart EMA. However, with regards to the integration of theory, the studies in this thesis were exploratory and relevant theory emerged as the thesis progressed, although influenced by biopsychosocial and ecological perspectives of health and functioning.

The second limitation of this PhD study is the lack of validation of the EMA components. The difficulty of establishing validity EMA data has already been discussed in chapter 5. There are currently no standards of practice for developing EMA's and most validated measures of fatigue reflect trait fatigue rather than state fatigue. The numeric rating scale of state energy and the short PVT both need further testing to investigate their psychometric properties. It is unclear whether PVT response time is related to fatigue. The decision to focus on usability first (rather than establishing the validity of the EMA components) was driven partly by pragmatic issues around the scale of the project for a PhD thesis. However, it was also essential to test whether a reaction time component to repeated EMA was feasible for use by ABI survivors and explore the parameters of what was

acceptable, before determining the validity of the test. In the next iteration of the smart EMA, the addition of a rating scale of fatigue may help to establish convergent validity.

Finally, the development of the smart EMA was only possible because of a goodwill collaboration with Jose Vegas at Dublin City University. Whilst Jose has considerable professional experience developing apps, he donated his time and expertise to the project. This meant that aspects of the app design were scaled down, some hoped-for areas of development did not happen (for example, pairing the app with a wearable device) and problems with the sound alert on the app were not rectified in time for the usability evaluation. Nevertheless, Jose brought invaluable expertise to the project that made the app development possible and contributed to users' positive experiences of the app. The prototype tested with ABI survivors was positively rated for its ease of use and simple design.

#### **8.4. Future directions and recommendations**

The vision at the beginning of this PhD was to develop a tool that might assist ABI survivors, therapists and skilled carers or volunteers in managing fatigue. With changes in medical device regulations in 2017, such use of the smart EMA would now classify it as a medical device. As such it needs to be evidenced as safe, reliable, secure, effective, and usable, in accordance with the regulations (MHRA, 2020). This means that further studies are necessary to investigate the validity of the EMA components, particularly the short reaction time test. In addition, areas that were identified in the usability evaluation need addressing to improve the usefulness and usability of the app.

Currently, the app streams data to a secure server and no information is held on the mobile phone. However, for the app to be useful, feedback summaries from the app data need to be developed and presented within the app interface. Whilst participants in the usability evaluation discussed what type of feedback they wanted, further collaboration with ABI survivors is essential to design the feedback component of the app.

The smart EMA of fatigue and activity may also have a wider application beyond the brain injury population and be relevant to other research studies in its current form (once the usability issues identified have been resolved). Consequently, the app is being made available for other researchers within the MOREeS group at Oxford Brookes University and other opportunities for widening the application of the app are being explored.

This thesis proposed a model which explains how participation is affected by an individual's fatigue experiences and their perceived self-efficacy at coping with fatigue whilst engaging in their daily activities. Further research is now needed to test the relationships presented within the model and its potential for guiding fatigue management interventions.

Finally, smart EMAs offer clinicians opportunities to gain insight into their patient's experiences in the context of everyday life and has been heralded as a new therapeutic tool (Leneart *et al.*, 2020). Additionally, there is increasing interest in smart ecological momentary interventions, using mobile technology to deliver interventions as they are needed (van de Ven *et al.*, 2017; Dicianno *et al.*, 2015). Rapid technological advances over the last decade have broadened the scope, accessibility, and utility of ecological momentary assessment. However, there is a need for accessible and secure platforms to support the use of EMA in clinical practice, and to raise awareness of the potential benefits EMA for rehabilitation practice and research. Ideally, a shift in approaches to clinical assessment is needed where therapists and clinicians partner with publishers of standardised assessments to develop an accessible and secure platform for the design and delivery of smart ecological momentary assessments.

## References.

- Aarnes, R., Stubberud, J. and Lerdal, A. (2019) 'A literature review of factors associated with fatigue after stroke and a proposal for a framework for clinical utility', *Neuropsychological Rehabilitation*, 30(8), pp. 1449-1476. doi: NRH-OA 79.18.R2.
- Abrahamson, V. W., PM. (2019) 'How unmet are unmet needs post-stroke? A policy analysis of the six-month review', *BMC Health Services Research*, 19(1), pp. 1-9. doi: doi:10.1186/s12913-019-4210-2.
- Acciarresi, M., Bogousslavsky, J. and Paciaroni, M. (2014) 'Post-stroke fatigue: epidemiology, clinical characteristics and treatment', *Eur Neurol*, 72(5-6), pp. 255-61. doi: 10.1159/000363763.
- Adjust (2019) *Adjust Global App Trends 2019*. @adjustcom Available at: <https://www.adjust.com/resources/ebooks/adjust-global-app-trends-report-2019/> (Accessed: 22/04/20).
- Agarwal, A. L., et al., (2016) 'Guidelines for reporting of health interventions using mobile phones: mobile health (mHealth) evidence reporting and assessment (mERA) checklist', *BMJ*, 352, pp. i1174. doi: 10.1136/bmj.i1174.
- Almalki, M., Gray, K. and Sanchez, F. M. (2015) 'The use of self-quantification systems for personal health information: big data management activities and prospects', *Health Information Science and Systems*, 3(Suppl 1), pp. S1. doi: 10.1186/2047-2501-3-s1-s1
- Ancker, J., et al. (2015) "'You Get Reminded You're a Sick Person": Personal Data Tracking and Patients With Multiple Chronic Conditions', *J Med Internet Res*, 17(8), pp. e202. doi: doi:10.2196/jmir.4209.
- Andelic, N., et al. (2018) 'Disability and Quality of Life 20 Years After Traumatic Brain Injury', *Brain and behavior*, 8(7). doi: 10.1002/brb3.1018.
- Andersen, G., et al. (2012) 'Post-stroke fatigue and return to work: a 2-year follow-up', *Acta neurologica Scandinavica*, 125(4), pp. 248-53. doi: 10.1111/j.1600-0404.2011.01557.x.
- Andrykowski, M. A., Donovan, K. A. and Jacobsen, P. B. (2009) 'Magnitude and Correlates of Response Shift in Fatigue Ratings in Women Undergoing Adjuvant Therapy for Breast Cancer', *J Pain Symptom Manage*, 37(3), pp. 341-51. doi: 10.1016/j.jpainsymman.2008.03.01.
- Arora, S., Yttri, J. and Nilse, W. (2014) 'Privacy and Security in Mobile Health (mHealth) Research', *Alcohol Res*, 36(1), pp. 143-51.
- Arsintescu, L., Mulligan, J. B. and Flynn-Evans, E. E. (2017) 'Evaluation of a Psychomotor Vigilance Task for Touch Screen Devices', *Hum Factors*, 59(4), pp. 661-670. doi: 10.1177/0018720816688394.
- Arsintescu, L. K., KH. Cravalho, PF. Feick. NH, Stone, LS. Flynn-Evans, EE. (2019) 'Validation of a touchscreen psychomotor vigilance task', *Accident & Analysis Prevention*, 126, pp. 173-176, doi: 10.1016/j.aap.2017.11.041.
- Ashman, T. A., et al. (2008) 'Objective measurement of fatigue following traumatic brain injury', *Journal of Head Trauma Rehabilitation*, 23(1), pp. 33-40. doi: 10.1097/01.HTR.0000308719.70288.22
- Atler, K., Malcolm, M. and Greife, C. (2015) 'A follow-up study on the relationship among participation, activity and motor function in survivors of stroke following constraint-induced therapy', *Disability & Rehabilitation*, 37(2), pp. 121-128. doi: 10.3109/09638288.2014.910560.
- Austin, P.C. and Leckie, G. (2018) 'The effect of number of clusters and cluster size on statistical power and Type I error rates when testing random effects variance components in multilevel linear and logistic regression models', *Journal of Statistical Computation and Simulation*, 88(16), pp. 3151-3163. doi: 10.1080/00949655.2018.1504945.
- Badley, E. M. (2008) 'Enhancing the conceptual clarity of the activity participation components of the International Classification of Disability and Health', *Social Science and Medicine*, 66(11), pp. 23335-45. doi: 10.1016/j.socscimed.2008.01.026.

- Baharuddin, R., Dalbir, S. and Razali, R. (2013) 'Usability Dimensions for Mobile Applications-A Review', *Research Journal of Applied Sciences, Engineering and Technology*, 5(6), pp. 2225-2231. doi: 10.19026/rjaset.5.4776
- Bahja, M. H., R. Bahka, M. 'User-driven development for UK M-health patient management system | Proceedings of the 32nd International BCS Human Computer Interaction Conference'. *HCI '18: Proceedings of the 32nd International BCS Human Computer Interaction Conference*, 1-10.
- Bangor, A., Kortum, T. and Miller, J. (2008) 'An empirical evaluation of the system usability scale.', *International Journal of Human-Computer Interaction.*, 4(6), pp. 574-594. doi: 10.1080/10447310802205776
- Banks, L., Kuper, H. and Polack, S. (2020) 'Poverty and disability in low- and middle-income countries: A systematic review', *Plos One*, 13(9), pp. e0204881. doi: 10.1371/journal.pone.0189996.
- Barbour, V. and Mead, G. (2012) 'Fatigue after Stroke: The Patient's Perspective', *Stroke Research and Treatment*, (ID 863031), pp. 6. doi:10.1155/2012/863031.
- Barker-Collo, S., Feigin, V. L. and Dudley, M. (2007) 'Post stroke fatigue--where is the evidence to guide practice?', *The New Zealand Medical Journal*, 120(1264), pp. U2780-U2780.
- Bartlett, D., et al. (2006) 'Advancing rehabilitation research: an interactionist perspective to guide question and design', *Disabil Rehabil*, 28(19), pp. 1169-76. doi: 10.1080/09638280600551567.
- Basner, M. and Dinges, D. F. (2011) 'Maximizing sensitivity of the psychomotor vigilance test (PVT) to sleep loss', *Sleep*, 34(5), pp. 581-91. doi: 10.1093/sleep/34.5.581.
- Basner, M., et al. (2018) 'Repeated Administration Effects on Psychomotor Vigilance Test Performance', *Sleep*, 41(1). doi: 10.1093/sleep/zsx187.
- Basner, M., Mollicone, D. and Dinges, D. F. (2011) 'Validity and Sensitivity of a Brief Psychomotor Vigilance Test (PVT-B) to Total and Partial Sleep Deprivation', *Acta Astronaut*, 69(11-12), pp. 949-959. doi: 10.1016/j.actaastro.2011.07.015.
- Basner, M. Dinges, D. (2012) 'An Adaptive-Duration Version of the PVT Accurately Tracks Changes in Psychomotor Vigilance Induced by Sleep Restriction', *Sleep*, 35(2), pp. 193-202. doi: 10.5665/sleep.1620.
- Baum, C. and Edwards, D. 2001. Activity Sort Card. St Louis, MO.: Washington University School of Medicine.
- Bay, E. and Xie, Y. (2009) 'Psychological and Biological Correlates of Fatigue After Mild-to-Moderate Traumatic Brain Injury', *Western Journal of Nursing Research*, 31(6), pp. 731-747. doi: 10.1177/0193945909334856.
- Beaulieu-Bonneau, S. and Ouellet, M.-C. (2017) 'Fatigue in the first year after traumatic brain injury: Course, relationship with injury severity, and correlates', *Neuropsychological Rehabilitation*, 27(7), pp. 983-1001. doi: 10.1080/09602011.2016.1162176.
- Bejot, Y., et al. (2014) 'Trends in the incidence of ischaemic stroke in young adults between 1985 and 2011: the Dijon Stroke Registry', *J Neurol Neurosurg Psychiatry*, 85(5), pp. 509-13. doi: 10.1136/jnnp-2013-306203.
- Belmont, A., Agar, N. and Azouvi, P. (2009) 'Subjective fatigue, mental effort, and attention deficits after severe traumatic brain injury', *Neurorehabilitation and Neural Repair*, 23(9), pp. 939-944. doi: 10.1177/1545968309340327.
- Bengtsson, M. (2016) 'How to plan and perform a qualitative study using content analysis', *Nursing Plus Open*, 2, pp. 8-14. doi: 10.1016/j.npls.2016.01.001.
- Bennett, S., et al. (2016) 'Educational interventions for the management of cancer-related fatigue in adults', *Cochrane Database Syst Rev*, 11, pp. Cd008144. doi: 10.1002/14651858.CD008144.pub2.
- Bentsen, L., et al. (2014) 'Outcome and risk factors presented in old patients above 80 years of age versus younger patients after ischemic stroke', *J Stroke Cerebrovasc Dis*, 23(7), pp. 1944-8. doi: 10.1016/j.jstrokecerebrovasdis.2014.02.002.

- Berger, E., Neitzel, R. and Kladden, C. (2010) 'Noise Navigator™ Sound Level Database'. Available at: [http://www.trpa.org/documents/rseis/3.6%20Noise/3.6\\_Berger%202006\\_Noise%20Navigator%20Sound.pdf](http://www.trpa.org/documents/rseis/3.6%20Noise/3.6_Berger%202006_Noise%20Navigator%20Sound.pdf) (Accessed 7.06.20).
- Berges, I.M., Seale, G. S. and Ostir, G. V. (2012) 'The role of positive affect on social participation following stroke', *Disability And Rehabilitation*, 34(25), pp. 2119-2123. doi: 10.3109/09638288.2012.673684.
- Bergner, M., et al. (1981) 'The Sickness Impact Profile: Development and Final Revision of a Health Status Measure', *Medical Care*, 19, pp. 787--805. doi: 10.1097/00005650-198108000-00001.
- Beute, F., de Kort, Y. and Ijsselstein, W. (2016) 'Restoration in Its Natural Context: How Ecological Momentary Assessment Can Advance Restoration Research', *Int J Environ Res Public Health*, 13(4), pp. 420. doi: 10.3390/ijerph13040420.
- Bickenbach, J. (2014) 'Reconciling the Capability Approach and the ICF', *ALTER - European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap*, 8, pp. 10-23. doi: 10.1007/978-3-030-11899-0\_1
- Birkhoff, S. D. and Smeltzer, S. C. (2017) 'Perceptions of Smartphone User-Centered Mobile Health Tracking Apps Across Various Chronic Illness Populations: An Integrative Review', *J Nurs Scholarsh*, 49(4), pp. 371-378. doi: 10.1111/jnu.12298.
- Blikman, L. J., et al. (2013) 'Effectiveness of energy conservation treatment in reducing fatigue in multiple sclerosis: a systematic review and meta-analysis', *Arch Phys Med Rehabil*, 94(7), pp. 1360-76. doi: 10.1016/j.apmr.2013.01.025.
- Blomer, A., et al. (2015) 'Does the frequency of participation change after stroke and is this change associated with the subjective experience of participation?', *Archives of Physical Medicine and Rehabilitation*, 90(3), pp. 456-63. doi: 10.1016/j.apmr.2014.09.003.
- Blomgren, C., et al. (2018) 'Long-term performance of instrumental activities of daily living (IADL) in young and middle-aged stroke survivors: Results from SAHLSIS outcome', *Scandinavian Journal of Occupational Therapy*, 25(2), pp. 119-126. doi: 10.1080/11038128.2017.1329343.
- Bolton, D. and Gillet, G. 2019. The Biopsychosocial Model 40 Years On. In: The Biopsychosocial Model of Health and Disease. Cham: Palgrave Pivot.
- Boren, M. and Ramey, J. (2000) 'Thinking aloud, reconciling theory and practice.', *IEE Transactions on professional communication.*, 43(3), pp. 261-278. doi: 10.1109/47.867942.
- Bourgeois, A. L., A. Meyers, M. (2010) 'Full-Scale and Short-Form of the Profile of Mood States: A Factor Analytic Comparison.', *Journal of Sport Behaviour*, 33(4), pp. 355-376.
- Braley, T. J., Chervin, R. D. and Segal, B. M. (2012) 'Fatigue, Tiredness, Lack of Energy, and Sleepiness in Multiple Sclerosis Patients Referred for Clinical Polysomnography', *Multiple Sclerosis International*, 2012. doi: 10.1155/2012/673936.
- Brands, I., et al. (2014) 'Influence of self-efficacy and coping on quality of life and social participation after acquired brain injury: a 1-year follow-up study', *Archives Of Physical Medicine And Rehabilitation*, 95(12), pp. 2327-2334. doi: 10.1016/j.apmr.2014.06.006.
- Brasure, M., et al. (2013) 'Participation after multidisciplinary rehabilitation for moderate to severe traumatic brain injury in adults: a systematic review', *Arch Phys Med Rehabil*, 94(7), pp. 1398-420. doi: 10.1016/j.apmr.2012.12.019.
- Broderick, J. E., et al. (2008) 'The accuracy of pain and fatigue items across different reporting periods', *Pain*, 139(1), pp. 146-57. doi: 10.1016/j.pain.2008.03.024.
- Brooke, J. (1996) 'SUS: A "quick and dirty" usability scale.', in Jordan, P.W., et al. (eds.) *Usability evaluation in industry*. London: Taylor & Francis., pp. 189-194.
- BSI (2016) 'PD IEC/TR 62366-2:2016 Medical devices Part 2: Guidance on the application of usability engineering to medical devices.': British Standards Institute.
- BSI (2017): *Systems and software engineering - Systems and software product Quality Requirements and Evaluation (SQuaRE) - Common Industry Format (CIF) for usability: General framework for usability-related information*: British Standards Institute Limited.

- BSI (2019a) 'Ergonomics of human-system interaction — Part 210: Human-centred design for interactive systems (ISO 9241-210:2019). Brussels: British Standards Institute Limited.
- BSI (2019b) 'Systems and software engineering - Systems and software Quality Requirements and Evaluation (SQuaRE) - Common Industry Format (CIF) for Usability - Evaluation Report'. BS EN ISO 25066:2019. British Standards Institute Limited.
- Buono, V., et al. (2015) 'Coping strategies and health-related quality of life after stroke:' *Journal of Health Psychology*, 22(1), pp. 16-28. doi: 10.1177\_1359105315595117.
- Burke, L. E., et al. (2017) 'Ecological Momentary Assessment in Behavioral Research: Addressing Technological and Human Participant Challenges', *J Med Internet Res*, 19(3), pp. e77. doi: 10.2196/jmir.7138.
- Bushman, B. and Wang, M. (2009) 'Vote counting procedures in meta analysis', in Cooper, H., Hedges, L. & Valentine, J. (eds.) *Handbook Research Synthesis*. 2nd edn. New York: Russel Sage Foundation, pp. 193–213.
- Bushnik, T., Englander, J. and Wright, J. (2008) 'Patterns of fatigue and its correlates over the first 2 years after traumatic brain injury', *Journal of Head Trauma Rehabilitation*, 23(1), pp. 25-32. doi: 10.1097/01.HTR.0000308718.88214.bb.
- Butler, A., et al. (2006) 'Attempting to improve function and quality of life using the FTM Protocol: case report', *Journal Of Neurologic Physical Therapy: JNPT*, 30(3), pp. 148-156.
- Butt, Z., et al. (2013) 'Measurement of fatigue in cancer, stroke, and HIV using the Functional Assessment of Chronic Illness Therapy - Fatigue (FACIT-F) scale', *Journal Of Psychosomatic Research*, 74(1), pp. 64-68. doi: 10.1016/j.jpsychores.2012.10.011.
- Cantor, J., et al. (2008) 'Fatigue after traumatic brain injury and its impact on participation and quality of life', *J Head Trauma Rehabil*, 23(1), pp. 41-51. doi: 10.1097/01.HTR.0000308720.70288.af.
- Cantor, J. B., et al. (2014) 'Systematic review of interventions for fatigue after traumatic brain injury: a NIDRR traumatic brain injury model systems study', *J Head Trauma Rehabil: Vol. 6*. United States, pp. 490-7. doi: 10.1097/HTR.0000000000000102
- Cantor, J. B., Gordon, W. and Gumber, S. (2013) 'What is post TBI fatigue?', *Neurorehabilitation*, 32(4), pp. 875-883. doi: 10.3233/nre-130912.
- Capela, N., et al. (2016) 'Evaluation of a Smartphone Human Activity Recognition Application With Able-Bodied and Stroke Participants', *Journal of neuroengineering and rehabilitation*, 13. doi: 10.1186/s12984-016-0114-0.
- Cardol, M., et al. (2001) 'Psychometric properties of the impact on Participation and Autonomy Questionnaire', *Archives of Physical Medicine and Rehabilitation*, 82(2), pp. 210-216. doi: 10.1053/apmr.2001.18218.
- Carlson, M. and Morrison, R. (2009) 'Study Design, Precision, and Validity in Observational Studies.', *Journal of Palliative Medicine*, 12(1), pp. 77-82. doi: 10.1089/jpm.2008.9690
- Carod-Artal, F. J., et al. (2009) 'Determinants of quality of life in Brazilian stroke survivors', *Journal Of The Neurological Sciences*, 284(1-2), pp. 63-68. doi: 10.1016/j.jns.2009.04.008.
- Carter, B. S., et al. (2000) 'Factors associated with reintegration to normal living after subarachnoid hemorrhage', *Neurosurgery*, 46(6), pp. 1326-1333. doi:10.1097/00006123-200006000-00008.
- Case, M. A., et al. (2015) 'Accuracy of Smartphone Applications and Wearable Devices for Tracking Physical Activity Data.', *JAMA*, 316(6), pp. 625. doi:10.1001/jama.2014.17841.
- Cerniauskaite, M., et al. (2011) 'Systematic literature review on ICF from 2001 to 2009: its use, implementation and operationalisation', *Disability and rehabilitation*, 33(4). doi: 10.3109/09638288.2010.529235.
- Chahal, N., Barker-Collo, S. and Feigin, V. (2011) 'Cognitive and functional outcomes of 5-year subarachnoid haemorrhage survivors: comparison to matched healthy controls', *Neuroepidemiology*, 37(1), pp. 31-38. doi: 10.1159/000328647.



- Chammas, A. Q., M. Mont'Alvao, C. (2015) 'A Closer look on the User Centred Design Approach', *Procedia Manufacturing*, 3, pp. 5397-5404, doi: 10.1016/j.promfg.2015.07.656.
- Chan, V., *et al.* (2017a) 'Clinical profile and comorbidity of traumatic brain injury among younger and older men and women: a brief research notes.', *BMC Res Notes*, 10(371):361. doi 10.1186/s13104-017-2682-x.
- Chan, Y., *et al.* (2017b) 'The Asthma Mobile Health Study, a Large-Scale Clinical Observational Study Using ResearchKit', *Nature biotechnology*, 35(4). doi: 10.1038/nbt.3826.
- Charters, E. (2003) 'The Use of Think-aloud Methods in Qualitative Research. An Introduction to Think-aloud Methods.', *Brock Education.*, 12(2), pp. 68-82. doi: 10.26522/BROCKED.V12I2.38
- Chaudhuri, A. and Behan, P. (2000) 'Fatigue and basal ganglia', *Journal of the Neurological Sciences*, 179(1-2), pp. 34--42. doi: 10.1016/S0022-510X(00)00411-1.
- Chaudhuri, A. and O Behan, P. (2004) 'Fatigue in Neurological Conditions', *The Lancet*, 363(9413), pp. 978-988, Available at: <http://www.sciencedirect.com/science/article/pii/S0140673604157942> (Accessed 1.12.14). doi: doi:10.1016/S0140-6736(04)15794-2.
- Christopher, E., Alsaffarini, K. W. and Jamjoom, A. A. (2019) 'Mobile Health for Traumatic Brain Injury: A Systematic Review of the Literature and Mobile Application Market', *Cureus*, 11(7). doi: 10.7759/cureus.5120.
- Cicerone, K. (2013) 'Participation After Multidisciplinary Rehabilitation for Moderate to Severe Traumatic Brain Injury in Adults', *Archives of Physical Medicine and Rehabilitation*, 94(7), pp. 1421-1423. doi: 10.1016/j.apmr.2013.04.003.
- Cicerone, K. and Azulay, J. (2007) 'Perceived Self-Efficacy and Life Satisfaction After Traumatic Brain Injury', *The Journal of head trauma rehabilitation*, 22(5). doi: 10.1097/01.Htr.0000290970.56130.81.
- Cicerone, K. D. (2004) 'Participation as an outcome of traumatic brain injury rehabilitation', *The Journal Of Head Trauma Rehabilitation*, 19(6), pp. 494-501. doi: 10.1097/00001199-200411000-00006.
- Cieza, A., *et al.* (2005) 'ICF linking rules: An update based on lessons learned', *Journal of Rehabilitation Medicine*, 37, pp. 212--218. doi: 10.1080/16501970510040263.
- Clarke, A., Barker-Collo, S. L. and Feigin, V. L. (2012) 'Poststroke Fatigue: Does Group Education Make a Difference? A Randomized Pilot Trial', *Topics in Stroke Rehabilitation*, 19(1), pp. 32-39.
- Clarke, P., *et al.* (1999) 'Handicap in stroke survivors', *Disability And Rehabilitation*, 21(3), pp. 116-123.
- Cogan, A. M. and Carlson, M. (2018) 'Deciphering participation: an interpretive synthesis of its meaning and application in rehabilitation', *Disabil Rehabil*, 40(22), pp. 2692-2703. doi: 10.1080/09638288.2017.1342282.
- Colombo, D., *et al.* (2019) 'Current State and Future Directions of Technology-Based Ecological Momentary Assessment and Intervention for Major Depressive Disorder: A Systematic Review', *Journal of clinical medicine*, 8(4). doi: 10.3390/jcm8040465.
- Colorafi, K. J. and Evans, B. (2016) 'Qualitative Descriptive Methods in Health Science Research', *Herd*, 9(4), pp. 16-25. doi: 10.1177/1937586715614171.
- Conner, T., *et al.* (2009) 'Experience sampling methods: A modern idiographic approach to personality research. - PsycNET', *Social and Personality Psychology Compass*, 3(3), pp. 292--313. doi: 10.1111/j.1751-9004.2009.00170.x.
- Cooper, C. L., *et al.* (2015) 'The role of emotion regulation on social participation following stroke', *The British Journal Of Clinical Psychology*, 54(2), pp. 181-199. doi: 10.1111/bjc.12068.
- Cooper, H., Hedges, L. and Valetine, J. (Ed.s). (2009) *The Handbook of Research Synthesis and Meta-Analysis*. 2<sup>nd</sup> edition. Russell Sage Foundation.
- Cornet, V. P. and Holden, R. J. (2018) 'Systematic review of smartphone-based passive sensing for health and wellbeing', *J Biomed Inform*, 77, pp. 120-132. doi: 10.1016/j.jbi.2017.12.008.

- Corrigan, J. and Deming, R. (1995) 'Psychometric characteristics of the Community Integration Questionnaire: Replication and extension.', *Journal of Head Trauma Rehabilitation*, 10, pp. 41-53.
- Corrigan, J. D., et al. (2014) 'US population estimates of health and social outcomes 5 years after rehabilitation for traumatic brain injury', *J Head Trauma Rehabil*, 29(6), pp. E1-9. doi: 10.1097/htr.000000000000020.
- Coskun, D., Incel, O. and Ozgovde, A. 'Phone position/placement detection using accelerometer: Impact on activity recognition.'. *IEEE Tenth International Conference on Intelligent Sensors, Sensor Networks and Information Processing (ISSNIP)*. Singapore, 1-6.
- Coursaris, C. and Kim, D. (2011) 'A Meta-Analytical Review of Empirical Mobile Usability Studies', *Journal of Usability Studies.*, 6(3), pp. 117-171. doi: 10.5555/2007456.2007459
- Crichton, S. L., et al. (2016) 'Patient outcomes up to 15 years after stroke: survival, disability, quality of life, cognition and mental health', *J Neurol Neurosurg Psychiatry*, 87(10), pp. 1091-8. doi: 10.1136/jnnp-2016-313361.
- Crosby, G. A., et al. (2012) 'Fatigue after stroke: frequency and effect on daily life', *Disabil Rehabil*, 34(8), pp. 633-7. doi: 10.3109/09638288.2011.613517.
- Daly, J., Armstrong, L. and Martin, S. (2016) 'User centred design and validation during the development of domestic brain computer interface applications for people with acquired brain injury and therapists: a multi-stakeholder approach', *Journal of Assistive Technologies*, vol 10(2), pp. 68-78. doi: 10.1108/JAT-01-2016-0002
- De Doncker, W., et al. (2017) 'Mechanisms of poststroke fatigue', *Journal of Neurology, Neurosurgery & Psychiatry*, 89(3). doi: 10.1136/jnnp-2017-316007.
- Degroote, L., et al. (2020) 'Content Validity and Methodological Considerations in Ecological Momentary Assessment Studies on Physical Activity and Sedentary Behaviour: A Systematic Review', *The international journal of behavioral nutrition and physical activity*, 17(1). doi: 10.1186/s12966-020-00932-9.
- Dehlendorff, C., Andersen, K. K. and Olsen, T. S. (2015) 'Sex Disparities in Stroke: Women Have More Severe Strokes but Better Survival Than Men', *J Am Heart Assoc*, 4(7). doi: 10.1161/jaha.115.001967.
- Delgado, D. A., et al. (2018) 'Validation of Digital Visual Analog Scale Pain Scoring With a Traditional Paper-based Visual Analog Scale in Adults', *J Am Acad Orthop Surg Glob Res Rev*, 2(3), Available at: <http://dx.doi.org/10.5435/JAAOSGlobal-D-17-00088>. doi: 10.5435/JAAOSGlobal-D-17-00088.
- Della Mea, V., Simoncello, A., (2012), ' An ontology-based exploration of the concepts and relationships in the activities and participation component of the international classification of functioning, disability and health', *Journal of Biomedical Semantics* 3 (1). doi:10.1186/2041-1480-3-1.
- Desrosiers, J., et al. (2005) 'Participation after Stroke Compared to Normal Aging', *Journal of Rehabilitation Medicine*, 37(6), pp. 353-357. doi: 10.1080/16501970510037096
- Desrosiers, J., et al. (2008) 'Short-term changes in and predictors of participation of older adults after stroke following acute care or rehabilitation', *Neurorehabilitation And Neural Repair*, 22(3), pp. 288-297. doi: 10.1177/1545968307307116.
- Desrosiers, J., et al. (2002) 'Predictors of handicap situations following post-stroke rehabilitation', *Disability And Rehabilitation*, 24(15), pp. 774-785. doi: 10.1080/09638280210125814
- Desrosiers, J., et al. (2006) 'Long-term changes in participation after stroke', *Topics In Stroke Rehabilitation*, 13(4), pp. 86-96. doi: 10.1310/tsr1304-86.
- Dicianno, B., et al. (2015) 'Perspectives on the Evolution of Mobile (mHealth) Technologies and Application to Rehabilitation', *Physical Therapy*, 95(3), pp. 397-405. doi: 10.2522/ptj.20130534.

- Dijkers, M. P. (2010) 'Issues in the conceptualization and measurement of participation: an overview', *Archives of Physical Medicine and Rehabilitation*, 91(9 Suppl), pp. S5--16. doi: 10.1016/j.apmr.2009.10.036.
- Dinges, D. and Powell, J. (1986) 'Microcomputer analyses of performance on a portable, simple visual RT task during sustained operations', *Behavior Research Methods, Instruments, & Computers*, 17(6), pp. 652-655. doi: doi:10.3758/BF03200977.
- Ditchman, N., et al. (2016) 'Predictors of social integration for individuals with brain injury: An application of the ICF model', *Brain Injury*, 30(13-14), pp. 1581-1589. doi: 10.1080/02699052.2016.1199900.
- Dobkin, B. (2016) 'Behavioral self-management strategies for practice and exercise should be included in neurologic rehabilitation trials and care.', *Current Opinion in Neurology*, 29(6), pp. 693-699. doi: 10.1097/wco.0000000000000380.
- Dopp, A., et al. (2019) 'Integrating implementation and user-centred design strategies to enhance the impact of health services: protocol from a concept mapping study', *Health Research Policy and Systems*, 17(1), pp. 1-11. doi: doi:10.1186/s12961-018-0403-0.
- Dubad, M., et al. (2018) 'A Systematic Review of the Psychometric Properties, Usability and Clinical Impacts of Mobile Mood-Monitoring Applications in Young People', *Psychological medicine*, 48(2). doi: 10.1017/s0033291717001659.
- Dumont, C., et al. (2004) 'Toward an explanatory model of social participation for adults with traumatic brain injury', *Journal of Head Trauma Rehabilitation*, 19(6), pp. 431-444.
- Duncan, F., et al. (2014) 'Clinically significant fatigue after stroke: a longitudinal cohort study', *Journal Of Psychosomatic Research*, 77(5), pp. 368-373. doi: 10.1016/j.jpsychores.2014.06.013
- Duncan, F., et al. (2015) 'Exploratory longitudinal cohort study of associations of fatigue after stroke', *Stroke (00392499)*, 46(4), pp. 1052-1058. doi: 10.1161/STROKEAHA.114.008079.
- Duncan, F., Wu, S. and Mead, G. E. (2012) 'Frequency and natural history of fatigue after stroke: a systematic review of longitudinal studies', *Journal of psychosomatic research*, 73(1), pp. 18-27. doi: 10.1016/j.jpsychores.2012.04.001.
- Duncan, P., et al. (1999) 'The Stroke Impact Scale Version 2.0: Evaluation of reliability, validity, and sensitivity to change', *Stroke*, 30(10), pp. 2131-2140.
- Dunton, G., Dzibur, E. and Intille, S. (2016) 'Feasibility and Performance Test of a Real-Time Sensor-Informed Context-Sensitive Ecological Momentary Assessment to Capture Physical Activity', *Journal of medical Internet research*, 18(6). doi: 10.2196/jmir.5398.
- Duque, E., et al. (2019) 'A systematic literature review on user centered design and participatory design with older people', *IHC '19: Proceedings of the 18th Brazilian Symposium on Human Factors in Computing Systems*. Brazil, pp. Pages 1–11.
- Durcan, D. and Bell, R. (2015) 'Local action on health inequalities: reducing social isolation across the lifecourse.'. London: UCL Institute of Health Equity.
- Egan, M., et al. (2014) 'Participation and well-being poststroke: Evidence of reciprocal effects', *Archives of Physical Medicine and Rehabilitation*, 95(2), pp. 262-8. doi: 10.1016/j.apmr.2013.08.013.
- Egan, M., et al. (2015) 'Very low neighbourhood income limits participation post stroke: preliminary evidence from a cohort study', *BMC Public Health*, 15, pp. 528-528. doi: 10.1186/s12889-015-1872-5.
- Eilertsen, G., Ormstad, H. and Kirkevold, M. (2013) 'Experiences of poststroke fatigue: qualitative meta-synthesis', *Journal of advanced nursing*, 69(3), pp. 514-25. doi: 10.1111/jan.12002.
- Elf, M., et al. (2016) 'Self-Reported Fatigue and Associated Factors Six Years after Stroke', *PLoS One*, 11(8), pp. e0161942. doi: 10.1371/journal.pone.0161942.
- Elo, S. and Kyngas, H. (2007) 'The qualitative content analysis process.', *Journal of Advanced Nursing*, 62(1), pp. 107-115
- Engel-Yeger, B., et al. (2018) 'Scoping Review: The Trajectory of Recovery of Participation Outcomes following Stroke', *Behavioural Neurology*, 2018. doi: 10.1155/2018/5472018.

- Engström, A., Lexell, J. and Lund, M. (2010) 'Difficulties in using everyday technology after acquired brain injury: a qualitative analysis', *Scand J Occup Ther*, 17(3), pp. 233-243. doi: 10.3109/11038120903191806.
- Erler, K., *et al.* (2018) 'Predicting the trajectory of participation after traumatic brain injury: A longitudinal analysis.', *The Journal of Head Trauma Rehabilitation*, 33(4), pp. 257–265. doi: 10.1097/HTR.0000000000000383.
- Esliger, D., *et al.* (2011) 'Validation of the GENE Accelerometer', *Medicine and science in sports and exercise*, 43(6), pp. 1085-93. doi: 10.1249/MSS.0b013e31820513be.
- Eurostat (2019) 'Harmonised European Time Use Surveys (HETUS) 2018 Guidelines'. Luxemborg. Available at: <https://ec.europa.eu/eurostat/documents/3859598/9710775/KS-GQ-19-003-EN-N.pdf/ee48c0bd-7287-411a-86b6-fb0f6d5068cc>.
- Eyssen, I. C., *et al.* (2011) 'A Systematic Review of Instruments Assessing Participation: Challenges in Defining Participation', *Archives of Physical Medicine and Rehabilitation*, 92(6), pp. 983-997. doi: 10.1016/j.apmr.2011.01.006.
- Ezekiel, L., *et al.* (2019) 'Factors Associated With Participation in Life Situations for Adults With Stroke: A Systematic Review', *Archives Of Physical Medicine And Rehabilitation*, 100(5), pp. 945-955. doi: 10.1016/j.apmr.2018.06.017.
- Ezekiel, L., Dawes, H. and Collett, J. (2015) *Protocol: Factors associated with participation for community dwelling adults with stroke*. University of York Centre for Reviews and Dissemination: PROSPERO International Prospective Register of Systematic Reviews Available at: [http://www.crd.york.ac.uk/PROSPERO/display\\_record.asp?ID=CRD42015017909](http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42015017909).
- Ezekiel, L., *et al.* (2020) 'Experiences of fatigue in daily life of people with acquired brain injury: a qualitative study', *Disabil Rehabil*, pp. 1-9. doi: 10.1080/09638288.2020.1720318.
- Farao, J., *et al.* (2020) 'A user-centred design framework for mHealth'. PLOS ONE 15, e0237910. doi:10.1371/journal.pone.0237910.
- Falkenström, F., Solomonov, N. and Rubel, J. (2020) 'Using time - lagged panel data analysis to study mechanisms of change in psychotherapy research: Methodological recommendations.', *Counselling and Psychotherapy Research*, 20, pp. 435-441. doi: 10.1002/capr.12293.
- Fallahpour, M., *et al.* (2011) 'Perceived participation and autonomy: aspects of functioning and contextual factors predicting participation after stroke', *Journal Of Rehabilitation Medicine*, 43(5), pp. 388-397. doi: 10.2340/16501977-0789.
- Faulkner, L. (2003) 'Beyond the five-user assumption: Benefits of increased sample sizes in usability testing | SpringerLink', *Behaviour Research Methods, Instruments & Computers*, 35(3), pp. 379-383. doi: 10.3758/bf03195514.
- Feigin, V. L., *et al.* (2012) 'Prevalence and predictors of 6-month fatigue in patients with ischemic stroke: a population-based stroke incidence study in Auckland, New Zealand, 2002-2003', *Stroke (00392499)*, 43(10), pp. 2604-2609.
- Feigin, V. L., *et al.* (2010) 'Auckland Stroke Outcomes Study. Part 1: Gender, stroke types, ethnicity, and functional outcomes 5 years poststroke', *Neurology*, 75(18), pp. 1597-1607. doi: 10.1212/WNL.0b013e3181fb44b3.
- Fischer, U., *et al.* (2006) 'Impact of comorbidity on ischemic stroke outcome', *Acta Neurol Scand*, 113(2), pp. 108-113. doi: 10.1111/j.1600-0404.2005.00551.x.
- Fisher, C. and March, L. (2012) 'Using experience sampling methodology in organizational behavior.', *Journal of Organizational Behaviour*, 33(7), pp. 865-877. doi: 10.1002/job.1803.
- Fitzgerald-DeJean, D. M., Rubin, S. S. and Carson, R. L. (2012) 'An application of the experience sampling method to the study of aphasia: A case report', *Aphasiology*, 26(2), pp. 234-251. doi: 10.1080/02687038.2011.621208.
- Flinn, N. a. and Stube, J. E. (2010) 'Post-stroke fatigue: qualitative study of three focus groups', *Occupational therapy international*, 17(2), pp. 81-91. doi: 10.1002/oti.286.

- Fougeyrollas, P., *et al.* (1999) 'Measure of the Quality of the Environment, Version 2.0', *International Network of the Disability Creation Process*.
- Gale, N., *et al.* (2013) 'Using the framework method for the analysis of qualitative data in multi-disciplinary health research', *BMC Medical Research Methodology*, 13, pp. 117-124. doi: 10.1186/1471-2288-13-117.
- Gall, S., *et al.* (2009) 'Handicap 5 years after stroke in the North East Melbourne Stroke Incidence Study', *Cerebrovascular Diseases (Basel, Switzerland)*, 27(2), pp. 123-130. doi: 10.1159/000177919.
- Geraghty, K.J., Esmail, A., 2016. Chronic fatigue syndrome: is the biopsychosocial model responsible for patient dissatisfaction and harm?. *British Journal of General Practice* 66, 437–438.. doi:10.3399/bjgp16x686473.
- Geyh, S., *et al.* (2011) 'The Personal Factors of the International Classification of Functioning, Disability and Health in the literature - a systematic review and content analysis', *Disability and Rehabilitation*, 33(13-14). doi: 10.3109/09638288.2010.523104.
- Ghaemi, N., (2011) 'The Biopsychosocial Model in Psychiatry: A Critique' *Existenz*, 6(1), pp.1-8. Available at: <http://www.existenz.us> (Accessed on 30.04.21).
- Ghazali, M., Arrifin, N A.M., Omar.R., (2014) 'User centered design practices in healthcare: A systematic review', *3rd International Conference on User Science and Engineering (i-USER)*. Malaysia, pp.91-96. doi: 10.1109/IUSER.2014.7002683.
- Glymour, M., *et al.* (2007) 'Lesion Characteristics, NIH Stroke Scale, and Functional Recovery After Stroke', *American Journal of Physical Medicine and Rehabilitation*, 86(9), pp. 725-33. doi: 10.1097/PHM.0b013e31813e0a32.
- Gottlieb, A., *et al.* (2001) 'The influence of social support and perceived control on handicap and quality of life after stroke', *Aging, Clinical and Experimental Research*, 13(1), pp. 11-15. doi: 10.1007/bf03351488
- Goverover, Y., *et al.* (2017) 'Changes in activity participation following traumatic brain injury', *Neuropsychol Rehabil*, 27(4), pp. 472-485. doi: 10.1080/09602011.2016.1168746.
- Grant, D. A., *et al.* (2017) '3-minute smartphone-based and tablet-based psychomotor vigilance tests for the assessment of reduced alertness due to sleep deprivation', *Behav Res Methods*, 49(3), pp. 1020-1029. doi: 10.3758/s13428-016-0763-8.
- Graven, C. (2011) 'Are rehabilitation and/or care co-ordination interventions delivered in the community effective in reducing depression, facilitating participation and improving quality of life after stroke?', *Disability and Rehabilitation*.
- Greenland, S. and O'Rourke, K. (2008) 'Meta-Analysis', in Kenneth, J., Rothman., Sander, G. & Timothy, L., Lash (eds.) *Modern Epidemiology*. Third edn. Philadelphia: Lippincott, Williams & Wilkins, pp. 652-682.
- Gulliksen, J., *et al.* (2003) 'Key principles for user-centred systems design.', *Behaviour and Information Technology*, 22(6). doi: 10.1080/01449290310001624329
- Gum, A., Snyder, C. R. and Duncan, P. W. (2006) 'Hopeful thinking', *Psychology & Health*, 21(3), pp. 319-334. doi: 10.1080/14768320500422907.
- Haggstrom, A. and Lund, M. L. (2008) 'The Complexity Of Participation In Daily Life: A Qualitative Study Of The Experiences Of Persons With Acquired Brain Injury', *Journal of Rehabilitation Medicine*, 40(2), pp. 89-95. doi: 10.2340/16501977-0138.
- Harari, G. M., *et al.* (2016) 'Using Smartphones to Collect Behavioral Data in Psychological Science: Opportunities, Practical Considerations, and Challenges', *Perspect Psychol Sci*, 11(6), pp. 838-854. doi: 10.1177/1745691616650285.
- Harrison, R., Flood, D. and Duce, D. (2013) 'Usability of mobile applications: literature review and rationale for a new usability model', *Journal of Interaction Science*, 1(1), pp. 1-16. doi: doi:10.1186/2194-0827-1-1.
- Harrison, S. (2007) *Fatigue Management for people with Multiple Sclerosis*. 2nd edn. London: College of Occupational Therapists Specialist Section Neurological Practice

- Hartson, H., Andre, T. and Williges, R. (2009) 'Criteria For Evaluating Usability Evaluation Methods', *International Journal of Human-Computer Interaction*, Vol. 13, No. 4, December 2001, pp. 373–410. doi: 10.1207/S15327590IJHC1304\_03.
- Harwood, R., Gompertz, P. and Ebrahim, S. (1994) 'Handicap one year after a stroke: validity of a new scale', *Journal Of Neurology, Neurosurgery, And Psychiatry*, 57(7), pp. 825-829.
- Harwood, R. H., *et al.* (1997) 'Determinants of handicap 1 and 3 years after a stroke', *Disability And Rehabilitation*, 19(5), pp. 205-211.
- Headway (2019a) *Acquired Brain Injury 2016-2017: statistics based on UK admissions*. Available at: <https://www.headway.org.uk/about-brain-injury/further-information/statistics/>.
- Headway (2019b) 'Brain drain: experiences of fatigue after brain injury'. UK: Headway brain injury association. Available at: <https://www.headway.org.uk/media/6916/final-report-brain-drain-wake-up-to-fatigue.pdf> (Accessed: 08/05/2020).
- Heinemann, A. W., *et al.* (2015) 'Environmental Factors Item Development for Persons With Stroke, Traumatic Brain Injury, and Spinal Cord Injury', *Archives of physical medicine and rehabilitation*, 96(4), pp. 589-595. doi: 10.1016/j.apmr.2013.11.024.
- Heo, J., *et al.* (2009) 'A framework for evaluating the usability of mobile phones based on multi-level, hierarchical model of usability factors', *Interacting with Computers*, 21, pp. 263-275, doi: 10.1016/j.intcom.2009.05.006
- Herdman, M., *et al.* (2011) 'Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L)', *Qual Life Res*, 20(10), pp. 1727-36. doi: 10.1007/s11136-011-9903-x.
- Heron, K. and Smyth, J. (2010) 'Ecological momentary interventions: Incorporating Mobile Technology into Psychosocial and Health Behaviour Treatments.', *British Journal of Health Psychology*, 15, pp. 1-39. doi: 10.1348/135910709X466063.
- Hinkle, J. L., *et al.* (2017) 'Poststroke Fatigue: Emerging Evidence and Approaches to Management: A Scientific Statement for Healthcare Professionals From the American Heart Association'. doi: 10.1161/STR.000000000000132.
- Hjermstad, M. F., PM. Haugen, DF. Caraceni, A. Hanks, GW. Loge, JH. Fainsinger, RAass, N. Kaasa, S. (2011) 'Studies Comparing Numerical Rating Scales, Verbal Rating Scales, and Visual Analogue Scales for Assessment of Pain Intensity in Adults: A Systematic Literature Review', *Journal of Pain and Symptom Management*, 41(6), pp. 1073-1093. doi: 10.1016/j.jpainsymman.2010.08.016.
- Hoermann, H.J., Uken, T., Voss, F.R., (2012) 'The Psychomotor Vigilance Test – A Measure of Trait or State?' *Proceedings of the 30th EAAP Conference*, 24-28 September, Italy.
- Holone, H. H., J. 'Three tensions in participatory design for inclusion | Proceedings of the SIGCHI Conference on Human Factors in Computing Systems'. *CHI '13: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, April 2013, 2903–2906.
- Hornsby, B. W., Naylor, G. and Bess, F. H. (2016) 'A Taxonomy of Fatigue Concepts and Their Relation to Hearing Loss', *Ear Hear*, 37(Suppl 1), pp. 136S-44S. doi: 10.1097/aud.0000000000000289.
- Hubbard, A., Golla, H. and Lausberg, H. (2020) 'What's in a name? That which we call Multiple Sclerosis Fatigue:' *Multiple Sclerosis Journal*, pp. 1-6. doi: 10.1177\_1352458520941481.
- Hulley, S.B. *et al.*, (2013) ' *Designing clinical research : an epidemiologic approach*', Philadelphia: Lippincott Williams & Wilkins
- Huguet, A., *et al.* (2015) 'Testing the Feasibility and Psychometric Properties of a Mobile Diary (myWHI) in Adolescents and Young Adults with Headaches.', *JMIR mHealth uHealth*, 3(2), pp. 1-21. doi:10.2196/mhealth.3879
- Iivari, J., Isomaki, H. and Pekkola, S. (2010) 'The user – the great unknown of systems development: reasons, forms, challenges, experiences and intellectual contributions of user involvement.', *Info Systems J(2010)20*, 109–117, 20, pp. 109-117. doi: 10.1111/j.1365-2575.2009.00336.x.
- Inal, Y., Wake, J, Guribye, F. Nordgreen, T. (2020) 'Usability Evaluations of Mobile Mental Health Technologies: Systematic Review', *Journal of Internet Medical Research*, 22(1), pp. e15337. doi: 10.2196/15337

- Incisive Health International (2017) *Taking the pulse of eHealth in the EU*. Available at: <https://www.incisivehealth.com/wp-content/uploads/2018/08/Report-Taking-the-pulse-of-eHealth-in-the-EU-.pdf> (Accessed: 22/04/20).
- Intercollegiate Stroke Working Party (2016) National clinical guideline for stroke. 5th. London: Royal College of Physicians. Available at: [https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-\(1\).aspx](https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-(1).aspx). (Accessed on 03/05/21)
- Jackson, D. (2020) *AX3 GUI*. Available at: <https://github.com/digitalinteraction/openmovement/wiki/AX3-GUI> (Accessed: 22/07).
- Jackson, S., Mercer, C. and Singer, B. J. (2018) 'An exploration of factors influencing physical activity levels amongst a cohort of people living in the community after stroke in the south of England', *Disabil Rehabil*, 40(4), pp. 414-424. doi: 10.1080/09638288.2016.1258437.
- Jamieson, M., et al. (2017) 'Technological memory aid use by people with acquired brain injury', *Neuropsychol Rehabil*, 27(6), pp. 919-936. doi: 10.1080/09602011.2015.1103760.
- Jansen, H., et al. (2012) 'Social Activity One and Three Years Post-Stroke', *Journal of Rehabilitation Medicine*, 44(1), pp. 47-50. doi: <http://dx.doi.org/10.2340/16501977-0908>.
- Janssen, M. F., et al. (2013) 'Measurement properties of the EQ-5D-5L compared to the EQ-5D-3L across eight patient groups: a multi-country study', *Qual Life Res*, 22(7), pp. 1717-27, Available at: <http://dx.doi.org/10.1007/s11136-012-0322-4>. doi: 10.1007/s11136-012-0322-4
- Jaracz, K., Mielcarek, L. and Kozubski, W. (2007) 'Clinical and psychological correlates of poststroke fatigue. Preliminary results', *Neurologia I Neurochirurgia Polska*, 41(1), pp. 36-43.
- Jaspers, M. (2009) 'A comparison of usability methods for testing interactive health technologies: methodological aspects and empirical evidence.', *International Journal of Medical Informatics* ,, 78(5), pp. 340-353. doi: 10.1016/j.ijmedinf.2008.10.002.
- Jean, F. A., et al. (2013) 'Daily life behaviors and depression risk following stroke: a preliminary study using ecological momentary assessment', *J Geriatr Psychiatry Neurol*, 26(3), pp. 138-43. doi: 10.1177/0891988713484193.
- Jellema, S., et al. (2016) 'Role of Environmental Factors on Resuming Valued Activities Poststroke: A Systematic Review of Qualitative and Quantitative Findings', *Archives of physical medicine and rehabilitation*, 97(6). doi: 10.1016/j.apmr.2016.01.015.
- Jette, A. M., Tao, W. and Haley, S. M. (2007) 'Blending activity and participation sub-domains of the ICF', *Disabil Rehabil*, 29(22), pp. 1742-50. doi: 10.1080/09638280601164790.
- Johansson, B., Berglund, P. and Ronnback, L. (2009) 'Mental fatigue and impaired information processing after mild and moderate traumatic brain injury', *Brain Injury*, 23(13-14), pp. 1027-1040. doi: 10.3109/02699050903421099.
- Johansson, B., Bjuhr, H. and Rönnbäck, L. (2012) 'Mindfulness-based stress reduction (MBSR) improves long-term mental fatigue after stroke or traumatic brain injury', *Brain Injury*, 26(13/14), pp. 1621-1628. doi: 10.3109/02699052.2012.700082.
- Johnson, E. I., et al. (2009) 'Feasibility and validity of computerized ambulatory monitoring in stroke patients', *Neurology*, 73(19), pp. 1579-1583. doi: 10.1212/WNL.0b013e3181c0d466.
- Johnston, M. V., Goverover, Y. and Dijkers, M. (2005) 'Community activities and individuals' satisfaction with them: Quality of life in the first year after traumatic brain injury. ', *Archives of Physical Medicine and Rehabilitation*., 86, pp. 735-745. doi: 10.1016/j.apmr.2004.10.031
- Jolliffe, L., et al. (2018) 'Systematic review of clinical practice guidelines to identify recommendations for rehabilitation after stroke and other acquired brain injuries', *BMJ open*. doi: 10.1136/bmjopen-2017-018791.
- Jourdan, C., et al. (2016) 'A comprehensive picture of 4-year outcome of severe brain injuries. Results from the Paris-TBI study', *Annals Of Physical And Rehabilitation Medicine*, 59(2), pp. 100-106. doi: 10.1016/j.rehab.2015.10.009.

- Juengst, S., *et al.* (2015) 'Pilot feasibility of an mHealth system for conducting ecological momentary assessment of mood-related symptoms following traumatic brain injury', *Brain Inj*, 29(11), pp. 1351-61. doi: 10.3109/02699052.2015.1045031.
- Juengst, S. B., *et al.* (2019) 'Variability in daily self-reported emotional symptoms and fatigue measured over eight weeks in community dwelling individuals with traumatic brain injury', *Brain Inj*, 33(5), pp. 567-573. doi: 10.1080/02699052.2019.1584333.
- Karasz, A. and McKinley, P. S. (2007) 'Cultural differences in conceptual models of everyday fatigue: a vignette study', *J Health Psychol*, 12(4), pp. 613-26. doi: 10.1177/1359105307078168.
- Kay, M., *et al.* (2013) 'PVT-Touch: Adapting a Reaction Time Test for Touchscreen Devices.', *7th International Conference on Pervasive Computing Technologies for Healthcare and Workshops*. San Diego. doi: 10.4108/icst.pervasivehealth.2013.252078
- Kendall, D.E., Terry, D.J.(2008) ' Understanding adjustment following traumatic brain injury: is the Goodness-of-Fit coping hypothesis useful?', *Soc Sci Med*, 67(8), pp.1217-24. doi: 10.1016/j.socscimed.2008.05.033.
- Kessler, D. and Egan, M. (2012) 'A review of measures to evaluate participation outcomes post-stroke', *British Journal of Occupational Therapy*, 75(9), pp. 403-11. doi: 10.4276/030802212X13470263980757
- Kettlewell, J., *et al.* (2018) 'Informing evaluation of a smartphone application for people with acquired brain injury: a stakeholder engagement study', *BMC Med Inform Decis Mak*, 18. doi: 10.1186/s12911-018-0611-0.
- Khan, A. P., M. Brayne, C. Prina, AM. (2015) 'Lifetime Prevalence and Factors Associated with Head Injury among Older People in Low and Middle Income Countries: A 10/66 Study', *Plos One*, 10(7), pp. e0132229. doi: 10.1371/journal.pone.0132229.
- Kim, H., Sefcik, J. and Bradway, C. (2017) 'Characteristics of Qualitative Descriptive Studies: A Systematic Review', *Research in Nursing & Health*, 40(1), pp. 23-42. doi: 10.1002/nur.21768.
- Kim, J., *et al.* (2019) 'Potential benefits of integrating ecological momentary assessment data into mHealth care systems', *BioPsychoSocial Medicine*, 13(1), pp. 19. doi: 10.1186/s13030-019-0160-5.
- Kirkevoid, M., *et al.* (2012) 'Fatigue after stroke: manifestations and strategies', *Disabil Rehabil*, 34(8), pp. 665-70. doi: 10.3109/09638288.2011.615373.
- Kisala, P., *et al.* (2019) 'Measuring Fatigue in TBI: Development of the TBI-QOL Fatigue Item Bank and Short Form.', *The Journal of Head Trauma Rehabilitation*, 34(5), pp. 289-297. doi: 10.1097/HTR.0000000000000530.
- Kjeverdu, A., *et al.* (2020) 'Trajectories of fatigue among stroke patients from the acute phase to 18 months post-injury: A latent class analysis', *PLoS ONE*, 15 (4), e0231709. doi: 10.1371/journal.pone.0231709
- Kluger, B. M., Krupp, L. B. and Enoka, R. M. (2013) 'Fatigue and fatigability in neurologic illnesses Proposal for a unified taxonomy', *Neurology*, 80(4), pp. 409-416. doi: 10.1212/WNL.0b013e31827f07be.
- Kluth, W., Krempels, K. and Samsel, C. 'Automated Usability Testing for Mobile Applications.'. *Proceedings of the 10th International Conference on Web Information Systems and Technologies*.
- Korpershoek, Y.J.G.*et al.*,(2020) ' User-Centered Design of a Mobile Health Intervention to Enhance Exacerbation-Related Self-Management in Patients With Chronic Obstructive Pulmonary Disease (Copilot): Mixed Methods Study' *J Med Internet Res*, 6,pp. e15449. doi: 10.2196/15449.
- Kramer, I., *et al.* (2014) 'A therapeutic application of the experience sampling method in the treatment of depression: a randomized controlled trial', *World Psychiatry*, 13(1), pp. 68-77. doi: 10.1002/wps.20090.



- Krupp, L. B., *et al.* (1989) 'The fatigue severity scale. Application to patients with multiple sclerosis and systemic lupus erythematosus', *Arch Neurol*, 46(10), pp. 1121-3. doi: 10.1001/archneur.1989.00520460115022.
- Kubler, A. H., *et al.* (2014) 'The User-Centered Design as Novel Perspective for Evaluating the Usability of BCI-Controlled Applications', *PLoS ONE*, 9(12), pp. e112392. doi: 10.1371/journal.pone.0112392.
- Kujala, S. (2003) 'User involvement- a review of the benefits and challenges.', *Behaviour and Information Technology*, 22(1), pp. 1-16. doi: 10.1080/01449290301782.
- Kuppuswamy, A. (2017) 'The fatigue conundrum', *Brain*, 140(8), pp. 2240-2245. doi: 10.1093/brain/awx153.
- Kuppuswamy, A., *et al.* (2015) 'Post-stroke fatigue: a problem of altered corticomotor control?', *J Neurol Neurosurg Psychiatry*, 86(8), pp. 902-4. doi: 10.1136/jnnp-2015-310431.
- Lakshminarayan, K., *et al.* (2014) 'Trends in 10-year survival of patients with stroke hospitalized between 1980 and 2000: the Minnesota stroke survey', *Stroke*, 45(9), pp. 2575-81. doi: 10.1161/strokeaha.114.005512.
- Landis, J. R. and Koch, G. G. (1977) 'The Measurement of Observer Agreement for Categorical Data', *Biometrics*, 33(1), pp. 159-174. doi: 10.2307/2529310.
- Larsson, J., *et al.* (2013) 'Factor Affecting Participation After Traumatic Brain Injury', *Journal Rehabilitation Medicine* 45, pp. 765–770. doi: 10.2340/16501977-1184.
- Lassalle-Lagadec, S., *et al.* (2012) 'Linking MRI to daily life experience: The example of poststroke depression', *Neurology*, 78(5), pp. 322-325. doi: 10.1212/WNL.0b013e31824528b2.
- Lassalle-Lagadec, S., *et al.* (2013) 'Cerebellum involvement in post-stroke mood: a combined ecological and MRI study', *Psychiatry Research*, 212(2), pp. 158-160. doi: 10.1016/j.psychres.2013.01.003.
- Lathia, N., *et al.* 'Contextual Dissonance: Design Bias in Sensor-Based Experience Sampling Methods'. *ACM international joint conference on pervasive and ubiquitous computing*. Zurich, Switzerland.
- Law, M., *et al.* (1996) 'The Person-Environment-Occupation Model: A transactive approach to occupational performance', *The Canadian Journal of Occupational Therapy*, 63(1), pp. 9-23. doi: 10.1177/000841749606300103.
- Lawrence, T., Helmy, A., Bouamra, O., Woodford, M., Lecky, F., Hutchinson, P.J. (2016.) 'Traumatic brain injury in England and Wales: prospective audit of epidemiology, complications and standardised mortality.', *BMJ Open*, 6,, pp. e012197. doi: doi:10.1136/bmjopen-2016-012197.
- Leavitt, V. M. and DeLuca, J. (2010) 'Central fatigue: issues related to cognition, mood and behavior, and psychiatric diagnoses', *Pm r*, 2(5), pp. 332-7. doi: 10.1016/j.pmrj.2010.03.027.
- Leavitt, V. M. D., J. (2010) 'Central Fatigue: Issues related to Cognition, Mood and Behaviour; and Psychiatric Diagnoses.', *PM&R*, 2(5), pp. 332-337. doi: 10.1016/j.pmrj.2010.03.027.
- Leckie, G. (2013) *Three-Level Multilevel Models-Concepts*. LEMMAVLE Module 11,1-47. Available at: <http://www.bristol.ac.uk/cmm/learning/course.html>.
- Lee, D., Heffron, J. and Mirza, M. (2019) 'Content and Effectiveness of Interventions Focusing on Community Participation Poststroke: A Systematic Review', *Archives of physical medicine and rehabilitation*, 100(11). doi: 10.1016/j.apmr.2019.06.008.
- Lee, I. S., *et al.* (2010) 'Number of Lapses during the Psychomotor Vigilance Task as an Objective Measure of Fatigue', *J Clin Sleep Med*, 6(2), pp. 163-8. doi:10.5664/jcsm.27766
- Lee, P., *et al.* (2019) *Deloitte's 2019 global mobile consumer survey*. @DeloitteInsight Available at: <https://www2.deloitte.com/us/en/insights/industry/telecommunications/global-mobile-consumer-survey.html> (Accessed: 22/04/20).
- Lees, K.R.,*et al.*(2012) ' Contemporary Outcome Measures in Acute Stroke Research', *Stroke*,43 (4),pp. 1163–1170. doi: 10.1161/STROKEAHA.111.641423.

- Lenaert, B., *et al.* (2017) 'Exploring the feasibility and usability of the experience sampling method to examine the daily lives of patients with acquired brain injury', *Neuropsychological Rehabilitation*, 29(5), pp. 754-766. doi: 10.1080/09602011.2017.1330214.
- Lenaert, B., *et al.* (2020) 'Post-stroke fatigue and daily activity patterns during outpatient rehabilitation: An experience sampling method study', *Arch Phys Med Rehabil.* doi: 10.1016/j.apmr.2019.12.014.
- Lerdal, A. and Kottorp, A. (2011) 'Psychometric properties of the Fatigue Severity Scale-Rasch analyses of individual responses in a Norwegian stroke cohort', *International journal of nursing studies*, 48(10), pp. 1258-65. doi: 10.1016/j.ijnurstu.2011.02.019.
- LeRouge, C., *et al.* (2019) 'Design Guidelines for a Technology-Enabled Nutrition Education Program to Support Overweight and Obese Adolescents: Qualitative User-Centered Design Study', *J Med Internet Res*, 21(7), pp. e14430. doi: 10.2196/14430.
- LeRouge, C. and Wickramasinghe, N. (2013) 'A Review of User-Centered Design for Diabetes-Related Consumer Health Informatics Technologies', *Journal of Diabetes Science and Technology*, 7(4), pp. 1039-1056. doi: 10.1177/193229681300700429.
- Levasseur, M., *et al.* (2010) 'Inventory and Analysis of Definitions of Social Participation Found in the Aging Literature: Proposed Taxonomy of Social Activities', *Social science & medicine*, 71(12), pp. 2141-2149. doi: 10.1016/j.socscimed.2010.09.041.
- Lewin, A., Jobges, M. and Werheid, K. (2013) 'The influence of self-efficacy, pre-stroke depression and perceived social support on self-reported depressive symptoms during stroke rehabilitation', *Neuropsychol Rehabil*, 23(4), pp. 546-62. doi: 10.1080/09602011.2013.794742.
- Lewin, A., Jöbges, M. and Werheid, K. (2013) 'The influence of self-efficacy, pre-stroke depression and perceived social support on self-reported depressive symptoms during stroke rehabilitation', <http://dx.doi.org/10.1080/09602011.2013.794742>, 23(4), pp. 546-562. doi: Neuropsychological Rehabilitation, Vol. 23, No. 4, August 2013, pp. 546–562.
- Lewis, J. (2018) 'The System Usability Scale: Past, Present, and Future. *International Journal of HUMAN-Computer Interaction.*, 34(7), pp. 577-590. doi: 10.1080/10447318.2018.1455307.
- Liebold, A. and Mathiowetz, V. (2005) 'Reliability and validity of the Self-Efficacy for Performing Energy Conservation Strategies Assessment for persons with multiple sclerosis', *Occupational Therapy International*, 12(3), pp. 234-249. doi: 10.1002/oti.5.
- Longino, C.F. & Murphy, J.W. (2020) 'The Old Age Challenge to the Biomedical Model: Paradigm Strain and Health Policy', Oxford: Routledge.
- Liu, T.-W., *et al.* (2015) 'Fear Avoidance Behavior, Not Walking Endurance, Predicts the Community Reintegration of Community-Dwelling Stroke Survivors', *Archives of Physical Medicine & Rehabilitation*, 96(9), pp. 1684-1690 7p. doi: 10.1016/j.apmr.2015.05.005.
- Lo, R., *et al.* (2008) 'Handicap and its determinants of change in stroke survivors: one-year follow-up study', *Stroke (00392499)*, 39(1), pp. 148-153. doi: 10.1161/STROKEAHA.107.491399.
- Loh S, L. N., Dorrian J, Roach G, Dawson D. (2004) 'The validity of psychomotor vigilance tasks of less than 10-minute duration', *Behav.Res.Methods Instrum.Comput.*, 36, pp. 339-346. doi: 10.3758/BF03195580.
- Loy, B. D., Cameron, M. H. and O'Connor, P. J. (2018) 'Perceived Fatigue and Energy are Independent Unipolar States: Supporting Evidence', *Med Hypotheses*, 113, pp. 46-51. doi: 10.1016/j.mehy.2018.02.014.
- Lu, W., Krellman, J. and Dijkers, M. (2016) 'Can Cognitive Behavioral Therapy for Insomnia Also Treat Fatigue, Pain, and Mood Symptoms in Individuals With Traumatic Brain Injury? - A Multiple Case Report', *NeuroRehabilitation*, 38(1), pp. 59-69. doi: 10.3233/NRE-151296.
- Lukoschek, C., *et al.* (2015) 'Fatigue in Multiple Sclerosis Compared to Stroke', *Front Neurol*, 6, pp. 116. doi: 10.3389/fneur.2015.00116.

- Lynch, J., *et al.* (2007) 'Fatigue after stroke: The development and evaluation of a case definition', *Journal of Psychosomatic Research*, 63(5), pp. 539-544. doi: 10.1016/j.jpsychores.2007.08.004.
- Lyon, A. and Koerner, K. (2016) 'User-Centered Design for Psychosocial Intervention Development and Implementation', *Clinical Psychology : a Publication of the Division of Clinical Psychology of the American Psychological Association*, 23(2), pp. 180-200. doi: 10.1111/cpsp.12154.
- Malley, D. (2017) 'Managing fatigue in adults after acquired brain injury', in Wilson, B.A., *et al.* (eds.) *Neuropsychological rehabilitation: The international handbook*. New York, NY, US: Routledge/Taylor & Francis Group, pp. 391-402.
- Malley, D., Wheatcroft, J. and Gracey, F. (2014) 'Fatigue after acquired brain injury: A model to guide clinical management', *Advances in Clinical Neuroscience and Rehabilitation*, 14, pp. 17-19, Available at: <https://www.acnr.co.uk/wp-content/uploads/2014/06/rehab-article1.pdf>
- Mallinson, T. and Hammel, J. (2010) 'Measurement of participation: Intersecting person, task, and environment', *Archives of Physical Medicine and Rehabilitation*, 91(9 SUPPL.), pp. S29--S33. doi: 10.1016/j.apmr.2010.04.027.
- Maltseva, K. and Lutz, C. (2017) 'A quantum of self: a study of self quantification and self disclosure', *Computers in Human Behaviour*, 81, pp. 102-114. doi:10.1016/j.chb.2017.12.006.
- Marcilly, R., Peute, L. and Beuscart-Zephir, M. C. (2016) 'From Usability Engineering to Evidence-based Usability in Health IT', *Stud Health Technol Inform*, 222, pp. 126-38. doi: 10.3233/978-1-61499-635-4-126.
- Marmot, M.,(2010) 'Strategic Review of Health Inequalities in England post-2010. Fair society, healthier lives: The Marmot review', Available at: <http://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review/fair-society-healthy-lives-the-marmot-review-full-report.pdf>
- Marmot, M.,*et al.*,(2020) ' Build Back Fairer: The COVID-19 Marmot Review. The Pandemic, Socioeconomic and Health Inequalities in England'.
- Marshall, S., *et al.* (2015) 'Updated clinical practice guidelines for concussion/mild traumatic brain injury and persistent symptoms', *Brain Inj*, 29(6), pp. 688-700. doi: 10.3109/02699052.2015.1004755.
- Martin-Hammond, A.M, *et al.*,(2016) 'Designing an over-the-counter consumer decision-making tool for older adults', *Journal of Biomedical Informatics*, pp. 113-123. doi: 10.1016/j.jbi.2015.07.006.
- Mathias, J. and Wheaton, P. (2007) 'Changes in attention and information-processing speed following severe traumatic brain injury: A meta-analytic review.', *Neuropsychology*, 21(2), pp. 212–223, Available at: /doiLanding?doi=10.1037/0894-4105.21.2.212
- Matthew-Maich, N., Harris, L. P., J and Markle-Reid, M. V., R. Ibrahim, S. Gafni, A. Isaacs, S. (2016) 'Designing, Implementing, and Evaluating Mobile Health Technologies for Managing Chronic Conditions in Older Adults: A Scoping Review', *JMIR Mhealth Uhealth* 2016;4(2):e29. doi:10.2196/mhealth.5127.
- Mayo, N. E., *et al.* (2016) 'How have research questions and methods used in clinical trials published in Clinical Rehabilitation changed over the last 30 years?', *Clin Rehabil*, 30(9), pp. 847-64. doi: 10.1177/0269215516658939
- Mazure, C. M., *et al.* (2014) 'Gender and stress in predicting depressive symptoms following stroke', *Cerebrovascular Diseases (Basel, Switzerland)*, 38(4), pp. 240-246. doi: 10.1159/000365838.
- McCarthy, M., Ballinger, R., Lewis, H., (2020) ' Advancing digital endpoints. An end-to-end approach to managing wearable devices through clinical development' ICON. Available at: <https://www.iconplc.com/insights/digital-disruption/mHealth-wearables/digital-endpoints/> Lewis, H. (Accessed on 01.02.2021).
- McCurdie, T., *et al.* (2012) 'mHealth consumer apps: the case for user-centered design', *Biomed Instrum Technol, Suppl*, pp. 49-56. doi: 10.2345/0899-8205-46.s2.49.

- McHugh, M. L. (2012) 'Interrater reliability: the kappa statistic', *Biochem Med (Zagreb)*, 22(3), pp. 276-82, Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3900052/#!po=4.54545>. (Accessed on 10.10.2019)
- McLean, A. M., *et al.* (2014) 'Associations between social participation and subjective quality of life for adults with moderate to severe traumatic brain injury', *Disabil Rehabil*, 36(17), pp. 1409-18. doi: 10.3109/09638288.2013.834986.
- Mead, G., *et al.* (2007) 'Evaluation of fatigue scales in stroke patients', *Stroke (00392499)*, 38(7), pp. 2090-2095. doi: 10.1161/STROKEAHA.106.478941.
- Mercer, V., *et al.* (2009) 'Step Test scores are related to measures of activity and participation in the first 6 months after stroke', *Physical Therapy*, 89(10), pp. 1061-71. doi: 10.2522/ptj.20080368
- MHRA (2020) *Medical device stand-alone software including apps (including IVDMDs) v1.07*. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/957090/Software\\_flow\\_chart\\_Ed\\_1-07b-UKCA\\_\\_002\\_\\_FINAL.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/957090/Software_flow_chart_Ed_1-07b-UKCA__002__FINAL.pdf). (Accessed on 15.01.21).
- Migliorini, C., *et al.* (2016) 'Community integration questionnaire: Outcomes of people with traumatic brain injury and high support needs compared with multiple matched controls', *Brain Injury*, 30(10), pp. 1201-1207. doi: 10.1080/02699052.2016.1175666.
- Mills, R. J., *et al.* (2012) 'Validation of the Neurological Fatigue Index for stroke (NFI-Stroke)', *Health and quality of life outcomes*, 10, pp. 51-51. doi: 10.1186/1477-7525-10-51.
- Moher, D., *et al.* (2009) 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement.', *PLoS Med* 6(7). doi: doi:10.137.
- Mohr, D. C. (2010) *The Stress and Mood Management Program for Individuals With Multiple Sclerosis: Workbook* Workbook edition, Oxford: Oxford University Press.
- Mohr, D. C., *et al.* (2014) 'The behavioral intervention technology model: an integrated conceptual and technological framework for eHealth and mHealth interventions', *J Med Internet Res*, 16(6), pp. e146. doi: 10.2196/jmir.3077.
- Molich, R. (2010) 'A Commentary of "How To Specify the Participant Group Size for Usability Studies: A Practitioner's Guide" *Journal of Usability Studies*, 5(3), pp. 124-128. Available at: <https://uxpajournal.org/a-commentary-of-how-to-specify-the-participant-group-size-for-usability-studies-a-practitioners-guide-by-r-macefield/>. (Accessed on 03.05.21).
- Mollaveva, T., *et al.* (2014) 'A systematic review of fatigue in patients with traumatic brain injury: The course, predictors and consequences', *Neuroscience and Biobehavioral Reviews*, 47, pp. 684-716. doi: 10.1016/j.neubiorev.2014.10.024.
- Moore, G., *et al.* (2019) 'Participatory Methods to Engage Health Service Users in the Development of Electronic Health Resources: Systematic Review', *J Participat Med*, 11(1), pp. e11474. doi: doi:10.2196/11474.
- Moskowitz, D. S. and Young, S. N. (2006) 'Ecological momentary assessment: what it is and why it is a method of the future in clinical psychopharmacology', *J Psychiatry Neurosci*, 31(1), pp. 13-20.
- Muina-Lopez, R. and Guidon, M. (2013) 'Impact of post-stroke fatigue on self-efficacy and functional ability', *European Journal of Physiotherapy*, 15(2), pp. 86-92. doi: 10.3109/21679169.2013.792868.
- Muller, M. and Druin, A. (2007) 'Participatory Design: The Third Space in HCI', in Andrew Sears & Julie A. Jacko (Eds.), *The Human-Computer Interaction Handbook Fundamentals, Evolving Technologies and Emerging Applications*. 2nd edn. Boca Raton: CRC Press, pp. 1-70.
- Muller, T. and Apps, M. A. J. (2019) 'Motivational fatigue: A neurocognitive framework for the impact of effortful exertion on subsequent motivation', *Neuropsychologia*, 123, pp. 141-151. doi: 10.1016/j.neuropsychologia.2018.04.030.

- Nadarajah, M. and Goh, H. T. (2015) 'Post-stroke fatigue: a review on prevalence, correlates, measurement, and management', *Top Stroke Rehabil*, 22(3), pp. 208-20. doi: 10.1179/1074935714z.0000000015.
- Naess, H., Lunde, L. and Brogger, J. (2012) 'The effects of fatigue, pain, and depression on quality of life in ischemic stroke patients: the Bergen Stroke Study', *Vascular Health And Risk Management*, 8, pp. 407-413. doi: 10.2147/VHRM.S32780.
- Naess, H., *et al.* (2006) 'Health-related quality of life among young adults with ischemic stroke on long-term follow-up', *Stroke; a journal of cerebral circulation*, 37(5), pp. 1232-6. doi: 10.1161/01.STR.0000217652.42273.02.
- Neergaard, M., *et al.* (2009) 'Qualitative description – the poor cousin of health research?', *BMC Medical Research Methodology*, 9(1), pp. 1-5. doi: doi:10.1186/1471-2288-9-52.
- Neff, A., *et al.* (2020) 'Ecological Momentary Assessment of Social Interactions: Associations With Depression, Anxiety, Pain, and Fatigue in Individuals With Mild Stroke', *Archives of Physical Medicine and Rehabilitation*, 102, pp. 395-405. doi: 10.1016/j.apmr.2020.08.007.
- NHLBI (2014a) *Background: Development and Use of Study Quality Assessment Tools.*: National Institute of Health Available at: <https://www.nhlbi.nih.gov/health-pro/guidelines/in-develop/cardiovascular-risk-reduction/tools/background> (Accessed: 13.04.15).
- NHLBI (2014b) *Quality Assessment Tool for Observational Cohort and Cross-sectional Studies.* Available at: <https://www.nhlbi.nih.gov/health-pro/guidelines/in-develop/cardiovascular-risk-reduction/tools/cohort> (Accessed: 13.04.15).
- Nicholson, S. L., *et al.* (2014) 'A qualitative theory guided analysis of stroke survivors' perceived barriers and facilitators to physical activity', *Disabil Rehabil*, 36(22), pp. 1857-68. doi: 10.3109/09638288.2013.874506.
- Noonan, V., *et al.* (2009) 'A review of participation instruments based on the International Classification of Functioning, Disability and Health.', *Disability and Rehabilitation.*, 31(23), pp. 1883-901. doi: 10.1080/09638280902846947.
- Noreau, L. and Boschen, K. (2010) 'Intersection of participation and environmental factors: A complex interactive process', *Archives of Physical Medicine and Rehabilitation*, 91(9 SUPPL.), pp. S44--S53. doi: 10.1016/j.apmr.2009.10.037.
- Noreau, L., *et al.* (2004) 'Measuring social participation: reliability of the LIFE-H in older adults with disabilities', *Disabil Rehabil*, 26(6), pp. 346-52. doi: 10.1080/09638280410001658649.
- Norlander, A., *et al.* (2016) 'Long-Term Predictors of Social and Leisure Activity 10 Years after Stroke', *Plos One*, 11(2), pp. e0149395-e0149395. doi: 10.1371/journal.pone.0149395.
- Norrie, J., *et al.* (2010) 'Mild traumatic brain injury and fatigue: A prospective longitudinal study', *Brain Injury*, 24(13/14), pp. 1528-1538. doi: 10.3109/02699052.2010.531687.
- Northcott, S., *et al.* (2016) 'A systematic review of the impact of stroke on social support and social networks: associated factors and patterns of change', *Clin Rehabil*, 30(8), pp. 811-31. doi: 10.1177/0269215515602136.
- O'Cathain, A., *et al.* (2019) 'Guidance on how to develop complex interventions to improve health and healthcare', *BMJ Open*, 9(8). doi: 10.1136/bmjopen-2019-029954.
- O'Connor, P. J. (2004) 'Evaluation of four highly cited energy and fatigue mood measures', *J Psychosom Res*, 57(5), pp. 435-41. doi: 10.1016/j.jpsychores.2003.12.006.
- O'Dea, S. (2019) *UK: smartphone ownership by age 2018 | Statista.* Statista Available at: <https://www.statista.com/statistics/271851/smartphone-owners-in-the-united-kingdom-uk-by-age/> (Accessed: 22/04/20).
- Obembe, A. and Eng, J. (2016) 'Rehabilitation Interventions for Improving Social Participation after Stroke: a Systematic Review and Meta-analysis', *Neurorehabilitation and Neural Repair*, 30(4), pp. 384-392. doi: 10.1177/1545968315597072.
- Ofcom (2019) 'Access and Inclusion in 2018 Consumers' experiences in communications markets.'. Available at: [https://www.ofcom.org.uk/data/assets/pdf\\_file/0018/132912/Access-and-Inclusion-report-2018.pdf](https://www.ofcom.org.uk/data/assets/pdf_file/0018/132912/Access-and-Inclusion-report-2018.pdf).

- OfCom (2020) 'Online Nation': OfCom. Available at: [https://www.ofcom.org.uk/\\_data/assets/pdf\\_file/0027/196407/online-nation-2020-report.pdf](https://www.ofcom.org.uk/_data/assets/pdf_file/0027/196407/online-nation-2020-report.pdf) (Accessed: 01/04/21).
- Ologeanu-Taddei, R. (2020) 'Assessment of mHealth Interventions: Need for New Studies, Methods, and Guidelines for Study Designs', *JMIR Med Inform* 2020;8(11):e21874. doi:10.2196/21874.
- Ono, M., et al. (2019) 'What Affects the Completion of Ecological Momentary Assessments in Chronic Pain Research? An Individual Patient Data Meta-Analysis', *J Med Internet Res*, 21(2), e11398. doi: 10.2196/11398
- Oort, F., Visser, M. and Sprangers, M. (2009) 'Formal definitions of measurement bias and explanation bias clarify measurement and conceptual perspectives on response shift', *Journal of clinical epidemiology*, 62(11). doi: 10.1016/j.jclinepi.2009.03.013.
- Ormstad, H. and Eilertsen, G. (2015) 'A biopsychosocial model of fatigue and depression following stroke', *Medical Hypotheses*, 85(6), pp. 835-841. doi: 10.1016/j.mehy.2015.10.001.
- Ostir, G. V., et al. (2006) 'Preliminary Results for the PAR-PRO: A Measure of Home and Community Participation', *Archives of physical medicine and rehabilitation*, 87(8), pp. 1043-1051. doi: 10.1016/j.apmr.2006.04.024.
- Oswal, S. (2014) 'Participatory Design: Barriers and Possibilities', *Communication Design Quarterly*, 2, pp. 14-19. doi:10.1145/2644448.2644452
- Ouellet, M.-C. and Morin, C. M. (2006) 'Fatigue following traumatic brain injury: Frequency, characteristics, and associated factors', *Rehabilitation Psychology*, 51(2), pp. 140-149. doi: 10.1037/0090-5550.51.2.140.
- Pacella, M., et al. (2018) 'Postconcussive Symptoms Over the First 14 Days After Mild Traumatic Brain Injury: An Experience Sampling Study', *The Journal Of Head Trauma Rehabilitation*, 33(3), pp. E31-E39. doi: 10.1097/htr.0000000000000335.
- Palstam, A., Sjodin, A. and Sunnerhaden, K. (2019) 'Participation and autonomy five years after stroke: A longitudinal observational study', *Plos One*, 14(7), pp. e0219513. doi: 10.1371/journal.pone.0219513.
- Palstam, A., Törnbohm, M. and Sunnerhagen, K. S. (2018) 'Experiences of returning to work and maintaining work 7 to 8 years after a stroke: a qualitative interview study in Sweden', *BMJ Open*, 8(7). doi: 10.1136/bmjopen-2017-021182
- Palstam, A. S., A, Sunnerhaden, KS. (2019) 'Participation and autonomy five years after stroke: A longitudinal observational study', *Plos One*, 14(7), pp. e0219513. doi: 10.1371/journal.pone.0219513.
- Patel, M., et al. (2006) 'Relationships between long-term stroke disability, handicap and health-related quality of life', *Age and Ageing*, 35, pp. 273-279. doi: 10.1093/ageing/afj074.
- Pearce, S. C., et al. (2016) 'Sleep disturbance and deficits of sustained attention following stroke', *J Clin Exp Neuropsychol*, 38(1), pp. 1-11. doi: 10.1080/13803395.2015.1078295.
- Pearson, E., et al. (2018) 'Interventions for cancer - related fatigue: a scoping review.', *European Journal of Cancer Care.*, 27, pp. e12516. doi: 10.1111/ecc.12516.
- Peiris D, M. J., Mohr DC (2018) ' Going beyond killer apps: building a better mHealth evidence base. ', *BMJ Global Health*, 3(1), pp. e000676. doi:10.1136/bmjgh-2017-000676.
- Perenboom, R. and Chorus, A. (2003) 'Measuring participation according to the International Classification of Functioning, Disability and Health (ICF).', *Disability and rehabilitation*, 25(11-12), pp. 577--587. doi: 10.1080/0963828031000137081.
- Piercy, K. L., et al. (2019) 'The Physical Activity Guidelines for Americans', *JAMA*, 320(19), pp. 2020-2028. doi: 10.1001/jama.2018.14854.
- Pindus, D., et al. (2018) 'Stroke Survivors' and Informal Caregivers' Experiences of Primary Care and Community Healthcare Services - A Systematic Review and Meta-Ethnography', *PloS one*, 13(2). doi: 10.1371/journal.pone.0192533.

- Plummer, P., *et al.* (2013) 'Cognitive-Motor Interference during Functional Mobility after Stroke: State of the Science and Implications for Future Research', *Arch Phys Med Rehabil*, 94(12). doi: 10.1016/j.apmr.2013.08.002.
- Ponchel, A., *et al.* (2015) 'Factors Associated with Poststroke Fatigue: A Systematic Review', *Stroke Research and Treatment*, 2015, pp. 347920. doi: 10.1155/2015/347920.
- Ponsford, J., Schonberger, M. and Rajaratnam, S. M. (2015) 'A Model of Fatigue Following Traumatic Brain Injury', *J Head Trauma Rehabil*, 30(4), pp. 277-282. doi: 10.1097/htr.0000000000000049.
- Ponsford, J. L., *et al.* (2014) 'Longitudinal follow-up of patients with traumatic brain injury: outcome at two, five, and ten years post-injury', *Journal Of Neurotrauma*, 31(1), pp. 64-77. doi: 10.1089/neu.2013.2997.
- Popay, J., *et al.* (2006) 'Guidance on the conduct of narrative synthesis in systematic reviews: Final report', ESCR Methods Programme. Available at: <https://www.lancaster.ac.uk/media/lancaster-university/content-assets/documents/fhm/dhr/chir/NSsynthesisguidanceVersion1-April2006.pdf>. (Accessed: 03/05/2021).
- Post, M. M., *et al.* (2012) 'Validity of the Utrecht Scale for Evaluation of Rehabilitation-Participation', *Disability and Rehabilitation*, 34(6), pp. 478-485. doi: 10.3109/09638288.2011.608148.
- Post, M. W., *et al.* (2008) 'Development and validation of IMPACT-S, an ICF-based questionnaire to measure activities and participation', *J Rehabil Med*, 40(8), pp. 620-7. doi: 10.2340/16501977-0223.
- Powell, D. J. H., *et al.* (2017) 'Tracking daily fatigue fluctuations in multiple sclerosis: Ecological momentary assessment provides unique insights', *Journal of Behavioral Medicine*, 40(5), pp. 772-783. doi: 10.1007/s10865-017-9840-4.
- Price, C., Curless, R. and Rodgers, H. (1999) 'Can stroke patients use visual analogue scales?', *Stroke*, 30, pp. 1357-61. doi: 10.1161/01.STR.30.7.1357.
- Price, E., *et al.* (2017) 'Validation of a Smartphone-Based Approach to In Situ Cognitive Fatigue Assessment', *JMIR Mhealth Uhealth* 2017;5(8):e125. doi: doi:10.2196/mhealth.6333.
- Price, E., *et al.* 'User Centred Design of a Smartphone-based Cognitive Fatigue Assessment Application'. *Proceedings of the 14th International Conference on Advances in Mobile Computing and Multi Media*, 11/28/2016: ACM, 120-127.
- Probst, B. (2021) 'The Eye Regards Itself: Benefits and Challenges of Reflexivity in Qualitative Social Work Research', *Social Work Research*, 39(1), pp. 37-48. doi: 10.1093/swr/svu028.
- Puetz, T. (2012) 'Physical Activity and Feelings of Energy and Fatigue | SpringerLink', *Sports medicine*, 36(9), pp. 767-780. doi: 10.2165/00007256-200636090-00004.
- Rabinowitz, A. R. and Levin, H. S. (2014) 'Cognitive Sequelae of Traumatic Brain Injury', *Psychiatr Clin North Am*, 37(1), pp. 1-11. doi: 10.1016/j.psc.2013.11.004.
- Radloff, L. (1977) 'The CES-D Scale: A Self-Report Depression Scale for Research in the General Population', *Applied Psychological Measurements*, 1(3), pp. 385-401. doi: 10.1177\_014662167700100306.
- Raina, K. D., *et al.* (2016) 'Feasibility of a Cognitive Behavioral Intervention to Manage Fatigue in Individuals With Traumatic Brain Injury: A Pilot Study', *The Journal Of Head Trauma Rehabilitation*, 31(5), pp. E41-E49. doi: 10.1097/HTR.0000000000000196.
- Ram, N., *et al.* (2017) 'The Questionable Ecological Validity of Ecological Momentary Assessment: Considerations for Design and Analysis', *Res Hum Dev*, 14(3), pp. 253-70. doi: 10.1080/15427609.2017.1340052.
- Redmayne, M. (2017) 'Where's Your Phone? A Survey of Where Women Aged 15-40 Carry Their Smartphone and Related Risk Perception: A Survey and Pilot Study', *PLoS One*, 12(1). doi: 10.1371/journal.pone.0167996

- Reistetter, T. and Abreu, B. (2005) 'Appraising evidence on community integration following brain injury: A systematic review.', *Occupational Therapy International*, 12(4), pp. 196--217. doi: 10.1002/oti.8.
- Ritchie, J., et al. (2013) *Qualitative Research Practice*. 2nd edn. London: Sage Publications.
- Richie, L., et al., (2014) 'Community Integration After Traumatic Brain Injury: A Systematic Review of the Clinical Implications of Measurement and Service Provision for Older Adults', *Archives of Physical Medicine and Rehabilitation*, 95(1), pp:163-174. doi: 10.1016/j.apmr.2013.08.237
- Roach, G. D., Dawson, D. and Lamond, N. (2006) 'Can a shorter psychomotor vigilance task be used as a reasonable substitute for the ten-minute psychomotor vigilance task?', *Chronobiol Int*, 23(6), pp. 1379-87. doi: 10.1080/07420520601067931.
- Robertson, K. and Schmitter-Edgecombe, M. (2017) 'Focused and divided attention abilities in the acute phase of recovery from moderate to severe traumatic brain injury', *Brain Inj*, 31(8), pp. 1069-76. doi: 10.1080/02699052.2017.1296192.
- Rochette, A., Desrosiers, J. and Noreau, L. (2001) 'Association between personal and environmental factors and the occurrence of handicap situations following a stroke', *Disability And Rehabilitation*, 23(13), pp. 559-569. doi: 10.1080/09638280010022540.
- Rochette, A., et al. (2006) 'Adaptation and coping following a first stroke: a qualitativ... : International Journal of Rehabilitation Research', *International Journal of Rehabilitation Research*, 29(3), pp. 247-249. doi: 10.1097/01.mrr.0000230051.24228.c8.
- Rosenthal, R. and Rosnow, R. L. (1984) *Essentials of Behavioral Research: Methods and Data Analysis*. New York: McGraw-Hill.
- Rowe, F. H., LR, Howard, C. Hanna, KL, Cheyne, CP, Curry, J. (2019) 'High incidence and prevalence of visual problems after acute stroke: An epidemiology study with implications for service delivery', *PLoS ONE*, 14(e), pp. e0213035. doi: 10.1371/journal.pone.0213035.
- Rubin, H. and Rubin, I. (2012) *Qualitative Interviewing: the art of hearing data*. 3rd edn. Thousand Oaks: Sage.
- Ruet, A., et al. (2019) 'A Detailed Overview of Long-Term Outcomes in Severe Traumatic Brain Injury Eight Years Post-injury', *Frontiers In Neurology*, 10, pp. 120-120. doi: 10.3389/fneur.2019.00120.
- Salinas, J., et al. ' 2016. An International Standard Set of Patient-Centered Outcome Measures After Stroke. *Stroke* 47, 180–186. doi:10.1161/strokeaha.115.010898,
- Salter, K., et al. (2013) 'Outcome Measures in Stroke Rehabilitation'. Canada: EBRSR. Available at: [http://www.ebrsr.com/sites/default/files/Chapter%2020\\_Outcome%20Measures.pdf](http://www.ebrsr.com/sites/default/files/Chapter%2020_Outcome%20Measures.pdf). (Accessed on 05.01.21).
- Salter, K., et al. (2008) 'The experience of living with stroke: a qualitative meta-synthesis.', *Journal of rehabilitation medicine*, 40(8), pp. 595--602. doi: 10.2340/16501977-0238.
- Salter, K., et al. (2005) 'Issues for selection of outcome measures in stroke rehabilitation: ICF Participation', *Disability and Rehabilitation*, 27(9), pp. 507-28. doi: 10.1080/0963828040008552.
- Sandelowski, M. (2000) 'Whatever happened to qualitative description?', *Research in Nursing & Health*, 23, pp. 334-340. doi: 10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G.
- Sauro, J. and Lewis, J. 'When designing usability questionnaires, does it hurt to be positive? | CHI '11: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, 2215–2224. doi: 10.1145/1978942.1979266.
- Scheenen, M., et al. (2017) 'Stability of coping and the role of self-efficacy in the first year following mild traumatic brain injury', *Social science & medicine (1982)*, 181. doi: 10.1016/j.socscimed.2017.03.025.
- Schepers, V., et al. (2005) 'Prediction of social activity 1 year poststroke', *Arch Phys Med Rehabil*, 86(7), pp. 1472-6. doi: 10.1016/j.apmr.2004.11.039.
- Schipper, K., et al. (2011) 'Participation of People With Acquired Brain Injury: Insiders Perspectives', *Brain injury*, 25(9). doi: 10.3109/02699052.2011.589796.



- Schrimsher, G. and Filtz, K. (2011) 'Assessment Reactivity: Can Assessment of Alcohol Use During Research be an Active Treatment?', *Alcoholism Treatment Quarterly*, 29 (2). pp: 108–115. doi: 10.1080/07347324.2011.557983.
- Schuling, J., et al. (1993) 'The Frenchay Activities Index. Assessment of functional status in stroke patients', *Stroke; A Journal Of Cerebral Circulation*, 24(8), pp. 1173-1177. doi: 10.1161/01.STR.24.8.1173.
- Schwandt, T. (1998) 'Constructivist, Interpretativist Approaches to Human Inquiry', in Denzin, N. & Lincoln, Y. (eds.) *From the Landscape of Qualitative Research: Theories and Issues*. Thousand Oaks: Sage, pp. 221-259.
- Schwartz, C. E. (2010) 'Applications of response shift theory and methods to participation measurement: A brief history of a young field', *Archives of Physical Medicine and Rehabilitation*, 91(9 SUPPL.), pp. S38--S43. doi: 10.1016/j.apmr.2009.11.029.
- Seekins, T., Ipsen, C., Arnold, N.L., (2007) 'Using Ecological Momentary Assessment to Measure Participation: A Preliminary Study' *Rehabilitation Psychology*, 52(3,) pp: 319-330. doi: 10.1037/0090-5550.52.3.319.
- Seminog, O.O., et al. (2019) 'Determinants of the decline in mortality from acute stroke in England: linked national database study of 795 869 adults', *BMJ*, 365, pp. 1778. doi: 10.1136/bmj.l1778.
- Shany-Ur, T., et al. (2020) 'Efficacy of Postacute Neuropsychological Rehabilitation for Patients with Acquired Brain Injuries is Maintained in the Long-Term ', *Journal of the International Neuropsychological Society*, 26(1), pp. 130-141. doi: doi:10.1017/S1355617719001024.
- Sherer, M., et al. (2014) 'Prognostic importance of self-reported traits/problems/strengths and environmental barriers/facilitators for predicting participation outcomes in persons with traumatic brain injury: a systematic review', *Archives Of Physical Medicine And Rehabilitation*, 95(6), pp. 1162-1173. doi: 10.1016/j.apmr.2014.02.006.
- Shiffman, S., Stone, A. A. and Hufford, M. R. (2008) 'Ecological momentary assessment', *Annu Rev Clin Psychol*, 4, pp. 1-32. doi: 10.1146/annurev.clinpsy.3.022806.091415.
- Shuman-Paretsky, M., Gumber, S. and Dams-O'Connor, K. (2017) 'Interventions for Posttraumatic Brain Injury Fatigue: An Updated Review', *Current Physical Medicine and Rehabilitation Reports*, 5(1), pp. 12-21. doi: doi:10.1007/s40141-017-0147-8.
- Sibon, I., et al. (2012) 'Evolution of depression symptoms following stroke: a prospective study using computerized ambulatory monitoring', *Cerebrovascular Diseases (Basel, Switzerland)*, 33(3), pp. 280-285. doi: 10.1159/000334663.
- Sinclair, K. L., et al. (2013) 'Sustained attention following traumatic brain injury: use of the Psychomotor Vigilance Task', *J Clin Exp Neuropsychol*, 35(2), pp. 210-24. doi: 10.1080/13803395.2012.762340.
- Singam, A., et al. (2015) 'Participation in Complex and Social Everyday Activities Six Years after stroke: Predictors for Return to Pre-Stroke Level', *PLoS One*, 10(12), pp. e0144344. doi: 10.1371/journal.pone.0144344.
- Sivan, M., et al. (2011) 'Systematic review of outcome measures used in the evaluation of robot-assisted upper limb exercise in stroke', *Journal of Rehabilitation Medicine*, 43(3), pp. 181-9.
- Skaansar, O., et al., (2020) 'Traumatic brain injury—the effects of patient age on treatment intensity and mortality', *BMC Neurology*, 20 (1), pp.1-10. doi: 10.1186/s12883-020-01943-6.
- Skinner, E. and Zimmer-Gembeck, M. (2007) 'The development of coping', *Annual Review of Psychology*, 58, pp. 119-144. doi: 10.1146/annurev.psych.58.110405.085705.
- Skogestad, I., et al. (2019) 'Lack of content overlap and essential dimensions – A review of measures used for post-stroke fatigue', *Journal of Psychosomatic Research*. doi: 1715562.
- Skogestad, I. K., M. Indredavik, B. Gay, C. and Lerdal, A. V. (2019) 'Lack of content overlap and essential dimensions – A review of measures used for post-stroke fatigue', *Journal of Psychosomatic Research*. doi: 1715562.

- Skolarus, L. E., *et al.* (2014) 'Understanding stroke survivorship: expanding the concept of poststroke disability', *Stroke*, 45(1), pp. 224-30. doi: 10.1161/strokeaha.113.002874.
- Smith, B., *et al.* (2012) 'Enhancing behavioral health treatment and crisis management through mobile ecological momentary assessment and SMS messaging', *Health Informatics Journal*, 18(4), pp. 294-308. doi: 10.1177/1460458212445349.
- Smith, P. and Little, D. (2018) 'Small is beautiful: In defense of the small- N design', *Psychonomic Bulletin & Review*, 25(6), pp. 2083-2101. doi: doi:10.3758/s13423-018-1451-8.
- So, S., *et al.* (2015) 'Are Stamina and Fatigue Polar Opposites? A Case Study', *J Prev Interv Community*, 43(1), pp. 32-41. doi: 10.1080/10852352.2014.973235.
- Soyster, P. and Fisher, A. J. (2019) 'Involving stakeholders in the design of ecological momentary assessment research: An example from smoking cessation', *PLoS ONE*, 14(5), pp. e0217150. doi: 10.1371/journal.pone.0217150.
- Srinivas, P., *et al.* (2019) 'Context-Sensitive Ecological Momentary Assessment: Application of User-Centered Design for Improving User Satisfaction and Engagement During Self-Report', *JMIR Mhealth Uhealth* 2019;7(4):e10894. doi: doi:10.2196/10894.
- Stallinga, H., *et al.* (2014) 'The Ambiguity of the Concept of Participation in Measurement Instruments: Operationalization of Participation Influences Research Outcomes', *Clinical rehabilitation*, 28(12). doi: 10.1177/0269215514537092.
- Staub, F. and Bogousslavsky, J. (2001) 'Post-stroke depression or fatigue', *European neurology*, 45(1), pp. 3-5. doi: 10.1159/000052081.
- Stephan, K. E., *et al.* (2016) 'Allostatic Self-efficacy: A Metacognitive Theory of Dyshomeostasis-Induced Fatigue and Depression', *Front Hum Neurosci*, 10, pp. 550. doi: 10.3389/fnhum.2016.00550.
- Stineman, M. G. & Streim, J. E. (2010) 'The Biopsychological Paradigm: A Foundational Theory for Medicine'. *PM&R*, 2, pp. 1035-1045. doi:10.1016/j.pmrj.2010.06.0131035.
- Stone, A., *et al.* (2003) 'Intensive momentary reporting of pain with an electronic diary: reactivity, compliance, and patient satisfaction.', *Pain*, 104(1-2), pp. 343-351. doi: 10.1016/s0304-3959(03)00040-x.
- Stroke Association (2016) 'State of the Nation: stroke statistics January 2016': Stroke Association 25/08/2015). Available at: [https://www.stroke.org.uk/sites/default/files/stroke\\_statistics\\_2015.pdf](https://www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf).
- Stubberud, J., *et al.* (2019) 'Description of a multifaceted intervention programme for fatigue after acquired brain injury: a pilot study', *Neuropsychological Rehabilitation*, 29(6), pp. 946-968. doi: 10.1080/09602011.2017.1344132.
- Sturm, J., *et al.* (2002) 'Brief comprehensive quality of life assessment after stroke: the Assessment of Quality of Life Instrument in the North East Melbourne Stroke Incidence Study (NEMESIS)', *Stroke*, 33(12), pp. 2888-94. doi: 10.1161/01.STR.0000040407.44712.C7.
- Tao, D., *et al.* (2016) 'Predicting Factors of Consumer Acceptance of Health Information Technologies: A Systematic Review'. Conference: 2016 HFES Annual Meeting: Washington. doi: 10.1177\_1541931213601137.
- Tate, R., *et al.* (1999) 'Measuring psychosocial recovery after traumatic brain injury: psychometric properties of a new scale', *The Journal Of Head Trauma Rehabilitation*, 14(6), pp. 543-557. doi: 10.1097/00001199-199912000-00003.
- Taylor, K. I., *et al.* (2020) 'Outcome measures based on digital health technology sensor data: data- and patient-centric approaches'. *npj Digital Medicine*, 3(97). doi:10.1038/s41746-020-0305-8.
- Teasell, R., *et al.* (2012) 'Time to rethink long-term rehabilitation management of stroke patients',

- Top Stroke Rehabil*, 19(6), pp. 457-62. doi: 10.1310/tsr1906-457.
- Theadom, A., *et al.* (2016) 'Exploring the experience of sleep and fatigue in male and female adults over the 2 years following traumatic brain injury: a qualitative descriptive study', *BMJ Open*, 6(4), pp. e010453. doi: 10.1136/bmjopen-2015-010453.
- Thomas, K., *et al.* (2019) 'How is poststroke fatigue understood by stroke survivors and carers? A thematic analysis of an online discussion forum.', *BMJ Open*, pp. 9:e028958. doi: 10.1136/bmjopen-2019-028958.
- Tielemans, N. S., *et al.* (2015) 'Associations of proactive coping and self-efficacy with psychosocial outcomes in individuals after stroke', *Archives Of Physical Medicine And Rehabilitation*, 96(8), pp. 1484-1491. doi: 10.1016/j.apmr.2015.04.009
- Timmer, B. H. B., Hickson, L. and Launer, S. (2017) 'Ecological Momentary Assessment: Feasibility, Construct Validity, and Future Applications'. doi: 105908890026003S0436.
- Tinson, A., *et al.* (2016) 'Disability and poverty. Why disability must be at the centre of poverty reduction.': New Policy Institute. Available at: [https://www.npi.org.uk/files/3414/7087/2429/Disability\\_and\\_poverty\\_MAIN\\_REPORT\\_FINAL.pdf](https://www.npi.org.uk/files/3414/7087/2429/Disability_and_poverty_MAIN_REPORT_FINAL.pdf).
- Tong, A., Sainsbury, P. and Craig, J. (2007) 'Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups', *International Journal for Quality in Health Care*, 19(6), pp. 349-357. doi: 10.1093/intqhc/mzm042.
- Törnbom, K., Lundälv, J. and Sunnerhagen, K. S. (2019) 'Long-term participation 7-8 years after stroke: Experiences of people in working-age', *PLoS One*, 14(3). doi: 10.1371/journal.pone.0213447.
- Törnbom, K., *et al.* (2017) 'The impact of physical function on participation in the first year post-stroke', *Acta Neurologica Scandinavica*, 135(6), pp. 649-655. doi: 10.1111/ane.12661.
- Torous, J., *et al.* (2018) 'Clinical review of user engagement with mental health smartphone apps: evidence, theory and improvements', *Evid Based Ment Health*, 21(3), pp. 116-119. doi: 10.1136/eb-2018-102891.
- Tramonti, F., Giorgi, F. and Fanali, A. (2019) 'General system theory as a framework for biopsychosocial research and practice in mental health', *Syst Res Behav Sci*. 36, pp. 332-341. doi.org/10.1002/sres.2593.
- Triberti, S. and Barelllo, S. (2016) 'The quest for engaging Aml: Patient engagement and experience design tools to promote effective assisted living', *J Biomed Inform*, 63, pp. 150-156. doi: 10.1016/j.jbi.2016.08.010.
- Trull, T.J., Ebner-Priemer, U. (2009) 'Using Experience Sampling Methods/Ecological Momentary Assessment (ESM/EMA) in Clinical Assessment and Clinical Research: Introduction to the Special Section', *Psychological Assess.*, 21(4), pp. 457-462. doi: 10.1037/a0017653.
- Tse, T., *et al.* (2017) 'Increased work and social engagement is associated with increased stroke specific quality of life in stroke survivors at 3 months and 12 months post-stroke: a longitudinal study of an Australian stroke cohort', *Top Stroke Rehabil*, 24(6), pp. 405-414. doi: 10.1080/10749357.2017.1318339.
- Tse, T., *et al.* (2013) 'Measuring participation after stroke: A review of frequently used tools', *Archives of Physical Medicine and Rehabilitation*, 94(1), pp. 177-92. doi: 10.1016/j.apmr.2012.09.002.
- Tseng, B., *et al.* (2010) 'Exertion fatigue and chronic fatigue are two distinct constructs in people

- post-stroke', *Stroke* (00392499), 41(12), pp. 2908-2912. doi: 10.1161/STROKEAHA.110.596064.
- Tseng, B. Y., Gajewski, B. J. and Kluding, P. M. (2010) 'Reliability, Responsiveness, and Validity of the Visual Analog Fatigue Scale to Measure Exertion Fatigue in People with Chronic Stroke: A Preliminary Study', *Stroke Res Treat*, 2010. doi: 10.4061/2010/412964.
- Tullis, T. and Stetson, J. 'A comparison of questionnaires for assessing website usability.'. *Proceedings of UPA 2004 Conference* . Minneapolis, Minnesota.
- Turnbull, J., *et al.* (2000) 'Validation of the Frenchay Activities index in a general population aged 16 years and older', *Archives of Physical Medicine and Rehabilitation*, 81(8), pp. 1034-1038. doi: 10.1053/apmr.2000.7162.
- Turton, A. A., J. Chapman, M. Daniel, A. Longley, V. Clatworthy, P. Gilchrist, ID. (2015) 'Visual search training in occupational therapy: an example of expert practice in community-based stroke rehabilitation', *British Journal of Occupational Therapy*, 78(11), pp. 674-687. doi: 10.1177/0308022615600180.
- Tyson, S. F. and Brown, P. (2014) 'How to measure fatigue in neurological conditions? A systematic review of psychometric properties and clinical utility of measures used so far', *Clin Rehabil*, 28(8), pp. 804-816. doi: 10.1177/0269215514521043.
- Vaghefi, I. and Tulu, B. (2019) 'The Continued Use of Mobile Health Apps: Insights From a Longitudinal Study', *JMIR Mhealth Uhealth*, 7(8), Available at: <http://dx.doi.org/10.2196/12983>. doi: 10.2196/12983.
- Vaismoradi, M., Turunen, H. and Bondas, T. (2013) 'Content analysis and thematic analysis: implications for conducting a qualitative descriptive study.', *Nursing and Health Sciences.*, 15(3), pp. 3 98-405. doi: 10.1111/nhs.12048.
- Valko, P. O., *et al.* (2008) 'Validation of the Fatigue Severity Scale in a Swiss Cohort', *Sleep*, 31(11), pp. 1601-7. doi: 10.1093/sleep/31.11.1601.
- van de Port, I., *et al.* (2007) 'Is fatigue an independent factor associated with activities of daily living, instrumental activities of daily living and health-related quality of life in chronic stroke?', *Cerebrovascular Diseases (Basel, Switzerland)*, 23(1), pp. 40-45. doi: 10.1159/000095757.
- van de Ven, P., *et al.* (2017) 'ULTEMAT: A mobile framework for smart ecological momentary assessments and interventions', *Internet Interventions*, 9, pp. 74-81. doi: 10.1016/j.invent.2017.07.001.
- Van den Bergh, O. and Walentynowicz, M. (2016) 'Accuracy and bias in retrospective symptom reporting', *Curr Opin Psychiatry*, 29(5), pp. 302-8. doi: 10.1097/ycp.0000000000000267.
- van der Krieken, L., *et al.* (2015) 'Ecological Momentary Assessments and Automated Time Series Analysis to Promote Tailored Health Care: A Proof-of-Principle Study', *JMIR Res Protoc*, 4(3). doi: 10.2196/resprot.4000.
- van der Zee, C. H., *et al.* (2013) 'Participation in the Chronic Phase of Stroke', *Topics in Stroke Rehabilitation*, 20(1), pp. 52-61. doi: 10.1310/tsr2001-52.
- van Mierlo, M. L., *et al.* (2016) 'Quality of Life during the First Two Years Post Stroke: The Restore4Stroke Cohort Study', *Cerebrovascular Diseases (Basel, Switzerland)*, 41(1-2), pp. 19-26. doi: 10.1159/000441197.
- van Os, J., *et al.* (2017) 'The experience sampling method as an mHealth tool to support self-monitoring, self-insight, and personalized health care in clinical practice', *Depress Anxiety*, 34(6), pp. 481-493. doi: 10.1002/da.22647.

- Vanroy, C. V., D.Vanlandewijck, Y. Cras, P. Feys, H. Truijen, S. Michielsen, M. (2014) 'Is a Coded Physical Activity Diary Valid for Assessing Physical Activity Level and Energy Expenditure in Stroke Patients?', *Plos One*, 9(6), pp. e98735. doi: 10.1371/journal.pone.0098735.
- Vansimaey, C., et al. (2017) 'Combining Standard Conventional Measures and Ecological Momentary Assessment of Depression, Anxiety and Coping Using Smartphone Application in Minor Stroke Population: A Longitudinal Study Protocol', *Front Psychol*, 8, pp. 1172. doi: 10.3389/fpsyg.2017.01172.
- Veras, M., et al. (2017) 'Scoping review of outcome measures used in telerehabilitation and virtual reality for post-stroke rehabilitation', *J Telemed Telecare*, 23(6), pp. 567-587. doi: 10.1177/1357633x16656235.
- Villain, M., et al. (2017) 'Very early social support following mild stroke is associated with emotional and behavioral outcomes three months later', *Clinical Rehabilitation*, 31(1), pp. 135-141. doi: 10.1177/0269215515623600.
- Vincent, A., et al. (2013) 'Beyond pain in fibromyalgia: insights into the symptom of fatigue', *Arthritis Res Ther*, 15(6), pp. 221. doi: 10.1186/ar4395
- Visser-Keizer, A. C., et al. (2015) 'Dutch Multifactor Fatigue Scale: A New Scale to Measure the Different Aspects of Fatigue After Acquired Brain Injury', *Archives of Physical Medicine and Rehabilitation*. doi: 10.1016/j.apmr.2014.12.010.
- Viswanathan, M., et al. (2013) 'Approaches to Assessing the Risk of Bias in Studies'. Agency for Healthcare Research and Quality (US). Available at: <http://www.ncbi.nlm.nih.gov/books/NBK154465/>. (Accessed on 03.05.21).
- Voicu, R. A., et al. (2019) 'Human Physical Activity Recognition Using Smartphone Sensors', *Sensors*, 19(3). doi: 10.3390/s19030458
- Wade, D. and Halligan, P. (2004) Do biomedical models of illness make for good healthcare systems?. *BMJ*, 329, pp.1398–1401. doi: 10.1136/bmj.329.7479.1398.
- Wade, D. and Halligan, P. (2017) 'The biopsychosocial model of illness: a model whose time has come.', *Clinical Rehabilitation*, 31(8), pp. 995-1004. doi: 10.1177/0269215517709890.
- Walsh, M., et al. (2015) 'Factors associated with community reintegration in the first year after stroke: a qualitative meta- synthesis', *Disabil Rehabil*, 37(18), pp. 1599--1608. doi: 10.3109/09638288.2014.974834.
- Ware, J. and Sherbourne, C. (1992) 'The MOS 36-item Short-Form Health Survey (SF-36): I. Conceptual framework and item selection.', *Medical Care*, 30, pp. 473-83.
- Wei, C., Zhang, F., Chen, L., Ma, X., Zhang, N., Hao, J., 2016. RETRACTED ARTICLE: Factors associated with post-stroke depression and fatigue: lesion location and coping styles. *Journal of Neurology* 263, 269–276. doi:10.1007/s00415-015-7958-2
- Westerlind, E. P., HC. Sunnerhagen, KS. (2017) 'Return to Work after a Stroke in Working Age Persons; A Six-Year Follow Up', *PLoS One*, 12(1), pp. e0169759. doi: 10.1371/journal.pone.0169759.
- White, J. H., et al. (2014) 'Predictors of depression and anxiety in community dwelling stroke survivors: a cohort study', *Disabil Rehabil*, 36(23), pp. 1975-82. doi: 10.3109/09638288.2014.884172.
- White, J. H., et al. (2012) 'Exploring the experience of post-stroke fatigue in community dwelling stroke survivors: a prospective qualitative study', *Disabil Rehabil*, 34(16), pp. 1376-84. doi: 10.3109/09638288.2011.645111.
- Whitehead, L. (2009) 'The measurement of fatigue in chronic illness: a systematic review of unidimensional and multidimensional fatigue measures', *J Pain Symptom Manage*, 37(1), pp. 107-28. doi: 10.1016/j.jpainsymman.2007.08.019.
- Whiteneck, G. (2006) 'Conceptual Models of Disability: Past, Present, and Future.', in Field, M., Jette, A. & Martin, L. (eds.) *Workshop on Disability in America: A New Look. Summary and Background Papers*. Washington DC: National Academies Press, pp. 50-66.

- Whiteneck, G. and Dijkers, D. (2009) 'Difficult to Measure Constructs: Conceptual and Methodological Issues Concerning Participation and Environmental Factors', *Archives of Physical Medicine and Rehabilitation*, 90(11), pp. S22--S35. doi: 10.1016/j.apmr.2009.06.009.
- Whiteneck, G. (2010) 'Issues affecting the selection of participation measurement in outcomes research and clinical trials', *Arch Phys Med Rehabil*, 91(9 Suppl), pp. S54-9. doi: 10.1016/j.apmr.2009.08.154.
- Willemse-van Son, A.H.P. *et al.*, (2007) 'Prognostic factors of long-term functioning and productivity after traumatic brain injury: A systematic review of prospective cohort studies', *Clinical Rehabilitation*, 21(11).pp: 1024–1037. doi: 10.1177/0269215507077603.
- Wise, E. K., *et al.* (2010) 'Impact of traumatic brain injury on participation in leisure activities', *Arch Phys Med Rehabil*, 91(9), pp. 1357-62. doi: 10.1016/j.apmr.2010.06.009.
- Wolf, T., *et al.* (2012) 'Activity Participation Differences Between Younger and Older Individuals with Stroke', *Brain Impairment*, 13(1), pp. 16-23. doi: 10.1017/BrImp.2012.1.
- Wong, D., *et al.* (2017) 'Smartphones as assistive technology following traumatic brain injury: a preliminary study of what helps and what hinders', *Disabil Rehabil*, 39(23), pp. 2387-2394. doi: 10.1080/09638288.2016.1226434.
- Wood-Dauphinee, S. L., *et al.* (1988) 'Assessment of global function: The Reintegration to Normal Living Index', *Arch Phys Med Rehabil*, 69(8), pp. 583-90.
- Wood, J. P., Connelly, D. M. and Maly, M. R. (2010) 'Getting back to real living': A qualitative study of the process of community reintegration after stroke', *Clin Rehabil*, 24(11), pp. 1045-56. doi: 10.1177/0269215510375901.
- Woodman, P., *et al.* (2014) 'Social participation post stroke: a meta-ethnographic review of the experiences and views of community-dwelling stroke survivors', *Disabil Rehabil*, 36(24), pp. 2031-43. doi: 10.3109/09638288.2014.887796.
- World Health Organization (2001) *The International Classification of Functioning, Disability and Health (ICF)*. Geneva: WHO Available at: <http://www.who.int/classifications/icf/en/>.
- World Health Organisation, (2002) 'Towards a Common Language for Functioning, Disability and Health: ICF.'. Geneva: World Health Organisation. Available at: <http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf> (Accessed: 25/08/2015).
- World Health Organisation, (2013). How to use the ICF: A practical manual for using the International Classification of Functioning, Disability and Health (ICF). Exposure draft for comment. Geneva: WHO.
- World Health Organisation, (2017) *ICF browser*. Available at: <https://apps.who.int/classifications/icfbrowser/>
- Wu, S., *et al.* (2014) 'Psychological Associations of Post-stroke Fatigue . A systematic review and meta analysis'. *Stroke*, 45(6), 178-1783. doi:10.1161/STROKEAHA.113.004584.
- Wu, S., *et al.* (2015a) 'Interventions for post-stroke fatigue ( Review )', *Cochrane Database of Systematic Reviews.*, (Issue 7.). doi: DOI: 10.1002/14651858.CD007030.pub3.
- Wu, S., *et al.* (2015b) 'Model of Understanding Fatigue After Stroke', *Stroke*, 46. , pp. 893-898. doi: 10.1161/STROKEAHA.114.006647.).
- Wylie, G. R. and Flashman, L. A. (2017) 'Understanding the interplay between mild traumatic brain injury and cognitive fatigue: models and treatments', *Concussion*, 2(4). doi: 10.2217/cnc-2017-0003.
- Yardley, L., *et al.* (2015a) 'The person-based approach to enhancing the acceptability and feasibility of interventions', *Pilot and Feasibility Studies*, 1(1), pp. 1-7. doi: doi:10.1186/s40814-015-0033-z.
- Yardley, L., *et al.* (2015b) 'The Person-Based Approach to Intervention Development: Application to Digital Health-Related Behavior Change Interventions', *J Med Internet Res*, 17(1), Available at: <http://dx.doi.org/10.2196/jmir.4055>. doi: 10.2196/jmir.4055

- Yen, P.-Y. and Bakken, S. (2012) 'Review of health information technology usability study methodologies', *Journal of the American Medical Informatics Association*, 19(3), pp. 413-422. doi: 10.1136/amiajnl-2010-000020.
- Yesavage, J. A., *et al.* (1982) 'Development and validation of a geriatric depression screening scale: a preliminary report', *J Psychiatr Res*, 17(1), pp. 37-49. doi: 10.1016/0022-3956(82)90033-4.
- Zapata, B. C., *et al.* (2015) 'Empirical studies on usability of mHealth apps: a systematic literature review', *J Med Syst*, 39(2), pp. 1. doi: 10.1007/s10916-014-0182-2.
- Zedlitz, A. M., *et al.* (2012) 'Cognitive and graded activity training can alleviate persistent fatigue after stroke: a randomized, controlled trial', *Stroke*, 43(4), pp. 1046-51. doi: 10.1161/strokeaha.111.632117.
- Zheng, Y., *et al.* (2013) 'An Idiographic Examination of Day-to-Day Patterns of Substance Use Craving, Negative Affect and Tobacco Use among Young Adults in Recovery', *Multivariate Behav Res*, 48(2), pp. 241-66. doi: 10.1080/00273171.2013.763012.
- Ziino, C. and Ponsford, J. (2005) 'Measurement and prediction of subjective fatigue following traumatic brain injury', *Journal Of The International Neuropsychological Society: JINS*, 11(4), pp. 416-425. doi: 10.1017/S1355617705050472.
- Ziino, C. and Ponsford, J. (2006) 'Vigilance and fatigue following traumatic brain injury', *J Int Neuropsychol Soc*, 12(1), pp. 100-10. doi: 10.1017/s1355617706060139.
- Zwarts, M. J., Bleijenberg, G. and van Engelen, B. G. M. (2008) 'Clinical neurophysiology of fatigue', *Clinical neurophysiology : official journal of the International Federation of Clinical Neurophysiology*, 119(1), pp. 2-10. doi: 10.1016/j.clinph.2007.09.126.

## Appendices.

<i>Appendix A</i>	Search strategy adapted for Medline	225
<i>Appendix B</i>	NHLB quality assessment tool	226
<i>Appendix C</i>	Factors only appearing once in the systematic review studies.	229
<i>Appendix D</i>	Study characteristics.	231
<i>Appendix E</i>	Interview Guide.	251
<i>Appendix F</i>	Short demographic questionnaire.	252
<i>Appendix G</i>	System Usability Scale	253
<i>Appendix H</i>	Usability study interview guide.	254
<i>Appendix I</i>	App instructions	255
<i>Appendix J</i>	Participant's summarised data	260
<i>Appendix K</i>	Reported activities and mean NRS scores for participants	263
<i>Appendix L</i>	Mean NRS scores by activity type for participants 7,8,9,11.	269
<i>Appendix M</i>	Published papers	270



**Appendix A:** Search strategy adapted for Medline

Limits: English, Human.

1. participation OR handicap OR productivity OR reintegration OR re-integration OR integration
2. instrument OR measure OR scale OR interview OR questionnaire OR assess\* OR outcome
3. (MH "Hemiplegia") OR (MH "Paresis+")
4. ( TI (hemipleg\* or hemipar\* or paresis or paretic) ) OR ( AB (hemipleg\* or hemipar\* or paresis or paretic) )
5. ( TI ((brain\* or cerebr\* or cerebell\* or intracran\* or intracerebral) N5 (isch?emi\* or infarct\* or thrombo\* or emboli\* or occlus\*)) ) OR ( AB ((brain\* or cerebr\* or cerebell\* or intracran\* or intracerebral) N5 (isch?emi\* or infarct\* or thrombo\* or emboli\* or occlus\*)) )
6. ( TI ((brain\* or cerebr\* or cerebell\* or intracerebral or intracranial or subarachnoid) N5 (h?emorrhage\* or h?ematoma\* or bleed\*)) ) OR ( AB ((brain\* or cerebr\* or cerebell\* or intracerebral or intracranial or subarachnoid) N5 (h?emorrhage\* or h?ematoma\* or bleed\*)) )
7. (MH "Cerebrovascular Disorders") OR ( (MH "Brain Infarction+") OR (MH "Brain Ischemia+") ) OR ( (MH "Carotid Artery Diseases+") OR (MH "Stroke+") OR (MH "Cerebrovascular Trauma+") ) OR (MH "Hypoxia-Ischemia, Brain") OR (MH "Intracranial Arterial Diseases+") OR (MH "Intracranial Arteriovenous Malformations") OR ( (MH "Intracranial Embolism and Thrombosis+") ) OR (MH "Intracranial Hemorrhages+") OR ( (MH "Vasospasm, Intracranial") OR (MH "Vertebral Artery Dissection") ) NOT ("heat stroke") NOT (swim )
8. TI (stroke or poststroke or post-stroke or cerebrovasc\* or brain vas\* or cerebral vas\* or CVA\* or apoplex\* or SAH) OR AB (stroke or poststroke or post-stroke or cerebrovasc\* or brain vas\* or cerebral vas\* or CVA\* or apoplex\* or SAH)
9. S3 OR S4 OR S5 OR S6 OR S7 OR S8
10. S1 AND S2 AND S9
11. (MH "Social Participation") OR "participation"
12. S1 OR S11
13. S2 AND S9 AND S12

**Appendix B:** Quality assessment tool for observational and cross-sectional studies

Accessed at <https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools>

Criteria	Yes	No	Other (CD, NR, NA)*
1. Was the research question or objective in this paper clearly stated?			
2. Was the study population clearly specified and defined?			
3. Was the participation rate of eligible persons at least 50%?			
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?			
5. Was a sample size justification, power description, or variance and effect estimates provided?			
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?			
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?			

Criteria	Yes	No	Other (CD, NR, NA)*
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?			
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
10. Was the exposure(s) assessed more than once over time?			
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
12. Were the outcome assessors blinded to the exposure status of participants?			
13. Was loss to follow-up after baseline 20% or less?			
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?			

Quality Rating (Good, Fair, or Poor)

Rater #1

Rater #2 initials:

Additional Comments (If POOR, please state why):

\*CD, cannot determine; NA, not applicable; NR, not reported

**Appendix C:** Factors only appearing once in the systematic review studies.

Author	Factor with statistically significant associations with participation outcomes	Factor where associations with participation outcomes were not statistically significant.
Cooper <i>et al.</i> , 2014; Cooper <i>et al.</i> , 2015)	Emotional perception	
Cruice <i>et al.</i> , 2003	Near vision.	
Egan <i>et al.</i> , 2015	Low income	
Gum, Snyder and Duncan, 2006.	Hope	
Liu <i>et al.</i> , 2015.	Fear avoidance behaviour, number of falls	
Mayo <i>et al.</i> , 2009.	Apathy	
Stummer <i>et al.</i> , 2015.	Hyperlipidemia, swallowing problems, care giver strain index, physical health measure, atrial fibrillation.	Heart disease, myocardial infarction, diabetes

## Appendix D

Study characteristics.

Legend: N (number participants), SAH (subarachnoid haemorrhage), IS (IS stroke), HS (haemorrhagic stroke), AS (AS), NR (not reported), NS (not stated), SD (standard deviation), C (community), R (residential/nursing facility).

LHS (London Handicap scale), RNLI (Re-integration to normal living index).

Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(Adamit <i>et al.</i> , 2015)	80	Prospective cohort	68.6 SD 9.9	6	IS	Yes	mild only	C	RNLI	Israel.	Fair
(Ahn, 2016)	63	Cross-sectional	58.6 SD 15.2	33.4 range 1-160	NR	NR	NR	NR	ACS	Republic of Korea	High
(Akosile <i>et al.</i> , 2016)	71	Cross-sectional	64.14 SD 10.26	NR	NR	NR	NR	C	RNLI	Nigeria	High
(Barker-Collo <i>et al.</i> , 2010)	307	Prospective cohort	72.9 mean SD 11.1	60	AS	Yes	NR	NS	LHS	Australia	Low

Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(Berges, Seale and Ostir, 2012)	605	prospective cohort	71.6 SD 10.3	3	AS.	Yes	NR	NR	ParPro	USA	Fair
(Blomer <i>et al.</i> , 2015)	325	Prospective cohort	66.9 SD 12.2	12	AS	Yes	Minor to moderate stroke	mixed	USER	Netherlands	Low
(Boerboom <i>et al.</i> , 2016)	64	Prospective cohort	52.5 (10.7)	60	SAH	NR	Moderate to severe	C	CIQ	Netherlands	Low
(Carod-Artal <i>et al.</i> , 2008)	260	cross sectional	55.9,SD 14.5.	mean 20.7 SD 24.8	AS.	NR	mild to moderate stroke	NR	Stroke Impact Scale	Brazil	Low
(Carter <i>et al.</i> , 2000)	182	Retrospective cohort	52	mean 33	SAH	Yes	mild-severe stroke	NS	RNLI	USA	Low
(Chahal, Barker-Collo and Feigin, 2011)	27	cross sectional	62.22	61.2 SD 6.36	SAH	Yes	NR	mixed	LHS	New Zealand	Fair
(Chau <i>et al.</i> , 2009)	188	prospective cohort	71.7 SD 10.2	12	AS	NR	NR	mixed	LHS	Hong Kong	Fair

Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(Chau <i>et al.</i> , 2010)	210	cross sectional	71.7, SD	6	AS	NR	NR	mixed	LHS	Hong Kong	Fair
(Clarke <i>et al.</i> , 1999)	135	prospective cohort	71 (SD 13.2)	12	IS	No	mild-severe stroke	mixed.	RNLI	Canada	Low
(Cooper <i>et al.</i> , 2014)	28	Prospective cohort	67.75 SD 9.17	14	NR	NR	NR	C	mFPL	UK	Unclear
(Cooper <i>et al.</i> , 2015)	48	Prospective cohort	67.3	18	NR	Yes	NR	C	m FPL	UK	High
(Cruice <i>et al.</i> , 2003)	30	cross sectional	70.7 SD 8.4, range 57-88	41 mean, SD 25.6, range 10-108	NR	NR	NR	mixed	SF 36	Australia	High
(D'Alisa <i>et al.</i> , 2005)	73	cross sectional	62.6 range 24-83.	mean 60, SD 52.8, range 2.4-180	NR	NR	NR	NR	LHS	Italy	High
(Dalemans <i>et al.</i> , 2010b)	150	cross sectional	64.2 range 35-87	90.6, range 6-372	NR	NR	NR	C	CIQ	Netherlands	High



Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(Dalemans <i>et al.</i> , 2010a)	150	cross sectional	64.2 range 35-87	90.6, range 6-372	NR	NR	NR	C	CIQ	Netherlands	High
(Daneski <i>et al.</i> , 2003)	76	cross sectional	67.1 range 33.7-91.9, SD	3-12	NR	Yes	NR	NR	RNLI	UK	Unclear
(Danielsson, Willen and Sunnerhagen, 2011)	31	cross sectional	59.7 SD 81 range 36-73	102 mean. range 84-120	AS	NR	NR	NR	Stroke Impact Scale	Sweden	Fair
(De Haan <i>et al.</i> , 1993)	87	Cross-sectional	79.1 SD 11.52	6	AS	NR	Mild	NR	SIP	Netherlands	High
(Desrosiers <i>et al.</i> , 2006)	66	prospective cohort	67.6 SD 13.7	24-26	AS	NR	NR	mixed	Life-H	Canada	Fair
(Desrosiers <i>et al.</i> , 2002)	102	prospective cohort	60.9, SD 13.5	6	NR	No	NR	mixed	Life-H	Canada	High

Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(Desrosiers <i>et al.</i> , 2003b)	102	Prospective cohort	69.9 SD 13.5	6 post discharge	AS	NR	NR	NR	Life-H	Netherlands	High
(Desrosiers <i>et al.</i> , 2008)	197	prospective cohort	acute 77.2 SD 7.1 rehab 76.7, SD 7.0	6	AS	No	mild-moderate stroke	C	Life-H	Canada	Fair
(Desrosiers <i>et al.</i> , 2003a)	102	prospective cohort	68.9 SD 14.1	6 months post discharge	NR	No	NR	mixed	Life-H	Canada	High
(Edwards and O'Connell, 2003)	74	Cross-sectional	58.35, SD 14.8, range 20-80	58, range 2-180	NR	NR	NR	C	SIS	Australia	High
(Edwards, 2006)	361	retrospective cohort	65.52, SD 15.24, range: 22-99	6	IS	No	Minor moderate stroke	C	ACS	USA	Unclear
(Egan <i>et al.</i> , 2014)	55	prospective cohort	64.8 range 33-88	24 SD 6 months post discharge	NR	Yes	NR	NR	RNLI	Canada	High

Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(Egan <i>et al.</i> , 2015)	55	prospective cohort	64.8 range 33-88	24 SD 6 months post discharge	NR	Yes	NR	NR	RNLI	Canada	High
(Eriksson <i>et al.</i> , 2013)	116	cross-sectional	62.4 SD 12.7	6.4	NR	NR	mild-moderate stroke	mixed	SIS	USA	High
(Fallahpour <i>et al.</i> , 2011)	102	cross sectional	58.3. range 27-57	months 17.7 SD 10.1 range 5-36	Exclude SAH	yes	NR	C	IPAQ.	Iran	Low
(Feigin <i>et al.</i> , 2010)	418	retrospective cohort	66.98, SD 12.5	>60	AS	No	mild to severe stroke	mixed	LHS	New Zealand	Low
(Finestone <i>et al.</i> , 2010)	58	prospective cohort	65.3,SD 12.31	12, SD 11.7	NR	NR	NR	C	RNLI	Canada	Fair
(Flansbjerg, Downham and Lexell, 2006)	50	cross sectional	age 59,range 46-72	17months	AS	NR	NR	C	Stroke Impact Scale	Sweden	Unclear

Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(French <i>et al.</i> , 2016)	59	Prospective cohort – secondary data analysis	59 SD 11	44 SD 63.1	NR	Yes	NR	C	SIS-P	USA	High
(Fróes <i>et al.</i> , 2011)	64	cross sectional	58.80 SD 11.72	24-84	AS	No	NR	NR	SF 36	Brazil	Low
(Gadidi <i>et al.</i> , 2011)	71	prospective cohort	67	48	Exclude SAH	Yes	mild-severe stroke	mixed	FAI	Israel	Fair
(Gall <i>et al.</i> , 2009)	351	prospective cohort	Median age 73 (IQR63-79)	60	Exclude SAH	Yes	mild to moderate stroke	mixed	LHS	Australia	Fair
(Gottlieb <i>et al.</i> , 2001)	100	retrospective cohort	73	15	IS.	NR	NR	C	LHS	Israel	Fair
(Griffen <i>et al.</i> , 2009)	90	Cross sectional	57.1 SD 11.5, range30-87	20, range 3-330	NR	NR	NR	C	SIS-p	USA	High
(Gum, Snyder and Duncan, 2006)	110	cross sectional	72.5 SD 9.75	3-4	Exclude SAH	NR	minor to severe stroke	NR	Stroke Impact Scale	USA	Fair

Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(Hamzat and Peters, 2009)	16	Prospective cohort	NR	6	AS	NR	NR	C	LHS	Nigeria	High
(Harris and Eng, 2006)	93	cross sectional	68.79 SD 9.4, range 50-93	61.2, SD 49.2	AS	NR	NR	NR	RNLI	Canada	Unclear
(Harris and Eng, 2007)	93	cross sectional	68.79 SD 9.4, range 50-93	61.2, SD 49.2	AS	NR	NR	NR	RNLI	Canada	High
(Harwood, Gompertz and Ebrahim, 1994)	89	cross sectional	71	12	NR	NR	NR	mixed	LHS	UK	Fair
(Harwood <i>et al.</i> , 1997)	102	Prospective cohort	73 range 28-99	24-36	NR	NR	NR	mixed	LHS	UK	Fair
(Hoffman T <i>et al.</i> , 2003)	51	Retrospective cohort	69 SD 11.5 range 44-90	18 SD 9.4 range 5-36	AS	Yes	NR	C	RNLI	Australia	Fair
(Huenges Wajer <i>et al.</i> , 2016) (2016)	67	Prospective cohort	53.3 SD11.2	6	SAH	Yes	Moderate to severe	mixed	User-p	Netherlands	Fair

Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(Jansen <i>et al.</i> , 2012)	190	Prospective cohort	Mean 55.8	36	AS.	Yes	NR	C	FAI	Netherlands	Fair
(Kreiter <i>et al.</i> , 2013)	216	Prospective cohort	51.2 SD 13.8	12	SAH	NR	mild to severe	NR	Sickness Impact Profile	USA	High
(Liu <i>et al.</i> , 2015)	57	cross sectional	61.14 SD 6.66	8.14 SD 4.34	AS	NR	NR	C	CIQ	Hong Kong	High
(Lo <i>et al.</i> , 2008)	268	Prospective cohort	70.5	12	AS	Yes	mild-severe stroke	mixed	LHS	Hong Kong	High
(Mayer <i>et al.</i> , 2002)	113	Prospective cohort	49.4, SD 13, range	3	SAH	Yes	Mild to severe	NR	SIP	USA	Fair
(Mayer and Reid, 2004)	18	Prospective cohort	67.5 SD13.4 range 49-89	Mean 82	NR	N	NR	C	IPAQ	Canada	High
(Mayo <i>et al.</i> , 2009)	408	Prospective cohort	66.5 SD 14.6	12	NR	Yes	mild- severe stroke	NR	Stroke Impact Scale	Canada	Fair

Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(Mercer <i>et al.</i> , 2009)	33	Prospective cohort	58.73 SD 17.27, range 24-	6	AS	Yes	NR	mixed	Stroke Impact Scale	USA	High
(Muren, Hütler and Hooper, 2008)	30	cross sectional	58	60	AS	yes	Mild stroke	NR	Stroke Impact Scale	Norway	Unclear
(Murtezani <i>et al.</i> , 2009)	44	cross sectional	49.8 range 18-80	NR	AS	NR	NR	NR	RNLI	Kosovo	Unclear
(Mutai <i>et al.</i> , 2013)	160	Retrospective cohort	71.7	24	AS	No	NR	mixed	FAI	Japan	Fair
(Naess <i>et al.</i> , 2006)	190	cross sectional	47.8	72 (range 16.8-147.6)	IS	No	NR	NR	SF 36	Norway	Low
(Beckley, 2007)	95	cross sectional	68.46. SD12.16	3-6	AS.	NR	NR	C	RNLI	USA	High
(Norlander <i>et al.</i> , 2016)	145	Prospective cohort	66	240	AS	Yes	mild	mixed	FAI	Sweden	Low

Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(Obembe <i>et al.</i> , 2013)	90	cross sectional	58.3	mean 26	AS	Yes	NR	NR	RNLI	Nigeria	Fair
(Ownsworth and Shum, 2008)	27	Prospective cohort	47.3 SD 10.7 range 24-61	Mean 25.2	AS	NR	NR	C	Sydney psychosocial integration scale	Australia	High
(Pang <i>et al.</i> , 2011)	75	cross sectional	64.4 SD 12.3	67.2 SD 44.4	AS.	No	NR	C	RNLI	Hong Kong	High
(Patel <i>et al.</i> , 2006)	342	Prospective cohort	67.2 SD 13.1	36	AS	yes	NR	NR	FAI	UK	Fair
(Pedersen <i>et al.</i> , 1996)	417	Prospective cohort	73.8 SD 11.1	6	IS	No	NR	mixed	FAI	Denmark	Fair
(Pettersen, Dahl and Wyller, 2002)	103	Prospective cohort	Median 75 range 41-91	36	AS	No	Median score: mild stroke	mixed	FAI	Norway	Fair
(Plante <i>et al.</i> , 2010)	111	Prospective cohort	76.7 SD 7.0 range 65-92	6	AS	No	mild-moderate stroke	C	Life-H	Canada	Fair



Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(Rochette and Desrosiers, 2002)	76	Prospective cohort	68.3 SD 13.5, range 24-93	6	NR	No	NR	mixed	Life-H	Canada	Unclear
(Rochette <i>et al.</i> , 2007)	88	Prospective cohort	71.8 range 46-89	6	NR	Yes	mild-moderate stroke	mixed	Life-H	Canada	High
(Rochette, Desrosiers and Noreau, 2001)	51	cross sectional	71.3 SD 13, range 40-97	6	AS		NR	mixed	Life-H	Canada	High
(Schepers <i>et al.</i> , 2005)	250	Prospective cohort	56.3	12	AS	Yes	NR	C	FAI	Netherlands	High
(Schmid <i>et al.</i> , 2012)	77	Cross sectional	64.1 SD 8.8	52 SD 42	AS	No	NR	NR	IMPACT	USA	High
(Schuling <i>et al.</i> , 1993)	96	Prospective cohort	74 SD 6 range 65-91	6	NR	No	NR	mixed	FAI	Netherlands	High

Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(Seymour and Wolf, 2014)	13	Cross sectional	62.1 SD 15.1 range 36-82	Range 6-18	NR	Yes	Mild stroke	C	SIS	USA	High
(Singam <i>et al.</i> , 2015)	121	Prospective cohort	63.4 range 25-84	72	NR	No	Mild -severe	C	FAI	Sweden	Low
(Spitzer <i>et al.</i> , 2011)	30	cross sectional	59 SD 14.91, range 20- 81	mean 58, SD 30.93 range 27-165	NR	NR	mild to moderate stroke	NR	ACS	Australia	High
(Stummer <i>et al.</i> , 2015)	378	Prospective cohort	69.4 SD 10.3	6	AS	NR	Mild to severe stroke	NR	Sickness impact profile	Europe	Fair
(Sturm <i>et al.</i> , 2002)	101	Prospective cohort	72	12	AS	Yes	NR	mixed	LHS	Australia	Fair
(Sturm <i>et al.</i> , 2004)	226	Prospective cohort	NR	Mean 24, median 24 range 21 -30	excluded SAH	Yes	moderate-severe stroke.	mixed	LHS	Australia	Fair

Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(Tse <i>et al.</i> , 2017b)	98	Prospective cohort	66 SD 13	Mean 99 days	IS	NR	Mild stroke	mixed	ACS	Australia	Unclear
(Tse <i>et al.</i> , 2017a)	166	Prospective cohort	67 SD 13	12 months	IS	NR	Mild stroke	community	SIS	Australia	Low
(van der Zee <i>et al.</i> , 2013)	111	prospective cohort	57.2 SD 10.7	median 3.4 IQR 2.4-4.6	AS	NR	NR	NR	USER-P	Netherlands	Fair
(van Mierlo <i>et al.</i> , 2016)	344	Prospective cohort	66.8, SD 12.3	24	AS	NR	Minor - severe	mixed	USER-P	Netherlands	Low
(Van Puymbroeck <i>et al.</i> , 2014)	77	cross sectional	64.06 SD 8.78	> 9	AS	No	NR	NR	IPAQ	USA	High
(van Straten <i>et al.</i> , 2000)	418	Prospective cohort	70 SD 13	6	IS,HS, exc SAH	No	NR	NR	SIP	Netherlands	Low

Authors	N	Type study	Age participants in years (mean unless otherwise)	Time since stroke (months).	Type of stroke.	First-time stroke only	Stroke severity	Residence	Participation Measure	Nation	Risk of bias
(Verhoeven <i>et al.</i> , 2011)	92	cross-sectional	63.7 SD 14.4	mean 12.56 SD 0.7	IS	Yes	minor to severe stroke	mixed	FAI	Netherlands	Unclear
(Vincent-Onabajo <i>et al.</i> , 2016)	96	Cross-sectional	56.6, SD 12, range 30-85	19 SD 24.6 range 1-144	AS	NR	NR	C	LHS	Nigeria	Unclear
(Wade, Legh-Smith and Langton Hewer, 1985)	444	prospective cohort	71 SD10.2	12	NR	NR	NR	mixed	FAI	UK	Fair

## References

- Adamit, T., *et al.* (2015) 'Impact of first-ever mild stroke on participation at 3 and 6 month post-event: the TABASCO study', *Disability And Rehabilitation*, 37(8), pp. 667-673. doi: 10.3109/09638288.2014.923523.
- Ahn, S. (2016) 'Measurement of balance function and community participation in stroke survivors', *Journal Of Physical Therapy Science*, 28(8), pp. 2268-2270. doi: 10.1589/jpts.28.2268.
- Akosile, C., *et al.* (2016) 'Community reintegration and related factors in a Nigerian stroke sample', *African Health Sciences*, 16(3), pp. 772-780. doi: 10.4314/ahs.v16i3.18.
- Barker-Collo, S., *et al.* (2010) 'Auckland Stroke Outcomes Study. Part 2: Cognition and functional outcomes 5 years poststroke', *Neurology*, 75(18), pp. 1608-1616. doi: 10.1212/WNL.0b013e3181fb44c8.
- Beckley, M. N. (2007) 'The influence of the quality and quantity of social support in the promotion of community participation following stroke', *Australian Occupational Therapy Journal*, 54(3), pp. 215-220. doi:10.1111/j.1440-1630.2007.00643.x.
- Berges, I.-M., Seale, G. S. and Ostir, G. V. (2012) 'The role of positive affect on social participation following stroke', *Disability And Rehabilitation*, 34(25), pp. 2119-2123. doi: 10.3109/09638288.2012.673684.
- Blomer, A., *et al.* (2015) 'Does the frequency of participation change after stroke and is this change associated with the subjective experience of participation?', *Archives of Physical Medicine and Rehabilitation*, 90(3), pp. 456-63. doi: 10.1016/j.apmr.2014.09.003.
- Boerboom, W., *et al.* (2016) 'Unmet needs, community integration and employment status four years after subarachnoid haemorrhage', *Journal Of Rehabilitation Medicine*, 48(6), pp. 529-534. doi: 10.2340/16501977-2096.
- Carod-Artal, F., *et al.* (2008) 'The Stroke Impact Scale 3.0: evaluation of acceptability, reliability, and validity of the Brazilian version', *Stroke*, 39(9), pp. 2477-84. doi: 10.1161/STROKEAHA.107.513671.
- Carter, B. S., *et al.* (2000) 'Factors associated with reintegration to normal living after subarachnoid hemorrhage', *Neurosurgery*, 46(6), pp. 1326-1333. doi: 10.1097/00006123-200006000-00008.
- Chahal, N., Barker-Collo, S. and Feigin, V. (2011) 'Cognitive and functional outcomes of 5-year subarachnoid haemorrhage survivors: comparison to matched healthy controls', *Neuroepidemiology*, 37(1), pp. 31-38. doi: 10.1159/000328647.
- Chau, J. P. C., *et al.* (2010) 'Depression among Chinese stroke survivors six months after discharge from a rehabilitation hospital', *Journal Of Clinical Nursing*, 19(21-22), pp. 3042-3050. doi: 10.1111/j.1365-2702.2010.03317.x.
- Chau, J. P. C., *et al.* (2009) 'Determinants of participation restriction among community dwelling stroke survivors: a path analysis', *BMC Neurology*, 9, pp. 49-49. doi: 10.1186/1471-2377-9-49.
- Clarke, P. J., *et al.* (1999) 'Handicap in stroke survivors', *Disability And Rehabilitation*, 21(3), pp. 116-123.
- Cooper, C. L., *et al.* (2014) 'Links between emotion perception and social participation restriction following stroke', *Brain Injury*, 28(1), pp. 122-126. doi: 10.3109/02699052.2013.848379.
- Cooper, C. L., *et al.* (2015) 'The role of emotion regulation on social participation following stroke', *The British Journal Of Clinical Psychology / The British Psychological Society*, 54(2), pp. 181-199. doi: 10.1111/bjc.12068.
- Cruice, M., *et al.* (2003) 'Finding a focus for quality of life with aphasia: Social and emotional health, and psychological well-being', *Aphasiology*, 17(4), pp. 333-353. doi: 10.1080/02687030244000707.
- D'Alisa, S., *et al.* (2005) 'How does stroke restrict participation in long-term post-stroke survivors?', *Acta Neurologica Scandinavica*, 112(3), pp. 157-162. doi: 10.1111/j.1600-0404.2005.00466.x

- Dalemans, R. J., *et al.* (2010a) 'Psychometric properties of the Community Integration Questionnaire adjusted for people with aphasia', *Archives of Physical Medicine & Rehabilitation*, 91(3), pp. 395-399. doi: 10.1016/j.apmr.2009.10.021.
- Dalemans, R. J. P., *et al.* (2010b) 'An investigation into the social participation of stroke survivors with aphasia', *Disability & Rehabilitation*, 32(20), pp. 1678-1685. doi: 10.3109/09638281003649938.
- Daneski, K., *et al.* (2003) 'Reliability and validity of a postal version of the Reintegration to Normal Living Index, modified for use with stroke patients', *Clinical Rehabilitation*, 17(8), pp. 835-9.
- Danielsson, A., Willen, C. and Sunnerhagen, K. S. (2011) 'Is walking endurance associated with activity and participation late after stroke?', *Disability and Rehabilitation*, 33(21-22), pp. 2053-2057. doi: 10.3109/09638288.2011.560329.
- De Haan, R., *et al.* (1993) 'A comparison of five stroke scales with measures of disability, handicap, and quality of life', *Stroke; A Journal Of Cerebral Circulation*, 24(8), pp. 1178-1181.
- Desrosiers, J., *et al.* (2008) 'Short-term changes in and predictors of participation of older adults after stroke following acute care or rehabilitation', *Neurorehabilitation And Neural Repair*, 22(3), pp. 288-297. doi: 10.1177/1545968307307116.
- Desrosiers, J., *et al.* (2003a) 'Arm and leg impairments and disabilities after stroke rehabilitation: relation to handicap', *Clinical Rehabilitation*, 17(6), pp. 666-673. doi:10.1191/0269215503cr662oa.
- Desrosiers, J., *et al.* (2002) 'Predictors of handicap situations following post-stroke rehabilitation', *Disability And Rehabilitation*, 24(15), pp. 774-785. doi: 10.1080/09638280210125814
- Desrosiers, J., *et al.* (2006) 'Long-term changes in participation after stroke', *Topics In Stroke Rehabilitation*, 13(4), pp. 86-96.
- Desrosiers, J., *et al.* (2003b) 'Comparison of two functional independence scales with a participation measure in post-stroke rehabilitation', *Archives Of Gerontology And Geriatrics*, 37(2), pp. 157-172. doi: 10.1016/S0167-4943(03)00044-X.
- Edwards, B. and O'Connell, B. (2003) 'Internal consistency and validity of the Stroke Impact Scale 2.0 (SIS 2.0) and SIS-16 in an Australian sample', *Quality Of Life Research: An International Journal Of Quality Of Life Aspects Of Treatment, Care And Rehabilitation*, 12(8), pp. 1127-1135. doi: 10.1023/A:1026109920478.
- Edwards, D. F. *et al.*, (2006) 'The impact of mild stroke on meaningful activity and life satisfaction.', *Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association*, 15(4), pp. 151--7. doi: 10.1016/j.jstrokecerebrovasdis.2006.04.001.
- Egan, M., *et al.* (2014) 'Participation and well-being poststroke: Evidence of reciprocal effects', *Archives of Physical Medicine and Rehabilitation*, 95(2), pp. 262-8. doi: 10.1016/j.apmr.2013.08.013
- Egan, M., *et al.* (2015) 'Very low neighbourhood income limits participation post stroke: preliminary evidence from a cohort study', *BMC Public Health*, 15, pp. 528-528. doi: 10.1186/s12889-015-1872-5. doi: 10.1186/s12889-015-1872-5.
- Eriksson, G., *et al.* (2013) 'Perceived Participation After Stroke: The Influence of Activity Retention, Reintegration, and Perceived Recovery', *The American Journal of Occupational Therapy*, 67(6), pp. e131-e138. doi: 10.5014/ajot.2013.008292.
- Fallahpour, M., *et al.* (2011) 'Perceived participation and autonomy: aspects of functioning and contextual factors predicting participation after stroke', *Journal Of Rehabilitation Medicine*, 43(5), pp. 388-397. doi: 10.2340/16501977-0789.
- Feigin, V. L., *et al.* (2010) 'Auckland Stroke Outcomes Study. Part 1: Gender, stroke types, ethnicity, and functional outcomes 5 years poststroke', *Neurology*, 75(18), pp. 1597-1607. doi: 10.1212/WNL.0b013e3181fb44b3.
- Finestone, H. M., *et al.* (2010) 'Driving and reintegration into the community in patients after stroke', *PM & R: The Journal Of Injury, Function, And Rehabilitation*, 2(6), pp. 497-503. doi: 10.1016/j.pmrj.2010.03.030.

- Flansbjerg, U., Downham, D. and Lexell, J. (2006) 'Knee muscle strength, gait performance, and perceived participation after stroke', *Archives of Physical Medicine and Rehabilitation*, 87(7), pp. 974-80. doi: 10.1016/j.apmr.2006.03.008
- French, M. A., *et al.* (2016) 'Self-efficacy Mediates the Relationship between Balance/Walking Performance, Activity, and Participation after Stroke', *Top Stroke Rehabil*, 23(2), pp. 77-83. doi: 10.1080/10749357.2015.1110306.
- Fróes, K.S.D.S.O. *et al.*, (2011) 'Factors associated with health-related quality of life for adults with stroke sequelae', *Arquivos De Neuro-Psiquiatria*, 69(2B), pp. 371-376. doi: 10.1590/S0004-282X2011000300020.
- Gadidi, V., *et al.* (2011) 'Long-term outcome poststroke: predictors of activity limitation and participation restriction', *Archives Of Physical Medicine And Rehabilitation*, 92(11), pp. 1802-1808. doi: 10.1016/j.apmr.2011.06.014.
- Gall, S. L., *et al.* (2009) 'Handicap 5 years after stroke in the North East Melbourne Stroke Incidence Study', *Cerebrovascular Diseases (Basel, Switzerland)*, 27(2), pp. 123-130. doi: 10.1159/000177919.
- Gottlieb, A., *et al.* (2001) 'The influence of social support and perceived control on handicap and quality of life after stroke', *Aging (Milan, Italy)*, 13(1), pp. 11-15. doi: 10.1007/bf03351488.
- Griffen, J. A., *et al.* (2009) 'Driving status and community integration after stroke', *Topics In Stroke Rehabilitation*, 16(3), pp. 212-221. doi: 10.1310/tsr1603-212.
- Gum, A., Snyder, C. R. and Duncan, P. W. (2006) 'Hopeful thinking', *Psychology & Health*, 21(3), pp. 319-334. doi: 10.1080/14768320500422907.
- Hamzat, T. K. and Peters, G. O. (2009) 'Motor function and participation among Nigerian stroke survivors: 6-month follow-up study', *Neurorehabilitation*, 25(2), pp. 137-142. doi: 10.3233/NRE-2009-0509.
- Harris, J. and Eng, J. (2006) 'Individuals with the Dominant Hand Affected following Stroke Demonstrate Less Impairment Than Those with the Nondominant Hand Affected', *Neurorehabilitation and Neural Repair*, 20(3), pp. 380-9. doi: 10.1177/1545968305284528.
- Harris, J. E. and Eng, J. J. (2007) 'Paretic upper-limb strength best explains arm activity in people with stroke', *Physical Therapy*, 87(1), pp. 88-97. doi: 10.2522/ptj.20060065.
- Harwood, R. H., Gompertz, P. and Ebrahim, S. (1994) 'Handicap one year after a stroke: validity of a new scale', *Journal Of Neurology, Neurosurgery, And Psychiatry*, 57(7), pp. 825-829. doi: 10.1136/jnnp.57.7.825
- Harwood, R. H., *et al.* (1997) 'Determinants of handicap 1 and 3 years after a stroke', *Disability And Rehabilitation*, 19(5), pp. 205-211. doi: 10.3109/09638289709166528.
- Hoffman T, *et al.* (2003) 'Outcomes after stroke: basic and instrumental activities of daily living, community reintegration and generic health status', *Australian Occupational Therapy Journal*, 50(4), pp. 225-233. doi: 10.1046/j.1440-1630.2003.00376.x.
- Huenges Wajer, I. M. C., *et al.* (2016) 'Restrictions and satisfaction with participation in patients who are ADL-independent after an aneurysmal subarachnoid hemorrhage', *Topics In Stroke Rehabilitation*, pp. 1-8. doi: 10.1080/10749357.2016.1194557.
- Jansen, H. E., *et al.* (2012) 'Social Activity One and Three Years Post-Stroke', *Journal of Rehabilitation Medicine*, 44(1), pp. 47-50. doi: 10.2340/16501977-0908.
- Kreiter, K. T., *et al.* (2013) 'Depressed mood and quality of life after subarachnoid hemorrhage', *Journal of the Neurological Sciences*, 335(1-2), pp. 64-71. doi: 10.1016/j.jns.2013.08.024/
- Liu, T.-W., *et al.* (2015) 'Fear Avoidance Behavior, Not Walking Endurance, Predicts the Community Reintegration of Community-Dwelling Stroke Survivors', *Archives of Physical Medicine & Rehabilitation*, 96(9), pp. 1684-1690 7p. doi: 10.1016/j.apmr.2015.05.005.
- Lo, R. S., *et al.* (2008) 'Handicap and its determinants of change in stroke survivors: one-year follow-up study', *Stroke (00392499)*, 39(1), pp. 148-153. doi: 10.1161/STROKEAHA.107.491399.
- Mayer, R. and Reid, D. (2004) 'Changes in Autonomy and Participation in Seniors After Stroke: A Pilot Study', *Activities, Adaptation & Aging*, 28(3), pp. 49-70. doi: 10.1300/J016v28n03\_04.

- Mayer, S. A., *et al.* (2002) 'Global and domain-specific cognitive impairment and outcome after subarachnoid hemorrhage', *Neurology*, 59(11), pp. 1750-1758. doi: 10.1212/01.WNL.0000035748.91128.C2.
- Mayo, N. E., *et al.* (2009) 'A longitudinal view of apathy and its impact after stroke', *Stroke; A Journal Of Cerebral Circulation*, 40(10), pp. 3299-3307. doi: 10.1161/STROKEAHA.109.554410.
- Mercer, V. S., *et al.* (2009) 'Step Test scores are related to measures of activity and participation in the first 6 months after stroke', *Physical Therapy*, 89(10), pp. 1061-1071. doi: 10.2522/ptj.20080368.
- Muren, M. A., Hütler, M. and Hooper, J. (2008) 'Functional capacity and health-related quality of life in individuals post stroke', *Topics In Stroke Rehabilitation*, 15(1), pp. 51-58. doi: 10.1310/tsr1501-51.
- Murtezani, A., *et al.* (2009) 'Factors associated with reintegration to normal living after stroke', *Medicinski Arhiv*, 63(4), pp. 216-219.
- Mutai, H., *et al.* (2013) 'Long-term outcome in stroke survivors after discharge from a convalescent rehabilitation ward', *Psychiatry and Clinical Neurosciences*, 67(6), pp. 434-440. doi: 10.1111/pcn.12075.
- Naess, H., *et al.* (2006) 'Health-related quality of life among young adults with ischemic stroke on long-term follow-up', *Stroke; a journal of cerebral circulation*, 37(5), pp. 1232-6. doi: 10.1161/01.STR.0000217652.42273.02.
- Norlander, A., *et al.* (2016) 'Long-Term Predictors of Social and Leisure Activity 10 Years after Stroke', *Plos One*, 11(2), pp. e0149395-e0149395. doi: 10.1371/journal.pone.0149395.
- Obembe, A., *et al.* (2013) 'Community reintegration in stroke survivors: Relationship with motor function and depression', *Hong Kong Physiotherapy Journal*, 31(2), pp. 69-74. doi: 10.1016/j.hkpj.2013.04.001.
- Ownsworth, T. and Shum, D. (2008) 'Relationship between executive functions and productivity outcomes following stroke', *Disability & Rehabilitation*, 30(7), pp. 531-540. doi: 10.1080/09638280701355694.
- Pang, M., *et al.* (2011) 'Development and validation of the Chinese version of the reintegration to normal living index for use with stroke patients', *Journal of Rehabilitation Medicine*, 43(3), pp. 243-50.
- Patel, M., *et al.* (2006) doi: 10.2340/16501977-0660. 'Relationships between long-term stroke disability, handicap and health-related quality of life', *Age and Ageing*, 35, pp. 273-279. doi: 10.1093/ageing/afj074.
- Pedersen, P. M., *et al.* (1996) 'The impact of aphasia on ADL and social activities after stroke: The Copenhagen Stroke Study', *Journal of Neurologic Rehabilitation*, 10(2), pp. 91-96. doi: 10.1177/154596839601000202.
- Pettersen, R., Dahl, T. and Wyller, T. (2002) 'Prediction of long-term functional outcome after stroke rehabilitation', *Clinical Rehabilitation*, 16(2), pp. 149-59. doi: 10.1191/0269215502cr482oa.
- Plante, M., *et al.* (2010) 'Grand rounds. Association between daily activities following stroke rehabilitation and social role functioning upon return to the community', *Topics in Stroke Rehabilitation*, 17(1), pp. 47-57. doi: 10.1310/tsr1701-47.
- Rochette, A., *et al.* (2007) 'Adaptation process, participation and depression over six months in first-stroke individuals and spouses', *Clinical Rehabilitation*, 21(6), pp. 554-62. doi: 10.1177/0269215507073490.
- Rochette, A. and Desrosiers, J. (2002) 'Coping with the consequences of a stroke', *International Journal Of Rehabilitation Research. Internationale Zeitschrift Für Rehabilitationsforschung. Revue Internationale De Recherches De Réadaptation*, 25(1), pp. 17-24. doi: 10.1097/00004356-200203000-00003.
- Rochette, A., Desrosiers, J. and Noreau, L. (2001) 'Association between personal and environmental factors and the occurrence of handicap situations following a stroke', *Disability And Rehabilitation*, 23(13), pp. 559-569. doi: 10.1080/09638280010022540.



- Schepers, V. P., *et al.* (2005) 'Prediction of social activity 1 year poststroke', *Arch Phys Med Rehabil*, 86(7), pp. 1472-6. doi: 10.1016/j.apmr.2004.11.039..
- Schmid, A., *et al.* (2012) 'Balance and balance self-efficacy are associated with activity and participation after stroke: A cross-sectional study in people with chronic stroke', *Archives of Physical Medicine and Rehabilitation*, 93(6), pp. 1101-7. doi: 10.1016/j.apmr.2012.01.020.
- Schuling, J., *et al.* (1993) 'The Frenchay Activities Index. Assessment of functional status in stroke patients', *Stroke; A Journal Of Cerebral Circulation*, 24(8), pp. 1173-1177. doi: 10.1161/01.STR.24.8.1173.
- Seymour, L. M. and Wolf, T. J. (2014) 'Participation changes in sexual functioning after mild stroke', *OTJR: Occupation, Participation And Health*, 34(2), pp. 72-80. doi: 10.3928/15394492-20131217-01.
- Singam, A., *et al.* (2015) 'Participation in Complex and Social Everyday Activities Six Years after Stroke: Predictors for Return to Pre-stroke Level.', *PLOS ONE*, 10(12). doi: 10.1371/journal.pone.0144344.
- Spitzer, J., *et al.* (2011) 'Mild impairment of cognition impacts on activity participation after stroke in a community-dwelling Australian cohort', *OTJR: Occupation, Participation and Health*, 31(Suppl 1), pp. S8-S15.
- Stummer, C., *et al.* (2015) 'Predicting sickness impact profile at six months after stroke: further results from the European multi-center CERISE study', *Disability And Rehabilitation*, 37(11), pp. 942-950. doi: 10.3109/09638288.2014.948137.
- Sturm, J. W., *et al.* (2002) 'Handicap after stroke: how does it relate to disability, perception of recovery, and stroke subtype? The North East Melbourne Stroke Incidence Study (NEMESIS)', *Stroke (00392499)*, 33(3), pp. 762-768.
- Sturm, J. W., *et al.* (2004) 'Determinants of handicap after stroke: the North East Melbourne Stroke Incidence Study (NEMESIS)', *Stroke (00392499)*, 35(3), pp. 715-720.
- Tse, T., *et al.* (2017a) 'Increased work and social engagement is associated with increased stroke specific quality of life in stroke survivors at 3 months and 12 months post-stroke: a longitudinal study of an Australian stroke cohort', *Top Stroke Rehabil*, 24(6), pp. 405-414. doi: 10.1080/10749357.2017.1318339.
- Tse, T., *et al.* (2017b) 'Reduction in retained activity participation is associated with depressive symptoms 3 months after mild stroke: An observational cohort study', *Journal Of Rehabilitation Medicine*, 49(2), pp. 120-127. doi: 10.2340/16501977-2184.
- van der Zee, C. H., *et al.* (2013) 'Participation in the chronic phase of stroke', *Topics Stroke Rehabilitation*, 20(1), pp. 52-61.
- van Mierlo, M. L., *et al.* (2016) 'Quality of Life during the First Two Years Post Stroke: The Restore4Stroke Cohort Study', *Cerebrovascular Diseases (Basel, Switzerland)*, 41(1-2), pp. 19-26. doi: 10.1159/000441197.
- Van Puymbroeck, M., *et al.* (2014) 'The Influence of Mood-Related Variables on Activity and Participation in Individuals With Chronic Stroke', *Topics in Geriatric Rehabilitation*, 30(3), pp. 216-222. doi: 10.1097/tgr.0000000000000030.
- van Straten, A., *et al.* (2000) 'Clinical meaning of the Stroke-Adapted Sickness Impact Profile-30 and the Sickness Impact Profile-136', *Stroke (00392499)*, 31(11), pp. 2610-2615.
- Verhoeven, C. L. M., *et al.* (2011) 'Is cognitive functioning 1 year poststroke related to quality of life domain?', *Journal Of Stroke And Cerebrovascular Diseases: The Official Journal Of National Stroke Association*, 20(5), pp. 450-458. doi: 10.1016/j.jstrokecerebrovasdis.2010.02.018.
- Vincent-Onabajo, G. O., *et al.* (2016) 'Impact of social support on participation after stroke in Nigeria', *Topics In Stroke Rehabilitation*, 23(5), pp. 305-310. doi: 10.1080/10749357.2016.1155279.
- Wade, D., Legh-Smith, J. and Langton Hewer, R. (1985) 'Social Activities after stroke: measurement and natural history using the Frenchay Activities Index', *International Rehabilitation Medicine*, 7, pp. 176-181.

## Appendix E.

### Interview Guide.

#### Introduction

Introduce self and purpose of interview, thank for participation. Check consent and ask for consent form to be signed.

Explain format of the interview

Include:

- length of interview: 1 hour
- Opportunities for breaks
- Record the interview.
- freedom to stop or not answer questions.

#### Topics and possible questions.

Effects of ABI: How have you have been affected by your stroke/head injury (prompts: has it affected you physically, emotionally, mentally?)

Experiences of fatigue: I would like to ask you about your experiences of being tired/fatigued.

What usually happens when you become tired or fatigued (Interviewer listens to the language used to describe fatigue and adopts that language in the remainder of the interview). Probes: What do you expect to happen when you feel tired? What are the signs that you are becoming tired? How does fatigue affect your thinking/speech/mobility?)

Can you tell me about a time or situation when you became very tired? (Probes : What happened? Where were you? What were you doing? Did you realise you were becoming tired. What happened then? Did anyone else notice? What did you do once you were fatigued? How long did it take until you felt rested? What happens after that? )

Fatigue and daily activities: How does fatigue/tiredness affect your day to day routine? (Prompts: Can you give me examples of things that you avoid or do differently because of fatigue? Are there situations that you avoid or that make it worse? Can you give me an example?) .

Adapting and coping. Can you tell me how you usually cope with your fatigue? (What helps you, what doesn't work for you?).

What advice would you give to other people who have brain injury and fatigue?

Is there anything else you have noticed about your fatigue we haven't already spoken about?

Thank you for your time and for taking part in the research.

Tell participant what happens next and ask if they would like a summary of the findings.

**Appendix F** Short demographic questionnaire

Name: \_\_\_\_\_ Date: \_\_\_\_\_

1. What is your current age?
2. What year did you have your brain injury?
3. Did you have a: stroke    head injury    infection    other type of brain injury.  
(please circle the answer which applies to you)
4. If you circled "other", what type of brain injury did you have?
5. If you have experienced more than one brain injury, please state the types of brain injury and the year(s) in which they occurred.
6. Do you live alone?    YES    NO
7. If no", do you live:    with your family    with friends    in a group home  
in a care home.    (Please circle the answer which applies to you)
8. Are you currently:    in paid work    retired    studying  
unemployed
9. What is your ethnic group? Please circle that best applies to you.

A. White British

B Any other White background

B. Mixed ethnic background

C. Asian / Asian British

D. Black / African / Caribbean / Black British

**Appendix G**

**System Usability Scale**

© Digital Equipment Corporation, 1986.

	Strongly disagree				Strongly agree
1. I think that I would like to use this system frequently	1	2	3	4	5
2. I found the system unnecessarily complex	1	2	3	4	5
3. I thought the system was easy to use	1	2	3	4	5
4. I think that I would need the support of a technical person to be able to use this system	1	2	3	4	5
5. I found the various functions in this system were well integrated	1	2	3	4	5
6. I thought there was too much inconsistency in this system	1	2	3	4	5
7. I would imagine that most people would learn to use this system very quickly	1	2	3	4	5
8. I found the system very cumbersome to use	1	2	3	4	5
9. I felt very confident using the system	1	2	3	4	5
10. I needed to learn a lot of things before I could get going with this system	1	2	3	4	5

## Appendix H

### Usability study interview guide.

Introduce the interview:

Introduce self and purpose of interview, thank for participation

Explain format of the interview Include:

- Length of interview: 30 minutes
- Explain that the interview can pause if needed.
- Record the interview.
- Freedom to stop or not answer questions.

### Topics and possible questions.

I am interested in your experience of using the app over the last 4/6 days. Tell me about the first few times the app prompted you? Probes: what happened next? Then what? How did you feel about? What did you notice about?

- start and end times.
- energy levels

Ask about each screen - energy rating. When you were thinking about energy -what were you thinking of?

EMA questions - how well did the options match what you were doing?

PVT test - tell me about your experience of completing the reaction time test.

What happened over the next day(s)? What changes did you notice in how you used the app as time went on?

### Ease of use

How easy or difficult did you find using the app? How did this change over time?

Did you notice the alerts?

### User satisfaction

What did you like about the app? What would you change about it?

Is there anything else you would like to add to our discussion?

What would you like to see from the app

Thank you for taking part in the interview.

## Appendix I

### INSTALLATION INSTRUCTIONS

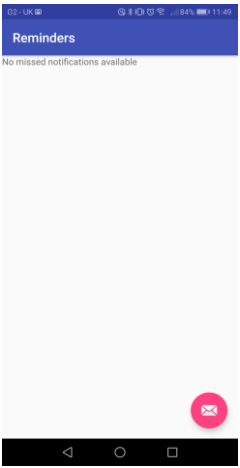
Click on the link sent via email.

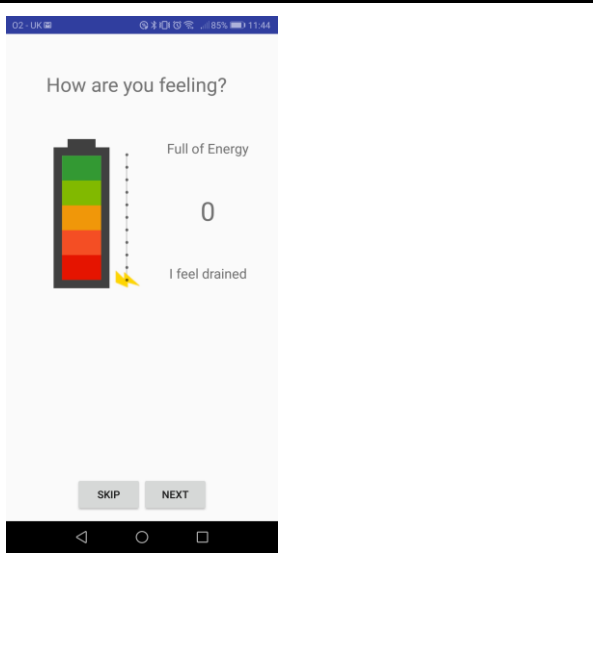
Open with “package installer”

You will see “Do you want to install this application? “. Select “Install”.

You will be prompted to allow access to microphone - select allow/yes

The app should now appear on your phone.

<p>When you touch the fatigue tracker icon you will see this as the first page.</p> <p>You can start the app by touching the envelope icon.</p>	
<p>The next screen is the battery icon.</p> <p>Here you are asked to rate your current energy levels.</p> <p>Slide the lightning bolt to the point that best reflects how you are feeling.</p>	



The next screen prompts you to think about what you have been doing for the last 10 minutes.

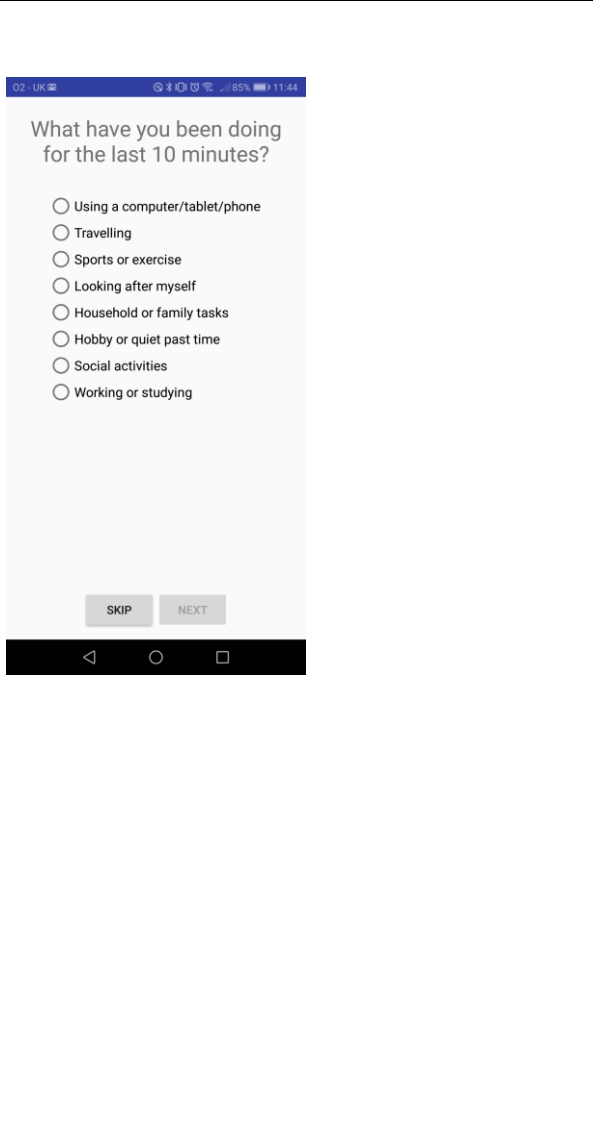
If you were doing more than one thing, select the one that you are most focused on or that you think is the main activity.

For example - if you were out walking but then your phone rings - walking would be the main activity.

If you are on the phone but you pace around whilst talking - being on the phone is most likely the main activity.

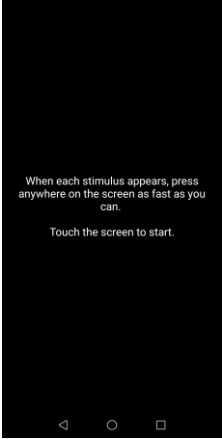
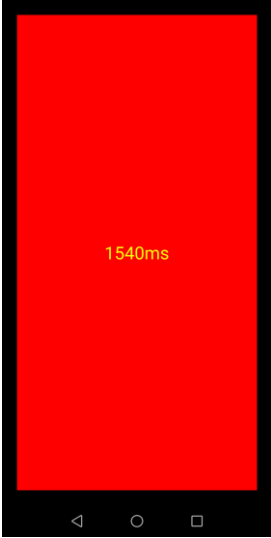
At the moment there is no option to go back a screen if you make a mistake. Choose the closest possible option.

The options will be in a different order each time - this is to avoid people randomly selecting an option.



<p>You will then be taken to the reaction time screen.</p> <p>The reaction time test takes 2 minutes so you have the option to skip this screen if is inconvenient or if you are too tired.</p> <p>Select “next” to start the reaction time test.</p> <p>Just select “skip” and then select “no time” or “too tired”.</p>	 <p>The screenshot shows a mobile application interface. At the top, there is a status bar with the text '02: UK' and various icons. Below that, the screen title is 'Reaction times' followed by the instruction: 'Please follow the instructions on the screen to check your reaction times'. At the bottom of the screen, there are two buttons: 'SKIP' and 'NEXT'. The bottom of the screenshot shows the standard Android navigation bar with back, home, and recent apps icons.</p>
<p>Read the instructions and touch the screen to start.</p>	



	
<p>The stimulus is a number rapidly counting up in milliseconds.</p> <p>Touch anywhere on the screen as soon as you see the number.</p> <p>The screen will then go black - wait for the next red screen and the number.</p> <p>If you touch the screen before the number appears, you will get a “too early” notice.</p> <p>Just continue with the test until you get the final black screen with the following message.</p> <p>“Thank you for participating, you are now finished”</p>	

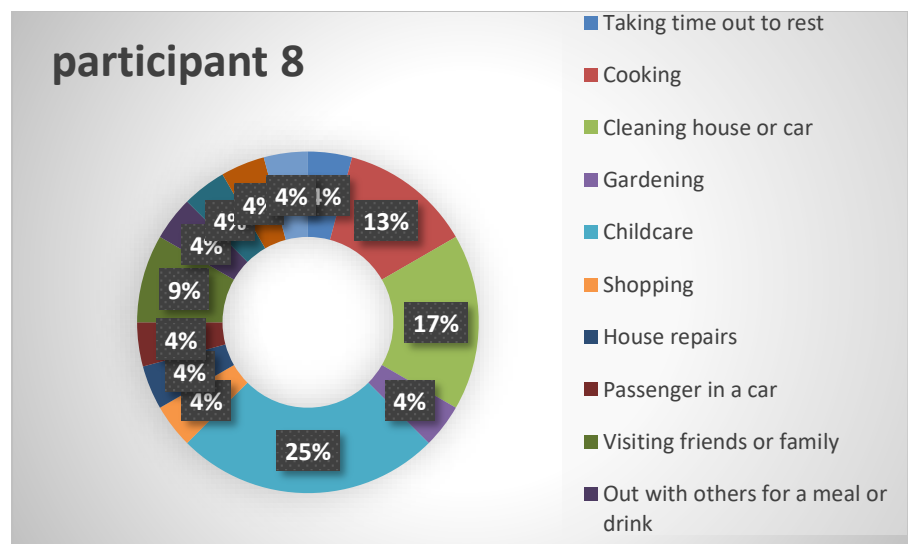
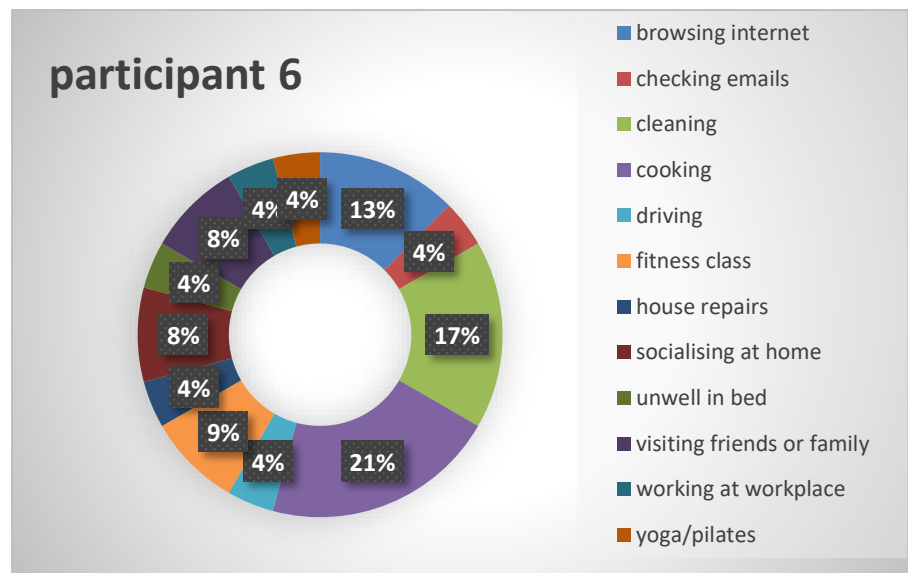
The options for “What were you doing in the last 10 minutes?”

Main screen	Next screen
Looking after myself	Getting washed or dressed Eating Sleeping Taking time out to rest Unwell in bed
Household or family tasks	Cooking Cleaning house or car Gardening Childcare Caring for another adult Financial or administrative tasks Shopping Laundry House repairs
<ul style="list-style-type: none"> <li>Working or studying</li> </ul>	Working from home Working at your workplace In a lesson Studying
<ul style="list-style-type: none"> <li>Travelling</li> </ul>	Driving Passenger in a car Using public transport Cycling Walking

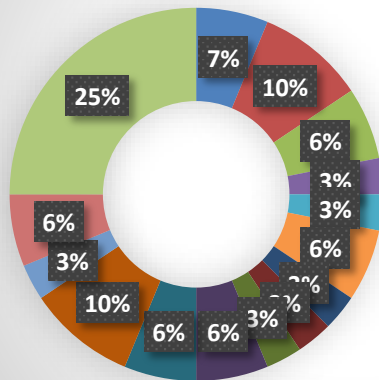
<ul style="list-style-type: none"> <li>• Social activities</li> </ul>	<p>Socialising at home</p> <p>Talking on the telephone</p> <p>Visiting friends or family</p> <p>Out with others for a meal or drinks</p> <p>At the cinema or theatre</p> <p>Watching live sport or music</p>
<ul style="list-style-type: none"> <li>• Using a computer/tablet/phone</li> </ul>	<p>Playing a game</p> <p>Watching videos</p> <p>Checking emails</p> <p>Browsing the internet</p> <p>Reading</p> <p>Listening to music/radio</p>
<ul style="list-style-type: none"> <li>• Sports or exercise</li> </ul>	<p>Walking</p> <p>Jogging/running</p> <p>Cycling</p> <p>Ball game</p> <p>Yoga/Pilates</p> <p>Fitness class</p> <p>Swimming</p>
<ul style="list-style-type: none"> <li>• Hobby or quiet past time</li> </ul>	<p>Watching television</p> <p>Reading</p> <p>Listening to music/radio</p> <p>Playing a musical instrument</p> <p>Art or craft work</p>

**Appendix J.**

Participant's summarised data (participants 6,8,10, 11 and 12).

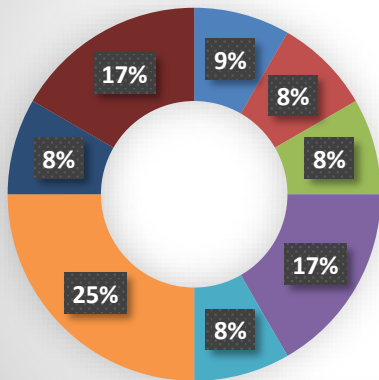


## Participant 10.



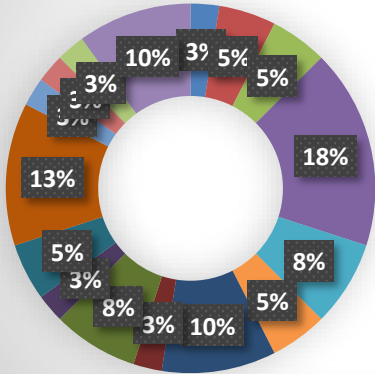
- listening to music/radio
- getting washed/dressed
- eating
- cooking
- cleaning house or car
- shopping
- laundry
- working at workplace
- using public transport
- walking
- visiting friends/family
- going out for meals/drinks
- checking emails
- reading
- yoga/pilates

## Participant 11



- Playing a game
- Getting washed or dressed
- Sleeping
- Working from home
- Using public transport
- Socialising at home
- Browsing the internet
- Watching television

# Participant 12



- Getting washed or dressed
- Eating
- Taking time out to rest
- Cooking
- Financial or administrative task
- Shopping
- Laundry
- Driving
- Passenger in a car
- Walking
- Out with others for a meal or drinks
- Checking emails
- Browsing the internet
- Listening to music/radio
- Yoga/Pilates
- Watching television

**Appendix K** Reported activities and mean daily NRS scores for participants.

Participant 6

Date	Activity	NRS energy	Mean NRS daily score.
06/03/2019	cooking	4	
	driving	0	
	cooking	3	
	socialising at home	5	3
07/03/2019	cooking	4	
	cleaning	6	
	browsing internet	2	
	browsing internet	1	3.25
08/03/2019	cleaning	4	
	cleaning	5	
	socialising at home	4	
	unwell in bed	0	3.25
09/03/2019	visiting friends or family	5	
	house repairs	3	4
10/03/2019	yoga/pilates	5	
	cooking	4	4.5
11/03/2019	cleaning	4	
	fitness class	3	
	cooking	5	3
12/03/2019	visiting friends or family	6	
	fitness class	6	6

Participant 8

Date	Activity	NRS energy	Mean daily NRS score.
09/4/19	Cleaning house or car	5	
	Passenger in a car	5	
	Shopping	4	
	Cooking	4	4.5
10/4/19	Childcare	7	
	Visiting friends or family	6	
	House repairs	5	
	Checking emails	4	
	Cleaning house or car	5	5.4
11/4/19	Cooking	4	
	Childcare	3	3.5
12/4/19	Childcare	5	

	Visiting friends or family	5	
	Childcare	3	4.3
13/4/19	Childcare	6	
	Watching television	6	
	Cleaning house or car	4	
	Cooking	4	
	Out with others for a meal or drinks	3	4.6
14/4/19	Taking time out to rest	4	
	Gardening	4	
	Browsing the internet	3	3.7
15/4/19	Childcare	7	
	Cleaning house or car	5	6

Participant 9.

Date	Activity	NRS energy	Mean daily NRS score.
15/04/19	checking emails	4	
	resting	5	
	eating	5	
	socialising at home	4	
	socialising at home	4	4.4
16/04/19	resting	5	
	washed/dressed	6	
	washed/dressed	6	
	eating	5	
	eating	6	
	sleeping	7	
	sleeping	7	
	walking	5	
	eating	5	
	watching TV	5	
	watching TV	4	
	watching TV	4	5.4
17/04/19	reading	6	
	eating	6	
	sleeping	5	
	socialising at home	6	
	eating	6	
	eating	6	
	watching TV	6	
	resting	6	
	watching videos	6	5.9



18/04/19	fitness class	5	
	fitness class	4	
	reading	5	
	reading	4	
	eating	3	
	sleeping	5	
	reading	5	
	reading	5	
	watching TV	5	
	washed/dressed	4	
	watching TV	5	4.5
19/04/19	walking	5	
	socialising at home	5	
	resting	5	
	watching TV	5	
	walkng	5	
	resting	5	
	watching TV	5	
	checking emails	5	
	fitness class	4	
	watching TV	5	
	watching TV	5	
	watching TV	4	
	resting	5	4.8
20/04/19	fitness class	5	
	browsing internet	5	
	fitness class	5	
	fitness class	5	
	sleeping	5	
	washed/dressed	5	
	eating	5	
	eating	5	
	watching TV	5	
	washed/dressed	5	
	resting	5	5
21/04/19	reading	6	
	checking emails	6	
	fitness class	3	
	watching TV	5	
	sleeping	6	
	resting	5	
	eating	5	
	watching TV	5	
	washed/dressed	5	
	watching TV	5	5.1

22/04/19	socialising at home	4	
	reading	4	
	reading	3	
	sleeping	5	
	sleeping	5	
	checking emails	5	
	watching TV	5	4.4

Participant 10

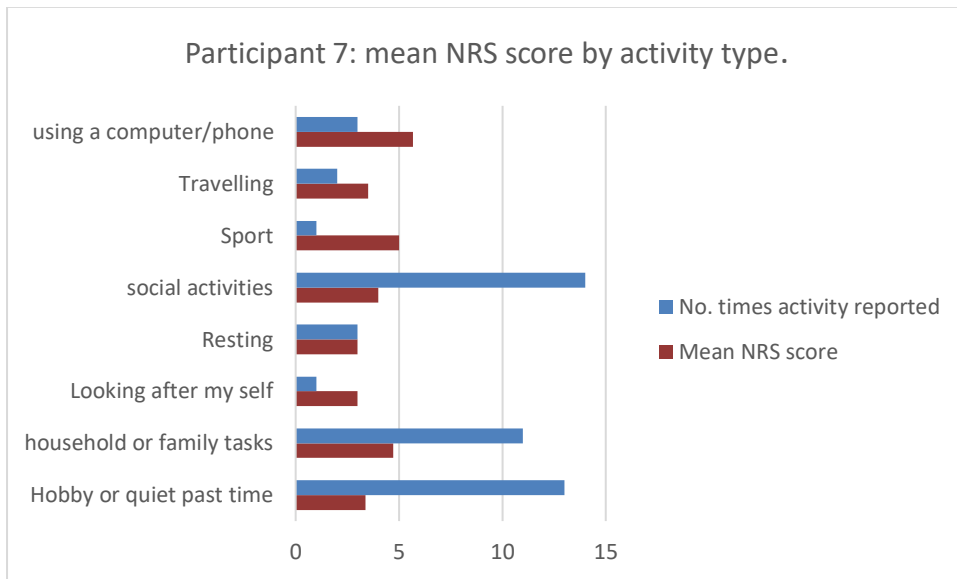
Date	Activity	NRS energy	Mean daily NRS score.
31/05/19	listening to music/radio	8	
	getting washed/dressed	9	7.5
01-Jun	listening to music/radio	8	
	getting washed/dressed	10	
	yoga/Pilates	6	
	visiting friends/family	7	
	getting washed/dressed	4	5
02-Jun	eating	7	
	yoga/Pilates	3	
	cleaning house/car	4	4.7
03-Jun	shopping	7	
	using public transport	9	
	yoga/Pilates	6	
	yoga/Pilates	5	
	out with others drinks/meal	5	
	walking	5	6.2
04-Jun	cooking	3	
	checking emails	0	
	out with others drinks/meal	8	
	out with others drinks/meal	9	
	yoga/Pilates	5	5
05-Jun	shopping	7	
	yoga/Pilates	6	
	visiting friends/family	6	6.3
06-Jun	reading	10	
	reading	7	
	yoga/Pilates	6	7.7
07-Jun	walking	7	

	yoga/Pilates	7	
	eating	0	4.7
08-Jun	laundry	9	
	working at workplace.	10	9

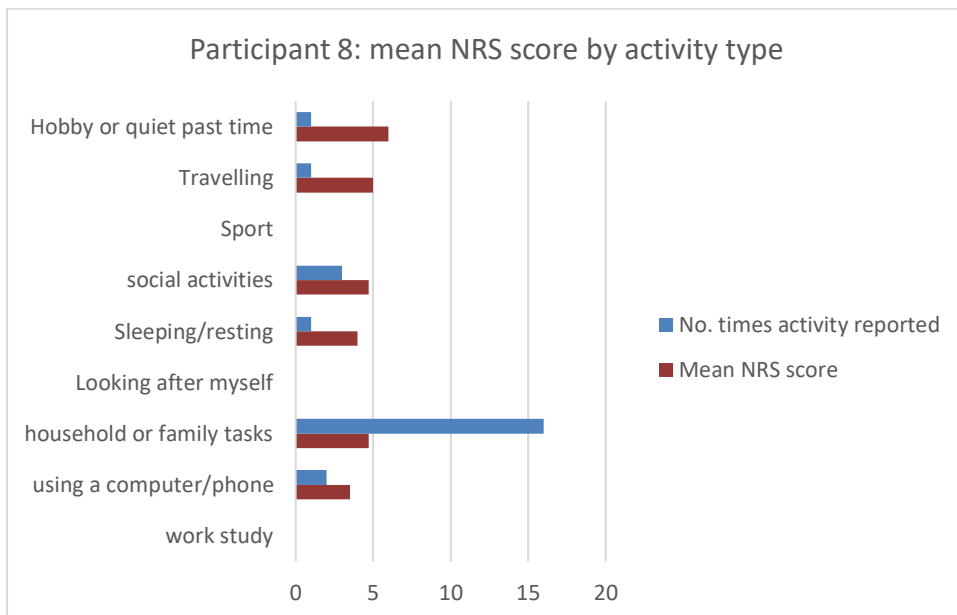
**Appendix L**

**Mean NRS scores by activity type for participants 7,8,9,11**

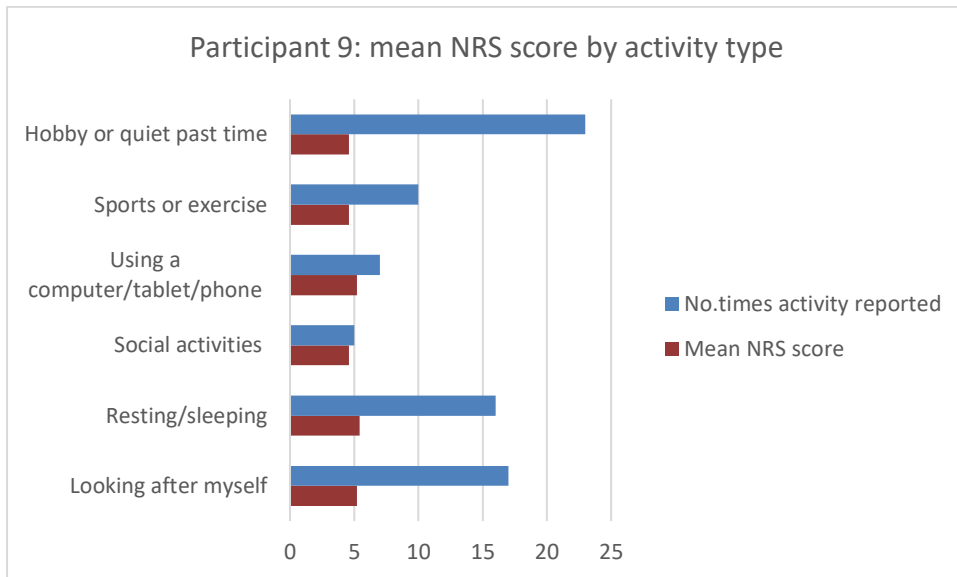
**Participant 7.**



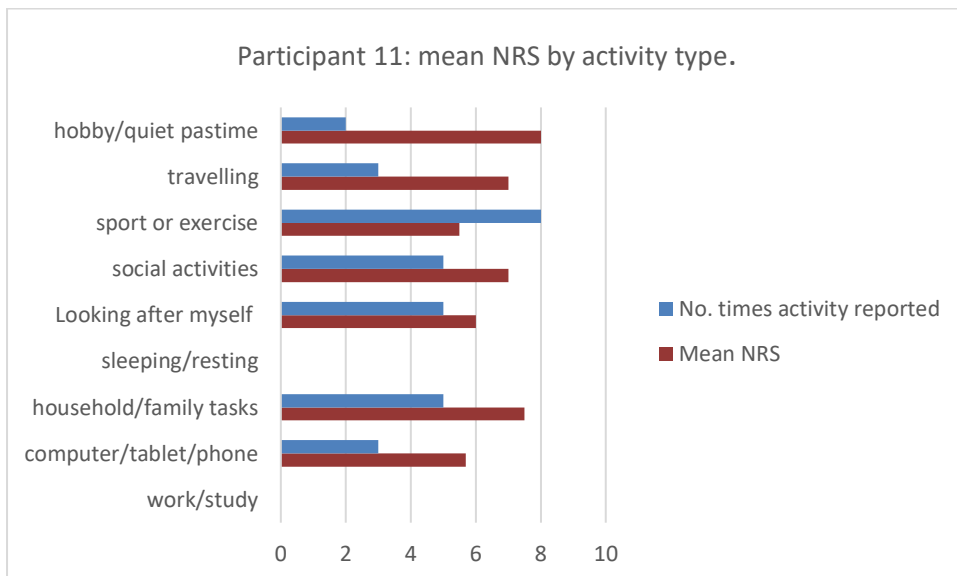
**Participant 8**



### Participant 9



### Participant 11.



*Appendix M Published papers.*

A published article has been removed from this version of the thesis due to copyright restrictions

Ezekiel L, Collett J, Mayo NE et al, *Factors Associated With Participation in Life Situations for Adults With Stroke: A Systematic Review*, Archives of Physical Medicine and Rehabilitation, 100(5), 945-955

doi: 10.1016/j.apmr.2018.06.017

A published article has been removed from this version of the thesis due to copyright restrictions

Ezekiel L, Field L, Collett J et al, *Experiences of fatigue in daily life of people with acquired brain injury; a qualitative study*, Disability and Rehabilitation

doi: 10.1080/09638288.2020.1720318