

THE UNIVERSITY OF HULL

**Examining the experiences of post-ABI and neurological condition sequelae and
workplace disclosure.**

being a Thesis submitted in partial fulfilment of the requirements for the degree of Doctor of
Clinical Psychology in the University of Hull

By

Katherine Watson, BSc Honours (First Class in Psychology, University of York)

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This thesis is dedicated to Vera Watson, for showing everyone around you the meaning of true compassion.

Overview

This thesis portfolio is comprised of three parts, a systematic literature review, an empirical thesis, and appendices.

Part 1 contains a systematic literature review, aiming to explore the experiences of individuals disclosing Multiple Sclerosis (MS) in the workplace. All qualitative data in this area was reviewed and the results of 10 studies were incorporated through a narrative synthesis. Four main themes were generated; Disclosure of MS, Transition in Identity, Group Reactions to the Individual following Disclosure and Locus of Change and Emotional Impact. These results have implications for ongoing support for individuals following an MS diagnosis.

Part 2 contains the empirical study, which aims to understand the properties of the Brain Injury Fatigue Scale (BIFS). This study was comprised of two main aims which contribute to a larger ongoing study, firstly to identify the underlying factor structure within the BIFS and secondly to explore the moderating effects of brain injury on the relationship between fatigue and anxiety, depression, age and gender. The exploratory factor analysis uncovered a two-factor structure, with the main factor of 'general fatigue' explaining the majority of variance within the scale. A secondary factor of 'cognitive and emotional impacts of fatigue' was also identified. Additionally, positive correlations were found between fatigue and age, anxiety and depression. Within this, brain injury was shown to moderate the relationship between anxiety and fatigue. These results inform the ongoing debate around the dimensional nature of fatigue and have implications for fatigue interventions for individuals having sustained a brain injury.

Part 3 contains the appendices. The attached appendices provide supporting documentation for the systematic literature review and the empirical study. Additionally, the appendices contain an epistemological statement and reflective statement written by the chief investigator.

The total wordcount for the portfolio thesis is 32020 (including figures, tables, references and appendices).

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PART ONE

**A Systematic Literature Review of People with MS' Experiences of Disclosure of their
condition within Paid Employment Contexts.**

Katherine Watson*¹, Stephen Evans², Peter M Fleming¹

1. School of Psychology and Social Work, Aire Building, University of Hull, Cottingham Road, Hull HU6 7RX, United Kingdom.
2. York Psychological Medicine. The Old Chapel, Bootham Park. York. YO31 8HE.

*Corresponding Author Email: k.watson-2019@hull.ac.uk

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Please see Appendix C for author guidelines

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Abstract

Background: People with Multiple Sclerosis (MS) face a range of barriers to employment. Previous research has indicated that experiences of disclosure can influence wellbeing and motivations to retain paid employment.

Objective: The review aims to explore individuals' experiences of disclosing MS in the workplace.

Design: A systematic literature review was conducted using Narrative Synthesis.

Methods: The primary researcher generated the search term alongside an experienced reviewer and searched APA PsycInfo, APA PsycArticles, CINAHL, Academic Search Premier and MEDLINE. The primary researcher screened the articles by title and abstract, before reading 42 articles in full. A final pool of 10 articles which met the inclusion criteria were included. Each was reviewed for quality and the data were examined through Narrative Synthesis.

Main Results: Four central themes emerged: Disclosure of MS, Transition in Identity, Group Reactions to the Individual following Disclosure, and Locus of Change and Emotional Impact

Conclusions and Implications for Future Research: This review indicates that disclosure has a significant impact on the workplace relationships and identities of individuals with MS and highlights the importance of considering wider factors when supporting individuals through their time in employment.

Keywords: Multiple Sclerosis, Disclosure, Systematic Literature Review, Employment & Experiences.

Introduction

Multiple Sclerosis (MS) is a chronic inflammatory disease which causes demyelination of the central nervous system. It has a range of symptoms including fatigue, changes in bladder function, cognition, visual disturbances, and motor difficulties [1]. Estimations of global prevalence fall around 2.8 million individuals, with a greater prevalence in women [2,3]. Most commonly, individuals are initially diagnosed with a relapsing-remitting course of MS, which progresses to secondary progressive MS for many [4].

The majority of individuals diagnosed with MS are between the ages of 20 and 40 and are in paid employment at the time of diagnosis [5,6]. Many individuals remain in employment after receiving an MS diagnosis. The literature indicates a higher quality of life and physical health for those who remain in employment [7,8]. However, people with MS report facing numerous barriers to employment across a variety of domains, including individual, cognitive, physical, social, legislative and contextual factors [9,10,11,12]. Because of this, some people with MS report that they cannot sustain employment, which is reflected in the estimated employment rates in Europe ranging from 30.4% to 42.1% for people with MS, compared with 90.78% for the general population during a similar time period [13,14].

Due to the nature of MS, some individuals have the ability to choose whether to disclose their diagnosis for a period of time. However, to access many types of employment support individuals must often disclose their needs, symptoms or diagnosis. Diagnostic disclosure has been represented as a continuum, with an individual choosing who to disclose to and determining how much information they wish to share [15]. The Disclosure Processes Model proposes that disclosure is an ongoing process, with regular opportunities for disclosure, particularly following a change in audience or symptoms [16].

One prominent discourse around disclosure throughout the literature is people's experience of stigma and discrimination [17,18], with up to 79.2% reporting some form of stigma [19]. People with MS have reported discrimination from both colleagues and employers following diagnostic disclosure [21,22,23,24]. This has been indicated as a factor in the decision to disclose and highlights the need for a greater understanding of people with MS' experiences surrounding disclosure.

A recent review [25] incorporated the experiences of disclosure of people living with invisible identities in a workplace setting into explanatory model. This model was based on two prior key models around disclosure, the Disclosure Process Model (DPM) [16] and the Disclosure Decision Making Model (DDMM) [26]. These models highlight the influence of environment, prior experience and individual factors relating to the self and others. The review also emphasised the circularity of the disclosure process and highlighted other impactful variables such as age, geographical location, disability type and gender and intersectional identity into the overall experience of disclosure. Many people with MS experience visible signs over time, therefore their experience of disclosure and support needs may differ from other invisible identities. Hence, this generalist model should therefore be complimented by narrower explorations of disclosure within disability types.

The available literature was scoped and no current review was found which focuses on the qualitative literature exploring people's lived experience of people disclosing their MS in the workplace. The review will focus on qualitative studies in order to understand the individual's experiences within a richer context. For the current review, 'employment' was defined as 'occupational role where one is paid, irrespective of number of hours or work environment'. Disclosure in this review is defined as 'purposefully sharing previously unknown information regarding either diagnosis or symptomology to one or more persons'. Therefore, this review

aims to provide an contemporary, systematic review of people with MS' experience of disclosure and social support at work by answering the question “What are the experiences of disclosure in the workplace for individuals with MS?”

Method

Search Terms and Strategy

A systematic search was conducted between February 2022 and March 2022. Five electronic databases were used to conduct the search: APA PsycInfo, APA PsycArticles, MEDLINE, CINAHL Complete and Academic Search Premier. These were selected to maximise the likelihood of finding all relevant articles across health and psychology related topics.

A scoping search was conducted in January 2022 in order to assess appropriate search terms. The terms were also discussed with a secondary researcher (PF). A protocol which included a research question, inclusion and exclusion criteria were generated. The final search terms used in March 2022 were:

“multiple sclerosis” OR “demyelinating disease*” OR “encephalomyelitis disseminata”

AND

(title) job* Or work* OR employ* OR occupation* OR career* OR profession* OR trade* OR
business* OR vocation* OR career* OR labour* OR labor*

AND

experience* OR attitude* OR perception* OR view* OR feel* OR change* OR thought* OR
relations* OR conceptualisation* OR qualitative*

In order to ensure the quality of the literature found, the limiter “peer reviewed articles” was used. As the primary researcher was only fluent in English, the search pool was limited to papers written

in English. To narrow the search to articles focusing on employment settings, the second term was limited to 'title'.

Selection

The primary researcher reviewed the titles of all articles generated in the search for relevance to the current research question and duplicate papers were removed. If there was uncertainty or ambiguity in the title, the abstract or in some cases, the full article was read. Articles identified during this screening processes were reviewed, and the inclusion criteria were applied.

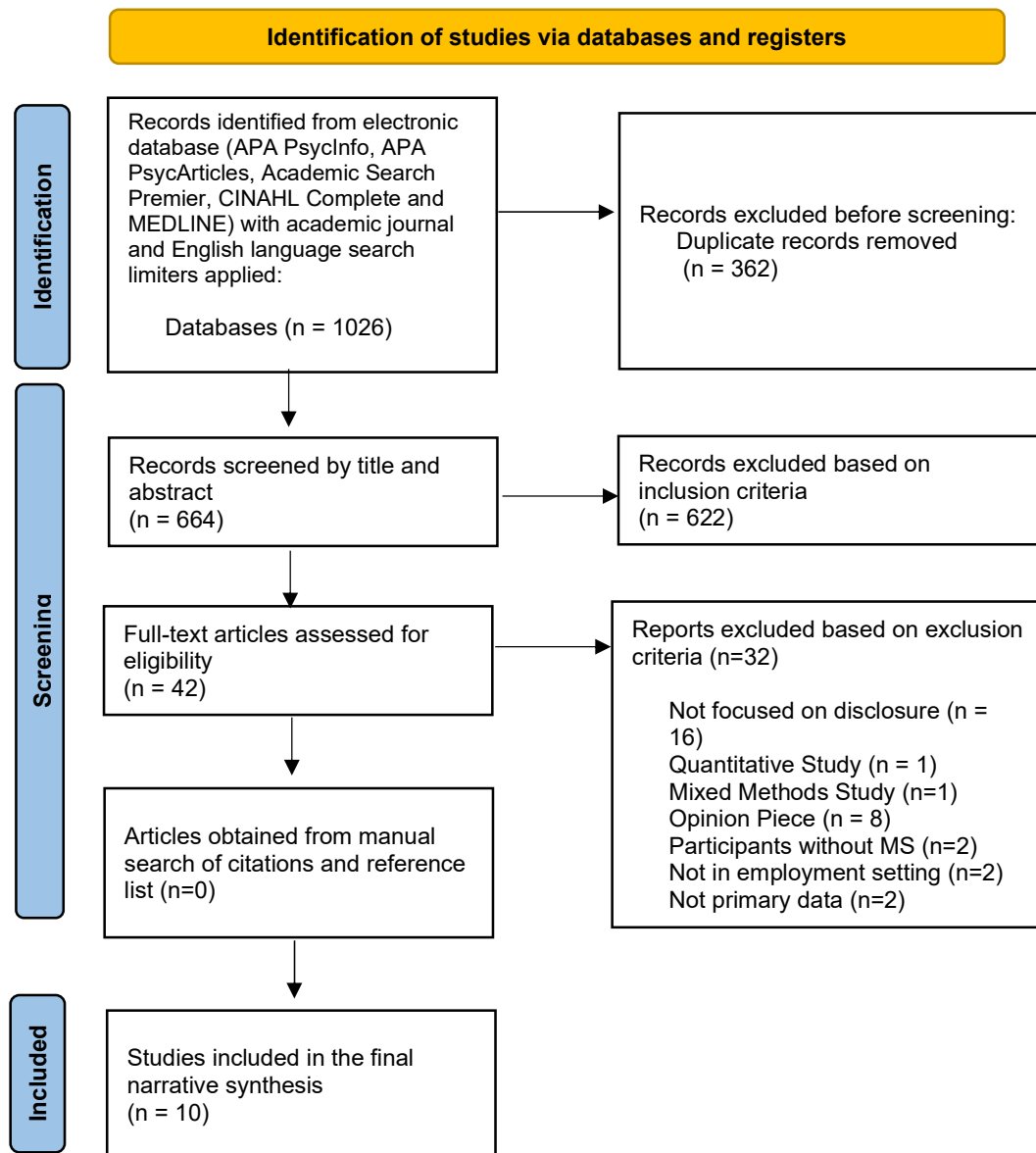
The following inclusion criteria was applied for the search, (1) All participants were diagnosed with MS, (2) Contained self-report data of the participants' experiences of disclosure in a paid employment context, (3) Results provided qualitative self-report data, (4) Papers providing primary data were published in peer reviewed journals to ensure quality and (5) The paper is written in English to minimise misinterpretation errors.

Papers were excluded if they met the following criteria, (1) Results aim to evaluate assessments or interventions, (2) Position or commentary papers, (3) Papers incorporating fictional data or (4) Quantitative or mixed methods results.

Articles which appeared to meet the inclusion criteria were reviewed in full by the primary researcher. Studies which did not meet these criteria were excluded at this stage. The reference sections of the final pool of papers was hand searched in order to identify other relevant articles. The same selection strategy was completed with these papers. Figure 1 provides a summary of the search and selection processes.

Figure 1

PRISMA Flow Diagram Demonstrating a Summary of the Article Screening and Selection Process [27].



Data Analysis

The Booth et al. [28] guidelines were consulted to determine the appropriate method of analysis. As the aims across the included papers were heterogeneous, thematic synthesis was deemed inappropriate as the final step aims to develop new constructs and hypotheses [29,30,31]. Meta-ethnography was considered; however, this aims for the researcher to re-interpret the data created by the authors, which was not appropriate as some of the data did not contain rich quotations [32]. Therefore, a narrative synthesis was selected with the aim of ‘telling the story’ and the Popay et al. [31] protocol was followed. Each paper was read several times by the primary researcher and relevant findings were extracted to generate key themes. The primary researcher reflected on their position and themes were triangulated through supervision throughout the research to maintain quality. The key themes were identified through the lens of the primary researcher, a white British cis-gender female in employment in clinical and academic settings and not diagnosed with MS.

Results

Data Extraction and Quality Assessment

After the search was completed, relevant information was extracted from each article. The full details of each article, including the year of publication, title etc was summarised in Table 1.

The quality of each included article was assessed using the National Institute for Health and Care Excellence quality assessment checklist (NICE, 2012; See Appendix D). This checklist was chosen in order to evaluate the ethical nature, rigorousness, trustworthiness, reliability, and validity of articles with a range of qualitative methods. It constitutes 16 questions across a range of topics in order to get an overall quality rating of ++, + or -. In order to assess interrater reliability through the consistency of quality assessment rating, three of the 10 included studies were randomly selected and reviewed for quality by an independent third party. The third party gave the same overall rating to the studies, and within the summary any discrepancies on individual questions were discussed and a joint resolution was reached.

Overview of included studies

270 participants were involved across the 10 studies [33-42] which met the inclusion and exclusion criteria for this study. Studies varied in their aims (see Table 1).

Overall, 198 Women and 53 Men participated in the studies, the gender identities of 19 participants were not disclosed. Of those not disclosed, 15 were participants involved in Reed et al. [33] study. Sample sizes in the included studies varied significantly from 6-72 participants. The studies were published between 2004-2021.

Three studies detailed the participants' individual disease courses, with 58 being diagnosed with Relapsing-Remitting Multiple Sclerosis 8 with secondary progressive, 2 with primary progressive and 2 being diagnosed with other courses of MS.

Three studies reported the ethnicities of their participants. Reed et al. [33] reported 25.7% of their participants as from BAME backgrounds. Bogenschutz, Rumrill, Inge and Hinterlong [34] reported that 66.6% of their sample was Caucasian, 22.2% were African American and 3.7% were from mixed heritage backgrounds and they did not report the ethnicities of 7.4% of their participants. Kruger & Coetzee [35] reported 100% of their sample as white.

Studies included data collection in both individual interviews [35,36,37,38,39,40] and focus groups [33,34,41] which were conducted in person, via telephone or via video call. Kirk-Brown & Van Dijk [42] used both individual interviews and focus groups in their data collection. Interviews ranged in length from 25 minutes to 3.5 hours and focus groups ranged from 60 to 120 minutes. Focus groups contained between five and 11 participants.

The studies utilised a range of qualitative methodologies, including Interpretative Phenomenological Analysis [36], Narrative Analysis [33], Heideggerian Phenomenology [38], Content Analysis [34,41], Thematic Analysis [35,37,39,40] and Inductive Thematic Approach [42]

Data collection took place in Australia [38,42], Canada [37], the Netherlands [39], South Africa [35], USA [33,34,36,41] and one did not explicitly mention sampling or data collection locations [40].

The employment roles were described in three studies and included office environments, University environments, schools, marketers, IT, healthcare [35,36,37].

Table 1*Overview of Studies Included in the Review.*

Author(s), Year of publication, Title	Research Aims	Sample characteristics	Design and Analysis	Relevant themes Identified*	Quality Assessment
Bogenschutz, Rumrill Jr, Seward, Inge & Hinterlong [34] Barriers and facilitators to employment among Americans with MS	To examine the barriers and facilitators to employment for people with MS	Sample size: n=27 (n = 19 Females, n=6 Males) Race and Ethnicity: n=18 Caucasian, n=6 African American, n=1 Multiple Heritage background Age range: 26-61 years MS type: Not reported Time since diagnosis: 0-21 years Employed status: Not reported Occupational role or setting: Not reported Disclosure status: Not reported Country: USA	Sampling: taken from sample of a larger study of physical disabilities (undefined). Email sent to 5 national organisations, including one MS society Method: Focus groups via telephone. Approximate duration of 60 minutes Data Analysis: Content Analysis	1. Facing future uncertainty a. Prospect of future decline b. Cognitive Changes 2. Feeling a sense of loss a. Competency questioned b. Self-confidence lowered c. Career changes 3. Navigating the workplace a. Accommodations b. Learning to cope 1. Benefits eligibility	++

<p>Gill & Hynes [40]</p> <p>Disclosing a diagnosis in the workplace: perspective of people with multiple sclerosis</p>	<p>To identify reasons for and against disclosure of MS diagnosis at work. Explore impact on relationships and engagement of disclosure or non-disclosure</p>	<p>Sample size: n=6 (n=3 Females, n=3 Males)</p> <p>Race and Ethnicity: Not reported</p> <p>Age range: 26-56 years</p> <p>MS type: Not reported</p> <p>Time since diagnosis: 2.5 to 27 years</p> <p>Employed status: n=6 in employment.</p> <p>Occupational role or setting: Not reported</p> <p>Disclosure status: n=4 disclosed.</p> <p>Country: Not reported</p>	<p>Sampling: Typical case purposeful sampling</p> <p>Method: Individual semi-structured interviews, via video call, telephone and face to face</p> <p>Data analysis: Reflexive thematic analysis</p>	<ol style="list-style-type: none"> 1. Accommodations 2. Workplace relationships 4. Balancing work and home life 	<p>++</p>
<p>Johnson et al. [36]</p> <p>The cost and benefits of employment: a qualitative study of experiences of persons with multiple sclerosis</p>	<p>To explore the benefits and barriers to employment experienced by people with MS</p>	<p>Sample size: n=16 (14 Females, 2 Males)</p> <p>Race and Ethnicity: Not reported</p> <p>Age range: 27-62 years</p> <p>MS type: Not reported</p> <p>Time since diagnosis: 4-12 years</p> <p>Employed status: n=10 in employment</p>	<p>Sampling: newsletter to MS associations, counsellors, MS clinic nurses and word of mouth</p> <p>Method: Semi structured interview</p> <p>Data Analysis: IPA</p>	<ol style="list-style-type: none"> 2. The cost-benefit economy of working <ol style="list-style-type: none"> a. The value of work b. The cost of work c. Work is therapeutic 3. Fatigue and cognitive changes <ol style="list-style-type: none"> a. Explaining fatigue: the MS perspective b. Fatigue alters thinking: thinking is hard work c. Fatigue as a surrogate for cognitive change 4. Stress in the workplace <ol style="list-style-type: none"> a. Stress is a feeling influenced by the work environment 	<p>++</p>

		Occupational role or setting: teacher, volunteer coordinator, administration, communications, software engineer, management, systems analyst, private investigator and financial sector.			<ul style="list-style-type: none"> b. Exceeding your resources c. Stress interferes with performance at work
		Disclosure status: Not reported			<ul style="list-style-type: none"> 5. Accommodations made to address barriers. <ul style="list-style-type: none"> a. Concerns about others' reactions b. Providing what is needed c. Work outside of workplace
		Country: USA			
Kirk-Brown & Van Dijk [42]	To examine perspectives of people with MS on relationship between disclosure, psychological safety, work efficacy and intention to leave employment	<p>Sample size: n=40 (28 Females, 12 Males)</p> <p>Race and Ethnicity: Not reported</p> <p>Age range: 18-65 years</p> <p>MS type: 73% RRMS</p> <p>Time since diagnosis: 1-30 years</p> <p>Employment status: 95% in employment</p> <p>Occupational role or setting: 43% large organisations</p>	<p>Sampling: letters and emails</p> <p>Method: Focus groups, n=15 participants in 3 focus groups. Duration 1-2 hours.</p> <p>Interviews: 25 participants in individual interviews (duration 30-60 minutes).</p> <p>Data Analysis: Grounded theory</p>	<ul style="list-style-type: none"> 1. Disability focused responses <ul style="list-style-type: none"> a. Discrimination <ul style="list-style-type: none"> i. Lower psychological safety ii. Higher turnover b. Paternalism <ul style="list-style-type: none"> i. Lower psychological safety ii. Lower Turnover 2. Ability focused Responses <ul style="list-style-type: none"> i. Higher Psychological Safety 1. Lower Turnover 	++

Country: Australia					
Kruger & Coetzee [35]	To examine experience of MS in South African office environment, the challenges and coping mechanisms	Sample size: n=7 (7 female, 0 Male)	Sampling: flyers, contact MS society, MS social media group.	1. Bringing MS into the workplace	++
Living with Multiple Sclerosis in South Africa: how is Multiple Sclerosis experienced in the workplace?		Race and Ethnicity: n=7 white	Data Collection: Semi Structured interviews lasting on average 40 minutes, with interviews ranging from 17 to 51 minutes	a. Fearing the consequences of disclosure b. Voluntary disclosure c. Involuntary disclosure	
		Age range: 27-46 years		2. Discussing accommodations with employers	
		MS type: n=6 diagnosed with RRMS, n=1 malignant MS		a. Getting to know MS b. Changing perspectives c. Coping with Ms in the workplace d. Discussing accommodations with employers	
		Time since diagnosis: 0.16-5 years	Data Analysis: Thematic analysis	3. Preparing for the future	
		Employed status: n=7 in employment		2.	
		Occupational role or setting: Office setting			
		Disclosure status: Not reported			
Country: South Africa					
Lee, Ditchman, Thomas & Tsen [41]	Explore the experiences of microaggressions experienced by people with MS at work, and the consequences on distress, relationships and coping strategies	Sample size: n=29 (n=22 Females, n=7 Males)	Sampling: email, website, local support groups, social media and print advertising through flyers	1. Microaggressions and distress	++
Microaggressions experienced by people with multiple sclerosis in the workplace: An exploratory study using Sue's taxonomy		Race and Ethnicity: Not reported	Method: 8 Focus groups via online video call and in person	a. Uncertainty of symptoms b. Job security	
		Age: range 25-62, average 47.76		2. Work related behaviours and retention	
		MS type: 83.8% RRMS	Data Analysis: Content Analysis	a. Work hours b. Decision to leave	
				3. Workplace relationships	
				a. Social distancing b. Ambiguity c. Positive relationships and attitudes	
				4. Coping strategies	

		Time since diagnosis: Not reported		a. Support group b. Meditation and exercise c. Emotional coping and locus of control d. Family support e. Pets f. Substance use g. Humour h. Creative activities i. Religion	
		Employed status: Not reported			
		Occupational role or setting: Not reported			
		Country: USA		3.	
Meide, Gorp, van der Hiele, & Visser [39]	To examine people with MS's perspectives on the meaning of work, the barriers and facilitators to employment	Sample size: n=19 (n=11 Female, n=6 Male, n=2 Not disclosed)	Sampling: Letters sent to outpatients from neurology department, newsletter, from prior study	1. Becoming familiar with the disease 2. Adjusting expectations 3. Having an understanding and realistic line manager 4. Seeing work as meaningful life activity 5. Strategic consideration	++
Always looking for a new balance": toward an understanding of what it takes to continue working while being diagnosed with relapsing-remitting multiple sclerosis		Race and Ethnicity: Not reported	Method: Semi structured interviews.		
		Age range: 29-55 years	Interview length: 40-95 minutes (average 61 minutes)		
		MS type: Not reported			
		Time since diagnosis: 2-32 years	Data Analysis: Thematic analysis		
		Employment status: 100% employed. Full time, n=14			
		Occupational role or setting: Not reported			
		Disclosure Status: not reported			
		Country: Netherlands			

<p>Reed, Meade, Jarnecke, Rumrill & Krause [33]</p> <p>Disclosing disability in the employment setting: Perspectives from workers with multiple sclerosis</p>	<p>To identify factors which impact decision to disclose MS diagnosis at work and the consequences of disclosure</p>	<p>Sample size: Two differing sample sizes are reported throughout the paper, n=72 and n=74. (n=57 Females)</p> <p>Race and Ethnicity: 25.7% BAME</p> <p>Age range: 20-81 years</p> <p>MS type: Not reported</p> <p>Time since diagnosis: 0-44 years</p> <p>Employment status: employed 57.7%, 39.4% unemployed, 2.8% retired</p> <p>Occupational role or setting: Not reported</p> <p>Country: USA</p>	<p>Sampling: MS advocacy and support groups</p> <p>Methods: 8 focus groups, with 5 to 11 participants in each group</p> <p>Data Analysis: Narrative analysis</p>	<ol style="list-style-type: none"> 1. Decision to disclosure <ol style="list-style-type: none"> a. Disclosing to explain, prepare, or educate b. General disclosure, no concerns c. Limiting, delaying, or deciding not to disclose d. Unsure about future disclosure were placed. 2. Consequences of disclosure <ol style="list-style-type: none"> a. Positive and supportive reactions b. Mixed or variable reaction in the same work environment c. No real reaction, positive or negative d. Leading to termination of employment 	<p>-</p>
<p>Stone, Crooks & Owen [37]</p> <p>Going through the back door: Chronically ill academics' experiences as 'unexpected workers'</p>	<p>Investigating the barriers and facilitators of seeking workplace accommodation. Explore relationships between experiences of accommodation, disclosure and gender</p>	<p>Sample size: n=35 (25 Females, 10 Males)</p> <p>Race and Ethnicity: Not reported</p> <p>Age range: 33-72 years</p> <p>MS type: Not reported</p> <p>Time since diagnosis: Not reported</p>	<p>Sampling: Snowball sampling and Print adverts</p> <p>Method: Individual semi structured via telephone, duration range 30-90 minutes</p> <p>Data analysis: Thematic analysis</p>	<ol style="list-style-type: none"> 4. Reasons for not pursuing accommodations 5. Surreptitious inquiries regarding accommodation 6. Responses to request for accommodations 3. Disclosure status and getting needs accommodated 	<p>++</p>

		Employment status: n=28 in employment, n=7 retired			
		Occupational role or setting: Canadian University			
		Country: Canada			
Vickers [38]	Exploring what work is like for people with MS	Sample size: n= 19 (n=12 Females, n=7 Males)	Sample: support groups and print advertising	1. I'm fine 2. I'm happy 3. I'm better than the others	-
Dark secrets and impression management: workplace masks of people with multiple sclerosis (MS)		Race and Ethnicity: Not reported	Method: individual interviews, duration of 45 minutes to 3.5 hours		
		Age range: Not reported	Data Analysis: Heideggerian Phenomenology		
		MS type: Not reported			
		Time since diagnosis: Not reported			
		Employed status: Not reported			
		Occupational role or setting: Not reported			
		Disclosure status: 100% disclosed to employer			
		Country: Australia			

*Numbers relate to main themes reported in the paper. Letters refer to subthemes within the general theme categories.

Methodological Quality Assessment of Included Studies

Overall, the included studies were rated as being of good quality. Quality assessment scores are shown for each study in Table 1. Eight articles received the highest quality rating (++), as they provided sufficient participant data through a rigorous and defensible procedure and analysis [34,35,36,37,39,40,41,42]. Vickers [38] received the quality rating of “-” as aims and role of the researcher were clearly explained, however there was not enough detail on participant demographic information to give context to the results and there was no mention of reflective practice or triangulation of the data. Reed et al. [33] received a “-” due to lack of information on data analysis methodology. All papers provided clear aims which were appropriate for qualitative methodologies used.

Detailed information about participants provides context through which qualitative data can be understood. Most studies were clear about their rationale for sampling individuals with MS, however, only three studies detailed the MS types of their participants. All studies provided information about participants’ gender. Within this, Reed et al. [33] only reported the number of female participants in the study, and Bogenschutz et al. [34] did not report demographic information on two of the 27 participants. Only three studies provided information on participants’ races or ethnicities. Most studies discussed the time since onset of MS. Four studies mentioned the occupation roles of the participants.

Many of the studies mentioned practicing reflexivity during the data analysis. Nine studies had multiple researchers involved in data analysis and described using the research team to triangulate results. No studies mentioned the epistemological positions of the researcher(s).

Nine studies described gaining consent from participants and three detailed discussing anonymity or confidentiality with participants.

Due to the lack of literature which met the inclusion criteria of this review, it was inappropriate to exclude papers based on quality assessment. Quality was considered during the interpretation of results.

Narrative Synthesis

The four themes generated are representative of the social experiences narrated across the 10 included articles.

1. Decision to disclose

The first theme encapsulates the factors considered during the individual's decision making. Within this theme, participants described personal motivators and barriers which were weighed up during the decision to disclose. Individuals based these on their expectations of others, the narratives around MS and disability and their anticipation of future losses and gains.

One motivating factor mentioned across eight articles was wanting to inform, educate and prepare others on the impacts of MS on their work [33,34,35,36,37,38,39,41]. These elements spanned across time, with reference to addressing past misinformation [35], present misunderstandings [39] and to prevent or prepare for future changes [33]. One participant reflected on the link between the invisibility of MS and their role in describing their experiences to others:

“If you do not show them what’s really going on inside you, you cannot get the understanding of your colleagues.” (2 p11)

Some articles explicitly mentioned this was to benefit other people, relating to a sense of obligation and responsibility:

“I knew I was gonna have to quit teaching (...) But I went ahead and told my employer in May that I probably wouldn’t be comin’ back the next year. And I jus’ kinda wanted to prepare him.”

(33 p177)

A further motivating factor mentioned in three of the articles was that individuals disclosed as a means of accessing accommodations, support or to transition in role [33,35,40]. Many participants explained that they chose to not disclose their MS diagnosis until they perceived themselves as requiring accommodations to remain in employment [33,37,41].

“So, they ah allowed me to work less hours, allowed me to do more stuff in the office, not having to go out to clients, they really adapted my workload to suit my medical requirements. So, they were fantastic.” (40 p4)

Across six of the articles, anticipation of the reactions of others influenced participants’ decision to disclose [33,35,36,38,40,42]. Participants anticipated negative consequences to disclosure, with both implicit and explicit references to fear of discrimination which could lead to a loss in financial security, losing job, barriers to promotion and changes in perception [33,35,36,40,42]. One participant reported disclosing their MS diagnosis as they anticipated an understanding response [33].

“I was afraid that if I told him that he will say “no but if you can’t do your job then sorry” (35 p2012)

Following a period of concealment, participants reported being unable to conceal their MS, leading to a lack of choice over disclosure. This was linked to external factors such as medical appointments, obtaining accommodations or observation of physical changes [33,36,40].

“And I didn’t want to tell her, but kept diggin’ and prying and askin’ ‘Is somthin’... ” So I said, ‘I didn’t wanna tell you, but I have MS. And that’s probably what’s goin’ on right now.’ (33 p178)

In other instances, participants recalled that disclosure was not their choice due to others sharing this information for them [33,40]. Within the articles reviewed, third party information sharing was generally presented as negative:

“And I get really pissed when they’ve heard already from someone because that is not their business. I just don’t like it. It’s up to me to make the decisions and not for somebody to be gossiping or whatever.” (33 p179)

Many individuals reported that the process of disclosure impacted their wellbeing [36,40]. Within this, individuals reported the experience of concealing their diagnosis as a burden [40], whereas other participants indicated that continual disclosure was burdening [36].

“I do know people who won’t disclose because of negative, if anybody walks in here and tells you they are not disclosing, that’s an awful burden to carry into work every day. People have to know it; they have to know that you are.” (40 p5)

2. Transition in Identity

Often following disclosure, people with MS reported a change in their social identity [33,34,35,36,37,38,40,41,42]. Participants described the people around them overgeneralising their experiences to be solely and directly related to MS, while ignoring other potential wider or contributing factors [33,40].

“I wanted to know that not all my symptoms are MS. There are some days I’m tired, and it’s not my MS. I didn’t want, ‘Oh, well, that’s why she’s doing that. That’s why she’s doing this.’”

(33 p178)

Participants linked the expectations of others to an alteration in their identity. Generally, this new identity was focused on a perceived reduction in their ability to perform tasks relevant to their work, with some participants recalling a disregard towards previous perceptions of professionalism or capability [42]. However, some participants reported that their workplace adopted an ability focused approach where perception of individuals was not limited [42].

“I don’t want people to see me as somebody with a disability, and it probably goes back to ... the time when I was diagnosed when the people close to me ... would sort of call up and say, ‘How are you feeling today, how are you feeling?’ instead of you know the casual, ‘Hi, how are,’ – it was like, ‘Are you okay, are you okay?’ and it was this, this whole like tiptoeing around me that I didn’t – I didn’t want to take on the illness role, like the sick role.” (37 p162)

Many participants stated that others’ perceptions of them had an influence on their self-perception and wellbeing [37,38,39,40].

“Not feeling worthy... like I’m not as good as anybody else...” (42 p1629)

Some people with MS adapted their behaviour to manage other’s perception of them, including increasing their working hours to increase work output [36,40], faking confidence [37], pretending to not be impacted by MS [37,38,40], making their own accommodations [38,40] and attempting to do more work than others [38,41].

“Yes! ... I’m always proving that I’m capable. You know, if I was told to photocopy, for example, a hundred copies, I’d probably photocopy two hundred, just to prove that I can do it, “And here’s

some more just in case” ... I don’t want anyone to think that I’m not up to speed or up to scratch, yes. So I probably do take on more work than I need to or I should.” (38 p187)

3. Group Reactions to the Individual following Disclosure

Following disclosure, participants recalled the responses of their co-workers. These reactions fell into the general categories of support [33,35,36] and discrimination [33,34,36,37,40,41]. The experiences of support were linked with an increased likelihood of future disclosure [33].

“They asked so many questions that they couldn’t understand why I leave every day at one o’clock, they couldn’t understand certain things that happen, but now that they’re also in the picture it’s almost like they are more patient with me too.” (35 p2012)

People described the discrimination in forms of microaggressions, lack of accommodation provisions, barriers to career advancement and unfair dismissal [33,34,36,37,39,40,41,42].

“So my company gave me a parking space closer to the building so I didn’t have a long way to walk to get to my office. And one of my coworkers said “it must be really nice to be close to the entrance.” But it was said in a way that made me feel ashamed about having a closer parking space.” (41 p5)

Many individuals reported suspicion and disbelief from their coworkers in response to their disclosure of symptoms and diagnoses [33,40,42]. Some people reported being perceived as lying about their symptoms and needs [33,38] and an increase in scrutiny [40,42].

“You always feel like there’s someone behind you watching you. Are you doing stuff right? It’s constant checking that’s what, you know, and you don’t do it right then it’s pointed out to yah and you know you’re not going to be arguing all the time.” (40 p5)

4. Locus of Change and Emotional Impact

One particularly notable aspect of individual’s narratives was the differences in who held the power to promote changes, such as provision of accommodations, and the emotional impact this had. People reported being informed of accommodations directly by their organisations or managers, as well as through indirect channels such as through their peers and witnessing the accommodations provided to others [37,42]. Many participants stated that they were not given sufficient information about potential accommodations [33,34,37,42].

“...made me feel unsafe in the sense I didn’t have anything, I didn’t know anyone, I didn’t know who to seek assistance for [sic], how to deal with it, whether if I did say anything whether that would mean that I would lose my position.” (42 p1628)

Once informed of possible accommodations, the power to determine which accommodations were appropriate varied between individuals. Some people with MS were consulted on their needs and their requests for accommodations [35,36,39], whereas some reported that they relied on their own assertiveness [37]. Others described not having a voice in determining their own accommodations, and instead being given solutions by others [33,42].

“...there was no mechanism for staff to really be honest about what they needed and wanted and to discuss or negotiate on matters.” (42 p1628)

Solutions given by others were linked to the provision of accommodations which were too restrictive [33,42] or insufficient [40], whereas others reported that they were provided with appropriate accommodations by their employer [42]. Some people with MS described that their accommodations provision was influenced by their gender [37].

“And he [supervisor] went, “We need to find you somewhere else where you can work.” I said, “But it’s not affecting my work.” ...He thought he was doing it in my best interest. Like his perspective was all wrong... He thought he was doing me a favour, which he wasn’t.”(42 p1628)

The process of obtaining accommodations was associated with experiences of happiness [42], shame [34,41], anxiety [36], guilt [35] and stress [37,41]. Participants reported distress upon receiving inappropriate or discriminatory accommodations. Likewise, participants reported that their colleagues’ reactions to accommodations impacted their experience of making these changes. One participant reported a sense of feeling like an outsider as a response to their accommodations:

“The attorneys we work with, particularly the defense attorneys, can be pretty demanding . . . they lack social skills; they can be very abrupt and aggressive and sometimes rude and patronizing, condescending, so that is stressful for me to deal with.” (36 p206)

Discussion

Many individuals with MS face systemic barriers to employment following the development of MS symptoms [44] and employment rates decrease over time at a greater rate than the general population [11]. This aim of this review was to critically evaluate the literature exploring people with MS' experiences of disclosure in the workplace. Through a process of narrative synthesis, four main themes were indicated within the literature: the decision to disclose, a transition in identity, Group Reaction to the Individual following Disclosure, and the Locus of change and emotional impact.

The findings suggest that individuals make incremental disclosures across time. These findings support theories of disclosure across multiple invisible identities, highlighting the influence of previous disclosures on the anticipated responses of others which is used to inform the amount of information and audience of disclosure [16,25]. In particular, these findings support the DDMM's and DPM's stances that disclosure is considered in the context of anticipated risks and rewards [26, 16]. The repetitive nature of disclosure therefore highlights the need for a longitudinal approach when considering supporting those with MS whose diagnosis and symptoms are known within the workplace. One notable aspect within this review was the distinction between disclosing symptoms of MS and diagnosis of MS, with individuals choosing to disclose one or other separately due to the anticipated impact of disclosure. While this theme emerged during this review, the distinction was not indicated directly through the interview structures of the included papers which instead chose to examine disclosure more broadly.

The results indicate that disclosure was linked to a transition in identity for people with MS, relating to both self-perception and their perception by others. The experience of workplace disclosure has been examined through Social Identity Theory [45] where individuals have been theorised to transition from 'ingroup' to 'outgroup' identity following disclosure [46]. Within this review, studies referred to both anticipated or experienced discrimination following disclosure, which

provides support previous literature following many people with MS' experiences of differentiation and discrimination after disclosing stigmatised identities [47,48]. It is notable that within the review, many of the participants' intersectional identities were not reported, such as educational background, sexual orientation, race, ability and socio-economic status among others. This is valuable information to contextualise the experiences of disclosure, as ethnicity and gender have been shown to impact someone's experiences within occupational settings [18,49,50,51] and will likely influence their experience of disclosing MS. Therefore, further research should be conducted which focuses on exploring the experience of disclosure for individuals of differing intersectional identities.

Strength of the Review

The majority of included studies were considered to be of reasonable quality. One major limitation was the lack of participant demographic details reported. The gender ratio of this review's sample falling in the high end of the reported range [52]. Whereas, MS type was disclosed in only three papers, where it was reported that the majority of participants experienced RRMS. While this fits with the typical trends of individuals diagnosis within the working population [53], it is possible that the experiences of individuals with other types of MS may not be represented in this review. In light of this, conclusions within this review were drawn on an overview of individuals with MS' experience and with acknowledgement that individuals will experience disclosure in the workplace differently based on MS type and symptoms.

A lack of geographical diversity was reported within the included papers. This effect could have been further emphasised due to the exclusion of papers not written in English. This impacts the legal systems and societal narratives contextualising the people with MS' experience of workplace disclosure within this review. Further research should be considered across a wider variety of geographical areas and studies written in a range of languages should be incorporated into future reviews.

One limitation of the review was the definition of workplace. The review aimed to examine the experiences of people with MS in paid employment, which excludes individuals' experiences of informal or unpaid work. Furthermore, only four studies referred to workplace characteristics such as organisational setting or size. Different work settings may be experienced differently by people while disclosing MS and further research into disclosure across various workplace settings would provide value to the literature.

Wider Implications of the review

Throughout this review, a range of factors were suggested to impact individuals' experiences around disclosure of MS in the workplace, leading to a range of implications and recommendations. Firstly, both individual factors, such as beliefs and previous experiences, and the responses of others within the organisation appear to influence the experience of disclosure for people with MS. Therefore, services should consider both individual and systemic approaches for supporting individuals with MS.

A relationship between appropriate accommodations and wellbeing was indicated within the literature. Centring people with MS in the process of planning and providing accommodations within the workplace should be promoted within organisations. Furthermore, as some individuals delay disclosure until the point at which they require accommodations, clear information regarding available accommodations should be made available prior to or at the point of disclosure.

This review emphasised the circular process of disclosing both diagnostic information and the symptoms of MS experienced, with a recognition that past experiences of disclosure influence future intentions to share health information. In light of this, idiosyncratic support should be

available to individuals throughout their time in employment, particularly following difficult experiences related to disclosure.

Conclusions

This review aimed to explore the experiences of individuals disclosing MS in the workplace. Individuals reported a range of motivators, experiences and reactions following disclosure of diagnosis, symptoms, and accommodations, many of which were suggested to influence further decisions to disclose. The response from others in the organisation appeared to lead to alterations in identity, experiences of othering and discrimination for many. The opportunity for interventions should be to individuals with MS choosing to remain in the workplace, including accommodations, individual, relational and organisational support, throughout their time at work.

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PART TWO

An investigation into the properties of the Brain Injury Fatigue Scale and variables which influence fatigue ratings.

This paper is written in the format ready for submission to the 'Journal of Neuropsychology'.

Please see Appendix E for the author guidelines.

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Katherine Watson*¹, Stephen Evans², Peter M Fleming¹

1. School of Psychology and Social Work, Aire Building, University of Hull, Cottingham Road,
Hull HU6 7RX, United Kingdom.

2. York Psychological Medicine, The Old Chapel, Bootham Park. York. YO31 8HE.

*Corresponding author information: K.watson-2019@hull.ac.uk

Abstract

Background: Fatigue is a prevalent sequela of both Acquired Brain Injuries (ABI) and neurological conditions. This study aimed to explore the factors contained within the Brain Injury Fatigue Scale (BIFS) and to investigate the relationship between fatigue reported, gender, age, anxiety and depression as moderated by the presence of an ABI/neurological conditions.

Method: 77 participants, 39 having sustained an ABI/neurological condition and 38 controls, completed the Hospital Anxiety and Depression Scale and the BIFS. A principal axis factor analysis was completed to explore the factors contained within the scale. Moderation analyses determined the effect of ABI/neurological condition status on the relationship between age, gender, anxiety and depression on BIFS scores.

Results: A two-factor structure was illustrated within the BIFS. 53.58% of the variance within the data was related to a single factor, labelled 'general fatigue'. A second factor, explaining an additional 7.58% of the variance, was labelled 'cognitive and emotional impacts of fatigue'. The ABI/neurological condition group reported significantly greater BIFS scores than control group participants. Positive correlations were shown between fatigue and age, group, anxiety and depression. The relationship between anxiety and fatigue was significantly moderated by the presence of an ABI/neurological condition, with a greater effect shown for those who have sustained an ABI/neurological condition.

Conclusions: The BIFS supports a unidimensional conceptualization of fatigue. ABI/Neurological conditions were shown to moderate the effect of anxiety on fatigue, which has clinical implications for fatigue interventions. Future research should be completed to replicate these effects with a larger participant cohort.

Keywords: Brain injury; Fatigue; Anxiety; Depression; Age; Gender.

Introduction

Acquired Brain Injuries (ABI) involve damage to the brain following birth which are not a result of degenerative processes, developmental disabilities or genetic disease (Cattelani, Zettin & Zoccolotti, 2010). A compilation of hospital records estimated that 349,000 individuals in the UK were admitted to hospital with an ABI within one year, with men 1.6 times more likely to be admitted to hospital (Headway, 2018). Recovery has been viewed through a staged approach, with many people experiencing a degree of immediate recovery without intervention (Nudo, 2013; Andelic, 2021). Some symptoms persist over months and years and have been shown to have a significant wider social impact for the individual (Ponsford et al., 2014).

One notable sequela across many ABI/neurological conditions is acute and chronic fatigue (Lannsjö, af Geijerstam, Johansson, Bring, & Borg, 2009). One study suggests that up to 94.9% of individuals report an initial increase in fatigue following a Traumatic Brain Injury (TBI) (Oulett & Morin, 2006). Chronic fatigue was reported by 68.5% of individuals seven years post injury (Oulett & Morin, 2006). Chronic post injury fatigue has been shown to contribute to ongoing disability (Juengst et al., 2013). When compared to the 38% of individuals in primary care settings reporting fatigue, there is a clear need to understand and provide evidence-based fatigue interventions for individuals with an ABI (Pawlikowska et al., 1994).

Some theories suggest that the aetiology of fatigue is due to damage to the normal processes at a synaptic level (Tsaneva & Markov, 1971; Van Zomeren, Bower & Deelman, 1984). In particular, the 'coping hypothesis' developed by Van Zomeren, Bower and Deelman (1984) suggests that cognitive impairments lead to an increase in required effort, which leads to an increase in fatigue. Other factors have been indicated to contribute to fatigue development such as sleep disturbance (Ponsford et al., 2012; Andelic, 2021).

Numerous definitions of fatigue exist across the literature (Oullet & Morin, 2006), often contingent on differing theories of fatigue. Multidimensional theories of fatigue argue that the broader concept of fatigue can be separated into distinct categories, such as physical, mental and emotional fatigue and unidimensional theories conceptualise a single component of fatigue (Whitehead, 2009). The following definition of fatigue was selected as the foundation of this paper as it was used by the authors of the BIFS during the development of the scale (Quinn et al., 2004).

“The experience of exhaustion and a decreased capacity for physical and/or mental activity due to an imbalance in the availability, utilization and/or restoration of resources needed to perform activity.” (Quinn et al., 2004, p.4)

Research has indicated a potential effect wherein women report greater fatigue across the general population (Bensing, Hulsman & Schreurs, 1999; Fuhrer & Wessley, 1995; Van Mens-Verhulst & Bensing, 1998). Bensing, Hulsman and Schreurs (1999) viewed their results through a biopsychosocial perspective, therefore highlighting that no single factor has been identified which explains the differences found in some studies.

Following an ABI, women report experiencing fatigue more commonly and severely than men (Whiteneck et al., 2004; Vlachos et al, 2022; Lerdal et al., 2011; Cantor et al., 2008; Englander, Bushnik, Oggins & Katznelson, 2010; Falconer, Walsh & Harbison, 2010). However, other studies found no gender difference in reported fatigue (Quinn et al., 2004; Appelros, 2006; Juengst, Nabasny & Terhorst, 2019). Interestingly, Norup et al. (2017) found that women with an ABI reported more fatigue than men with an ABI in certain subscales of fatigue, however this gender difference was not mirrored in the control group (Norup et al., 2017). Therefore, it is important to continue to assess whether women report experiencing greater fatigue than men, particularly when validating a new scale.

Within general populations, Bensing, Hulsman and Schreurs (1999) found that younger individuals reported greater mental fatigue. This effect was replicated within a population of individuals who have experienced an ABI (Andelic et al., 2021). One notable study by Preiss-Farazanegan et al. (2009) showed the moderating effect of gender on the relationship between age and fatigue. This indicates that adult women were more likely to report fatigue than adult men following a TBI, however this effect was not present for women under the age of 18. However, many studies have shown no effect of age on self-reported mental fatigue (Lerdal et al., 2011; Ziino & Ponsford, 2005; Cantor et al., 2012; Ouellet & Morin, 2006). Thus, it is valuable to understand the pattern of fatigue reporting across age within each scale.

A loss of energy is listed within diagnostic criteria for Major Depressive Disorder and Generalized Anxiety Disorder (American Psychiatric Association, 2013) and is experienced by many during periods anxiety or depression (Tylee, 2000; Watt et al., 2000). Studies routinely indicate correlations between fatigue and depression for individuals who have sustained an ABI/neurological condition (Cantor et al., 2008; Lerdal et al., 2011; Ziino & Ponsford, 2005; Walker, 1991; Englander, Bushnik, Oggins & Katznelson., 2010; Fuhrer & Wessley, 2009) and anxiety (Ouellet & Morin, 2006; Walker et al., 1991). However, several studies have gone further to suggest that depression is predictive of elevated fatigue following a brain injury (Norrie et al., 2010).

Measurement of Fatigue

A variety of tools exist which attempt to quantify aspects of fatigue caused by differing physical conditions (Whitehead, 2009; Belmont, Agar, Hugeron, Gallais & Azouvi, 2006). Two published scales have been specifically designed to measure fatigue for individuals who have sustained brain injuries. The Causes of Fatigue Scale (COF; Ziino & Ponsford, 2005) contains 12 items which direct individuals to report the extent to which specific mental and physical activities cause fatigue. The Barrow Neurological Institute Fatigue Scale (BNI; Borgaro, Kwasnica, Caples & Gierok,

2004) was developed to assess fatigue in the acute phase following a brain injury, with individuals in the original study completing the scale within 20 days of their injury. It has been shown to be a valid and reliable indicator of fatigue in the early stages following an ABI (Wäljas et al., 2012), however it was not designed for measuring chronic post-ABI fatigue.

The Brain Injury Fatigue Scale (BIFS; Quinn et al., 2004)

The BIFS was designed to quantify subjective fatigue levels for individuals who were experiencing chronic post-ABI fatigue (Quinn et al., 2004). The properties of the scale were explored in the unpublished thesis paper with a sample of 131 individuals in the UK, 65 of whom had sustained an ABI. This study suggested a non-significant positive relationship between age and fatigue across the total sample. Across the total sample, there was no significant effect for the relationship between gender and fatigue. A significant positive relationship was also shown between depression and anxiety ratings and fatigue. Quinn et al. found the BIFS has a Cronbach's alpha of 0.94 for the total sample and a split-half reliability co-efficient of 0.95. The latent variables identified across this scale included overall fatigue, disability, and pre-morbid function. However, the principal component analysis completed within this study was underpowered, and therefore should be replicated.

The BIFS has been well regarded in the field and has been used both in clinical practice and for research purposes (Cooper, Reynolds, & Bateman, 2009). The properties of the scale, while promising, have not been examined through the process of peer review nor replicated. Quinn et al. (2004) noted that their sample reflected the effects shown in self-selecting outpatient setting in a rural area currently seeking healthcare interventions. Since its development, the BIFS has been used within services which provide care to individuals with a range of neurological conditions. Therefore, there is a clear clinical need to explore the scope of the BIFS beyond those with a diagnosed acquired brain injury, to include participants with a range of neurological conditions.

Rationale

Fatigue is a common and debilitating experience following an ABI/neurological condition, indicating a clear need for available evidence-based tools. Providing data on the properties of the scale will provide greater certainty of the robustness of the scale and its utility within research and clinical practice. The literature indicates the presence of possible relationships between fatigue, gender, age, anxiety and depression, which may be moderated by the presence of an ABI/neurological condition. Therefore, the results will inform the interpretations of BIFS scores within clinical practice. Performing an adequately powered factor analysis will indicate the variables which are reported through the BIFS.

Aims and Hypotheses

The research in this study was based on the following two aims. Firstly, to verify and confirm the underlying constructs which are measured by the BIFS. Secondly, this research aimed to investigate the relationship between BIFS measure and age, gender, anxiety, and depression, and whether these effects are moderated by the presence of an ABI/neurological condition.

The following hypotheses were generated:

- 1) An increase in age will predict decreased self-reported fatigue across both groups, with no moderating effect of ABI/Neurological condition.
- 2) Women will report greater fatigue than men across both groups. This effect will be moderated by the presence of an ABI/Neurological condition, with a greater effect found in the ABI/Neurological condition group.
- 3) Greater self-rated depression and anxiety scores on the HADS will predict higher overall BIFS scores. ABI/Neurological conditions will increase the effect of HADS anxiety and depression scores on total BIFS scores.

Method

The design of the study was approved by the Cambridge NHS Research and Ethics Committee in April 2022 and the University of Hull. Approval was given by the contributing NHS trusts across Yorkshire and Lincolnshire and the third sector organisation Headway.

Participants

The opportunity sample of 77 participants was comprised of 39 participants with an ABI/neurological condition and 38 individuals who did not have an ABI/neurological condition, which comprised the control group. Recruitment occurred between July 2022 and March 2023 across England. Demographic information for all participants is summarised in Table 1.

The ABI/neurological condition sample were recruited by an opportunity sample across outpatient NHS services and Headway groups. The inclusion criteria for the ABI/neurological condition participants incorporated participants aged 18 or older who had had sustained an ABI or who had been diagnosed with a neurological condition, who were able to communicate in English and had the capacity to provide informed consent to the study. Individuals who reported neurodevelopmental conditions or fatigue symptoms relating to an unrelated condition were excluded from the study.

The control group were recruited through snowball sampling by researchers. The inclusion criteria for the control sample required that participants were 18 or older, had no history of brain injury, were able to communicate in English and had the capacity to take part in the study. Individuals who reported neurodevelopmental conditions, neurodegenerative conditions or fatigue symptoms relating to an unrelated condition were likewise excluded from the study.

Design and procedure

The independent variables in the study were age, gender, anxiety and depression. The dependent variable was total reported fatigue.

A range of procedures were approved to reflect the individual needs of services and service users participating this study. All participants were informed of the purpose and procedures of the study, given the opportunity to ask questions and provided with an information sheet (See Appendix J). Participants were informed of their right to withdraw, the confidentiality of the call or session and that their data would be anonymised. Those who provided informed consent to participate completed the demographic information form, which included their age, gender, injury type and years in education. Individuals in the ABI/neurological condition group were also asked their injury type and time since injury. Participants then completed the Brain Injury Fatigue Scale (BIFS; Quinn et al., 2004) followed by the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983).

The ABI/neurological condition group participants recruited through the NHS completed the measures of study with psychologists within clinical services as part of routine clinical assessments, or with the primary researcher, dependant on service capacity. Participants who completed the study with their clinician were informed of the study during their initial appointment and the information sheet was shared. Those who were interested in participating were invited to attend a follow up appointment at least 24 hours later where they had the opportunity to ask questions provided informed consent and completed the measures.

The primary researcher attended three third sector organisations between January to March 2023 and provided a 5-minute presentation on the study, followed by the opportunity to ask questions, and were provided with the information sheet. Those who were interested in taking part met with the researcher during the day in a private room to ensure confidentiality.

Participants were also able to complete data collection remotely with the primary researcher. This option was available to those in the ABI/neurological condition group recruited through NHS services, from the third sector organisations and control group participants. Those in the NHS and third sector settings were provided with a brief outline of the study and the information sheet with

the primary researcher's contact details through their organisations and control participants were provided the primary researcher's information through snowball recruitment. The participants contacted the researcher by email to express their interest in taking part. The researcher then provided an outline of the project, the opportunity to ask questions and both the information sheet and consent form were attached for the participant to review. If they provided informed consent, the researcher then screened for the inclusion criteria and offered to meet remotely with the primary researcher via telephone or video call. During this call, a further opportunity to ask questions was given prior to completing the measures.

Measures

The Brain Injury Fatigue Scale (BIFS; Quinn et al., 2004)

The measure constitutes a 20 item Likert scale, with each item scoring 1-5 on the degree of fatigue experienced during the previous month. A total fatigue score is then generated, ranging from 20-100. These fatigue scores are then classified into the following categories, 'normal' fatigue (total scores below 61), 'abnormal' fatigue (total score between 61-69), 'severe' (total scores between 70-79) and 'profound' (with total scores above 79).

The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)

The HADS was developed to screen for self-reported anxiety and depression. Each of the 14 question is formed of a 4-point Likert scale, with options differing across the test to refer to the question. This self-report measure generates two total scores, summarised from the 7 questions screening for depression (total 0-21) and the 7 questions screening for anxiety (0-21). Clinical cut off points indicate a 'normal' degree of reporting at <8, with 8-10 indicating 'borderline abnormal' data and a score of 11-21 indicating 'abnormal' data, which has been indicates as a valid screening tool for individuals with brain injuries (Schönberger & Ponsford, 2010).

Statistical Analysis

Research Aim 1 – To investigate the underlying constructs which are measured by the BIFS.

Data were analysed using the Statistical Package for the Social Sciences version 28.0.0.0 (SPSS; IBM, 2021). The BIFS data were analysed using principal axis factor analysis with an oblimin rotation. De Winter, Dodou & Wieringa (2009) found that in some conditions, a reliable EFA can be completed with under 50 participants. However, these as many of these factors could not be predicted for this study, an a priori sample size of n=200 was used (Guilford, 1954).

Research Aim 2 - To investigate the relationship between BIFS measure and age, gender, anxiety, and depression, and whether these effects are moderated by the presence of an ABI/neurological condition.

Firstly, the relationships were analysed using correlation analyses. Data were analysed on the Statistical Package for the Social Sciences version 28.0.0.0 (SPSS; IBM, 2021) using the PROCESS macro package version 4.2 (Hayes, 2013). To detect a possible relationship between the each of the independent variables, group and the interaction between the group and the other independent variable, with an effect size of 0.15, a total sample of 77 participants was predicted to be necessary using $\alpha = 0.05$ and power = 0.8 using GPower Version 3.1.9.2 software (Faul, Erdfelder, Lang & Buchner, 2008). An effect size of 0.15 was used to detect small effects, as found in the available literature (Farace & Alves, 2000; Cohen, 1988).

Results

An overall sample of data from 77 participants was collected. Demographic characteristics are illustrated in Table 1. Participants reported the following ABI/neurological conditions: traumatic brain injury (TBI) (n=17), cerebrospinal fluid leak (n=1), hypoxia (n=3), stroke (n=8), stroke+TBI (n=1), undiagnosed (n=2), functional neurological disorder (n=1), Progressive multifocal leukoencephalopathy (n=1), Multiple Sclerosis (MS) (n=3), TBI + MS (n=1) & haemorrhage + MS

(n=1). For participants with an ABI/neurological condition, the average time since injury was mean=10.35 years, range=3 months-35 years, SD = 10.39 years.

Table 1*Demographic characteristics of participants*

Demographic Characteristics	ABI/neurological condition sample (n=39)	Control Sample (n=38)
Age (years)	Mean = 50.79, range 20-80 ,SD 11.23	Mean = 37.79, range 21-79, SD 17.80
Gender	Male n=22 Female n=17 Non-Binary =0 Prefer not to say =0	Male n=15 Female n=21 Non-Binary =2 Prefer not to say =0
Mean Level of education (years)	Sample reported (n=29) Mean = 13.52, range = 9-23, SD = 2.84	Sample reported (n=32) Mean = 16.94, Range = 12-22, SD = 2.71
BIFS scores (Mean, range, SD)	Mean =67.72, range=20-92, SD =16.78 Median = 70	Mean = 44.42, range = 26-60, SD = 8.99 Median = 45
BIFS scores by gender (Mean, range, SD)	Male, mean = 64.73, range = 20-92, SD = 18.35 Female, mean = 71.59, range = 42-91, SD = 14.08	Male, mean = 43.27, range = 33-60, SD = 8.34 Female, mean = 44.71, range = 26-57, SD = 9.30 Non-Binary, mean = 50, range =40-60, SD = 14.14
Individuals in each category for BIFS (Quinn et al., 2004)	‘normal’ n=10 ‘abnormal’ n=9 ‘severe’ n=8 ‘profound’ n=12	‘normal’ n=38
HADS Depression scores (Mean, SD)	Mean = 7.69, range = 0-18, SD = 4.63 ‘normal’ n=22 ‘borderline abnormal’ n=10 ‘abnormal’ n=7	Mean=3.05, range = 0-12, SD = 3.14 ‘normal’ n=34 ‘borderline abnormal’ n=1 ‘abnormal’ n=3
HADS Anxiety (Mean, SD)	Mean = 9.21, range = 0-20, SD = 5.53 ‘normal’ n=15 ‘borderline abnormal’ n=8 ‘abnormal’ n=16	Mean = 6.95, range = 1-17, SD = 3.97 ‘normal’ n=26 ‘borderline abnormal’ n=4 ‘abnormal’ n=8

Within the control group BIFS data was normally distributed ($W=.974$, $df=38$, $p=.518$) and data was non-normally distributed in the ABI/neurological condition group ($W=.938$, $df=39$, $p=.033$).

Mann-Whitney U Test determined statistically significant difference between groups for BIFS scores between groups ($U = 1307.000$, $p < .001$) and depression scores ($U = 1220.000$, $p < .001$), indicating that the clinical group reported significantly greater levels of fatigue and depression. No statistically significant differences between anxiety scores were shown ($U = 922.000$, $p = 0.064$). Mann-Whitney U tests also revealed that the clinical group was significantly older than the control group ($U = 1078.000$, $p < .001$).

Research Aim 1: To investigate the underlying constructs which are measured by the BIFS.

A Principal axis factor analysis was undertaken to explore the possible underlying factors within the model. An oblimin rotation was used due to theoretical possibility of correlated factors (Reise et al., 2000).

Correlations were run to assess for multicollinearity. Three correlation coefficients greater than 0.8 were identified between item 20 and items 6, 18 and 19, therefore item 20 was removed (Field, 2013). All anti-image correlations were above the value of 0.5. Item 8 was identified as having a low communality (.342) with the factors within the scale (Child, 2006). Factor loadings were examined and items 3 and 16 were removed as all of the factor loadings for these items were lower than 0.4 (Guadagnoli & Velicer, 1988).

In order to increase the determinant of the correlation matrix to be within the recommended range (Field, 2013), the correlation matrix was analysed and the factors with the greatest number of correlations $>.7$ were examined and systematically removed. From this, items 15 and 18 were removed from analysis, and the final determinant of the correlation matrix was $1.056E-5$. The five excluded questions are illustrated in Table 2.

Table 2

A list of the Questions Removed from the BIFS Prior to the Final Exploratory Factor Analysis

Question	Question Content
Q3	After mental activity, I get tired
Q15	When I'm in a group of people, or things are busy, I tire very quickly
Q16	I feel much better after a rest
Q18	Even when I have regular meals and a good night's sleep, I still have problems with fatigue
Q20	My tiredness directly reduces my ability to live my life as I did prior to my illness/accident

Bartlett's test of sphericity indicated significant inter-correlations, $\chi^2(n=105) = 758.168$ ($p < .001$), therefore indicating that the data are not an identity matrix and can be analysed using EFA. The sampling adequacy was measured using Kaiser–Meyer–Olkin test, with results indicating sufficient sampling (0.917).

A final analysis was completed using 15 scale items. A two-factor solution was indicated by the scree plot (see Figure 1) and the eigenvalues >1 (see Table 3). These two factors explained a cumulative 61.263% of the variance within the data produced within the scale after extraction, with the first factor explaining 53.683% of the variance (See Table 3). The first factor is indicative of a unidimensional 'general fatigue' factor, with the second factor relating to 'cognitive and emotional impacts of fatigue'.

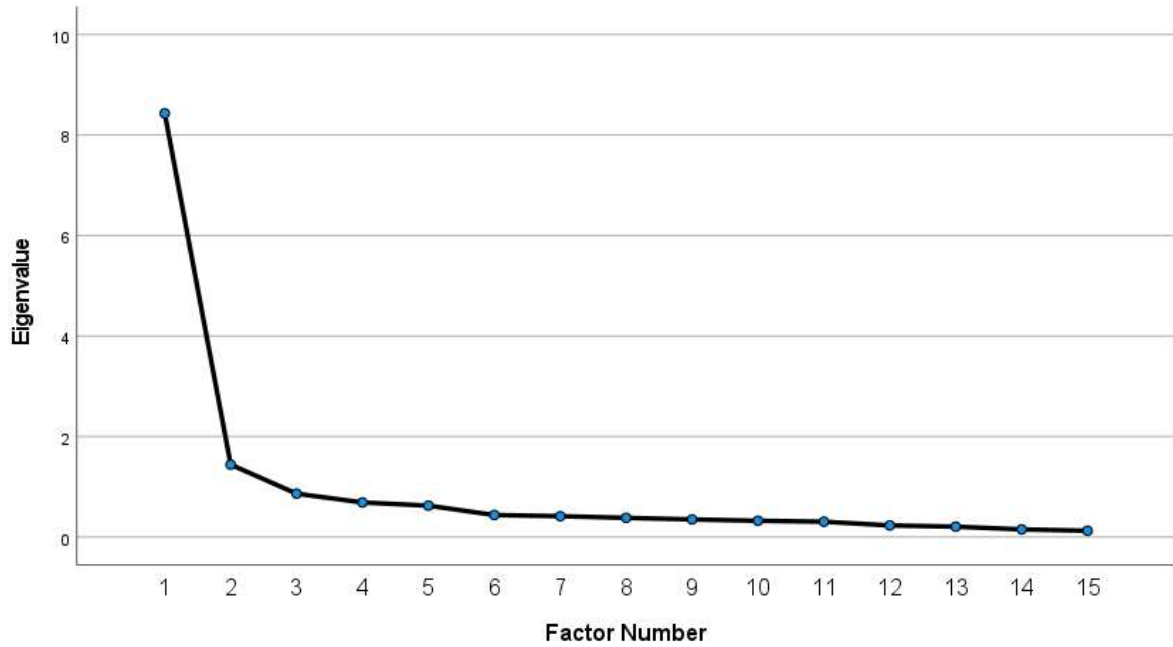
Table 3*The Pattern Matrix, Communalities and Variance Explained Across the Two Identified Factors*

	Question Content	Factor 1	Factor 2	Communalities
Q1	I have problems with tiredness not associated with being sleepy	.824	.030	.696
Q2	After physical activity I suffer from a loss of energy	.733	.002	.538
Q4	After being out socially, I feel exhausted	.696	.059	.515
Q5	I am unnaturally fatigued the day after activity	.771	-.013	.589
Q6	I have much less “get up and go” than I did before my accident/illness	.733	-.003	.536
Q7	I now find I tire much more quickly after routine activities (eg: housework, washing hair, shopping etc)	.839	.055	.737
Q8	I find I drop off to sleep during the day, much more than I ever did before	.645	-.217	.375
Q9	Over a longer period (i.e., a month) I sometimes have days when I’m so exhausted I can hardly get out of bed	.809	-.045	.633
Q10	When I’m tired, I get much more irritable	-.057	.889	.762
Q11	When I’m tired, I make more mistakes	.304	.755	.680
Q12	I get particularly tired when I have to do anything new	.664	.112	.500
Q13	I feel tired even when I don’t feel upset or depressed	.826	.032	.700
Q14	I find I tire quickly even when doing the things I enjoy the most	.852	.051	.757
Q17	I feel like I never really fully recharge my batteries	.730	-.002	.532
Q19	My tiredness directly affects my ability to do a/my job	.727	.179	.643
Eigenvalue		8.052	1.137	
% of variance explained		53.683	7.579	

Factor loadings >.4 are indicated in a bold font.

Figure 1

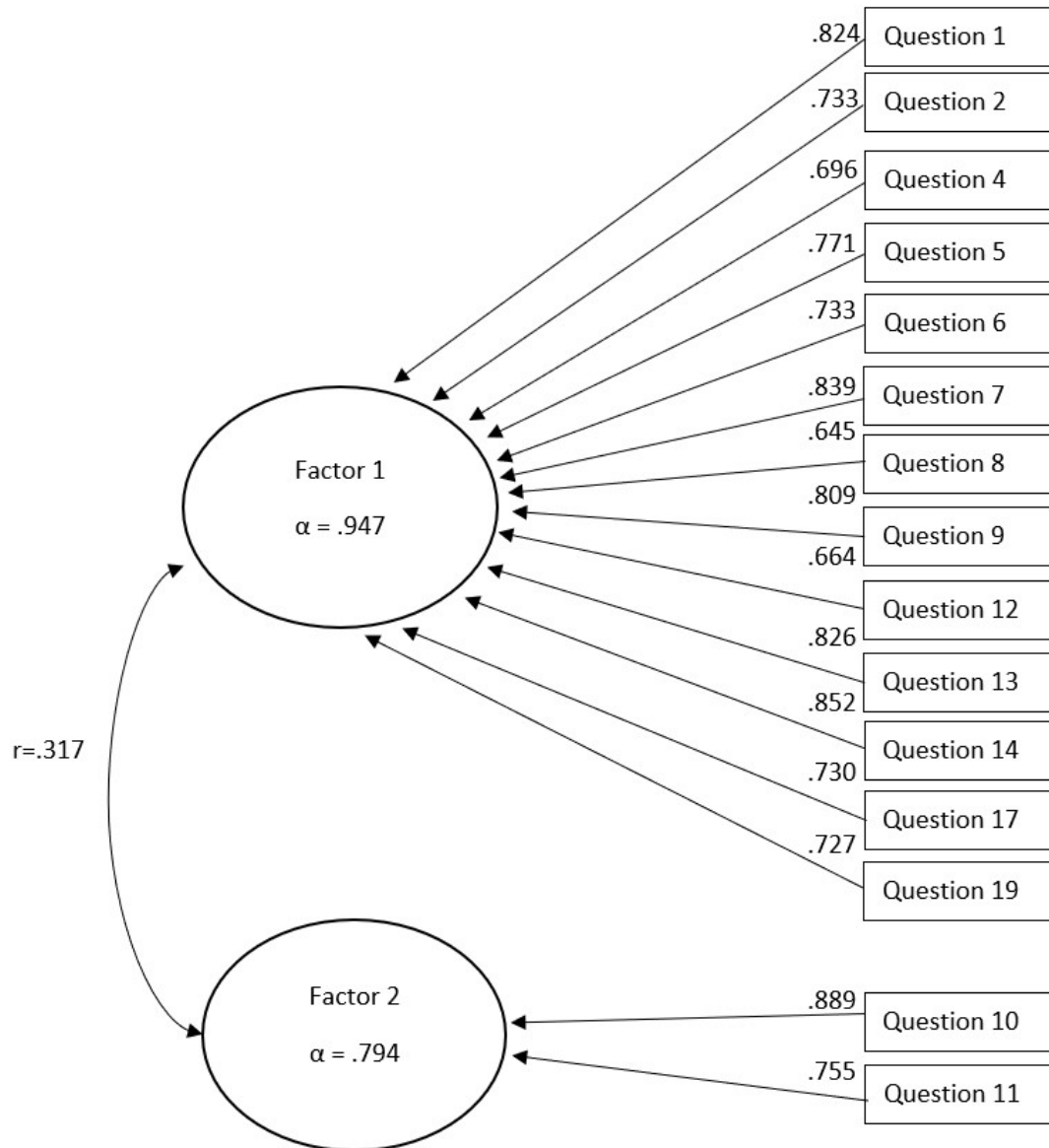
Scree Plot of the Eigenvalues Generated within the Principal Axis Factor Analysis



The within factor correlation for both the first factor ($r=.582$) and the second factor ($r=.663$) were determined to be greater than between factor correlations ($r=.317$) (see Figure 2). Cronbach's alpha was calculated for both factors, showing acceptable internal consistency for factor 1 ($\alpha = .947$) and factor 2 ($\alpha = .794$).

Figure 2

Factor Loadings, Within Factor Correlations and Internal Consistency of the Two Identified Factors



Research question 2: To investigate the relationship between BIFS measure and age, gender, anxiety, and depression, and whether these effects are moderated by the presence of an ABI/neurological condition.

Group was dummy coded as 1 for the control group and 2 for the clinical group. Gender was dummy coded as 1 for male participants and 2 for female participants. Statistically significant correlations were found using Pearson correlation between BIFS and group ($r=.658, p<.001$), age ($r=.336, p=.002$), depression ($r=.635, p<.001$) and anxiety ($r=.570, p<.001$). Significant correlations were also identified between group and age ($r=.406, p<.001$), depression ($r=-.509, p<.001$), anxiety ($r=.231, p=.023$). HADS Depression scores had a significant positive correlation with HADS Anxiety scores ($r=.671, p<.001$).

Table 4

Pearson's Correlations between Total BIFS Score, Group, Age, Gender, HADS Depression scores and HADS Anxiety scores.

	Group	BIFS	Age	Gender	HADS Depression	HADS Anxiety
Group						
BIFS	.658**					
Age	.406**	.336**				
Gender	-.203	-.007	-.204			
HADS Depression	.509**	.635**	.144	.058		
HADS Anxiety	.231*	.507**	-.012	.137	.671**	

*Correlation is significant at the 0.05 level, 2 tailed.

** Correlation is significant at the 0.01 level, 2 tailed.

As high correlations were noted, however each variable has a VIF<5, therefore the multicollinearity was determined to be low enough to run a regression analysis.

Homoscedasticity between predicted values and residuals was found for BIFS. Normality of errors was tested in each group using the Shapiro-Wilk test, with normally distributed errors being illustrated in both the control group ($W=.967$, $df=36$, $p=.359$) and clinical group ($W=.966$, $df=39$, $p=.278$).

Simple moderation regression models aimed to assess whether the relationship between depression, anxiety, age or gender and overall reported fatigue was moderated by the presence of an ABI/neurological condition. The independent variables within the data were depression, anxiety, age and gender, the moderating variable was ABI/Neurological conditions and the dependent variable was total fatigue score.

Moderation Analysis on the effect of Anxiety on Fatigue as moderated by Brain Injury

The regression model analysing the relationship between anxiety and total fatigue, as moderated by group identity was significant ($F(3,73)=49.21$, $R^2=.669$, $p<.001$). The interaction term of relationship between anxiety and total fatigue reported by group was significant ($b = 1.79$, $t(73)=3.38$, $p<.01$), this suggests that ABI/neurological condition presence moderates the relationship between anxiety and fatigue score. The interaction term explained an additional 5% of the variance within the model, ($F(1,73)=11.44$, R^2 change $=.05$, $p=.001$). Within the main model, the effect of anxiety on total fatigue was not significant ($b= -1.39$, $t(73) = -1.52$, $p=.134$). A significant effect was found between group and fatigue ($b= 20.39$, $t(73)= 8.29$, $p<.001$). The conditional effects of anxiety on fatigue in the ABI/neurological condition group was significant, ($\beta = 2.20$, $SE = .31$, $p <.001$) whereas these effects were not significant for the control group, ($\beta = .40$, $SE = .43$, $p=.356$).

Table 5*Model Summary: Moderation Analysis of Group, Anxiety and Fatigue*

Model Summary						
R	R Square	MSE	F	df1	df2	<i>p</i>
.8180	.6691	109.3998	49.2051	3.0000	73.0000	.0000

Table 6*Moderation Analysis: Group, Anxiety and Fatigue*

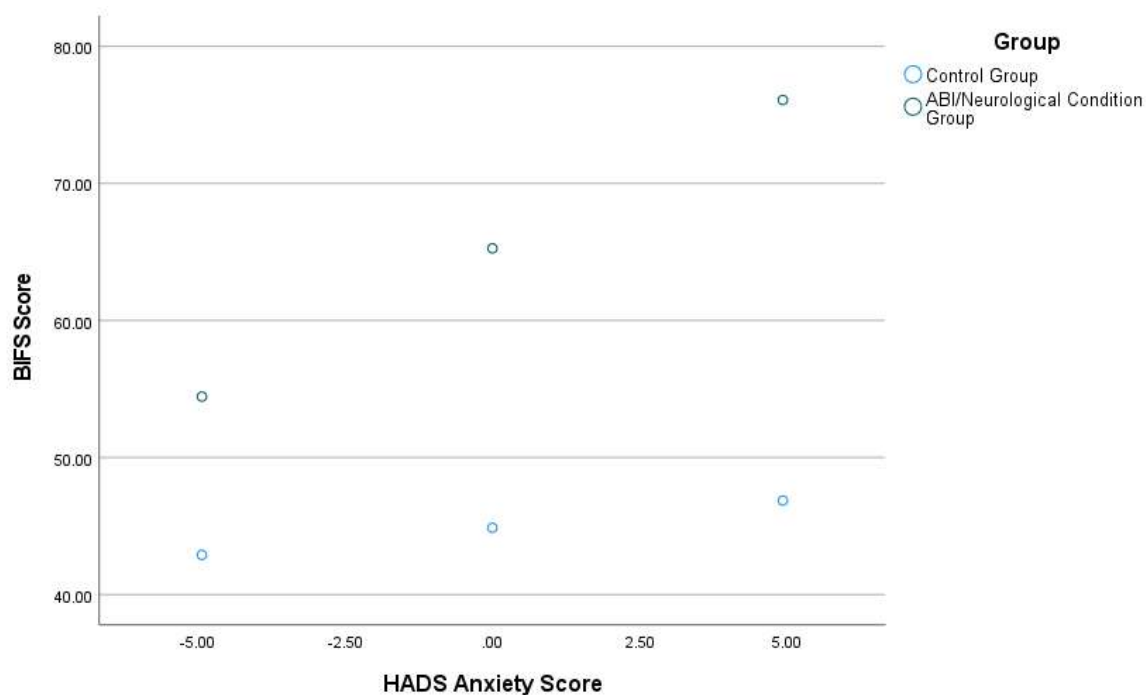
	b	SE	t	95% CI		<i>p</i>
				<i>LL</i>	<i>UL</i>	
Constant	24.4915	3.9265	6.2374	16.6659	32.3172	.0000
HADS	-1.3922	.9185	-1.5158	-3.2227	.4383	.1339
Anxiety						
Group	20.3895	2.4588	8.2923	15.4890	25.2899	.0000
Interaction	1.7944	.5305	3.3822	.7370	2.8518	.0012
Term						

CI = confidence interval, *LL* = lower limit, *UL* = upper limit.**Table 7***Moderation Analysis: Conditional Effects of Anxiety on Fatigue across groups*

Group Coefficients for Interaction Effect						
	Effect	SE	t	LLCI	ULCI	<i>p</i>
Control Group	.4022	.4329	.9292	-.4605	1.2649	.3559
ABI/neurological condition group	2.1966	.3068	7.1601	1.5852	2.8080	.0000

Figure 3

The relationship between mean centred HADS Anxiety scores and Fatigue across the ABI/neurological condition and control groups.



Moderation Analysis on the effect of Depression on Fatigue as moderated by Brain Injury

The regression model analysing the relationship between depression and total fatigue, as moderated by group identity was significant ($F(1,73)=31.19$, $R^2=.56$, $p<.001$). Within this model, there was a significant effect found between group identity and fatigue ($b= 16.86$, $t(73)=5.18$, $p<.001$). No significant relationship between depression and fatigue was shown ($b= -.04$, $t(73)=-.03$, $p=.976$). Within this model, group identity did not significantly moderate the relationship between depression and fatigue ($b= .96$, $t(73)=1.27$, $p=.209$). This indicates a significant difference in fatigue scores between groups, with no effect of depression which is also not moderated by the presence of group. This indicates that depression does not predict reported fatigue and that there is no significant moderating relationship of brain injury on this effect.

Table 8*Model Summary: Moderation Analysis of Group, Depression and Fatigue*

Model Summary						
R	R Square	MSE	F	df1	df2	p
.7511	.5641	144.1052	31.4945	3.0000	73.0000	.0000

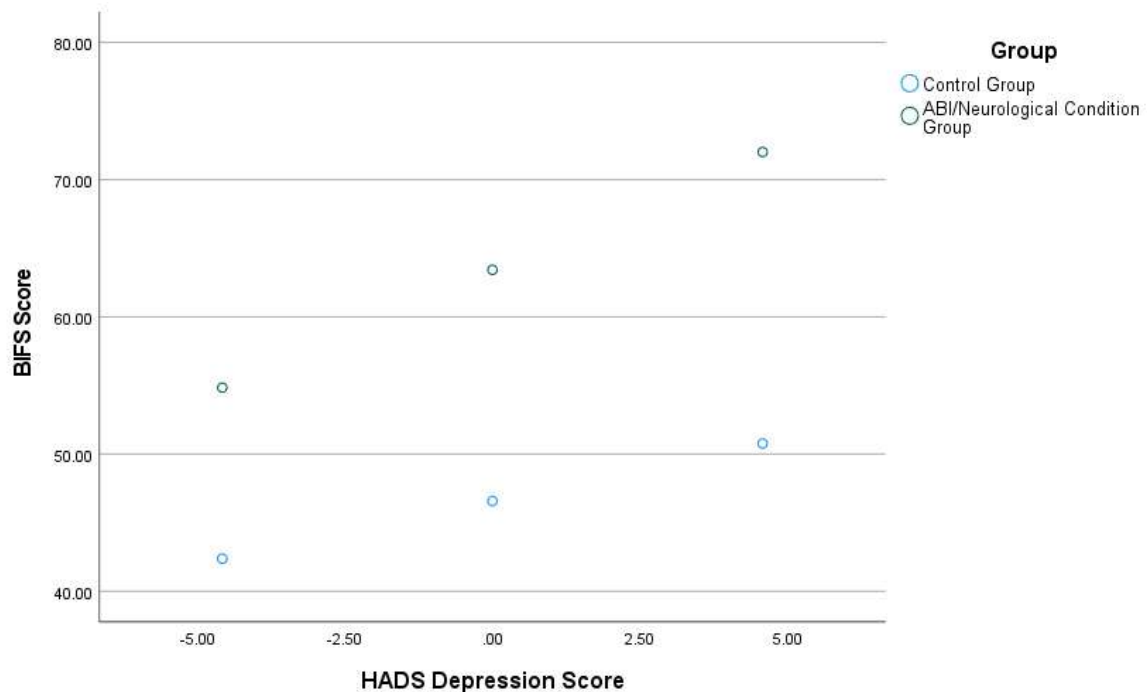
Table 9*Moderation Analysis: Group, Depression and Fatigue*

	b	SE	t	95% CI		p
				LL	UL	
Constant	29.7170	5.3375	5.5676	19.0793	40.3547	.0000
HADS	-.0406	1.3236	-.0307	-2.6785	2.5973	.9756
Depression						
Group	16.8566	3.2539	5.1805	10.3716	23.3416	.0000
Interaction	.9566	.7552	1.2666	-.5486	2.4618	.2093
Term						

CI = confidence interval, LL = lower limit, UL = upper limit.

Figure 4

The relationship between means centred HADS Depression scores and Fatigue across the ABI/neurological condition and control groups.



Moderation Analysis on the effect of Gender on Fatigue as moderated by Brain Injury

Due to the limitations of moderated regression data, the non-binary participant group did not meet adequate power for their results to be examined within the context of model and were therefore excluded. The regression model analysing the relationship between gender and total fatigue, as moderated by group identity was significant ($F(3,71)=19.92$, $R^2=.46$, $p<.001$). Within the model, there was no significant effect of gender ($b= -3.97$, $t(71)=-.39$, $p=.696$) or group ($b=16.047$, $t(71) = 1.59$, $p=.115$) on self-reported fatigue. The interaction term was not significant ($b=5.413$, $t(71) = .86$, $p=.394$), indicating no moderating effect of group on the relationship between gender and Fatigue.

Table 10*Model Summary: Moderation Analysis of Group, Gender and Fatigue*

Model Summary						
R	R Square	MSE	F	df1	df2	<i>p</i>
.6760	.4570	182.4465	19.9183	3.0000	71.0000	.0000

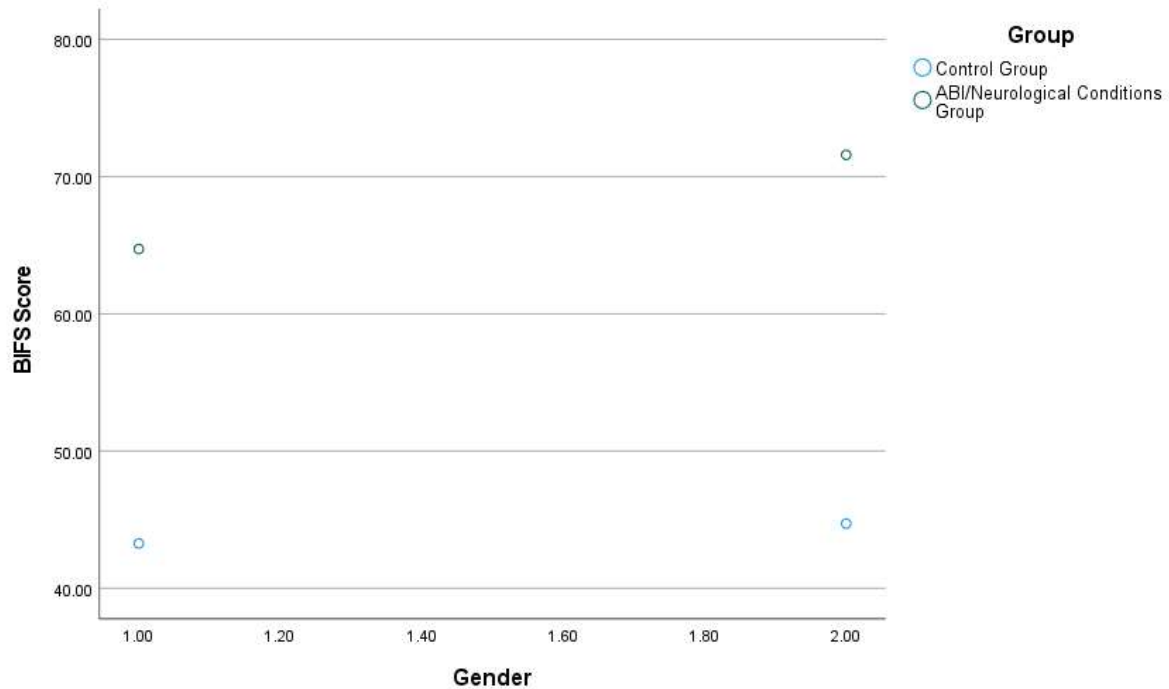
Table 11*Moderation Analysis: Group, Gender and Fatigue*

	b	SE	t	95% CI		<i>p</i>
				<i>LL</i>	<i>UL</i>	
Constant	25.7718	16.5307	1.5590	-7.1897	58.7333	.1234
Gender	-3.9657	10.1207	-.3918	-24.1460	16.2145	.6963
Group	16.0473	10.0620	1.5948	-4.0159	36.1105	.1152
Interaction	5.4133	6.3148	.8573	-7.1780	18.0047	.3942
Term						

CI = confidence interval, *LL* = lower limit, *UL* = upper limit.

Figure 5

The relationship between Gender and Fatigue across the ABI/neurological condition and control groups.



Moderation Analysis on the effect of Age on Fatigue as moderated by Brain Injury

The regression model analysing the relationship between age and total fatigue, as moderated by group identity was significant ($F(3,73)=19.81$, $R^2=.44$, $p<.001$). Within the model, there was no significant effect of age ($b= -.26$, $t(73)= -.81$, $p =.419$) on self-reported fatigue. A positive relationship was shown between group and fatigue ($b = 21.40$, $t(73)=6.25$, $p <.000$). The interaction term indicated no significant effect ($b=.270$, $t(73)=1.17$, $p=.247$), therefore indicating no significant effect of age on fatigue reporting and no significant moderating effect of group on this effect.

Table 12*Model Summary: Moderation Analysis of Group, Age and Fatigue*

Model Summary						
R	R Square	MSE	F	df1	df2	p
.6699	.4488	182.2331	18.8139	3.000	73.0000	.0000

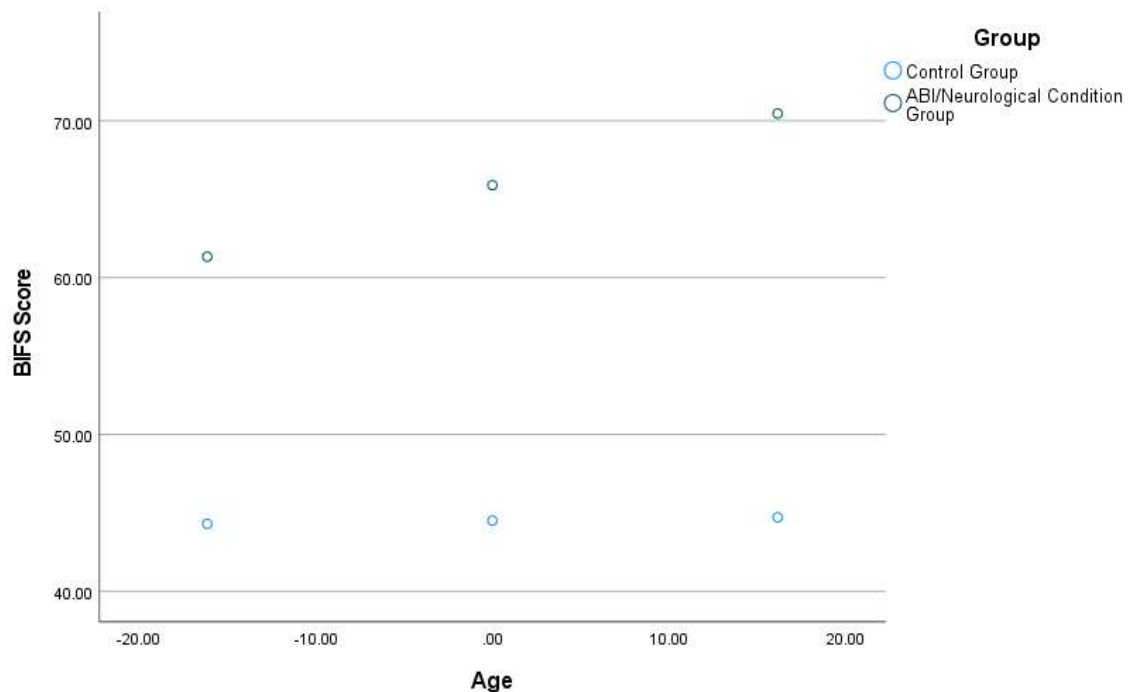
Table 13*Moderation Analysis: Group, Age and Fatigue*

	b	SE	t	95% CI		p
				LL	UL	
Constant	23.1105	5.3028	4.3581	12.5420	33.6791	.0000
Age	-.2571	.3166	-.8122	-.8880	.3738	.4193
Group	21.3957	3.4217	6.2530	14.5762	28.2151	.0000
Interaction	.2700	.2314	1.1671	-.1911	.7312	.2470
Term						

CI = confidence interval, LL = lower limit, UL = upper limit.

Figure 6

The relationship between means centred Age and Fatigue across the ABI/neurological condition and control groups.



Discussion

This study sought to explore the underlying factors measured within the BIFS and their relationship with age, gender, depression, and anxiety as moderated by the presence of an ABI/neurological condition.

The exploratory factor analysis generated two factors; a single factor explaining the majority (53.68%) of the variance, which can be best understood to reflect 'general fatigue', and an additional factor corresponding to the 'cognitive and emotional impacts of fatigue'. The results of this study suggest that the BIFS does not distinguish between different multiple dimensions of fatigue, such as mental and physical fatigue. Therefore, when drawing results from a relatively small and heterogenous sample, the BIFS does not reflect a multidimensional conceptualisation of fatigue and is a tool best suited to measurement from a unidimensional approach. This effect should

be further explored within individual diagnoses, to determine whether this unidimensional profile is similar across differing physical health conditions.

Unidimensional theories have been challenged by the factor structures of widely accepted multi-dimensional tools (Smets, Garssen, Bonke & De Haes, 1995; Stein, Martin, Hann & Jacobsen, 1998). However, several studies have failed to replicate the original factor structures of such scales, thereby calling into question whether these scales, and therefore the dimensional nature of fatigue itself (Hinz et al., 2020; Gentile, Delarozière, Favre, Sambuc & San Marco, 2003; Lequerica et al., 2012; Michielsen, De Vries, Van Heck, Van de Vijver, & Sijtsma, 2004). One clinical implication of the BIFS' unidimensional structure is that of informing the interpretation of the total score as a valid representation of the client's global fatigue.

While developing the BIFS, a principal component analysis was completed by Quinn et al. (2004). This reflected a three-factor structure, which they understood to represent 'overall fatigue' which incorporated 12 of the 19 questions analysed, 'disability' and 'pre-morbid function'. Their latent variable 'disability' was comprised of the same two questions of the BIFS replicated by these results, indicating a reliable structure for this factor. The third latent variable uncovered in the original BIFS paper comprised three questions. In order to undertake a principal axis factor analysis within the scale, five questionnaire items were required to be removed, which included two of the three questions within Quinn et al's third variable. Therefore, there is some ambiguity in the existing factor structure within the BIFS in its original state and the data should be re-examined within the context of a larger data pool (Comrey & Lee, 1992).

When compared between groups, total BIFS scores were significantly higher for the ABI/neurological condition group. This supports a large body of evidence indicating that fatigue increases following an ABI/neurological condition when compared to pre-morbid fatigue (Oullet & Morin, 2006). The categories generated within the scale were also qualitatively supported, with all 38 of the control sample falling within the 'normal' category of fatigue. Within the study,

74.36% of clinical participants reporting elevated levels of fatigue, spread relatively evenly across the 3 elevated fatigue categories, which falls within the high end of the reported prevalence ranges across the published literature (Ponsford et al., 2012; Bushnik, Englander, & Wright, 2008; Oullet & Morin, 2006). This implies that fatigue is a prevalent concern for individuals and should be considered while offering clinical interventions to clients with both recent and historical ABI/neurological conditions.

The effect of self-reported anxiety predicting greater fatigue scores was shown to be moderated by the presence of an ABI/neurological condition. This indicates that within the ABI/neurological condition group, anxiety has a greater effect on fatigue than in control groups. This has been linked to theories of secondary fatigue (Ponsford et al., 2012), suggesting that fatigue is caused by damage to normal functioning at a synaptic level (Van Zomeren, Brouwer & Deelman, 1984; Rönnbäck & Johansson, 2014) leads to increased effort to compensate, which contributes to anxiety and increased fatigue. The relationship between anxiety and fatigue in the clinical sample has clinical significance. Clinicians should incorporate both fatigue and anxiety into their assessment with individuals who have sustained a brain injury. Additionally, whilst studies into the effects of fatigue interventions on anxiety have shown mixed results (Stubberud et al., 2019; Cooper, Reynolds & Bateman, 2009), future studies should investigate the impact of anxiety interventions on self-reported fatigue within ABI/neurological condition populations.

Moderate positive correlations were found between age and fatigue across the whole sample, which contradicts evidence suggests that younger people generally report greater fatigue (Bensing et al., 1999; Andelic et al., 2021) or studies finding no effect (Lerdal et al., 2011; Ziino & Ponsford, 2005; Cantor et al., 2012; Ouellet & Morin, 2006). Within the regression model, age, group and the interaction effect showed no significant effects on fatigue. This effect supports the ‘coping hypothesis’ as it indicates that the effects of the brain injury or neurological condition impacted overall fatigue to a greater extent than demographic factors (Van Zomeren, Bower & Deelman, 1984; Ziino & Ponsford, 2006). One limitation of this conclusion is the skew in age across the two

groups, with the ABI/neurological condition group being significantly older than the control group and reporting higher fatigue than the control group. This reduces the validity of the interpretations which can be drawn from this result, and it should be replicated within age-matched samples.

Strong positive correlations were seen between BIFS scores and HADS Depression Scores. This supports findings across the literature (Ponsford et al., 2012; Belmont, Agar, Hugeron, Gallais & Azouvi, 2006), however it was not replicated within the regression model. Regression analyses instead suggest that while group had a significant effect on fatigue, the effect of depression was not significant and was not moderated by the presence of a brain injury or neurological condition. This evidence conflicts with a widely accepted theory of secondary fatigue, where increased fatigue from structural changes leads to increased stress and leads to increases in both depression and fatigue (Ponsford et al., 2012; Cantor et al., 2008). Rather, this evidence supports a relationship between depression and fatigue which does not differ significantly between groups, therefore not relying on structural changes to initiate a series of changes. The relationship between brain injury/neurological conditions, fatigue and depression could be different across time since diagnosis or between diagnoses, therefore this effect should be investigated further. Henceforth, it would be valuable to conduct future research exploring the causal relationship between depression and BIFS in future research, whilst controlling for factors such as time since injury, injury type and sleep disturbance.

Limitations

In order to conduct a statistically sound exploratory factor analysis with a small sample size, five questions were removed from the analysis. Because of this, the factor structure extracted is representative of the included data, therefore the factor structure should only be interpreted within the scope of the questions examined. This should be explored within the context of a larger sample.

During this study, participants completed only one fatigue measure. This decision was made to reduce the impact of data collection on fatigue for some participants. Future studies should explore the concurrent validity of the BIFS in relation to other available fatigue measures.

This research occurred within the context of the COVID-19 pandemic and the decision was made to collect much of the data with participants indirectly with their healthcare staff or remotely, via telephone or remote video communication. The staff pressures and increase in complex case presentations reported by services was a notably barrier to recruitment during this time-period. Additionally, remote working presented a barrier for some participants, particularly from the ABI/neurological condition group, who were unable to access or use telephone or video communication platforms due to socio-economic or health related factors (Bellon, Idle, Lay & Robinson, 2022). An attempt was made to mitigate this barrier in part by the researcher's attendance at third sector organisations, however, it continued to be a sustained barrier for those who were unable to attend these locations.

The exclusion criteria for this study were carefully considered in order to facilitate inclusion in the study whilst generating data which can answer the research questions posed within the scope of the study. Medications were not included as an exclusion-criteria, however the literature indicates that reported fatigue can be influenced by prescribed pain medication (Zlott & Byrne, 2010). Similarly, the phenomena of 'long COVID' had not been identified during the conceptualisation stage of the study. Long COVID has also been suggested to impact ongoing fatigue (Raveendran, Jayadevan & Sashidharan, 2021). Therefore, these results should be taken as a reflection of the fatigue reported, while considering other comorbidities which can elevate fatigue.

The scope of this study was expanded beyond Quinn et al's (2004) intentions when developing the scale to incorporate the wider community of people with neurological conditions. One limitation of this was that due to the small sample size, relatively few individuals with neurological conditions were recruited to the research. Because of this, valid conclusions could not be drawn on inter-group

differences and the validity and reliability of the scale within this population group. Therefore, further research should aim to explore the properties of this scale for individuals with a range of neurological conditions.

Conclusions

This study aimed to understand the properties of the BIFS by exploring the factor structure within the scale and the relationship between BIFS scores, age, gender, anxiety, and depression across those with an ABI/neurological condition and control groups.

A two-factor structure was indicated within the scale, with a first 'general fatigue' factor explaining 53.68% of the variance within the data, and a secondary factor, namely the 'cognitive and emotional impact of fatigue', explaining a further 7.58% of the variance. Across the whole sample, this result indicates a single unified construct, therefore supporting unidimensional theories of fatigue. This result was representative of a small sample, and further research should assess whether this pattern is replicated for individuals with different physical conditions.

Within the BIFS, participants with an ABI/neurological condition reported significantly greater fatigue than control group participants. Further, significant positive correlations were found between BIFS and age, depression and anxiety.

These relationship between BIFS and age, gender, anxiety and depression were analysed for the moderating effect of ABI/Neurological condition presence. It was shown that having an ABI/neurological condition moderated the effect of anxiety on fatigue, with participants who had sustained an ABI/neurological condition reporting a greater effect of anxiety on fatigue.

This relationship indicates the importance of incorporating fatigue, mental health and demographic factors into assessments for individuals who have sustained an ABI/neurological condition. It suggests that the BIFS is a valid tool for measuring general fatigue and should be researched further to provide a greater evidence base across larger samples.

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Part Three: Appendices

Appendix A: Epistemological Statement

Since the development of modern western psychological research, data analysis has been practiced through different branches of thought and methodology to reflect varying perspectives on the theory of truth and knowledge. In order to transparently disseminate collected data and for a thorough understanding of how conclusions have been reached within this field, it is imperative for researchers to define their ontological and epistemological stances (Williams, 2007). The following statement illustrates the ontological and epistemological stances underpinning the research contained in this portfolio thesis.

Ontology describes the understanding of the nature of reality (Willig, 2019) and is often viewed on a spectrum between objectivism and constructivism (Jonassen, 2019). Epistemology defines the various perspectives on how reality can be discovered (Hofer & Pintrich, 1997). Through an objectivist ontological framework, an objective reality exists can be discovered through quantitative measurement of phenomena such as the processes of cause and effect. A Positivist epistemological perspective maintains that an objective truth can theoretically be uncovered without researcher bias, which lends itself to quantitative hypothesis testing and replication of data. However, Quine (1951) posits that no question can be entirely answered as true or false, due to the ongoing possibility of chance observations. Alternatively, relativist views reality as socially constructed through language and interaction (Walsham, 1995).

Through individual and group reflections on where my beliefs on the nature of reality and knowledge acquisition lie, I found my position to exist between these two polar belief systems. My perspectives aligned with a critical realist perspective (Bhaskar, 1975), wherein an underlying reality can be perceived, understood and experienced differently based on co-existing societal factors (Patomaki & Wight, 2000).

The research topics within this thesis were generated in line with this theoretical understanding. During the empirical research study exploring individuals' self-reported experiences of fatigue, quantitative methodology was used to quantify how individuals reported their fatigue and define the demographic variables which could influence this experience. This reflects critical realist methodology because a true underlying factor is being explored and results were interpreted with considerations as to individual differences in experience, power and perspective.

While the above research was ongoing, the researcher chose to explore the literature around the experience of Multiple Sclerosis (MS) through a systematic literature review. Previous reviews exist which quantify the various factors which can influence systemic barriers to occupation for individuals with MS, therefore this piece of research built upon this work to explore how this was experienced by the individuals. A narrative synthesis approach was adopted to collate the qualitative research incorporated in the review and conclusions were drawn with a critical realist lens.

The researcher's perspectives on their ontological and epistemological positions were continually reviewed and held in mind throughout the process of research. To facilitate the continuity of approach, the researcher engaged in reflexion individually through writing a research diary and through the process of research supervision.

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Appendix B: Reflective Statement

The journey of compiling this portfolio thesis has privileged me with the opportunity to reflect on my knowledge of undertaking research within the field of clinical psychology. The past four years have contained highs and lows both academically and personally. These experiences, alongside the support of those around me, enabled me to develop a more nuanced understanding myself, my beliefs and the lens through which I have seen the world. This development felt like an endurance race at times, and a sprint at others and I hope to consolidate some of my reflections on my journey through the process of research in the below statement.

Empirical Study

Research Topic Development

My upbringing by two researchers shaped my understanding of research as a means of developing greater understanding and innovation. At the beginning of my undergraduate degree, I became aware of a clear interest in understanding post-brain injury sequelae. The motivation to pursue this topic was initially sparked within an academic context and was intensified through my work in brain injury rehabilitation services and was solidified by several individuals closely associated with me having their lives altered by brain injuries. This was therefore an understandably emotive topic area for me; hence I made a consistent effort throughout the process to decentre the individual experiences of those personally connected to me.

Within the broad topic of post-ABI sequelae, I was open to exploring a range of different experiences. On further reflections of the available literature and I found myself particularly drawn to intersectional experiences of gender and mental health difficulties following an ABI. At the research fair, I was inspired by Pete and Stephen who introduced me to an unpublished fatigue scale designed specifically for individuals who had sustained an ABI (BIFS).

Understanding fatigue was a novel research area to me, which I found intimidating at first due to the varying theoretical understandings of the nature of fatigue. The varying results around the relationships between age, gender and mental health difficulties within the population of individuals who had sustained an ABI was striking to me, therefore I was keen to investigate these relationships for individuals within the context of this scale. I worked alongside another trainee who was similarly passionate about this area to determine valuable contributions alongside one another.

Ethical approval

Retrospectively, the process of applying for ethical approval was the largest logistical and psychological hurdle I experienced during in the project. Writing the proposal application involved making a number of final decisions on the protocol and proposed data analysis for the project, which was difficult for me due to my own inexperience in conducting research, the changing context of COVID-19 protocols and varying perspectives of those with experience on whether the project would fall outside the scope what is possible within a DClinPsy project. I experienced a lot of self-doubt and uncertainty during this time, through which I was able to recognise that taking action based on my knowledge at that time was a valuable roadmap to lessons within the project which could not be learnt through thought alone. In order to enact this lesson, I relied on the support of those the trainees and staff members around me in addition to my own ability to make complex decisions in the face of contradicting advice.

Data collection

A series of cumulative delays led to final approval within the NHS trusts being granted during summer 2022. I sat with a weight of mixed feelings at this stage. On one hand I was to finally able to begin my long-anticipated data collection which was an invigorating and motivating

stage. However I had initially anticipated ending data collection at this date, and therefore I had to make a number of difficult decisions to limit the scope of the project.

During the recruitment and data collection stages, a number of unexpected understandable delays occurred due to staff shortages. This created some discomfort when contacting services for their data collection and recruitment numbers, as I was acutely aware of the pressures these shortages were causing for staff. Throughout this, the generosity with which the staff showed their enthusiasm and made time to support the project was deeply moving. The data collected with the support of staff was an invaluable asset towards this stage of the study and supporting proposed future projects.

Collecting data with participants

The process of collecting data with participants was deeply rewarding. I had anticipated that individuals may be hesitant to complete the research, however I was met with overwhelming enthusiasm from many of the participants. I was particularly struck by many of the journeys to recovery which were shared with me following data collection and participants' strong values of supporting others. I was eager to collect data with as many participants as I could facilitate, while maintaining a new job and taking care of myself. At times, I made the decision to purposefully slow the rate of progress within the project to create a sustainable pace of work.

I made the decision to attend third sector services as part of recruitment, to facilitate participation for individuals from a range of cultural backgrounds, from both urban and rural areas and different stages in their journey following brain injury/neurological condition outside the context of NHS services. I could not have completed the project without the generosity of the group members and staff who welcomed me to join third sector group meetings and those who shared information about the project.

Data analysis

At this stage, four years worth of work from myself, the participants and the staff members involved in the research was in front of me. I experienced a surge of excitement and motivation to see the results of the information which the participants provided. The statistical analyses were proposed under the supervision of a university statistician who retired during the project, therefore I was able to build my own knowledge of statistics alongside building new connections within the university to consult during statistical dilemmas.

One difficult decision I faced was during the exploratory factor analysis, wherein the statistical analysis demanded that I remove items from the scale to provide reliable and valid outcomes. I felt disheartened by removing questions within the BIFS for analysis, as my research question aimed to understand the factors within the complete scale. I was able to see some of the limitations of statistics within real data sets and this has informed my comprehension of subsequent research. When reflecting on these limitations and the stories which was shared by participants which I was unable to include within the research, I found myself repeatedly considering my own approach to research and the inclination to undertake qualitative or mixed methods analyses in future within this topic area to incorporate some of the richness of the data which was outside the scope of the current study.

Systematic Literature Review

After completing the empirical thesis planning and ethical approval, I began to turn my attention to the systematic literature review. I found that exploring qualitative research alongside undertaking quantitative research informed my lens and critical thinking when evaluating these very different approaches. I really valued the deeper exploration into individual experiences shown within the qualitative research, and I experienced some discomfort in attempting to summarise these into a unifying narrative. My own lens as an outsider to the experience of disclosing MS at work contributed to my desire to generate an

accurate representation of this important area. I spent much time considering my own blind spots within the literature and discourses and I cultivated my understanding of this through the use of a reflective diary and through supervision. Along this journey, I have recognised how much growth I have had during the past three years and the thought of transcribing my current understanding into stone has led me to feel a considerable amount of discomfort. Sitting with this discomfort and allowing myself the opportunity to grow further in my understanding has allowed me to see some of the limitations within this research. Because of this, I will provide myself the same space to reflect and develop in my future understanding of this topic and as a researcher.

Final reflections

This research has been a labour of love, with too many highs and lows to count. It has taught me about fatigue, MS, the process of research and about myself. I contended with a lot of self-doubt throughout the journey, which, while tough to sit with, has motivated me to grow in the depth and breadth of my understanding. Most importantly, I learnt that it is okay to ask for support from others around you. The participants told me the value they receive from supporting others through sharing their stories and I hope that this research project has given justice to encapsulating their experiences. I am both sad and relieved to end this part of my career, and most of all I'm proud of what I, the participants, my supervisors, the wider community around me were able to create.

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Updated 8th February 2023

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<p>Study identification: Include author, title, reference, year of publication</p>		
<p>Guidance topic: MS how to facilitate job retention</p>	<p>Key research question/aim: .</p>	
<p>Checklist completed by:</p>	<p>KW</p>	
<p>Theoretical approach: qualitative</p>		
<p>1. Is a qualitative approach appropriate? For example:</p> <ul style="list-style-type: none"> • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question? 	<p>Appropriate Inappropriate Not sure</p>	<p>Comments:</p>
<p>2. Is the study clear in what it seeks to do? For example:</p> <ul style="list-style-type: none"> • Is the purpose of the study discussed – aims/objectives/research question/s? • Is there adequate/appropriate reference to the literature? 	<p>Clear Unclear Mixed</p>	<p>Comments:</p>

<ul style="list-style-type: none"> • Are underpinning values/assumptions/theory discussed? 		
Study design		
<p>3. How defensible/rigorous is the research design/methodology?</p> <p>For example:</p> <ul style="list-style-type: none"> • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach? • Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified? 	<p>Defensible</p> <p>Indefensible</p> <p>Not sure</p>	<p>Comments:</p>
Data collection		
<p>4. How well was the data collection carried out?</p> <p>For example:</p> <ul style="list-style-type: none"> • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic? 	<p>Appropriately</p> <p>Inappropriately</p> <p>Not sure/inadequately</p>	<p>Comments:</p>

Trustworthiness		
<p>5. Is the role of the researcher clearly described?</p> <p>For example:</p> <ul style="list-style-type: none"> • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants? 	<p>Clearly described</p> <p>Unclear</p> <p>Not described</p>	<p>Comments:</p>
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<p>7. Were the methods reliable?</p> <p>For example:</p> <ul style="list-style-type: none"> • Was data collected by more than 1 method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to? 	<p>Reliable</p> <p>Unreliable</p> <p>Not sure</p>	<p>Comments:</p>

Analysis		
<p>8. Is the data analysis sufficiently rigorous?</p> <p>For example:</p> <ul style="list-style-type: none"> • Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? • How systematic is the analysis, is the procedure reliable/dependable? • Is it clear how the themes and concepts were derived from the data? 	<p>Rigorous</p> <p>Not rigorous</p> <p>Not sure/not reported</p>	<p>Comments:</p>
<p>9. Is the data 'rich'?</p> <p>For example:</p> <ul style="list-style-type: none"> • How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • How well has the detail and depth been demonstrated? • Are responses compared and contrasted across groups/sites? 	<p>Rich</p> <p>Poor</p> <p>Not sure/not reported</p>	<p>Comments:</p>
<p>10. Is the analysis reliable?</p> <p>For example:</p> <ul style="list-style-type: none"> • Did more than 1 researcher theme and code transcripts/data? • If so, how were differences resolved? 	<p>Reliable</p> <p>Unreliable</p> <p>Not sure/not reported</p>	<p>Comments:</p>

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<ul style="list-style-type: none"> • Are the implications of the research clearly defined? <p>Is there adequate discussion of any limitations encountered?</p>		
<p>Ethics</p>		
<p>14. How clear and coherent is the reporting of ethics?</p> <p>For example:</p> <ul style="list-style-type: none"> • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour? • Was the study approved by an ethics committee? 	<p>Appropriate</p> <p>Inappropriate</p> <p>Not sure/not reported</p>	<p>Comments:</p>
<p>Overall assessment</p>		
<p>As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)</p>	<p>++ -</p> <p>+</p> <p>-</p>	<p>Comments</p>

Appendix E: Submission Guidelines for Journal of Neuropsychology Review

Sections

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1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at <http://www.editorialmanager.com/jnp>

Click here for more details on how to use [Editorial Manager](#).

All papers published in the *Journal of Neuropsychology* are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

Data protection:

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at <https://authorservices.wiley.com/statements/data-protection-policy.html>.

Preprint policy:

This journal will consider for review articles previously available as preprints. Authors may also post the submitted version of a manuscript to a preprint server at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

2. AIMS AND SCOPE

The Journal of Neuropsychology publishes original contributions to scientific knowledge in neuropsychology including:

- clinical and research studies with neurological, psychiatric and psychological patient populations in all age groups
- behavioural or pharmacological treatment regimes

- cognitive experimentation and neuroimaging
- multidisciplinary approach embracing areas such as developmental psychology, neurology, psychiatry, physiology, endocrinology, pharmacology and imaging science

The following types of paper are invited:

- papers reporting original empirical investigations
- theoretical papers; provided that these are sufficiently related to empirical data
- review articles, which need not be exhaustive, but which should give an interpretation of the state of research in a given field and, where appropriate, identify its clinical implications
- brief reports and comments
- case reports
- fast-track papers (included in the issue following acceptance) reaction and rebuttals (short reactions to publications in JNP followed by an invited rebuttal of the original authors)
- special issues.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

- Research papers should be no more than 6000 words (excluding the abstract, reference list, tables and figures). Multiple citations for a single point are usually duplicative and authors are urged to cite the best reference. In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.
- Brief communications are short reports of original research or case reports. They are limited to a maximum of 1500 words (excluding the abstract, reference list, tables and figures) and have a total of up to three tables or figures, and no more than 10 references.
- Theoretical or review articles are full-length reviews of, or opinion statements regarding, the literature in a specific scientific area. They should be no more than 4000 words (excluding the abstract, reference list, tables and figures) and have no more than 45 references. Multiple citations for a single point are usually duplicative and authors are urged to cite the best reference. In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.
- Please refer to the separate guidelines for [Registered Reports](#).
- All systematic reviews must be pre-registered and an anonymous link to the pre-registration must be provided in the main document, so that it is available to reviewers. Systematic reviews without pre-registration details will be returned to the authors at submission.

4. PREPARING THE SUBMISSION

Free Format Submission

Journal of Neuropsychology now offers free format submission for a simplified and streamlined submission process.

Before you submit, you will need:

- Your manuscript: this can be a single file including text, figures, and tables, or separate files – whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. If the manuscript, figures or tables are difficult for you to read,

they will also be difficult for the editors and reviewers. If your manuscript is difficult to read, the editorial office may send it back to you for revision.

- The title page of the manuscript, including a data availability statement and your co-author details with affiliations. (*Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.*) You may like to use [this template](#) for your title page.

Important: the journal operates a double-blind peer review policy. Please anonymise your manuscript and prepare a separate title page containing author details. (*Why is this important? We need to uphold rigorous ethical standards for the research we consider for publication.*)

- An ORCID ID, freely available at <https://orcid.org>. (*Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.*)

To submit, login at <https://www.editorialmanager.com/jnp/default.aspx> and create a new submission. Follow the submission steps as required and submit the manuscript.

If you are invited to revise your manuscript after peer review, the journal will also request the revised manuscript to be formatted according to journal requirements as described below.

Revised Manuscript Submission

Contributions must be typed in double spacing. All sheets must be numbered.

Cover letters are not mandatory; however, they may be supplied at the author's discretion. They should be pasted into the 'Comments' box in Editorial Manager.

Parts of the Manuscript

The manuscript should be submitted in separate files: title page; main text file; figures/tables; supporting information.

Title Page

You may like to use [this template](#) for your title page. The title page should contain:

- A short informative title containing the major key words. The title should not contain abbreviations (see Wiley's [best practice SEO tips](#));
- A short running title of less than 40 characters;
- The full names of the authors;
- The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
- Abstract;
- Keywords;
- Data availability statement (see [Data Sharing and Data Accessibility Policy](#));
- Acknowledgments.

Authorship

Please refer to the journal's Authorship policy in the Editorial Policies and Ethical Considerations section for details on author listing eligibility. When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the

role that each author played in creating the manuscript. Please see the [Project CRediT](#) website for a list of roles.

Abstract

Please provide an abstract which gives a concise statement of the intention, results or conclusions of the article. The abstract should not include any sub-headings.

- Abstracts for Research Papers should not exceed 250 words.
- Abstracts for theoretical or review articles should not exceed 250 words.
- Abstracts for brief communications should not exceed 80 words.

Keywords

Please provide appropriate keywords.

Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Main Text File

As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors.

The main text file should be presented in the following order:

- Title
- Main text
- References
- Tables and figures (each complete with title and footnotes)
- Appendices (if relevant)

Supporting information should be supplied as separate files. Tables and figures can be included at the end of the main document or attached as separate files but they must be mentioned in the text.

- As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors. Please do not mention the authors' names or affiliations and always refer to any previous work in the third person.
- The journal uses British/US spelling; however, authors may submit using either option, as spelling of accepted papers is converted during the production process.

References

This journal uses APA reference style; as the journal offers Free Format submission, however, this is for information only and you do not need to format the references in your article. This will instead be taken care of by the typesetter.

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figures

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

[Click here](#) for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Supporting Information

Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.

[Click here](#) for Wiley's FAQs on supporting information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

For guidelines on editorial style, please consult the [APA Publication Manual](#) published by the American Psychological Association. The following points provide general advice on formatting and style.

- **Language:** Authors must avoid the use of sexist or any other discriminatory language.
- **Abbreviations:** In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.
- **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the [Bureau International des Poids et Mesures \(BIPM\) website](#) for more information about SI units.
- **Effect size:** In normal circumstances, effect size should be incorporated.
- **Numbers:** numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).

Wiley Author Resources

Manuscript Preparation Tips: Wiley has a range of resources for authors preparing manuscripts for submission available [here](#). In particular, we encourage authors to consult Wiley's best practice tips on [Writing for Search Engine Optimization](#).

Article Preparation Support: [Wiley Editing Services](#) offers expert help with English Language Editing, as well as translation, manuscript formatting, figure illustration, figure formatting, and graphical abstract design – so you can submit your manuscript with confidence.

Also, check out our resources for [Preparing Your Article](#) for general guidance and the [BPS Publish with Impact infographic](#) for advice on optimizing your article for search engines.

5. EDITORIAL POLICIES AND ETHICAL CONSIDERATIONS

Peer Review and Acceptance

Except where otherwise stated, the journal operates a policy of anonymous (double blind) peer review. Please ensure that any information which may reveal author identity is blinded in your submission, such as institutional affiliations, geographical location or references to unpublished research. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review. Before submitting, please read [the terms and conditions of submission](#) and the [declaration of competing interests](#).

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with patient populations is appropriately defined
- the word count is within the stated limit for the Journal (i.e. 6000 words)

The *Journal of Neuropsychology* is committed to a fast and efficient turnaround of papers, aiming to complete the review process in under two months.

Further information about the process of peer review and production can be found in '[What happens to my paper?](#)' Appeals are handled according to the [procedure recommended by COPE](#). Wiley's policy on the confidentiality of the review process is [available here](#).

Research Reporting Guidelines

Accurate and complete reporting enables readers to fully appraise research, replicate it, and use it. Authors are encouraged to adhere to recognised research reporting standards. The EQUATOR Network collects more than 370 reporting guidelines for many study types, including for:

- [Randomised trials: CONSORT](#)
- [Systematic reviews: PRISMA](#)
- [Interventions: TIDieR](#)
- [Clinical case reports: CARE](#)

We encourage authors to adhere to the APA Style Journal Article Reporting Standards for:

- [Manuscripts that report primary qualitative research](#)
- [Manuscripts that report the collection and integration of qualitative and quantitative data](#)
- [Manuscripts that report new data collections regardless of research design](#)

We also encourage authors to refer to and follow guidelines from the [FAIRsharing website](#).

Conflict of Interest

The journal requires that all authors disclose any potential sources of conflict of interest. Any interest or relationship, financial or otherwise that might be perceived as influencing an author's objectivity is considered a potential source of conflict of interest. These must be disclosed when directly relevant or directly related to the work that the authors describe in their manuscript. Potential sources of conflict of interest include, but are not limited to: patent or stock ownership, membership of a company board of directors, membership of an advisory board or committee for a company, and consultancy for or receipt of speaker's fees from a company. The existence of a conflict of interest does not preclude publication. If the authors have no conflict of interest to declare, they must also state this at submission. It is the responsibility of the corresponding author to review this policy with all authors and collectively to disclose with the submission ALL pertinent commercial and other relationships.

Funding

Authors should list all funding sources in the Acknowledgments section. Authors are responsible for the accuracy of their funder designation. If in doubt, please check the Open Funder Registry for the correct nomenclature: <https://www.crossref.org/services/funder-registry/>

Authorship

All listed authors should have contributed to the manuscript substantially and have agreed to the final submitted version. Authorship is defined by the criteria set out in the APA Publication Manual:

“Individuals should only take authorship credit for work they have actually performed or to which they have substantially contributed (APA Ethics Code Standard 8.12a, Publication Credit). Authorship encompasses, therefore, not only those who do the actual writing but also those who have made substantial scientific contributions to a study. Substantial professional contributions may include formulating the problem or hypothesis, structuring the experimental design, organizing and conducting the statistical analysis, interpreting the results, or writing a major portion of the paper. Those who so contribute are listed in the byline.” (p.18)

Data Sharing and Data Accessibility Policy

The *Journal of Neuropsychology* recognizes the many benefits of archiving data for scientific progress. Archived data provides an indispensable resource for the scientific community, making possible future replications and secondary analyses, in addition to the importance of verifying the dependability of published research findings.

The journal expects that where possible all data supporting the results in papers published are archived in an appropriate public archive offering open access and guaranteed preservation. The archived data must allow each result in the published paper to be recreated and the analyses reported in the paper to be replicated in full to support the conclusions made. Authors are welcome to archive more than this, but not less.

All papers need to be supported by a data archiving statement and the data set must be cited in the Methods section. The paper must include a link to the repository in order that the statement can be published.

It is not necessary to make data publicly available at the point of submission, but an active link must be included in the final accepted manuscript. For authors who have pre-registered studies, please use the Registered Report link in the Author Guidelines.

In some cases, despite the authors' best efforts, some or all data or materials cannot be shared for legal or ethical reasons, including issues of author consent, third party rights, institutional or national regulations or laws, or the nature of data gathered. In such cases, authors must inform the editors at the time of submission. It is understood that in some cases access will be provided under restrictions to protect confidential or proprietary information. Editors may grant exceptions to data access requirements provided authors explain the restrictions on the data set and how they preclude public access, and, if possible, describe the steps others should follow to gain access to the data.

If the authors cannot or do not intend to make the data publicly available, a statement to this effect, along with the reasons that the data is not shared, must be included in the manuscript.

Finally, if submitting authors have any questions about the data sharing policy, please access the [FAQs](#) for additional detail.

Open Research initiatives.

Recognizing the importance of research transparency and data sharing to cumulative research, *Journal of Neuropsychology* encourages the following Open Research practices.

Sharing of data, materials, research instruments and their accessibility. *Journal of Neuropsychology* encourages authors to share the data, materials, research instruments, and other artifacts supporting the results in their study by archiving them in an appropriate public repository. Qualifying public, open-access repositories are committed to preserving data, materials, and/or registered analysis plans and keeping them publicly accessible via the web into perpetuity. Examples include the Open Science Framework (OSF) and the various Dataverse networks. Hundreds of other qualifying data/materials repositories are listed at the Registry of Research Data Repositories (<http://www.re3data.org>). Personal websites and most departmental websites do not qualify as repositories.

Open Research Badges. In partnership with the non-profit Center for Open Science (COS), *Journal of Neuropsychology* offers all submitting authors access to the following three Open Research Badges— Open Materials, Open Data, and Preregistered Research Designs. We also award all qualifying authors Open Research Badges recognizing their contributions to the Open Research movement. The Open Research practices and associated award badges, as implemented by the Center for Open Science and supported by *Journal of Neuropsychology*, are the following:

The Open Materials Badge recognizes researchers who share their research instruments and materials in a publicly-accessible format, providing sufficient information for researchers to reproduce procedures and analyses of published research studies. A list of certified data repositories can be accessed at re3data.org or fairsharing.org. Guidelines about the use of data repositories can be found at websites such as The Wellcome Trust (<https://wellcomeopenresearch.org/for-authors/data-guidelines>) and the Center for Open Science (<https://cos.io/>).

The Open Data Badge recognizes researchers who make their data publicly available, providing sufficient description of the data to allow researchers to reproduce research findings of published research studies. An example of a qualifying public, open-access database for data sharing is the Open Science Framework repository. Numerous other data-sharing repositories are available through various Dataverse networks (e.g., <http://dataverse.org>) and hundreds of other databases available through the Registry of Research Data Repositories (<http://www.re3data.org>). There are, of course, circumstances in which it is not possible or advisable to share data publicly. For example, there are cases in which sharing participant data could violate confidentiality. In these cases, the authors may provide an explanation of such circumstances in the Alternative Note section of [the disclosure form](#). The information the authors provide will be included in the article's Open Research note.

The Preregistered Badge recognizes researchers who preregister their research plans (research design and data analysis plan) prior to engaging in research and who closely follow the preregistered design and data analysis plan in reporting their research findings. The criteria for earning this badge thus include a date-stamped registration of a study plan in such venues as the Open Science Framework (<https://osf.io>) or Clinical Trials (<https://clinicaltrials.gov>) and a close correspondence between the preregistered and the implemented data collection and analysis plans.

Authors will have an opportunity at the time of manuscript submission to inform themselves of this initiative and to determine whether they wish to participate. Applying and qualifying for Open Research Badges is not a requirement for publishing with *Journal of Neuropsychology*, but these badges are further incentive for authors to participate in the Open Research movement and thus to increase the visibility and transparency of their research. If you are interested in applying, please note that you will be asked to complete the Disclosure Form when submitting a revised manuscript.

More information about the Open Research Badges is available from the Open Science Framework [wiki](#).

Publication Ethics

Authors are reminded that the *Journal of Neuropsychology* adheres to the ethics of scientific publication as detailed in the [Ethical principles of psychologists and code of conduct](#) (American Psychological Association, 2010). The Journal generally conforms to the Uniform Requirements for Manuscripts of the International Committee of Medical Journal Editors ([ICJME](#)) and is also a member and subscribes to the principles of the Committee on Publication Ethics ([COPE](#)). Authors must ensure that all research meets these ethical guidelines and affirm that the research has received permission from a stated Research Ethics Committee (REC) or Institutional Review Board (IRB), including adherence to the legal requirements of the study county.

Note this journal uses iThenticate's CrossCheck software to detect instances of overlapping and similar text in submitted manuscripts. Read Wiley's Top 10 Publishing Ethics Tips for Authors [here](#). Wiley's Publication Ethics Guidelines can be found [here](#).

ORCID

As part of the journal's commitment to supporting authors at every step of the publishing process, the journal requires the submitting author (only) to provide an ORCID iD when submitting a manuscript. This takes around 2 minutes to complete. [Find more information here](#).

6. AUTHOR LICENSING

WALS + standard CTA/ELA and/or Open Access for hybrid titles

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BPS members and open access: if the corresponding author of an accepted article is a Graduate or

Chartered member of the BPS, the Society will cover will cover 100% of the APC allowing the article to be published as open access and freely available.

7. PUBLICATION PROCESS AFTER ACCEPTANCE

Accepted Article Received in Production

When an accepted article is received by Wiley's production team, the corresponding author will receive an email asking them to login or register with [Wiley Author Services](#). The author will be asked to sign a publication license at this point.

Proofs

Once the paper is typeset, the author will receive an email notification with full instructions on how to provide proof corrections.

Please note that the author is responsible for all statements made in their work, including changes made during the editorial process – authors should check proofs carefully. Note that proofs should be returned within 48 hours from receipt of first proof.

Early View

The journal offers rapid publication via Wiley's Early View service. [Early View](#) (Online Version of Record) articles are published on Wiley Online Library before inclusion in an issue. Before we can publish an article, we require a signed license (authors should login or register with [Wiley Author Services](#)). Once the article is published on Early View, no further changes to the article are possible. The Early View article is fully citable and carries an online publication date and DOI for citations.

8. POST PUBLICATION

Access and Sharing

When the article is published online:

- The author receives an email alert (if requested).
- The link to the published article can be shared through social media.
- The author will have free access to the paper (after accepting the Terms & Conditions of use, they can view the article).
- For non-open access articles, the corresponding author and co-authors can nominate up to ten colleagues to receive a publication alert and free online access to the article.

Promoting the Article

To find out how to best promote an article, click [here](#).

[Wiley Editing Services](#) offers professional video, design, and writing services to create shareable video abstracts, infographics, conference posters, lay summaries, and research news stories for your research – so you can help your research get the attention it deserves.

Measuring the Impact of an Article

Wiley also helps authors measure the impact of their research through specialist partnerships with [Kudos](#) and [Altmetric](#).

9. EDITORIAL OFFICE CONTACT DETAILS

For help with submissions, please contact: Hannah Wakley, Associate Managing Editor (jnp@wiley.com) or phone +44 (0) 116 252 9504.

Author Guidelines updated 14th October 2019

Appendix F: University Ethical Approval



**UNIVERSITY
OF HULL**

University of Hull
Hull, HU6 7RX
United Kingdom
T: +44 (0)1482 463336 | E: e.walker@hull.ac.uk
W: www.hull.ac.uk

PRIVATE AND CONFIDENTIAL

Katherine Watson
Faculty of Health Sciences
University of Hull
Via email

22nd November 2021

Dear Katherine

REF FHS377 - An investigation into the properties of the Brain Injury Fatigue Scale

Thank you for your responses to the points raised by the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the [Research Ethics Committee](#) web page for reporting requirements in the event of any amendments to your study.

Should an Adverse Event need to be reported, please complete the [Adverse Event Form](#) and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Professor Liz Walker
Chair, FHS Research Ethics Committee



**UNIVERSITY
OF HULL**

Liz Walker | Professor of Health and Social Work Research |
Faculty of Health Sciences

University of Hull
Hull, HU6 7RX, UK

www.hull.ac.uk

e.walker@hull.ac.uk | 01482 463336

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Appendix G: University Sponsorship



Dr David Richards, FEI
Pro-Vice-Chancellor (Research & Enterprise)
University of Hull
Hull, HU6 7RX
United Kingdom
T: +44 (0)1482 466732 | E: David.Richards@hull.ac.uk
w: www.hull.ac.uk

2 February 2022

Katherine Watson
University of Hull

Dear Katherine,

**Project Title: An investigation into the properties of the Brain Injury Fatigue Scale
RS164**

I am writing to confirm that the University of Hull has agreed to act as sponsor, subject to approval being granted in accordance with the Department of Health Research Governance Framework for the project : An investigation into the properties of the Brain Injury Fatigue Scale.

Yours sincerely,

Dr David Richards, FEI
Pro-Vice-Chancellor (Research & Enterprise)
(Chair of University Research Committee)

cc Dean
 Research Governance



East of England - Cambridge Central Research Ethics Committee

Equinox House
City Link
Nottingham
NG2 4LA

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

20 May 2022

Miss Katherine Watson

Trainee Clinical Psychologist

Humber NHS Foundation Teaching Trust

Doctorate in Clinical Psychology, Aire Building, University of
Hull Aire Building, University of Hull

Hull

HU67RX

Dear Miss Watson

Study title: An investigation into the properties of the Brain Injury
Fatigue Scale
REC reference: 22/EE/0099
Protocol number: N/A
IRAS project ID: 298405

The Proportionate Review Sub-committee of the East of England - Cambridge Central Research Ethics Committee reviewed the above application on 29 April 2022.

Ethical opinion

On behalf of the Research Ethics Committee (REC), the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Good practice principles and responsibilities

The [UK Policy Framework for Health and Social Care Research](#) sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of [research transparency](#):

1. [registering research studies](#)
2. [reporting results](#)
3. [informing participants](#)
4. [sharing study data and tissue](#)

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose,

‘clinical trials’ are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: [Research registration and research project identifiers](#)).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:

<https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/>

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at:

<https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/>

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see

“Conditions of the favourable opinion”).

Approved documents

The documents reviewed and approved were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [University_Approval_document]	V1	22 November 2021
Copies of materials calling attention of potential participants to the research [Recruitment_Poster]	V1	04 May 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence_Of_Sponsor_Insurance]	V1	02 November 2021
IRAS Application Form [IRAS_Form_23032022]		23 March 2022
IRAS Application Form XML file [IRAS_Form_23032022]		23 March 2022
IRAS Checklist XML [Checklist_23032022]		23 March 2022
Letter from sponsor [Sponsorship_Approval_document]	V1	02 February 2022
Non-validated questionnaire [Brain_Injury_Fatigue_Scale]	V1	22 February 2022
Other [ABI_Sample_Information_Sheet]	V1	15 September 2021

Other [Control_Sample_Poster]	V1	04 May 2021
Other [Field_Supervisor_CV]	V1	07 December 2021
Participant consent form [Consent_Form]	V1	04 May 2021
Participant information sheet (PIS) [Control_Sample_Information_Sheet]	V1	04 May 2021
Research protocol or project proposal [Research Proposal]	V1	03 June 2021
Summary CV for Chief Investigator (CI) [CV_Chief_Investigator_Katherine_Watson]	V1	16 November 2021
Summary CV for student [CV_Chief_Investigator_Katherine_Watson]	v1	16 November 2021
Summary CV for supervisor (student research) [Supervisor_CV_]	V1	15 July 2020
Validated questionnaire [Hospital_Anxiety_Depression_Scale]		

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

None.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:

<https://www.hra.nhs.uk/planning-and-improving-research/learning/>

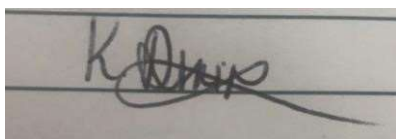
With the Committee’s best wishes for the success of this project.

IRAS project ID: 298405

Please quote this number on all correspondence

Yours sincerely

P.P.



Miss Stephanie Ellis Chair

Email: cambridgecentral.rec@hra.nhs.uk

Enclosures: List of names and professions of members who took part in the review

“After ethical review – guidance for researchers”

[Non CTIMP Standard Conditions of Approval](#)

Copy to: Ms Katie Skilton
Miss Katherine Watson, Humber NHS Foundation Teaching Trust
Lead Nation

England: approvals@hra.nhs.uk

East of England - Cambridge Central Research Ethics
Committee

**Attendance at PRS Sub-Committee of the REC meeting on 29 April
2022**

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Miss Stephanie Ellis	Former Civil Servant	Yes	Chair
Mr Stewart Fuller	Senior Research Nurse	Yes	
Ms Mary-Beth Sherwood		Yes	

Appendix I: HRA approval



N/AMiss

Katherine Watson

Trainee Clinical Psychologist

Email: approvals@hra.nhs.uk

Humber NHS Foundation Teaching Trust

Doctorate in Clinical Psychology, Aire Building,

University of Hull

Aire Building, University of Hull

Hull

HU67RXN/A

23 May 2022

Dear N/AMiss WatsonN/A

HRA and Health and Care

Study title:	An investigation into the properties of the Brain Injury Fatigue Scale
IRAS project ID:	298405
Protocol number:	N/A
REC reference:	22/EE/0099
Sponsor	University of Hull

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the “Information to support study set up” section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document “[After Ethical Review – guidance for sponsors and investigators](#)”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

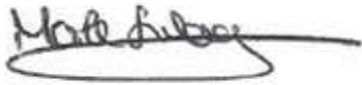
The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **298405**. Please quote this on all correspondence.

Yours sincerely,



Mark Sidaway

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: Ms Katie Skilton **List of Documents**

The final document set assessed and approved by HRA and HCRW Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [University_Approval_document]	V1	22 November 2021
Copies of materials calling attention of potential participants to the research [Recruitment_Poster]	V1	04 May 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence_Of_Sponsor_Insurance]	V1	02 November 2021
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IRAS Checklist XML [Checklist_23032022]		23 March 2022
Letter from sponsor [Sponsorship_Approval_document]	V1	02 February 2022
Non-validated questionnaire [Brain_Injury_Fatigue_Scale]	V1	22 February 2022
Organisation Information Document [Organisation_Information_Document_]	V1	
Other [ABI_Sample_Information_Sheet]	V1	15 September 2021
Other [Control_Sample_Poster]	V1	04 May 2021
Other [Field_Supervisor_CV]	V1	07 December 2021
Participant consent form [Consent_Form]	V1	04 May 2021
Participant information sheet (PIS) [Control_Sample_Information_Sheet]	V1	04 May 2021
Research protocol or project proposal [Research_Proposal]	V1	03 June 2021
Schedule of Events or SoECAT [Schedule_Of_Events]	V1	25 November 2021
Summary CV for Chief Investigator (CI) [CV_Chief_Investigator_Katherine_Watson]	V1	16 November 2021
Summary CV for student [CV_Chief_Investigator_Katherine_Watson]	v1	16 November 2021
Summary CV for supervisor (student research) [Supervisor_CV_]	V1	15 July 2020
Validated questionnaire [Hospital_Anxiety_Depression_Scale]		

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations
<p>This is a multisite study undertaking the same research activities. There is therefore one site type.</p> <p>Some participants may also be recruited outside the NHS. HRA approval does not cover research activities undertaken outside the NHS. Before recruiting outside the NHS the research team must follow the procedures</p>	<p>Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.</p>	<p>An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other agreement to be used with participating NHS organisations of this type.</p>	<p>No application for external funding will be made.</p>	<p>As per the Organisation Information Document Collaborate place at each participating Organisation assistance potential Local Collaborate required from the participating NHS Organisation</p>

<p>and governance arrangements of responsible organisations.</p>				
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Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales.

- The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix J: Clinical Participant Information Sheet

Katherine Watson
Version Number 1.1
IRAS ID: 298405
Date 15.09.2021



Participant Information Sheet (Version 1) – Clinical Sample

This research is being completed as part of the requirements of the Doctorate in Clinical Psychology course at the University of Hull. The researcher, Katherine Watson, is a Trainee Clinical Psychologist and this study is part of her thesis project.

Title of study: An investigation into the properties of the Brain Injury Fatigue Scale

We would like to invite you to participate in this research on the effects of Brain Injury on fatigue.

We are looking to recruit two groups of people for this study:

- 1) People who have an acquired brain injury or neurological condition
- 2) People who have NOT had any type of brain injury or neurological condition

Before you decide, we would like you to understand why the research is being done and what it would for you. Please take time to read the following information carefully. Talk to other people about the study if you wish. One of our team will also go through the information sheet with you and answer any questions you have.

Ask us if there is anything that is not clear, or if you have any questions. Please take your time in deciding if you would like to take part.

What is an acquired brain injury?

An acquired brain injury is a term used to describe damage to a part of the brain. This damage can happen for a number of reasons, including a physical force on the body, disease or a medical emergency such as a stroke.

What is the purpose of the study?

After an acquired brain injury or neurological condition, some people report feeling more fatigue. This research aims to provide information on the Brain Injury Fatigue Scale and the factors which influence how fatigue is rated. This will help health care teams measure fatigue and help people to manage these experiences.

Do I have to take part?

No, participation is completely voluntary. If you decide to take part, you will be asked to sign a consent form to indicate that you agree to take part and that you have read this information sheet. You are free to withdraw from the study up to the point that the results are analysed and written up and you do not have to give a reason for this. Your decision will not affect your medical care or your legal rights.

What will I be asked to do?

If you agree to take part and sign the consent form, then myself or a member of your care team will contact you to arrange a convenient time and date for the study. Due to current COVID-19 restrictions, this appointment may be done remotely over a video conferencing platform such as Microsoft Teams or Zoom. The appointment will last around 20 minutes.

- During the appointment, the researcher will ask you some questions about yourself, such as your age and your gender.
- You will then be offered to complete the Brain Injury Fatigue scale (BIFS) with you. This scale contains 20 questions where you are asked to rate the extent to which you agree with the statement, on a scale between 0-4.
- Following this, you will be offered to complete a second scale about your current mood. This contains 14 statements about your current mood and asks you to rate the extent to which you agree with each statement on a scale between 0-5.

What will happen if I decide I no longer wish to take part?

You are free to withdraw from the study before the results are analysed and the study is written-up without giving a reason. This will not affect your legal rights or the medical care that you receive.

Your rights.

- You do not have to take part
- You can withdraw from the study at any point without giving a reason
- You can contact the researcher via email and ask them to remove your data from the study up until the point where the data is analysed.
- All your data will be kept safe and cannot be linked back to you
- You have a right to ask questions about the research before and after participating
- Participating or not participating will have no effect on your medical care

What are the possible risks of taking part?

Participating in the study will take up to 30 minutes of your time and this may be inconvenient for you. The Brain Injury Fatigue Scale contains questions about your experience of fatigue and the second scale contains question about your current mood, if this causes distress you will be able to choose whether to continue and the researcher will provide contact details for organisations that may be able to help.

What are the possible benefits of taking part?

There are no direct benefits to you from taking part in the study. However, it is hoped that the information you provide will help us to understand more about the relationship between fatigue and acquired brain injury. It is hoped that this will improve how fatigue is measured within healthcare services for those who have experienced a brain injury.

What will happen as a result of the study?

The results of the study will be summarised in a written thesis as part of a Doctorate in Clinical Psychology. The research will also be submitted for publication in an academic journal and may be presented at conferences. The doctoral thesis will be available online to the public through the University of Hull at <https://hydra.hull.ac.uk>. You can also email the researcher, Katherine Watson, who will provide a written summary of the research. Your personal details and any identifiable data will not be included in the written thesis.

How will we use information about you?

We will collect the following information about you as part of this research study, which will be stored anonymously. This will include your:

- Name
- Contact details
- Date of birth
- Gender
- Level of education

The researcher will use this information to complete the research and to make sure your rights can be maintained. People who do not need to know your name or contact information will not have access to this information. Your data will be saved anonymously, with a number instead of your name. We will write the reports in a way where no one will be able to identify your information or work out that you took part in the study.

We will keep all information about you securely and safely and the data controller will be the University of Hull. The University will process your personal data for the research purposes outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest'. You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you. Information about how the University of Hull processes your data can be found at <https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx>

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, [comments](#) and requests about your personal data can also be sent to the University of Hull Information Compliance Manager (dataprotection@hull.ac.uk). If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

What are your choices about how your information is used?

You have the right to stop being part of the study at any time, without giving a reason. This means that before and during the data collection, you can choose not to participate in the study. Once the study has been completed, we will keep the information we already have. You will not be able to see or change the data we hold about you.

Withdrawing from the study will not affect you in any way. Participant's data cannot be withdrawn from the study once the data has been anonymised and analysed. If you choose to withdraw from the study before this point the data collected will be destroyed. You have up to until the data is analysed to withdraw your data from the research.

Where can you find out more about how your information is being used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to k.watson-2019@hull.ac.uk

Who has reviewed the study?

The study has been reviewed by an independent organisation called the Research Ethics Committee. The Research Ethics Committee protects the interest of people who participate in research.

What if something goes wrong?

If you wish to make a complaint about the study, you can contact the University of Hull using the research supervisor's details below for further advice and information:

If you have any questions or require more information about this study, please contact me using the following contact details:

Katherine Watson

Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
E-mail: k.watson-2019@hull.ac.uk

Dr Pete Fleming

Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: +44 (0) 1482 463254
Email address: p.fleming@hull.ac.uk

Thank you for reading this information and for considering taking part in this research.

Appendix K: Control Participant Information Sheet

Participant Information Sheet (Version 1) – Control Sample

This research is being completed as part of the requirements of the Doctorate in Clinical Psychology course at the University of Hull. The researcher, Katherine Watson, is a Trainee Clinical Psychologist and this study is part of her thesis project.

Title of study: An investigation into the properties of the Brain Injury Fatigue Scale

We would like to invite you to participate in this research on the effects of Brain Injury on fatigue.

We are looking to recruit two groups of people for this study:

- 1) People who have an acquired brain injury
- 2) People who have NOT had any type of brain injury.

Before you decide, we would like you to understand why the research is being done and what it would for you. Please take time to read the following information carefully. Talk to other people about the study if you wish. One of our team will also go through the information sheet with you and answer any questions you have.

Ask us if there is anything that is not clear, or if you have any questions. Please take your time in deciding if you would like to take part.

What is an acquired brain injury?

An acquired brain injury is a term used to describe damage to a part of the brain. This damage can happen for a number of reasons, including a physical force on the body, disease or a medical emergency such as a stroke.

What is the purpose of the study?

After an acquired brain injury, some people report feeling more fatigue. Currently, there are no published scales which measure people's experience of fatigue several months following a brain injury. This research aims to provide information on the Brain Injury Fatigue Scale. This will help health care teams measure fatigue and help people to manage this experience.

Do I have to take part?

No, participation is completely voluntary. If you decide to take part, you will be asked to sign a consent form to indicate that you agree to take part and that you have read this information sheet. You are free to withdraw from the study up to the point that the results are analysed and written up and you do not have to give a reason for this. Your decision will not affect your medical care or your legal rights.

What will I be asked to do?

If you agree to take part and sign the consent form, then I will contact you to arrange a convenient time and date for the study. Due to current COVID-19 restrictions, this appointment will be done remotely over a video conferencing platform such as Microsoft Teams or Zoom. The researcher will email a link to the appointment. The appointment will last around 20 minutes.

- During the appointment, the researcher will ask you some questions about yourself, such as your age and your gender.
- You will then be offered to complete the Brain Injury Fatigue scale with you. This scale contains 20 questions where you are asked to rate the extent to which you agree with the statement, on a scale between 0-4.
- Following this, you will be offered to complete a second scale about your current mood. This contains 14 statements about your current mood and asks you to rate the extent to which you agree with each statement on a scale between 0-5.

What will happen if I decide I no longer wish to take part?

You are free to withdraw from the study before the results are analysed and the study is written-up without giving a reason. This will not affect your legal rights or the medical care that you receive.

Your rights.

- You do not have to take part
- You can withdraw from the study at any point without giving a reason
- You can contact the researcher via email and ask them to remove your data from the study up until the point where the data is analysed.
- All your data will be kept safe and cannot be linked back to you
- You have a right to ask questions about the research before and after participating
- Participating or not participating will have no effect on your medical care

What are the possible risks of taking part?

Participating in the study will take up to 30 minutes of your time and this may be inconvenient for you. The Brain Injury Fatigue Scale contains questions about your experience of fatigue and the second scale contains question about your current mood, if this causes distress you will be able to choose whether to continue and the researcher will provide contact details for organisations that may be able to help.

What are the possible benefits of taking part?

There are no direct benefits to you from taking part in the study. However, it is hoped that the information you provide will help us to understand more about the relationship between fatigue and acquired brain injury. It is hoped that this will improve how fatigue is measured within healthcare services for those who have experienced a brain injury.

What will happen as a result of the study?

The results of the study will be summarised in a written thesis as part of a Doctorate in Clinical Psychology. The research will also be submitted for publication in an academic journal and may be presented at conferences. The doctoral thesis will be available online to the public through the University of Hull at <https://hydra.hull.ac.uk>. You can also email the researcher, Katherine Watson, who will provide a written summary of the research. Your personal details and any identifiable data will not be included in the written thesis.

How will we use information about you?

We will collect the following information about you as part of this research study, which will be stored anonymously. This will include your:

- Name
- Contact details
- Date of birth
- Gender
- Level of education

The researcher will use this information to complete the research and to make sure your rights can be maintained. People who do not need to know your name or contact information will not have access to this information. Your data will be saved anonymously, with a number instead of your name. We will write the reports in a way where no one will be able to identify your information or work out that you took part in the study.

We will keep all information about you securely and safely and the data controller will be the University of Hull. The University will process your personal data for the research purposes outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest'. You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you. Information about how the University of Hull processes your data can be found at <https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx>

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the University of Hull Information Compliance Manager (dataprotection@hull.ac.uk). If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

What are your choices about how your information is used?

You have the right to stop being part of the study at any time, without giving a reason. This means that before and during the data collection, you can choose not to participate in the study. Once the study has been completed, we will keep the information we already have. You will not be able to see or change the data we hold about you.

Withdrawing from the study will not affect you in any way. Participant's data cannot be withdrawn from the study once the data has been anonymised and analysed. If you choose to withdraw from the study before this point the data collected will be destroyed. You have up to until the data is analysed to withdraw your data from the research.

Where can you find out more about how your information is being used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to k.watson-2019@hull.ac.uk

Who has reviewed the study?

The study has been reviewed by an independent organisation called the Research Ethics Committee. The Research Ethics Committee protects the interest of people who participate in research.

What if something goes wrong?

If you wish to make a complaint about the study, you can contact the University of Hull using the research supervisor's details below for further advice and information:

If you have any questions or require more information about this study, please contact me using the following contact details:

Katherine Watson

Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
E-mail: k.watson-2019@hull.ac.uk

Dr Pete Fleming

Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: +44 (0) 1482 463254
Email address: p.fleming@hull.ac.uk

Thank you for reading this information and for considering taking part in this research.

Appendix L: Consent Form

CONSENT FORM

Title of Study: **The psychometric properties of the Brain Injury Fatigue scale (BIFS)**
Name of Researcher: Katherine Watson
Name of Clinician/ Person administering test (if appropriate):
Centre Number (if appropriate):
Participant Identification Number:

1. I confirm that I have read and understand the information sheet dated 04.05.2021 Version 1.1 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my healthcare or legal rights being affected.
3. I understand that the named researcher (Katherine Watson) will have access to the data I provide.
4. I understand that the service might share my demographic data (my age, my gender, the severity of my injury, my injury type) with researchers as part of my participation in this study and hereby authorize their access to such material.
5. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.
6. I give permission for the collection and use of my data to answer the research question in this study.
7. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

Appendix M: Brain Injury Fatigue Scale (Quinn, Jones, Fokias & Moss, 2004)

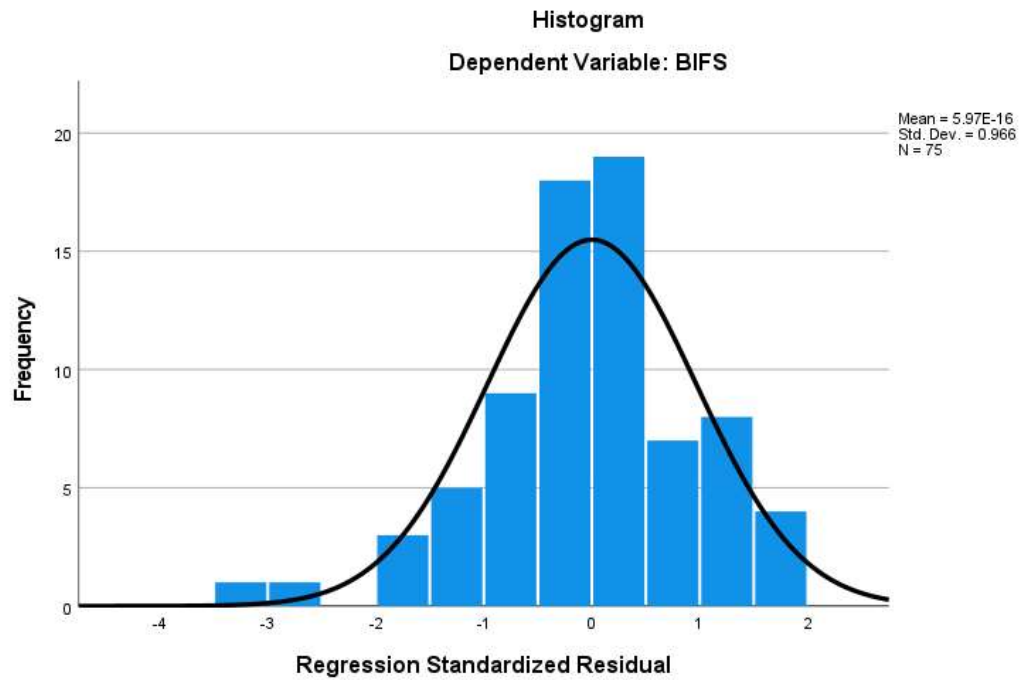
[Removed from digital archiving]

Appendix N: The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)

[Copyrighted, removed for digital archiving]

Appendix O: Data Outputs

Descriptives

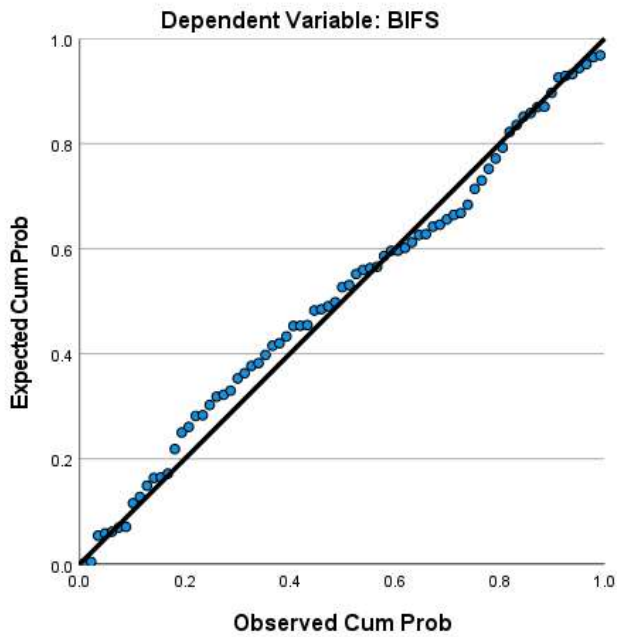


Independent-Samples Mann-Whitney U Test

Summary

Total N	77
Mann-Whitney U	1307.000
Wilcoxon W	2087.000
Test Statistic	1307.000
Standard Error	98.104
Standardized Test Statistic	5.769
Asymptotic Sig.(2-sided test)	<.001

Normal P-P Plot of Regression Standardized Residual



Tests of Normality

Group	Kolmogorov-Smirnov ^a			Shapiro-Wilk			
	Statistic	df	Sig.	Statistic	df	Sig.	
Standardized Residual	Control	.087	36	.200*	.967	36	.359
	ABI	.117	39	.198	.966	39	.278

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Correlations

Group		BIFS	Age	Gender	HADSD	HADSA
Group	Pearson Correlation	1	.658**	.406**	-.203	.509**
	Sig. (2-tailed)		<.001	<.001	.077	<.001
	N	77	77	77	77	77
BIFS	Pearson Correlation	.658**	1	.336**	-.007	.635**
	Sig. (2-tailed)	<.001		.003	.951	<.001
	N	77	77	77	77	77
Age	Pearson Correlation	.406**	.336**	1	-.204	.144
	Sig. (2-tailed)	<.001	.003		.075	.213
	N	77	77	77	77	77
Gender	Pearson Correlation	-.203	-.007	-.204	1	.058
	Sig. (2-tailed)	.077	.951	.075		.618
	N	77	77	77	77	77

	N	77	77	77	77	77	77
HADSD	Pearson Correlation	.509**	.635**	.144	.058	1	.671**
	Sig. (2-tailed)	<.001	<.001	.213	.618		<.001
	N	77	77	77	77	77	77
HADSA	Pearson Correlation	.231*	.570**	-.012	.137	.671**	1
	Sig. (2-tailed)	.044	<.001	.916	.236	<.001	
	N	77	77	77	77	77	77

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

- *Research Aim 1* – To investigate the underlying factors which are measured by the BIFS.

Within factor correlations

Summary Item Statistics							
	Mean	Minimum	Maximum	Range	Maximum / Minimum	Variance	N of Items
Inter-Item Correlations	.582	.305	.775	.469	2.536	.009	13

Summary Item Statistics							
	Mean	Minimum	Maximum	Range	Maximum / Minimum	Variance	N of Items
Inter-Item Correlations	.663	.663	.663	.000	1.000	.000	2

Correlation Matrix^a

		Q1	Q2	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q17	Q19	
Correlation	Q1	1.000	.544	.597	.688	.597	.755	.522	.672	.236	.433	.624	.715	.654	.590	.645	
	Q2	.544	1.000	.637	.682	.514	.614	.347	.582	.198	.318	.490	.625	.648	.519	.563	
	Q4	.597	.637	1.000	.684	.470	.608	.305	.518	.194	.379	.617	.589	.597	.417	.570	
	Q5	.688	.682	.684	1.000	.476	.549	.458	.701	.187	.384	.555	.596	.606	.533	.525	
	Q6	.597	.514	.470	.476	1.000	.706	.440	.524	.145	.375	.502	.560	.691	.581	.666	
	Q7	.755	.614	.608	.549	.706	1.000	.458	.650	.200	.509	.595	.752	.765	.614	.687	
	Q8	.522	.347	.305	.458	.440	.458	1.000	.501	-.040	.169	.438	.488	.471	.468	.397	
	Q9	.672	.582	.518	.701	.524	.650	.501	1.000	.151	.407	.507	.659	.700	.632	.581	
	Q10	.236	.198	.194	.187	.145	.200	-.040	.151	1.000	.663	.244	.226	.211	.139	.332	
	Q11	.433	.318	.379	.384	.375	.509	.169	.407	.663	1.000	.443	.438	.503	.436	.489	
	Q12	.624	.490	.617	.555	.502	.595	.438	.507	.244	.443	1.000	.553	.597	.439	.558	
	Q13	.715	.625	.589	.596	.560	.752	.488	.659	.226	.438	.553	1.000	.775	.626	.659	
	Q14	.654	.648	.597	.606	.691	.765	.471	.700	.211	.503	.597	.775	1.000	.639	.719	
	Q17	.590	.519	.417	.533	.581	.614	.468	.632	.139	.436	.439	.626	.639	1.000	.612	
	Q19	.645	.563	.570	.525	.666	.687	.397	.581	.332	.489	.558	.659	.719	.612	1.000	
	Sig. (1-tailed)	Q1		<.001	<.001	<.001	<.001	<.001	<.001	<.001	.022	<.001	<.001	<.001	<.001	<.001	<.001
		Q2	.000		.000	.000	.000	.000	.001	.000	.046	.003	.000	.000	.000	.000	.000
		Q4	.000	.000		.000	.000	.000	.004	.000	.050	.000	.000	.000	.000	.000	.000
		Q5	.000	.000	.000		.000	.000	.000	.000	.056	.000	.000	.000	.000	.000	.000
Q6		.000	.000	.000	.000		.000	.000	.000	.110	.001	.000	.000	.000	.000	.000	
Q7		.000	.000	.000	.000	.000		.000	.000	.045	.000	.000	.000	.000	.000	.000	
Q8		.000	.001	.004	.000	.000	.000		.000	.369	.077	.000	.000	.000	.000	.000	
Q9		.000	.000	.000	.000	.000	.000	.000		.101	.000	.000	.000	.000	.000	.000	
Q10		.022	.046	.050	.056	.110	.045	.369	.101		.000	.019	.027	.036	.121	.002	
Q11		.000	.003	.000	.000	.001	.000	.077	.000	.000		.000	.000	.000	.000	.000	
Q12	.000	.000	.000	.000	.000	.000	.000	.000	.019	.000		.000	.000	.000	.000		

Q1 3	.000	.000	.000	.000	.000	.000	.000	.000	.000	.027	.000	.000		.000	.000	.000
Q1 4	.000	.000	.000	.000	.000	.000	.000	.000	.000	.036	.000	.000	.000		.000	.000
Q1 7	.000	.000	.000	.000	.000	.000	.000	.000	.000	.121	.000	.000	.000	.000		.000
Q1 9	.000	.000	.000	.000	.000	.000	.000	.000	.000	.002	.000	.000	.000	.000	.000	

a. Determinant = 1.056E-5

KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.917
Bartlett's Test of Sphericity	Approx. Chi-Square	758.168
	df	105
	Sig.	<.001

Communalities

	Initial	Extraction
Q1	.736	.696
Q2	.624	.538
Q4	.630	.515
Q5	.725	.589
Q6	.614	.536
Q7	.781	.737
Q8	.409	.375
Q9	.661	.633
Q10	.540	.762
Q11	.647	.680
Q12	.537	.500
Q13	.720	.700
Q14	.771	.757
Q17	.575	.532
Q19	.657	.643

Extraction Method: Principal Axis Factoring.

Total Variance Explained

Factor	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings ^a
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
1	8.432	56.215	56.215	8.052	53.683	53.683	7.972
2	1.442	9.616	65.831	1.137	7.579	61.263	2.343
3	.865	5.766	71.597				
4	.689	4.595	76.193				
5	.627	4.177	80.370				
6	.440	2.931	83.300				
7	.417	2.777	86.078				
8	.383	2.553	88.631				
9	.352	2.347	90.978				
10	.325	2.168	93.146				
11	.307	2.046	95.193				
12	.233	1.551	96.743				
13	.208	1.387	98.130				
14	.154	1.024	99.155				
15	.127	.845	100.000				

Extraction Method: Principal Axis Factoring.

a. When factors are correlated, sums of squared loadings cannot be added to obtain a total variance.

Factor Matrix^a

	Factor	
	1	2
Q1	.832	-.062
Q2	.729	-.077
Q4	.717	-.021
Q5	.762	-.095
Q6	.728	-.082
Q7	.857	-.040
Q8	.551	-.267
Q9	.785	-.128
Q10	.314	.814
Q11	.584	.582
Q12	.706	.030
Q13	.834	-.060
Q14	.869	-.046
Q17	.725	-.081
Q19	.797	.085

Extraction Method: Principal Axis Factoring.

a. 2 factors extracted. 37 iterations required.

Pattern Matrix^a

	Factor	
	1	2
Q1	.824	.030
Q2	.733	.002
Q4	.696	.059
Q5	.771	-.013
Q6	.733	-.003
Q7	.839	.055
Q8	.645	-.217
Q9	.809	-.045
Q10	-.057	.889
Q11	.304	.677
Q12	.664	.112
Q13	.826	.032
Q14	.852	.051
Q17	.730	-.002
Q19	.727	.179

Extraction Method: Principal Axis Factoring.

Rotation Method: Oblimin with Kaiser Normalization.

a. Rotation converged in 4 iterations.

Factor Correlation Matrix

Factor	1	2
1	1.000	.317
2	.317	1.000

Extraction Method: Principal Axis Factoring.

Rotation Method: Oblimin with Kaiser Normalization.

- Research Aim 2 - To investigate the relationship between BIFS measure and age, gender, anxiety, and depression, and whether these effects are moderated by the presence of an ABI.

Regression output for Anxiety, Fatigue and Group

Run MATRIX procedure:

***** PROCESS Procedure for SPSS Version 4.2 beta *****

Written by Andrew F. Hayes, Ph.D. www.afhayes.com
Documentation available in Hayes (2022). www.guilford.com/p/hayes3

Model : 1
Y : BIFS
X : HADSA
W : Group

Sample
Size: 77

OUTCOME VARIABLE:
BIFS

Model Summary

	R	R-sq	MSE	F	df1	df2	p
	.8180	.6691	109.3998	49.2051	3.0000	73.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	41.6268	3.4528	12.0558	.0000	34.7453	48.5084
HADSA	.4022	.4329	.9292	.3559	-.4605	1.2649
Group	5.8710	4.7647	1.2322	.2218	-3.6251	15.3671
Int_1	1.7944	.5305	3.3822	.0012	.7370	2.8518

Product terms key:

Int_1 : HADSA x Group

Covariance matrix of regression parameter estimates:

	constant	HADSA	Group	Int_1
constant	11.9221	-1.3017	-11.9221	1.3017
HADSA	-1.3017	.1874	1.3017	-.1874
Group	-11.9221	1.3017	22.7024	-2.1680
Int_1	1.3017	-.1874	-2.1680	.2815

Test(s) of highest order unconditional interaction(s):

	R2-chng	F	df1	df2	p
X*W	.0519	11.4393	1.0000	73.0000	.0012

 Focal predict: HADSA (X)
 Mod var: Group (W)

Conditional effects of the focal predictor at values of the moderator(s):

Group	Effect	se	t	p	LLCI	ULCI
.0000	.4022	.4329	.9292	.3559	-.4605	1.2649
1.0000	2.1966	.3068	7.1601	.0000	1.5852	2.8080

Data for visualizing the conditional effect of the focal predictor:
 Paste text below into a SPSS syntax window and execute to produce plot.

```
DATA LIST FREE/
  HADSA      Group      BIFS      .
BEGIN DATA.
  3.0000     .0000     42.8334
  7.0000     .0000     44.4422
 14.0000     .0000     47.2576
  3.0000     1.0000     54.0877
  7.0000     1.0000     62.8741
 14.0000     1.0000     78.2504
END DATA.
GRAPH/SCATTERPLOT=
  HADSA      WITH      BIFS      BY      Group      .
```

***** ANALYSIS NOTES AND ERRORS *****

Level of confidence for all confidence intervals in output:
 95.0000

----- END MATRIX -----

Regression output for Depression, Fatigue and Group

Run MATRIX procedure:

***** PROCESS Procedure for SPSS Version 4.2 beta *****

Written by Andrew F. Hayes, Ph.D. www.afhayes.com
 Documentation available in Hayes (2022). www.guilford.com/p/hayes3

Model : 1
 Y : BIFS
 X : HADSD
 W : Group

Sample
 Size: 77

OUTCOME VARIABLE:
 BIFS

Model Summary

R	R-sq	MSE	F	df1	df2	p
.7511	.5641	144.1052	31.4945	3.0000	73.0000	.0000

Model	coeff	se	t	p	LLCI	ULCI
constant	41.6249	2.7317	15.2376	.0000	36.1805	47.0692
HADSD	.9160	.6276	1.4596	.1487	-.3348	2.1667
Group	11.6885	4.6479	2.5148	.0141	2.4252	20.9518
Int_1	.9566	.7552	1.2666	.2093	-.5486	2.4618

Product terms key:

Int_1 : HADSD x Group

Covariance matrix of regression parameter estimates:

	constant	HADSD	Group	Int_1
constant	7.4623	-1.2023	-7.4623	1.2023
HADSD	-1.2023	.3938	1.2023	-.3938
Group	-7.4623	1.2023	21.6030	-2.5602
Int_1	1.2023	-.3938	-2.5602	.5704

Test(s) of highest order unconditional interaction(s):

	R2-chng	F	df1	df2	p
X*W	.0096	1.6044	1.0000	73.0000	.2093

Focal predict: HADSD (X)
Mod var: Group (W)

Data for visualizing the conditional effect of the focal predictor:
Paste text below into a SPSS syntax window and execute to produce plot.

```
DATA LIST FREE/
  HADSD      Group      BIFS      .
BEGIN DATA.
  1.0000      .0000      42.5409
  5.0000      .0000      46.2048
  9.5200      .0000      50.3451
  1.0000      1.0000      55.1860
  5.0000      1.0000      62.6763
  9.5200      1.0000      71.1405
END DATA.
GRAPH/SCATTERPLOT=
  HADSD      WITH      BIFS      BY      Group      .
```

***** ANALYSIS NOTES AND ERRORS *****

Level of confidence for all confidence intervals in output:
95.0000

----- END MATRIX -----

Regression output for Gender, Fatigue and Group

Run MATRIX procedure:

***** PROCESS Procedure for SPSS Version 4.2 beta *****

Written by Andrew F. Hayes, Ph.D. www.afhayes.com
Documentation available in Hayes (2022). www.guilford.com/p/hayes3

```
Model : 1
Y : BIFS
X : Gender
W : Group
```

Sample
Size: 75

OUTCOME VARIABLE:
BIFS

Model Summary

R	R-sq	MSE	F	df1	df2	p
.6760	.4570	182.4465	19.9183	3.0000	71.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	41.8190	7.5723	5.5226	.0000	26.7202	56.9179
Gender	1.4476	4.5663	.3170	.7522	-7.6573	10.5526
Group	16.0473	10.0620	1.5948	.1152	-4.0159	36.1105
Int_1	5.4133	6.3148	.8573	.3942	-7.1780	18.0047

Product terms key:

Int_1 : Gender x Group

Test(s) of highest order unconditional interaction(s):

	R2-chng	F	df1	df2	p
X*W	.0056	.7349	1.0000	71.0000	.3942

Focal predict: Gender (X)
Mod var: Group (W)

Data for visualizing the conditional effect of the focal predictor:
Paste text below into a SPSS syntax window and execute to produce plot.

DATA LIST FREE/

```
Gender Group BIFS .
BEGIN DATA.
  1.0000 .0000 43.2667
  2.0000 .0000 44.7143
  1.0000 1.0000 64.7273
  2.0000 1.0000 71.5882
END DATA.
```

GRAPH/SCATTERPLOT=

```
Gender WITH BIFS BY Group .
```

***** ANALYSIS NOTES AND ERRORS *****

Level of confidence for all confidence intervals in output:
95.0000

----- END MATRIX -----

Regression output for Age, Fatigue and Group

Run MATRIX procedure:

***** PROCESS Procedure for SPSS Version 4.2 beta *****

Written by Andrew F. Hayes, Ph.D. www.afhayes.com
Documentation available in Hayes (2022). www.guilford.com/p/hayes3

```
Model : 1
Y : BIFS
X : Age
W : Group
```

Sample

Size: 77

OUTCOME VARIABLE:

BIFS

Model Summary

R	R-sq	MSE	F	df1	df2	p
.6699	.4488	182.2331	19.8139	3.0000	73.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	43.9327	5.1976	8.4525	.0000	33.5739	54.2914
Age	.0129	.1247	.1036	.9178	-.2357	.2615
Group	9.4124	11.3875	.8266	.4112	-13.2830	32.1077
Int_1	.2700	.2314	1.1671	.2470	-.1911	.7312

Product terms key:

Int_1 : Age x Group

Covariance matrix of regression parameter estimates:

	constant	Age	Group	Int_1
constant	27.0147	-.5880	-27.0147	.5880
Age	-.5880	.0156	.5880	-.0156
Group	-27.0147	.5880	129.6757	-2.5171
Int_1	.5880	-.0156	-2.5171	.0535

Test(s) of highest order unconditional interaction(s):

	R2-chng	F	df1	df2	p
X*W	.0103	1.3620	1.0000	73.0000	.2470

Focal predict: Age (X)
Mod var: Group (W)

Data for visualizing the conditional effect of the focal predictor:
Paste text below into a SPSS syntax window and execute to produce plot.

DATA LIST FREE/

```
Age      Group      BIFS      .  
BEGIN DATA.  
25.0000      .0000      44.2558  
46.0000      .0000      44.5272  
61.0000      .0000      44.7210  
25.0000      1.0000      60.4190  
46.0000      1.0000      66.3612  
61.0000      1.0000      70.6056
```

END DATA.

GRAPH/SCATTERPLOT=

```
Age      WITH      BIFS      BY      Group      .
```

***** ANALYSIS NOTES AND ERRORS *****

Level of confidence for all confidence intervals in output:

95.0000

----- END MATRIX -----

