A Mixed-Methods Investigation of Behavioural Activation Theory in Acquired Brain Injury

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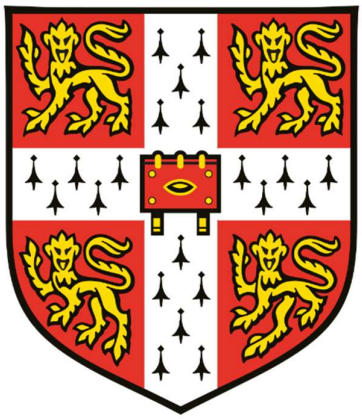
This dissertation is submitted for the degree of

Doctor of Philosophy



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October 2021

Declaration

This dissertation is the result of my own work and includes nothing which is the outcome of work done in collaboration except as explicitly declared here and specified in the text. No content of this thesis plagiarises or is substantially the same as any work that has been previously submitted for a degree and/or publication(s) except where explicitly declared here and specified in the text. This dissertation does not exceed the prescribed 60,000-word limit for the Degree Committee of the School of Clinical Medicine and Clinical Veterinary Medicine.

Chapters Two and Four are in progress for submission to academic journals for publication.

The protocol for the study described in Chapter Five has been published (although is included in this thesis in a modified format):

Andrea Kusec, Fionnuala C. Murphy, Polly V. Peers, Cara Lawrence, Emma Cameron, Claire Morton, Andrew Bateman, Peter Watson, & Tom Manly (2020). Mood, Activity Participation, and Leisure Engagement Satisfaction (MAPLES): A randomised controlled pilot feasibility trial for low mood in acquired brain injury. *BMC Pilot and Feasibility Studies, 6, 135*. https://doi.org/10.1186/s40814-020-00660-8

Acknowledgements

First, I want to thank my family for believing in me and my goal to pursue a degree abroad. Especially my mother, who would have been proud to know that I completed a PhD – I am proud to have been raised by her to be able to achieve this goal. To my partner Gianluca, thank you for your confidence in me and endless support.

This research, of course, would not have been possible without the many collaborators within Cambridgeshire Community Services, and staff based at Headway and the Stroke Association. Especially Abigail Methley, Cara Lawrence, Emma Cameron, Kate Psaila, Sue Brentnall, and Ron Bennett, who provided tremendous time and feedback into my research.

The Gates community, especially Nora, Luis, and Michael, have been some of the most wonderful people I have met in Cambridge. The Gates community has constantly pushed me to develop not just as a researcher, but as a leader. I would like to also thank the Gates Cambridge Trust and Fitzwilliam College for their support in my doctoral studies.

To my friends and "found family" at the CBU, who have made my time here in the UK so very memorable and full of love. Thank you Estela and Aleksandra for always being willing to lend a hand. Thank you Daisy, Sinead, Ivan, Carol, Alex I., Subbu and GiuGiu for your endless laughter and friendship. Thank you Silvana, Giacomo, and Alex Q. for, quite literally, helping me down a mountain, and being there when really I needed it. I will always fondly remember our portacabin days, our travelling adventures, and our "collegiate ambition" moments.

A simple acknowledgement does not even begin to describe the immense gratitude and recognition that my supervisor Tom Manly and advisors Fionnuala Murphy and Polly Peers deserve. I knew as soon as I applied, and I know with even more certainty now, that completing my PhD under their mentorship was one of the best decisions of my life, and without them, I would not have survived these past four years. So I especially thank Polly, for your thoughtful insights into my research and always keeping an eye toward its application; Fionnuala, for your seemingly endless wisdom and compassion; and Tom, for knowing when I needed a laugh, for your constant dedication and support despite many unplanned obstacles to my thesis, and for inspiring me to forward translational research.

Finally, I have had the immense privilege to listen to those with an acquired brain injury and I thank all who took the time to participate and share their stories with me. This thesis is dedicated to anyone with a brain injury, especially those wanting to be heard.

Abstract

In the UK alone, roughly 700 in every 100,000 individuals will sustain an acquired brain injury (ABI) annually, including non-progressive damage to the brain such as traumatic brain injury, stroke, anoxia, or pressure from a brain tumour. Roughly half of those with ABI will experience depression. Therapies for depression have variable efficacy in ABI, possibly due to high demands on cognitive capacities that may be impaired post-injury. Behavioural approaches to treating depression that place lesser demands on cognition, such as Behavioural Activation (BA) therapy, offer promise. BA theory posits that depression reduces energy levels and expectations of positive outcomes from activities, and increases avoidance, which exacerbates depression.

This dissertation provides a test of BA theory by investigating novel predictors of mood and activity levels, and outlines two interventions aimed at increasing activity levels and improving mood, in adults with an ABI from a wide variety of recruitment sources. I utilise both quantitative (e.g., structural equation modelling and mixed-effects models) and qualitative (e.g., interpretive description, thematic analysis) methodology to harmonise the individual perspective of ABI and to identify common patterns in ABI samples.

The first empirical chapter concerns how mood disorders, activation and avoidance relate to intolerance of uncertainty (IU), a set of negative beliefs about uncertainty and its implications, in ABI. I demonstrate that IU can be reliably assessed in ABI, and that despite changes in uncertainty due to COVID-19, IU remains a robust predictor of poor mental health, lower activity levels, and greater avoidance in ABI. When controlling for ABI symptoms, the inhibiting effects of uncertainty provided unique variance in anxiety disorders but not depression. Although not as strongly associated with decreases in activity level, higher IU was associated with increased avoidance and rumination.

The second empirical chapter focuses on discrepancies in estimation of functional capabilities ("impaired self-awareness"), specifically whether an individual with ABI overestimates or underestimates their ability relative to a family member. Using assessment data from over 200 adults assessed in NHS ABI neurorehabilitation services, those who overestimate themselves tended to be less depressed and anxious compared to those who underestimate and accurately estimate themselves, and had more severe injuries. However, those who overestimate themselves did not fare worse in long-term participation outcomes.

The third empirical chapter uses qualitative methodology to explore perspectives of individuals with an ABI on changes in activity levels, and their views on various BA components used to increase activity levels. Level of perceived effort, its potential emotional impact and relation to participant values, and whether the component was used at the "right time" post-ABI were central themes when attempting to increase activity level.

An investigation of two 8-week group interventions, designed to increase activity levels and mood in ABI, is presented in the final empirical chapter. Changes linked with each group are compared to waitlist controls in a pilot feasibility randomised controlled trial. The first intervention, "traditional" BA, uses therapeutic strategies and directly encourages individuals to plan and engage in reinforcing activities beyond group sessions. The second intervention, "experiential" BA, encourages participants to engage in reinforcing activities during group sessions only. Both interventions were feasible and acceptable, with approximately 50% - 60% of participants demonstrating clinically meaningful improvements in activity levels. In exploratory analyses of efficacy, both interventions improved mood, but only "traditional" BA resulted in lower anxiety, reductions in the impact of the inhibiting effects of uncertainty, and improvements in motivation. Analysis of qualitative data indicated that "traditional" BA seems to challenge negative self-beliefs and enhance confidence

through planning activities, while “experiential” BA provides a low-pressure environment to engage in reinforcing activities.

This dissertation demonstrates that increasing activity levels to improve mood in adults with ABI is an easily scalable and potentially effective therapeutic target, in alignment with BA theory. These data point towards potential expansions of BA theory in ABI, in particular the role of uncertainty and impaired self-awareness to activity level and their contributions to mood. This thesis concludes by stating that in clinical research, a mixed-methods approach to the application of relevant theory and intervention design is essential.

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Abbreviations

ABI – Acquired Brain Injury
ACT – Acceptance and Commitment Therapy
AE – Activity Engagement Group *or* Accurate Estimators
ANOVA – Analysis of Variance
AP – Activity Planning Group
BA – Behavioural Activation
BADS – Behavioural Activation for Depression Scale
BMQ-S – Brain Injury Rehabilitation Trust Motivation Questionnaire-Self
CBT – Cognitive Behavioural Therapy
CCNRP – Cambridge Cognitive Neuroscience Research Panel
CFT – Compassion Focused Therapy
COVID-19 – Coronavirus disease 2019
CSI – Carer Strain Index
DEX-R – Dysexecutive Questionnaire-Revised
DSM-5 – Diagnostic and Statistical Manual of Mental Disorders Fifth Edition
EBIQ – European Brain Injury Questionnaire
ECV – Explained Common Variance
GAD7 – Generalised Anxiety Disorder-7
GCS – Glasgow Coma Scale
ICC – Intraclass Correlation Coefficient
ICD-10 – International Classification of Diseases Tenth Revision
IU – Intolerance of Uncertainty
IU-SF – Intolerance of Uncertainty Scale-Short Form
MAPLES – Mood, Activity Participation, and Leisure Engagement Satisfaction
MCID – Minimal Clinically Important Difference
MI – Modification Indices
MPAI – Mayo Portland Adaptability Inventory
MRI – Magnetic Resonance Imaging
NHS – National Health Service
NICE – National Institute for Health and Care Excellence
OE – Overestimators
PHQ – Patient Health Questionnaire
PMM – Predictive Mean Matching
PSQ – Post Study Questionnaire
RSES – Rosenberg Self-Esteem Scale
SEM – Standard Error of Measurement
SPIN – Social Phobia Inventory
TBI – Traumatic Brain Injury
UE – Underestimators
WL – Waitlist Control Group

Chapter 1 – Introduction

Acquired brain injury (ABI) refers to any damage to the brain from events caused after birth, rather than from a congenital disorder, developmental disability, or a progressive neurological condition (Cattelani, Zettin, & Zoccoloti, 2010). An ABI can result from a blow to the head (traumatic brain injury; TBI), an interruption to the brain's blood supply (stroke, aneurysm) or oxygen supply (anoxia), a viral infection to the brain (e.g., encephalitis), or as a result of pressure from a growing tumour. In the United Kingdom (UK), approximately 700 per 100,000 individuals will be diagnosed with an ABI annually (Hyder et al., 2007; Global Burden of Disease Study, 2019; Howell et al., 2013; McKinney et al., 2004; Granerod et al., 2013).

ABI is marked by heterogeneous impairments in cognitive, perceptual, physical, emotional, and social domains (Hyder et al., 2007; Teasell et al., 2007). Physical impairments, for example, can include motor and sensory deficits, limb spasticity, reduced limb strength or hemiparesis, or balance and coordination difficulties (Marshall et al., 2007). Cognitive consequences can include poor memory and attention, impaired executive function and self-awareness, and changes to emotion regulation (Rabinowitz & Levin, 2014). Generally, more severe injuries with impairments present in multiple domains are associated with longer stays in acute care, longer recovery duration, and lesser gains in rehabilitation (Smania et al., 2013, Roozenbeek et al., 2013). Outcomes of ABI are made more variable due to the interaction of impairments with demographic characteristics, such as age, gender, and comorbid health conditions (Saatman et al., 2008), as well as socioenvironmental factors such as socioeconomic status and an existing network of family and peer support (Dhand et al., 2019).

The impact of ABI can further result in poor emotional outcomes. Up to 96% of individuals report lowered frustration tolerance and can experience “emotional outbursts” far

into the chronic stages of ABI (Alderman et al., 2013). Anxiety and depression are particularly common post-ABI (Mallya et al., 2015, Glenn et al., 2001; Whelan-Goodinson et al., 2009). Negative emotional outcomes can in part be due to difficulties in regulating emotions (e.g., increased emotional lability or emotionalism), as a response to ABI-related changes in daily functioning, and difficulties accepting the "new self" when adapting to the often widespread changes following ABI (Ownsworth, 2014). The combined impact of post-ABI impairments and associated emotional difficulties can lead to an increased dependency on others, a reduction in autonomy, and chronic social impairments that negatively affect social reintegration. This can culminate into a "systematic downward spiral" of social and occupational loss due to the ABI (Ylvisaker et al., 2005).

Given the variety of ways in which ABI can affect an individual, it is in some ways not surprising that the economic burden of ABI is high. The cost of just TBI and stroke in the UK is £15 billion and £8.9 billion per year, respectively (Parsonage, 2016; Saka et al., 2009). Taken together, ABI is a leading cause of long-term disability worldwide (Roozenbeek et al., 2013) and presents a considerable public health challenge. Positively, there is substantial evidence that comprehensive, holistic rehabilitation for those with ABI is efficacious (Cicerone et al., 2008; Geurtsen et al., 2010).

Acquired Brain Injury and Depression

One of the most common emotional difficulties experienced by those with an ABI is depression. In the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5; 2013), depression is characterised by two main symptoms: a depressed mood, and a loss of interest or pleasure in activities (termed anhedonia). Similarly, the International Statistical Classification of Diseases and Related Health Problems-10 (ICD-10; World Health Organisation, 2007) definition of depression includes persistent sadness or low mood, anhedonia, and reduced energy, occurring either with or without somatic symptoms.

Depression has been estimated to have a global lifetime prevalence in the general population of 10.8% (Lim et al., 2018), is the second leading cause of years lived with a disability worldwide (Ferrari et al., 2013), and in just England, approximately 1 in 6 individuals are estimated to experience either depression, anxiety or both (McManus et al., 2016).

Unfortunately, ABI substantially increases risk for depression. Approximately 1 in 3 individuals will have chronic depression, and those with ABI are three times as likely to commit suicide relative to the general population (Fazel et al., 2014). Access to suitable emotional support post-ABI is limited, as approximately two-thirds of those who require emotional support do not have their needs met (McKevitt et al., 2011). It has been argued that even these alarming statistics underestimate the scale of the problem, as post-ABI depression estimates can range from 17% to 61% (Rapoport, 2012).

Individuals with an ABI and depression are more likely, compared to those with ABI without depression, to experience greater difficulties in daily function (Saka et al., 2009; Roozenbeek et al., 2013), have a poorer quality of life, poorer recovery of cognitive function, reduced physical activity, lowered engagement in activities of daily living, and higher mortality rates (Fann et al., 2009; Chemerinski et al., 2001; Verdelho et al., 2004; House et al., 2001). In a meta-analysis of risk factors for post-stroke depression, greater severity of injury and level of handicap, a history of mental illness, female gender, lower age, higher levels of neuroticism, and a family history of mental illness were found to increase likelihood of depression (Shi et al., 2017). Similar risk factors have been found to contribute to depression post-TBI, with additional factors including unemployment (Scholten et al., 2016) and violent causes of injury such as assault (Stein et al., 2019). Although less has been researched into rates of depression in other forms of ABI, such as resected tumours, anoxia, and viral encephalitis, available evidence suggests similarly increased risks in these groups relative to the general population (Harris et al., 2020; Mugge et al., 2020).

Despite this increased risk, the current evidence on the development of depression, its treatment, and other emotional outcomes after ABI is limited. Much of psychological intervention research in ABI has been dominated by cognitive rehabilitation (Patterson et al., 2016). Consequently, best practice guidelines for treating emotional difficulties after ABI are inconclusive. For example, in TBI, the most current available guidance for psychological interventions in the UK explicitly states:

> "*The evidence relating to the psychotherapeutic treatment of depression after head injury is inconclusive and therefore no specific recommendation can be made"*
>
> (National Institute for Health and Care Excellence [NICE]; 2014, accessed October 2021)[1]

Though there is more evidence for individuals with stroke (three psychotherapeutic RCTs referenced)[2], the UK NICE guidelines for stroke state:

> "*Assess emotional functioning in the context of cognitive difficulties in people after stroke. Any intervention chosen should take into consideration the type of complexity of the person's neuropsychological presentation and relevant personal history."*
>
> (NICE, 2018; accessed October 2021)

Whilst, as I will discuss further, there is some promising preliminary evidence on the benefits of psychotherapeutic approaches in stroke in particular (e.g., Thomas et al., 2013; 2019), there is a lack of well-controlled, high-quality research designs in ABI. Perhaps more importantly, a lack of sufficient research in the wider ABI population may result in those who require emotional support being unable to access evidence-based treatments.

---

[1] In contrast, the same guidelines state of cognitive rehabilitation "*There is a considerable body of evidence relating to the effectiveness of cognitive rehabilitation interventions after brain injury including meta-analyses, systematic reviews, and RCTs…In most domains, the evidence suggests that the most effective interventions are those that focus on provision of cognitive strategies or external aids that compensate for a cognitive impairment in order to improve everyday functioning.*" NICE guidelines, 2014, accessed October 2021

[2] In comparison, 69 cognitive rehabilitation RCTs were identified in the same guidelines for interventions in executive function, neglect, memory, and attentional domains.

When designing and implementing research for depression in ABI, an important question is whether or not the "label" of depression is particularly useful. In the DSM-5 (2013) criteria, for example, a diagnosis of depression cannot be given if the depressive episode is attributable to a medical condition. Although depression-like symptoms can result from ABI, such as a reduced capacity to experience pleasure (Husain & Roiser, 2018), this does not preclude potential benefit from treatment. Depression both in ABI and in non-ABI populations often co-occur with other disorders, such as anxiety or post-traumatic stress disorder (Jorge & Arciniegas, 2014). Finally, there is increasing evidence suggesting that many underlying processes that contribute to depression, such as changes in affective processing, negative repetitive thinking, attentional and memory biases, and behavioural inhibition and avoidance, are common to a wide variety of mood disorders. Subsequently, there have been calls for treating transdiagnostic processes across all forms of emotional difficulties rather than focusing on disorder-specific processes (Clark & Steven, 2009; Dozois et al., 2009), and more recently, rehabilitation models of incorporating transdiagnostic approaches into efforts to enhance emotional outcomes in ABI (Gracey et al., 2016; Shields et al., 2015).

Psychological Theories of Depression

Throughout history, many psychological theories have sought to better elucidate the development and maintenance of depression. Various accounts of depression have focused on social (Allen & Badcock, 2003; Steger & Kashdan, 2009), behavioural (Ferster, 1973; Lewinsohn, 1974), cognitive (Beck, 1979; Wells & Carter, 2001), neuroanatomical (Mayberg, 1997; Drevets et al., 2008), and biological (Slavich & Irwin, 2014) determinants. In both those with and without ABI, perhaps the most eminent theory is Beck's (1979) Cognitive Theory, in which maladaptive beliefs about the self, others and the future lead to negative affect and behaviours that drive mood disorders. Maladaptive core beliefs or

"schemas" are developed in childhood in response to adverse events, and when a life stressor in adulthood occurs, the maladaptive schemas prime subjective interpretation of the situation and increase risk of depressed mood. Since its inception, Cognitive Behavioural Therapy (CBT) has been adapted to include behavioural components such as exposure therapy, and the contribution of maladaptive cognitions to mood disorders has been addressed in similar "third wave" therapeutic approaches such as Acceptance and Commitment Therapy (ACT) and Compassion-Focused Therapy (CFT). Combined, cognitive behavioural approaches to treating mood disorders have demonstrated impressive evidence over the years, are comparable to pharmacological interventions, and are recommended as the first line of treatment for a variety of mental health disorders outside of ABI (Barth et al., 2013).

Despite the wealth of evidence of cognitive-based psychotherapies outside of ABI, there is no conclusive evidence to make recommendations for its use in ABI. In a Cochrane review of non-pharmacological interventions for depression in TBI relative to waitlist controls, CBT was found to have no post-intervention effects (Gertler et al., 2015). The evidence is similarly mixed in stroke populations (Hackett et al., 2008b; Waldron et al., 2013); for example, a trial investigating CBT for depression within 1 year of stroke found no evidence for an effect on depression or activity-related outcomes when compared to standard care (Lincoln & Flannaghan, 2003). Possibly, the mixed evidence is the result of the heavy demands CBT and similar "cognitive restructuring" therapies place on cognitive ability, such as meta-awareness and psychological flexibility, which may be compromised following ABI. As a result, psychotherapeutic research in ABI has begun focusing on behavioural approaches that might be of equal benefit in the general population, but be particularly well-suited for those with an ABI (e.g., Mitchell et al., 2009; Thomas et al., 2013; 2019). In keeping with this, reviews of modifications for CBT in ABI have explicitly recommended focusing on behavioural techniques over abstract or "cognitive-heavy" ones (Gallagher et al., 2019),

indicating that CBT as it is typically used outside of ABI would at the very least need to be consistently modified for use in ABI.

Behavioural Activation Theory

Behavioural Activation (BA) theory (Lewinsohn, 1985a) is a theory of the onset and maintenance of depression that not only may be of particular relevance to people with ABI, but is also linked with a therapeutic approach that is well-suited to this group. BA theory is based on the straightforward premise that people with low mood tend to engage in fewer activities. They may feel that they lack the necessary energy, or may not be motivated to plan or avoid activities because they cannot imagine a positive outcome. As such, it becomes all too easy to imagine negative outcomes. Although this may feel protective of mood in the short-term, BA theory posits that this activity level decrease reduces the frequency of positive reinforcement, which in turn serves to only lower mood further. Subjective energy levels and motivation for activities decline again, and consequently, a "vicious cycle" is established in which mood and activity levels reduce in turn.

BA's inception is rooted in Ferster's (1973) functional analysis of depression and further developed in Lewinsohn's (1974) model. Lewinsohn elaborated the idea that reduced levels of activity may be *sufficient* to explain depression; in other words, that individuals with notionally normal mood, who had their activity restricted, could become depressed. He further argued that the total amount of reinforcement was a function *of the number of events* that are potentially reinforcing, the *availability* of these events in a person's environment, and an individual's *instrumental behaviour* in eliciting reinforcement (Dimidjian et al., 2011). This final point is key to Lewinsohn's position; it is not enough to simply *receive* reinforcement, it must occur in response to the production of a behaviour (activity) that is reinforced. Lewinsohn (1975) further endorsed Costello's (1972) position that depression was associated with reduced reinforcement from activities previously experienced as positive.

This should, it was argued, add momentum to the "vicious cycle" because motivation would be accordingly reduced. Evidence for this argument emerged from examining temporal associations of the links between pleasant activities and mood (Lewinsohn & Libet, 1972; Lewinsohn & Graf, 1973; Lewinsohn & MacPhillamy, 1974), and in lab- and home-based assessments of social interactions between depressed and non-depressed individuals (Libet & Lewinsohn, 1973; Lewinsohn & Shaffer, 1971).

So, if reduced activity primed a cycle that reduced mood, could increasing activity in itself be sufficient to reverse this cycle and enhance mood? Lewinsohn (1975) argued:

> *"The guiding principle for the behavioural treatment of depressed individuals is to restore an adequate schedule of positive reinforcement for the individual through altering the level, the quality, and the range of the patient's activities and interactions."*

Lewinsohn further postulated that whilst the general goal of increased positive reinforcement would be the same across all attempts to treat depression, the specific techniques to achieve this end would vary depending on individual circumstances. As such, precisely how this aim was pursued varied considerably, from reinforcing actions with tokens in institutions to advising smokers to deliberately think a "positive thought" and then reinforce it by lighting a cigarette (Seitz, 1971; Todd, 1972). The model that has come to be most associated with "Behavioural Activation" was described by Lewinsohn & Atwood (1969), in which those participating first thought of pleasant activities, scheduled them into their daily routines, reported back on their completion, and rated their moods. If there was difficulty identifying sufficient pleasurable activities, the therapist would assist, for example, by going through a list such as the Pleasant Events Schedule (MacPhillamy & Lewinsohn, 1982). Although initially highly behavioural, BA was further refined to specifically include social skills as a particular type of "instrumental behaviour" in maintaining positive

reinforcement. In response to increasingly available evidence supporting the contribution of maladaptive cognitions to depression (Beck, 1979, Ellis, 1962), including findings from BA theoretical research (Lewinsohn et al., 1982), BA was further adapted to model the influence of such cognitions and associated behaviour in those with depression, as shown in Figure 1.

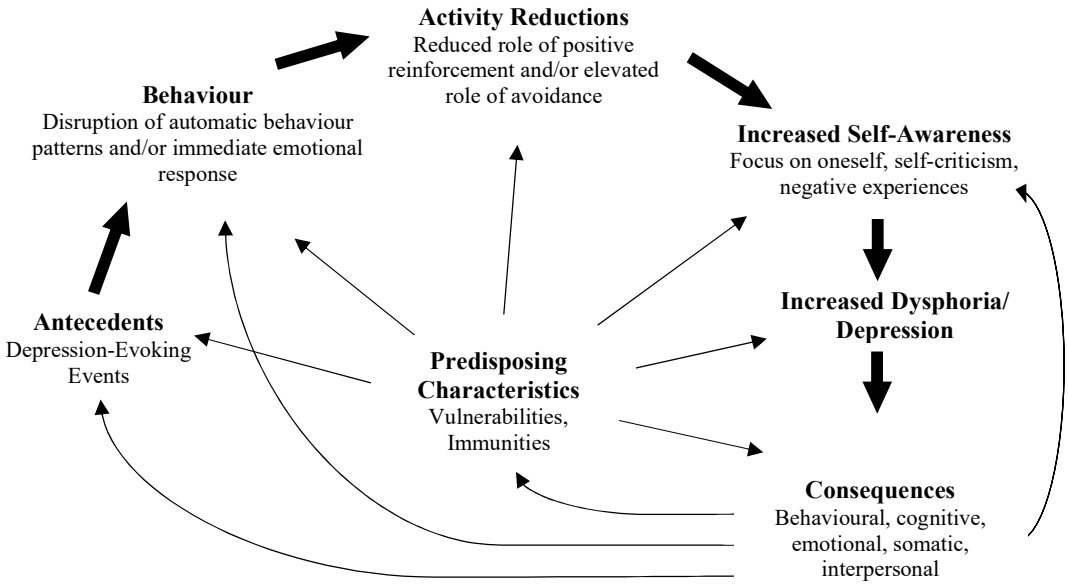


Figure 1. Lewinsohn's integrative model of depression (Adapted from Lewinsohn et al., 1985a). Reproduced with permission.[3]

In this model, antecedents or "depression-evoking events" result in an interruption to one's daily behaviours, including one's relationship with others, and causes a negative affective response. These behavioural changes thus result in varying levels of reductions in positive reinforcement and increases in avoidance. Individuals then attempt to cope with the consequences of the "depression-evoking event", and failures to do so result in increased "self-focused attention" or self-awareness of one's abilities, and consequently self-criticism. The combination of increases in self-focused attention and accompanying dysphoria are theorised to result in further cognitive, behavioural, and emotional difficulties associated with

[3] This article was published in *Theoretical Issues in Behavior Therapy,* 1, Reiss. S. & Bootzin, R.R. *An integrative theory of depression*, 331 – 359. Copyright Elsevier (1985a).

depression, which in turn maintain symptoms. The entire process can be exacerbated by an individual's predisposition to depression through social, cognitive, and biological risk factors, theorised to underlie individual risk of symptom severity.

Both BA and CBT therefore address maladaptive cognitions and behavioural changes linked with depression. Whereas CBT has framed cognition as a "privileged causal factor" in the development and maintenance of depression (Dimidjian et al., 2011), BA can be said to privilege behaviour, and hence this distinction drives the selection of intervention targets and associated therapeutic techniques. In the non-ABI population, BA therapy has repeatedly been demonstrated to be as effective as CBT and other forms of cognitive therapy in reducing depression (Jacobson et al., 1996; Dimidjian et al., 2006; Lorenzo-Luaces & Dobson, 2019; Ciharova et al., 2021; Mazzucchelli et al., 2009), *and* altering negative thinking (Jacobson et al., 1996; Fernandez & Mairal, 2017). BA therapy has been found to be as effective as pharmacological treatments for depression and is superior to antidepressants alone (Moradveisi et al., 2013). BA therapy can be feasibly delivered individually or in group formats (Ekers et al., 2014; Simmonds-Buckley et al., 2019), whether in person or online (Huguet et al., 2018). BA therapy is effective when delivered by those without extensive therapeutic training (Richards et al., 2016; Ekers et al., 2011), and is suitable across multiple cultural contexts (Arjadi et al., 2018; Collado et al., 2016; Chen et al., 2021; Lehman et al., 2020). Given its flexibility and comparable efficacy to CBT, it is not surprising that BA therapy has been widely adopted.

Though there is relatively little research explicitly focusing on BA theory in ABI, there is certainly ample evidence in this population linking reduced activity levels to depression (Egan et al., 2010; Landreville et al.., 2009, Larsson et al., 2013; Mausbach et al., 2011; Oddy et al., 2017; Tate et al., 2014; Bombardier et al., 2017). Causes of activity level decreases can be due to difficulties with activities of daily living, retiring from or losing paid

employment, increased dependency on others in accessing activities, fatigue, as well as physical and cognitive barriers resulting in increased effort associated with engaging in an activity. Perhaps more importantly, decreases in *social* activity levels after ABI are often associated with low mood and depression (Douglas, 2019; Northcott et al., 2016). Following ABI, social activity levels can be negatively affected by individual difficulties forming new relationships (Levack et al., 2010), challenges in existing relationships resulting in reduction of social contact (Salas et al., 2018), and long-term structural changes that make new relationships less likely, such as not returning to work (Lefebvre et al., 2008; Jourdan et al., 2016). In line with this evidence, the "Y-shaped model" of psychotherapy (Gracey et al., 2009a) states that withdrawal from social groups and relationships following ABI is due to factors such as perceived or actual social stigmatisation, feeling one's needs may not be understood, and fearing that one's impairments may be exposed to others. Psychological distress therefore occurs when unhelpful or maladaptive coping responses are used to provide short-term relief, but which do not resolve these issues. In summary, experiencing discrepancies between ideal and current social functioning, or a "social disconnect," has been viewed by those with ABI to be a particularly difficult and enduring negative consequence (Levack et al., 2010; Pearce et al., 2015).

In summary, there are a number of reasons that BA theory and intervention may be a particularly suitable approach to understanding and improving mood problems following ABI. Firstly, in various ways the injury may dramatically reduce activity levels and the opportunities to initiate and continue engagement in previously reinforcing behaviour. Secondly, whilst BA has an effect on cognition, this effect is less reliant on explicit report, examination, discussion, and reframing, than on implicit changes that follow from modulation of activity levels and mood. It is possible, therefore, that cognitive impairments that may follow from ABI are less of a barrier.

Current Evidence of Behavioural Activation Therapy in Acquired Brain Injury

Evidence of the efficacy of BA therapy in neurological populations was first demonstrated by Teri and colleagues (1997) as a method of reducing depression in individuals with dementia and their carers. Mitchell et al. (2009) first adapted BA for depression in early stroke (within 4 months of injury), delivered over 9 sessions individually by advanced practice nurses. In a randomised sample of 101 adults with stroke, depression scores were found to be significantly lower at 1-year post-baseline relative to treatment as usual. In a study using individual BA for post-stroke depression in those with aphasia with an average of 9 sessions over the course of 3 months, Thomas and colleagues (2013) reported that after controlling for baseline scores and level of communication impairment, participants demonstrated significant improvements in depression relative to usual care post-intervention and at 6 months post-baseline. This support for BA was extended in a pilot feasibility trial (Thomas et al., 2019), where 25 adults within 6 months to 5 years post-stroke with depression were offered one-to-one BA over an average of 8 sessions. BA was perceived as acceptable and feasible, and participants in the BA treatment arm showed clinically meaningful reductions in depression compared to a treatment-as-usual control arm. Of note, however, is that in a trial investigating the delivery of 6-session BA over the telephone versus in-person compared to usual care in a sample of 100 adults with stroke, Kirkness et al. (2017) reported no benefit of either approach in reducing post-stroke depression.

Conclusive evidence on the benefits of BA in ABI beyond stroke is far more limited. In an investigation of single-session BA followed by 8 weeks of daily text messages supporting implementing activity intentions in 59 adults with TBI, Hart et al. (2020) reported some improvements in emotional status, but these were of questionable clinical significance. It is possible that the relatively low intensity of the BA intervention was insufficient to provide definitive effects; further, there was an active control group employed but no passive

control. In a single-case experimental design study, Gertler & Tate (2021) found no evidence of effect of BA in improving participation and mood in three adults with ABI with complex cognitive impairments. Gertler & Tate (2021) speculated that the reasons why no conclusive support for effect of BA was due to extraneous variables (e.g., financial constraints, personal relationship difficulties). There is currently no evidence of BA efficacy for other types of ABI, such as encephalitis or brain tumours (Oates et al., 2020). Given the above, use of BA in ABI, in particular for non-stroke ABIs, would benefit from further investigation.

Taken together, BA therapy addresses three key aspects of effective intervention delivery in ABI: 1) impairments in cognitive abilities often require emphasis on behavioural approaches; 2) decreases in activity levels frequently occur post-ABI, indicating this as a modifiable intervention target, and 3) increases in social withdrawal and isolation is an important type of change in activity levels by those with ABI, and can persist into the chronic stages of ABI, thus interventions addressing social activity levels are more likely to be valid and acceptable. The combined association of cognitive impairments, activity limitations, and social withdrawal to low mood and depression thus highlights BA therapy as a prime candidate for reducing emotional distress is ABI.

Methods of Inquiry and Acquired Brain Injury

Often, rehabilitation research uses a positivist, quantitative approach to uncover objective, replicable general patterns and causal relationships between variables (Kroll & Morris, 2009). Constructivist qualitative approaches, in contrast, are used because they provide rich information about individual experiences that are difficult to capture in quantitative measures (O'Cathain, 2009). Arguably, a *mixed-methods* approach offers the best of both approaches (O'Cathain et al., 2007; 2009; Hunter & Armour, 2019; Tariq & Woodman, 2013) and is now recommended for health care research by funders including the Medical Research Council (Moore et al., 2015), the Economic and Social Research Council

National Centre for Research Methods (Wiles et al., 2009), National Institutes of Health (Creswell et al., 2011), and World Health Organisation (O'Sullivan & Khan, 2019).

Ideally, one method will complement the strengths of, and mitigate the weaknesses of, the other (see Kroll et al., 2005). For example, whilst quantitative methods better allow for evaluation of the frequency with which certain outcomes occur, their relationship to other study variables and weight of contribution to a specific effect, qualitative methods better capture why and how certain changes occur, and additional, unmeasured variables that may be contributing to outcome. In intervention research, integrating both quantitative and qualitative data in interpreting results can improve the application of outcomes to definitive trials and to "real world" settings (Richards et al., 2019), as well as enhance relevance of the study results to the population of interest (Kroll et al., 2005).

In ABI specifically, mixed-methods research has been employed in a broad range of applications, such as incorporating technology into rehabilitation and long-term care (de Joode et al., 2012; Jamieson et al., 2020; Ramirez-Hernandez et al., 2021) and informing outcomes of various intervention studies (Bragstad et al., 2019; Thomas et al., 2019; Kreutzer et al., 2010). For my thesis, I took a mixed-methods approach as a means of enhancing the person-centredness of my research. The common message from nearly any investigation into the ways in which ABI is researched is that every person interprets their experience as unique. As a clinical researcher, I cannot assume to fully understand an experience that I have not had, and therefore my research *must* in part rely on those who can. These experiences, therefore, provide my research with data that, in combination with quantitative analysis, serve to enhance the transfer and replication of results I find here. In commenting on rehabilitation research, Tate (2006) writes:

> "*We appear to be making a serious mistake by reducing scientific evidence in our field to one methodologic approach that mainly emphasises quantification of data.*

The translation of research into practice cannot be limited by data that is quantifiable, objective, and devoid of all individualities; on the contrary, it must include the richness of methods that can best help us capture individual variation in its physical, social, and psychological contexts."

In the endeavour to forward rehabilitation research, the combination of both methodologies is necessary.

Potential Extensions of Behavioural Activation Theory in ABI

In my thesis, I investigate constructs relevant to understanding changes in activity levels and mood in ABI, and outline the development and experimental investigation of two BA-focused interventions. I achieve this using quantitative, qualitative, and mixed-methods approaches. An overview of the topics in each thesis chapter is outlined below.

Chapter 2 – Activity, Mood, and Intolerance of Uncertainty

In BA theory, a wide variety of personal/environmental factors or "predisposing characteristics" are considered relevant to depression vulnerability, and response to BA interventions. A potentially important factor in ABI may be the way individuals cope with *uncertainty.* ABI often brings a huge amount of uncertainty into people's lives. Immediate questions may be "*How long will it take for me to get better? Will I be able to pay attention to things like I used to?*" There may be persistent, more existential questions such as "*Will I ever be the same person I was before my injury?*" While some will experience positive changes post-injury, others will not. In a meta-synthesis of 9 qualitative studies of adjustment to life post-stroke, Salter and colleagues (2008) report that a major theme is coping with sudden uncertainty. Participants noted that their "*future became painfully and consciously uncertain*", citing uncertainties that centred on fears of having another stroke, inability to identify why a stroke had occurred, irregular pattern of recovery following stroke, and functional capabilities becoming unreliable and unpredictable (Salter et al., 2008). Further

qualitative research has touted uncertainty as a "meta-theme" of adjustment post-ABI that affects the individual, family, and health care staff (Connolly et al., 2021; Cubis et al., 2018; Snell et al., 2020, Sorenson et al., 2019). Such uncertainty was reported to elicit a range of emotional responses such as frustration, anxiety, and helplessness.

Though such uncertainties are common, individuals may differ in their *responses* to uncertainty. Intolerance of uncertainty (IU), which has been defined as a "dispositional characteristic that reflects a set of negative beliefs about uncertainty and its implications" (Dugas & Robichaud, 2007), has been proposed as a transdiagnostic cognitive vulnerability to a range of mental health disorders (Carleton, 2016; McEvoy et al., 2019; Shihata et al., 2016). Surprisingly little quantitative work has investigated how IU is measured, and its relationship to mental health in ABI, despite the prominence of uncertainty in qualitative accounts of post-ABI recovery. Evaluating IU may be especially important given the high rates of psychological difficulties in ABI relative to the general population (Ayerbe et al 2013), and its subsequent negative effect on reducing activity levels (Flores et al., 2018). Chapter 2 focuses on measurement of IU in an ABI population, addressing an unexplored but potentially clinically-relevant construct to post-ABI rehabilitation.

Chapter 3 – Activity Level, Mood, and Impaired Self-Awareness

Somewhat ironically, though BA explicitly models "self-focused attention" or self-awareness of one's capabilities in the face of environmental stressors, its relationship to activity level outcomes outside of ABI is rarely discussed in modern BA research. "Self-focused attention" was historically posited as a "meta-construct" (in today's terms, a "transdiagnostic risk factor") for psychological disorders (Ingram, 1990) and may be seen as a central feature of processes such as rumination, worry, hypervigilance, and interoception. In a meta-analysis of 226 studies, self-focused attention was strongly associated with negative affect, with private self-focus (i.e., on one's own) more strongly associated with depression

(Mor & Winquist, 2002). Interestingly, in a recent study, reductions in linguistic markers of depression (decreased use of "I, me, my" pronouns), thought to be the result of changes in self-focused attention, were found to be strongly associated with improved outcomes in text-message based BA therapy outside of ABI (Burkhardt et al., 2021).

By contrast, in ABI, self-awareness and the degree to which it is impaired is a central feature of many models of rehabilitation (e.g., Crosson, 1989; Toglia & Kirk, 2000; Leung & Liu, 2011) and executive functioning (Stuss, 2007). Impaired self-awareness, where one is unable to recognize the presence or extent of impairments following ABI or their impact on everyday life, is thought to reduce motivation to engage in therapy, disrupt family systems, and negatively affect return to work and long-term participation outcomes (Tate et al., 2014; Leung & Liu, 2011; Schönberger et al., 2006). Accordingly, increasing the accuracy of self-awareness can itself be an important goal of rehabilitation (Ownsworth & Clare, 2006; Tate et al, 2014). Impaired self-awareness is viewed as a multidimensional construct, affected by multiple potential causal factors (Steward & Kretzmer, 2021). Increased self-awareness has been found to be associated with increased emotional distress in the early stages of ABI recovery (Ownsworth, 2016), and a "hyper-awareness" of one's deficits can lead to ongoing emotional distress (Ownsworth et al., 2007), not unlike Lewinsohn's (1985a) BA theory positing that increases in self-focused attention cause increased depression. In Chapter 3, I thus investigate how different levels of self-awareness relate to emotional and participation outcomes in ABI neurorehabilitation.

Chapter 4 – The Individual Perspective in Activity Levels

Though the central tenets of BA theory have remained constant over the years, what is included as part of BA therapy has been far more varied. The core of BA therapy, increasing engagement in reinforcing activities (i.e., "activity scheduling") is a central feature of extant BA treatment manuals (e.g., Lejeuz, Hopko, & Hopko, 2001). However, a range of ancillary

components has been explored, including mood monitoring, values and goals assessment, social skills training, and problem-solving (Kanter et al., 2010). Some components have been incorporated into BA to suit particular populations. For example, in Thomas' et al. (2019) BA trial, graded task assignment is used to ensure planned activities are achievable, as is commonly done in CBT-based approaches (Beck & Weishaar, 1989) and in rehabilitation (e.g., Lincoln et al., 1997). Further, BA components have been incorporated into other types of therapeutic programmes, including CBT, ACT, CFT, and Mindfulness.

When developing a form of BA that is likely to be acceptable in ABI, it is often beneficial to directly *ask* those with ABI for feedback on perceived challenges in attempting to increase activity levels. Further, collecting perceptions on whether specific BA components are useful in ABI can help inform their likely validity in an intervention. Such participatory approaches to research study is strongly recommended (e.g., Moore et al., 2015), particularly if the aims of the research are to investigate potential therapies/services that may be implemented in clinical settings. Accordingly, in Chapter 4, I use qualitative methodology to explore barriers and facilitators to increasing activity levels with people with ABI, and to collect feedback on 10 different components that may be incorporated as part of BA therapy. This informed the development of the BA intervention described in Chapter 5.

Chapter 5 – Interventions for Increasing Activity Level and Mood in Acquired Brain Injury

It is clear that from a theoretical and practical perspective, BA therapy is a promising and tractable intervention for people with ABI. In terms of intervention development, an important issue concerns the potentially negative impact of cognitive impairments on efficacy. Planning and remembering to engage in activities is central to activity scheduling in BA therapy, and are both areas in which individuals with impaired executive and memory function following ABI may struggle. Encouragingly, there is some evidence that goal management-based approaches can reduce the impact of these problems in everyday life

(Tate et al., 2014; Gracey et al., 2016; Levine et al., 2000; 2011; Miotto et al., 2009; Spikman et al., 2010). I discuss the incorporation of some of these techniques into the BA manual in Chapter 5.

To date, BA-focused interventions in ABI have been delivered individually. There are certainly advantages to this but also drawbacks. One is economic – in any limited capacity health care system, more people will be able to access a group intervention and fewer will have to wait. Another concerns what the group dynamic can bring to an individual's experience. Groups are often a preferred method of delivering neuropsychological rehabilitation (Cicerone, 2011; Tate et al., 2014; von Mensenkampff et al., 2015). Reasons for this include group problem solving of within-session tasks, discussion contributing toward enhanced awareness of abilities and difficulties, and providing a non-judgmental space to practice techniques (Yalom & Leszcz, 2020). Groups may further provide emotional peer support, encouragement, and help facilitate a sense of self in relation to others (Bertisch et al., 2011). Strong group cohesion can therefore help reduce feelings of stigmatisation and isolation (Patterson et al., 2019; Salas et al., 2020). Outside of ABI, there is ample evidence suggesting that group BA is feasible and acceptable (Simmonds-Buckley et al., 2019). For these reasons, I describe the development of a group BA intervention.

Of course, given the potential benefits of groups, it is possible that any improvement in mood observed in a BA group has nothing to do with activity scheduling and increased reinforcement *between* the sessions, and everything to do with group dynamics *within* the session. To examine the potential efficacy of the *BA specific* aspects of the group, I therefore compared it with another group of the same duration and frequency in which the aim was to collectively engage in pleasant, rewarding activities (as well as a third arm, waitlist condition). This "activities group" was not a placebo control condition but rather a potentially more implicit way of delivering BA. If people with low mood have become isolated and

avoidant of activity, the *experience* of being in such a group may challenge negative beliefs and expectations, and have a benefit that generalises to everyday life. Given the possibility of cognitive difficulties, potentially this implicit route could be *more* effective than the didactic, homework-based BA group. In this Chapter, I therefore describe the development and evaluation of a randomised controlled trial of two types of BA therapy in adults with an ABI.

Thesis Aims

This thesis aims to investigate the clinical application of BA theory in adults with an ABI using a mixed-methods approach. I first evaluate a measure of intolerance of uncertainty and its relationship to mental health and activity levels in ABI (Chapter 2). This is followed by an investigation of different levels of self-awareness and its contribution to mood and participation in ABI (Chapter 3). Chapter 4 focuses on collecting individual perspectives on increasing activity levels after ABI, which is then used to inform the development of a randomised controlled pilot feasibility study of group BA therapy (Chapter 5).

Chapter Two

Factor Structure, Reliability, and Validity of the Intolerance of Uncertainty Scale-Short Form in Adults with Acquired Brain Injury

This chapter describes two original research studies investigating the psychometric properties of the Intolerance of Uncertainty Scale-Short Form in acquired brain injury, and an amended follow-up study on the potential effects of the COVID-19 pandemic on intolerance of uncertainty. For the first two studies, I was responsible for the conceptualisation and development of the research questions. The development of the COVID-19 follow-up study was supported by my supervisor (Dr Tom Manly) and my advisors (Dr Fionnuala Murphy and Dr Polly Peers). For all studies, I was responsible for performing analyses and writing the thesis chapter.

Introduction

As discussed in Chapter 1, ABI is marked by its inherent complexity and variability in outcome. Though all will face increases in *amount* of uncertainty, individuals vary in *responses* to uncertainty. Intolerance of uncertainty (IU), a "dispositional characteristic that reflects a set of negative beliefs about uncertainty and its implications" (Dugas & Robichaud, 2007), has been found to be related to a variety of mental health disorders outside of ABI (Carleton, 2016; Hong & Cheung, 2015; McEvoy et al., 2019; Shihata et al., 2016). IU is thought to be a maladaptive core belief or "schema" that guides unhelpful cognitive, behavioural, and emotional responses to situations perceived to be lacking sufficient information (Carleton, 2016; Koerner et al., 2015). Those high in IU may engage in often counterproductive coping strategies such as avoiding tasks with uncertain outcomes, excessive information seeking, increased difficulties in decision-making and reassurance-seeking, and negative interpretations of ambiguous information (Dugas & Robichaud, 2007; Koerner & Dugas, 2008; Sankar et al., 2017).

Behavioural manipulations of IU outside of ABI have demonstrated its relationship to distress. In a series of studies by Mosca and colleagues (2016), undergraduate students without mood disorders were instructed to imagine a personal negative future event (e.g., not being admitted to higher education) and the negative consequences that might stem from this. Half of participants read statements designed to increase IU (e.g., "it is difficult not knowing what is happening"), while the other half read statements designed to reduce IU (e.g., "it doesn't bother me to not know what will happen to me"). Those in the first condition subsequently scored more highly on measures of state-IU, worry, and negative affect. These results are consistent with work demonstrating IU as a potential causal factor in anxiety, affect and worry (Ladouceur et al., 2000; Buhr & Dugas, 2009). IU has been further shown to increase avoidance in experimental tasks even when controlling for anxiety, and to contribute

to changes in motivation for future activities (Flores et al., 2018; San Martin et al., 2020). IU may thus play a similar role across mood disorders in ABI.

Positively, there is evidence that IU can be reduced through intervention in non-ABI populations (Bomyea et al., 2015; Hebert & Dugas, 2019). This raises the possibility that it could be a useful component of reducing the heightened risk of mood disorders and distress in post-ABI neurorehabilitation. However, very little quantitative work has measured IU in ABI, despite this potential therapeutic benefit. Whilst some of these uncertainties may be inherent post-ABI, the IU literature suggests there is variability in individual responses to uncertainty that contribute to psychological distress.

Though many measures from the general population capture constructs of interest in neurological populations, the degree to which such constructs are similarly stable is key to further empirical research. Measures used in ABI benefit from thorough psychometric evaluations, and clearly defined constructs enhance validity of ABI research (Tate & Perdices, 2017). Outside of ABI, measurement of IU has largely been conducted using self-report measures. Initially developed for generalised anxiety disorder, the 27-item Intolerance of Uncertainty Scale was the first measure in this area (Buhr & Dugas, 2002). This scale was shortened to a 12-item version via exploratory factor analysis (IU-Short Form; Carleton et al., 2007). The IU-SF is thought to assess two latent factors – Prospective Anxiety and Inhibitory Anxiety, reflecting approach-oriented and avoidance-oriented responses to uncertainty, respectively (Birrell et al., 2011). The IU-SF has demonstrated good reliability and validity outside of ABI (McEvoy & Mahoney 2011) and its two-factor structure has been replicated in several populations (Birrell et al., 2011). Given evidence of its psychometric strengths in those without ABI, together with the practicality of its relative brevity, the IU-SF was selected for investigation in ABI.

Study Purpose

This chapter reports two studies with the purpose of evaluating the factor structure, reliability and validity of the IU-SF in adults with an ABI. Study 1 specifically aims to:

1) Estimate the internal consistency and factor structure of the IU-SF;

While Study 2 aims to:

2) Estimate test-rest reliability, and
3) Evaluate the concurrent and predictive validity of the IU-SF against measures of depression, generalised anxiety, social anxiety, motivation, activation and avoidance.

Each study is presented with separate methods and results as relevant to the study objectives, and are discussed together in consideration of the role of IU and its measurement in ABI.

Due to COVID-19, this study was expanded from its initial objectives to ascertain the potential influence of the pandemic on IU. As COVID-19 caused marked increases in uncertainty globally, it is unsurprising that IU has been found to be a mediator of mental health throughout the pandemic (Akbari et al., 2021; Rettie & Daniels, 2021). As the pandemic may have unexpected effects on IU in ABI in future research, consideration that data were collected predominantly during COVID-19 should be noted when replicating or extending the present study results. However, *if* the IU-SF proves a reliable measure *despite* the changes taking place over this period, it would suggest that it genuinely measures individual differences in *responses* to uncertainty rather than simply indexing the *degree* of uncertainty at a given time point. This chapter thus reports the original psychometric validation studies, in combination with follow up data assessing the relationship of the COVID -19 pandemic to IU in ABI.

Methods

This study received ethics approval from the University of Cambridge Psychology Research Ethics Committee (PRE.2018.059). Participants were paid £6 per hour for their

time. The initial psychometric study was preregistered in August 2018 (https://osf.io/atbk3). The amended study addressing pandemic-related changes was preregistered in July 2021 (https://osf.io/eqbhy/).

Study Design and Sample Size

Study 1 uses a cross-sectional observational design, while Study 2 has a repeated measures observational design. The sample size for Study 1 and Study 2 was based on estimated numbers required to conduct a confirmatory factor analysis of the IU-SF. Based on the recommendations of MacCullum et al. (1999), the ideal sample size for a factor analysis should be based on study-specific participant to variable ratio and variable communality. For pre-established factors with high ($h^2 \geq .6$) communality (see Hale et al., 2016)[4], a minimum of 100 participants is sufficient. I aimed to recruit 120 participants for Study 1 to allow for missing data and outliers. To increase power in the event of obtaining lower than .60 communality estimates, and to prevent non-convergence (MacCullum et al., 1999), these data were combined with data from a separate study in which participants with ABI also completed the IU-SF (see Chapter 5). These participants completed the IU-SF prior to any experimental procedures that may have influenced scores.

Participant Identification

Participants, excluding those recruited for the separate study (see Chapter 5), were recruited from four sources:

1) the Cambridge Cognitive Neuroscience Research Panel (CCNRP), a panel of adults with stroke and resected brain tumours who have pre-consented to taking part in research;
2) UK-based ABI charities, including the Stroke Association and Headway;

[4] Based on data from Hale et al. (2016) using a sample of 663 participants, mean communality estimates (correlation of the items to the factor) of the Inhibitory Anxiety subscale is 0.69, and for the Prospective Anxiety subscale is 0.56. The scale total mean communality estimate is 0.61.

3) Social media ABI groups (e.g., via Twitter, Facebook);
4) Prolific Academic (hereafter "Prolific"), an online participant recruitment service (see https://prolific.co/)

Interested participants recruited via the CCNRP and ABI charities were invited to the MRC Cognition and Brain Sciences Unit to take part, or were emailed a link to complete the study online. Participants recruited via social media responded to adverts asking for volunteers with ABI and participated online.

Participants recruited via Prolific were screened prior to taking part. On joining Prolific, individuals answer a series of demographic questions including whether or not they have sustained a "head injury." As "head injury" could be interpreted as covering a range of injuries including those without neurological injury, I invited those who had responded "yes" to this item to complete a brief online pre-screen survey to establish whether the inclusion criteria (below) were met. This was done to increase likely consistency with the CCNRP and charity-recruited participants (i.e., a brain injury rather than simply an injury to the head). The inclusion criteria were:

1) Reaffirmed that they have had a head injury (i.e., identical endorsement to when they have joined Prolific);
2) Reported loss of consciousness for 30 minutes or longer from the head injury, or, in another item from the screening survey, reported having had another type of ABI (e.g., stroke) that may not be associated with acute loss of consciousness;
3) Reported receiving treatment in A&E, hospitalisation and/or were admitted to a rehabilitation facility as a result of the injury;
4) Reported that the injury occurred at age 18 or older.

At the pre-screen stage, there were 16 participants who indicated that they had less than 30 minutes of loss of consciousness (M = 9.72 minutes, SD = 8.71), but answered "yes"

to having another type of ABI and were invited to the main study. At the main study, however, they still endorsed a head injury rather than another ABI, possibly due to inconsistent use of "head injury" vs "concussion" vs "traumatic brain injury." These participants did not differ from those with 30 or greater minutes of loss of consciousness on study measures (*t*s = 0.18 – 1.14, *ps* = 0.26 – 0.86) and were thus retained in analyses for power.

Initially participation took part either in person or online, depending on preference and recruitment source. With the onset of the first UK COVID-19 lockdown and resulting social distancing regulations, all subsequent participation was online.

Study 1– Internal Consistency and Factor Structure of the IU-SF

Data Collection

After completing a basic demographics form, participants completed the IU-SF as part of a larger battery of questionnaires (see Study 2) or as part of a separate research study (see Chapter 5).

Study 1 Measures

The *Intolerance of Uncertainty Scale – Short Form* (IU-SF; Carleton et al., 2007) is a 12-item measure of responses to uncertainty, ambiguous situations, and the future. The IU-SF has two subscales: Prospective Anxiety (e.g. "I always want to know what the future has in store for me") and Inhibitory Anxiety (e.g. "The smallest doubt can stop me from acting"). Items are rated on a 5-point Likert scale ranging from 1 (Not at all characteristic of me) to 5 (Entirely characteristic of me). Prospective Anxiety scores range from 7 to 35, and Inhibitory Anxiety scores range from 5 to 25. Higher scores on the subscales indicate greater difficulties with Prospective and/or Inhibitory Anxiety. A total score based on all items can also be calculated.

Data Cleaning Procedures

The below data cleaning procedures were used for both Study 1 and Study 2. Participants who took part from any source were excluded if they had incomplete data (i.e., greater than 20% of responses missing at the observation level). Online participants were additionally excluded if they met one or more of the following criteria:

1) Failing to pass three embedded attention checks (i.e., responding "sometimes" or "not at all" on measures when instructed to do so, leaving a particular question blank; instructed to type a particular word);
2) Completing the entire study session at an impossibly quick rate (i.e., faster than two standard deviations below the mean);

This above resulted in the exclusion of *n=9* participants, with *n*=7 excluded due to fast completion time and *n*=2 excluded due to failing to pass all three attention checks.

Statistical Analyses

All analyses were conducted using R statistical software version 4.0.3 (R Core Team, 2020). Descriptive statistics were completed for all demographic and study measures.

To determine the internal consistency of the IU-SF, we used Cronbach's alpha and evaluated the data using Bland and Altman's (1997) criteria for an acceptable value ($\alpha > 0.70$).

To estimate the factor structure of the IU-SF, two confirmatory factor analyses were estimated using the lavaan package for R (Rosseel, 2012). Though previous evidence suggests that a two-factor model is a better fit (Carleton et al., 2007), the scale has not been used in ABI. Hence, both one-factor and two-factor models were estimated. A full information maximum likelihood estimation procedure (FIML) with a Yuan-Bentler scaling correction factor (Maximum Likelihood with Robust standard errors; MLR) to account for

data missing at the item level was used (Rosseel, 2012). Fit indices used to evaluate the models included:

1) Chi-square (χ^2) statistic (lower test statistic desirable);
2) Comparative Fit index (CFI) and Tucker-Lewis Index (TLI) (values greater than 0.95 indicate acceptable fit; Schermelleh-Engel et al., 2003);
3) The Root Mean Square Error of Approximation (RMSEA) (values lower than 0.08 indicate acceptable fit; Schermelleh-Engel et al., 2003), and
4) The Standardised Root Mean Square Residual (SRMR) (values lower than 0.05 indicate good fit; Schermelleh-Engel et al., 2003).

To statistically compare one-factor versus two-factor models, the Akaike Information Criterion (AIC) was used, with lower values indicating better fit (Schermelleh-Engel et al., 2003).

Study 1 Results

Demographics

A total of 176 participants were included in the final analysis (see Table 1).

IU-SF Scale Summary

The IU-SF was, overall, feasible to use with adults with ABI. Across all participants very few items were left blank (item 2 omitted by 2 participants, and items 3, 4, 9, and 12 omitted by 1 participant each). All items elicited a full range of responses across the 5-point Likert scale. An overview of IU-SF scale statistics is shown in Table 2.

Participants (N=176)		Min - Max
Gender – *n* (%)		
Male	92 (52.30%)	
Female	84 (47.70%)	
Age – Mean (*SD*)	49.81 (13.63)	24 – 78
Ethnicity – *n* (%)		
White British	161 (91.50%)	
Mixed Ethnicity	5 (2.80%)	
White Other	5 (2.80%)	
Black British	4 (2.30%)	
Asian British	1 (0.60%)	
Highest Level of Education – *n* (%)		
Primary	1 (0.60%)	
Secondary	7 (4.20%)	
GCSE/O-Level	24 (13.60%)	
A-Levels	29 (16.50%)	
College Diploma	21 (11.90%)	
Bachelor's Degree	54 (30.70%)	
Postgraduate Degree	36 (20.50%)	
Other	4 (2.30%)	
Living Situation – *n* (%)		
Living with Partner/Spouse	78 (44.30%)	
Living with Family	57 (32.40%)	
Living Alone	40 (22.70%)	
Other	1 (0.60%)	
Work Status – *n* (%)		
Full Time	55 (31.20%)	
Part Time	24 (13.60%)	
Retired (including Medical retirement)	48 (27.30%)	
Unemployed	29 (16.50%)	
Other	20 (11.40%)	
Type of ABI – *n* (%)		
Traumatic Brain Injury	87 (49.40%)	
Stroke	50 (28.40%)	
Tumour	29 (16.50%)	
Other	10 (5.70%)	
Years Post-ABI – Mean (*SD*)	9.77 (8.72)	0.20 – 41
Reported Duration of Loss of Consciousness in Minutes – Median[a]	30	0 – 64,080
Recruitment Source – *n* (%)		
Prolific	57 (32.40%)	
CCNRP	41 (23.30%)	
Social Media	36 (20.50%)	
ABI Charity	24 (13.60%)	
NHS ABI Services	18 (10.20%)	
Method of Assessment – *n* (%)		
Online	130 (73.90%)	
In Person	46 (26.10%)	

Table 1. Participant Characteristics. Of note, 82 participants (46.6%) completed the study prior to the first UK COVID-19 lockdown and the remaining 94 participants (53.4%) during COVID-19.
ABI = Acquired Brain Injury; CCNRP = Cambridge Cognitive Neuroscience Research Panel
[a]Only collected for individuals reporting a "head injury" or "traumatic brain injury."

IU-SF item	Item Mean (SD)	Raw Item-Total Correlation	Corrected Item-Total Correlation[1]	Prospective Anxiety Item-Total Correlation	Inhibitory Anxiety Item-Total Correlation
1. Unforeseen events upset me greatly. [a]	2.8 (1.2)	0.75	0.73	0.73	0.65
2. It frustrates me not having all the information I need. [a]	3.5 (1.1)	0.60	0.55	0.65	0.45
3. Uncertainty keeps me from living a full life. [b]	2.7 (1.3)	0.75	0.73	0.60	0.81
4. One should always look ahead so as to avoid surprises. [a]	3.2 (1.2)	0.61	0.57	0.71	0.42
5. A small unforeseen event can spoil everything, even with the best of planning. [a]	2.8 (1.3)	0.72	0.68	0.69	0.63
6. When it's time to act, uncertainty paralyses me. [b]	2.4 (1.2)	0.74	0.73	0.54	0.86
7. When I am uncertain I can't function very well. [b]	2.9 (1.3)	0.76	0.74	0.60	0.83
8. I always want to know what the future has in store for me. [a]	3.1 (1.3)	0.59	0.53	0.67	0.42
9. I can't stand being taken by surprise. [a]	2.7 (1.3)	0.66	0.62	0.65	0.57
10. The smallest doubt can stop me from acting. [b]	2.7 (1.3)	0.79	0.77	0.63	0.85
11. I should be able to organise everything in advance. [a]	3.2 (1.2)	0.54	0.48	0.66	0.32
12. I must get away from all uncertain situations. [b]	2.7 (1.3)	0.76	0.73	0.64	0.78

Table 2. IU-SF item statistics ($N = 176$).
[1]Correlation corrected based on item overlap and scale reliability.
[a]Items form part of Prospective Anxiety subscale. [b]Items form part of Inhibitory Anxiety subscale.

Average scores on the IU-SF total for participants was 34.57 (*SD* = 10.22). As shown in Table 3, IU-SF scores were overall somewhat elevated relative to previous studies with undergraduate students and the general population, though lower than those seeking treatment for psychological difficulties.

Mean (SD)	Present Study (*N* = 176)	Undergraduate Students (*N* = 818)[a]	General Population (*N* = 286)[b]	Treatment Seeking Sample (*N* = 463)[c]
IU-SF Total	34.57 (10.22)	25.85 (9.45)	30.69 (11.07)	37.49 (11.40)
Prospective	21.23 (5.80)	16.68 (6.00)	19.45 (6.58)	21.81 (6.92)
Inhibitory	13.34 (5.18)	9.17 (4.15)	11.24 (5.32)	15.68 (5.23)

Table 3. Descriptive statistics on the IU-SF in the current study compared to non-ABI student, general population, and treatment-seeking samples.
[a]Carleton et al. (2007) [b]Carleton et al. (2010) [c]McEvoy & Mahoney (2011).

IU-SF scores did not differ according to gender ($p = 0.36$), living situation ($p = 0.85$), work status ($p = 0.38$), or level of education ($p = 0.47$). Interestingly, IU-SF scores additionally did not differ with respect to whether data were collected pre or during COVID-19 ($p = 0.89$), whether data were collected in person or online ($p = 0.38$), or by type of ABI ($p = 0.11$). Participants recruited via the CCNRP had significantly lower IU-SF scores than those recruited via social media ($p < 0.01$); otherwise there were no significant differences on IU-SF scores across recruitment sources. IU-SF scores did not correlate with self-reported duration of loss of consciousness following ABI ($p = 0.71$), but were correlated with age ($r = -0.31$, $p < 0.001$). This may in part explain why the social media sample, who were younger, had higher IU-SF scores compared to CCNRP participants.

Internal Consistency

Internal consistency of the IU-SF scale total was excellent (α = 0.90, 95% CI 0.88 – 0.92). The Prospective Anxiety subscale (α = 0.81, 95% CI 0.76 – 0.85) and Inhibitory Anxiety subscale (α = 0.88, 95% CI 0.85 – 0.91) also demonstrated good and excellent internal consistency, respectively.

Factor Structure

First, the fit of a one-factor model of the IU-SF was estimated. The one-factor model displayed poor to acceptable fit statistics ($\chi^2 = 98.05$, $p < 0.001$, CFI = 0.93, TLI = 0.92, SRMR = 0.06, RMSEA = 0.08 [90% CI = 0.05 – 0.11], Yuan-Bentler Correction = 1.38). Next, the fit of a two-factor model, with items sorted to represent the previously proposed subscales Prospective Anxiety and Inhibitory Anxiety, was estimated. This displayed improved fit statistics ($\chi^2 = 85.15$, $p < 0.01$, CFI = 0.95, TLI = 0.94, SRMR = 0.06, RMSEA = 0.07 [90% CI = 0.04 – 0.09], Yuan-Bentler Correction = 1.36), and was a significant improvement from the one-factor model ($\chi^2\Delta = 7.44$, $df\Delta = 1$, $AIC\Delta = 17.90$, $p < 0.01$). An overview of the two-factor model is shown in Figure 2.

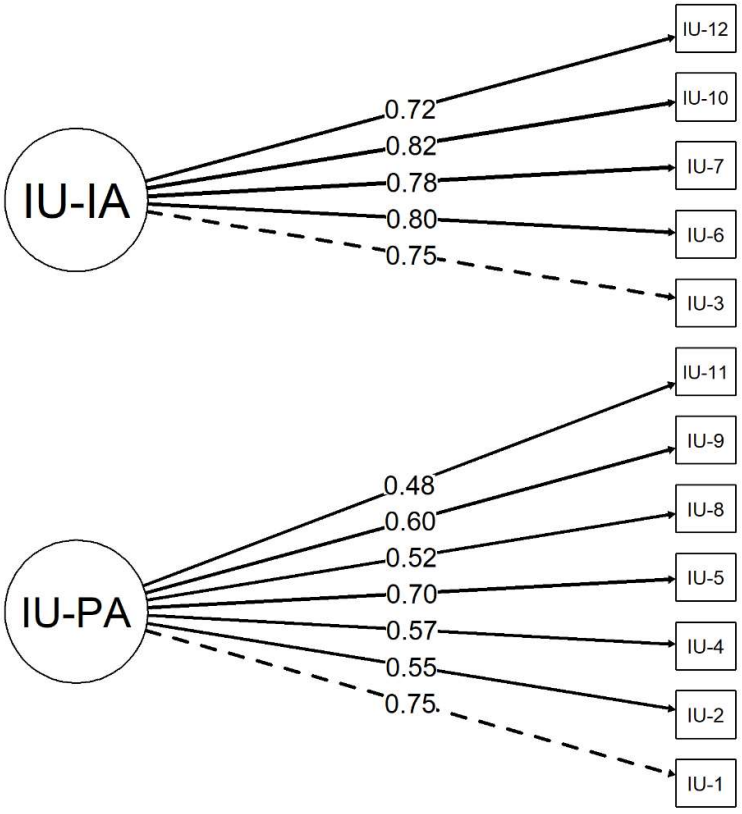


Figure 2. Confirmatory two-factor model of the IU-SF. Numbers on each line indicate the standardised factor loadings (λ). Dashed lines indicate the item that was fixed to the group factor as the starting point.

Despite the improved fit, from a conservative perspective, the fit of the two-factor model remained less than acceptable (Schermellegh-Engel et al., 2003).[5] Recent evidence in adults without ABI suggests that the IU-SF may comprise a bifactor structure (Bottesi et al., 2019; Hale et al., 2016; Saulnier et al., 2019; Shihata et al., 2018). In bifactor models, it is theorised that an overarching general factor *and* subscale or "group" factors provide unique variance in explaining responses to items. Hence, both the general and group factors are allowed to affect item responses simultaneously. For example, a bifactor model may suggest that a general factor represents overall levels of psychological distress, and individuals in part respond to items on the IU-SF based on this. However, how participants respond to items may be *additionally* influenced by how they perceive future uncertainty (Prospective Anxiety), or to what degree they feel paralysed by uncertainty (Inhibitory Anxiety). Given this is the first evaluation of the factor structure of the IU-SF in ABI, exploratory and confirmatory bifactor models were estimated.

Two exploratory bifactor models were estimated using the omega function in the psych package for R (Revelle, 2021). The omega function conducts an exploratory bifactor analysis and provides omega estimates, a more robust estimate of internal reliability than Cronbach's alpha (Flora, 2020). This includes ω_T, a reliability estimate of the general *and* group factors, and ω_h, a reliability estimate of the general factor. The explained common variance (ECV) is also computed to indicate the extent to which variance in item responses are attributable to the general factor, with ECV greater than 0.85 indicating that a scale may comprise only a general factor ("unidimensionality"; Stucky & Edelen, 2015).

[5] Modification indices (MI), or data-driven modifications of the original model, were considered to improve the two-factor model, however changing the two-factor model with the MI suggestions with the largest chi-square change resulted in either the model failing to converge (resulting from including item 6 into the Prospective subscale) or poorer fit statistics and item loadings (resulting from including item 11 into the Inhibitory subscale).

First, the default minimum for number of group factors (three) using omega was set. Items were not set to correspond with the Prospective Anxiety and Inhibitory Anxiety subscales and were allowed to load to group factors freely. The combined general and group factors displayed high internal reliability ($\omega_T = 0.92$), with a ω_h estimate of 0.67. The three-factor bifactor model had good fit statistics ($\chi^2 = 34.63$, p = ns, SRMR = 0.04, RMSEA = 0.02 [90% CI = 0.00 – 0.06]).

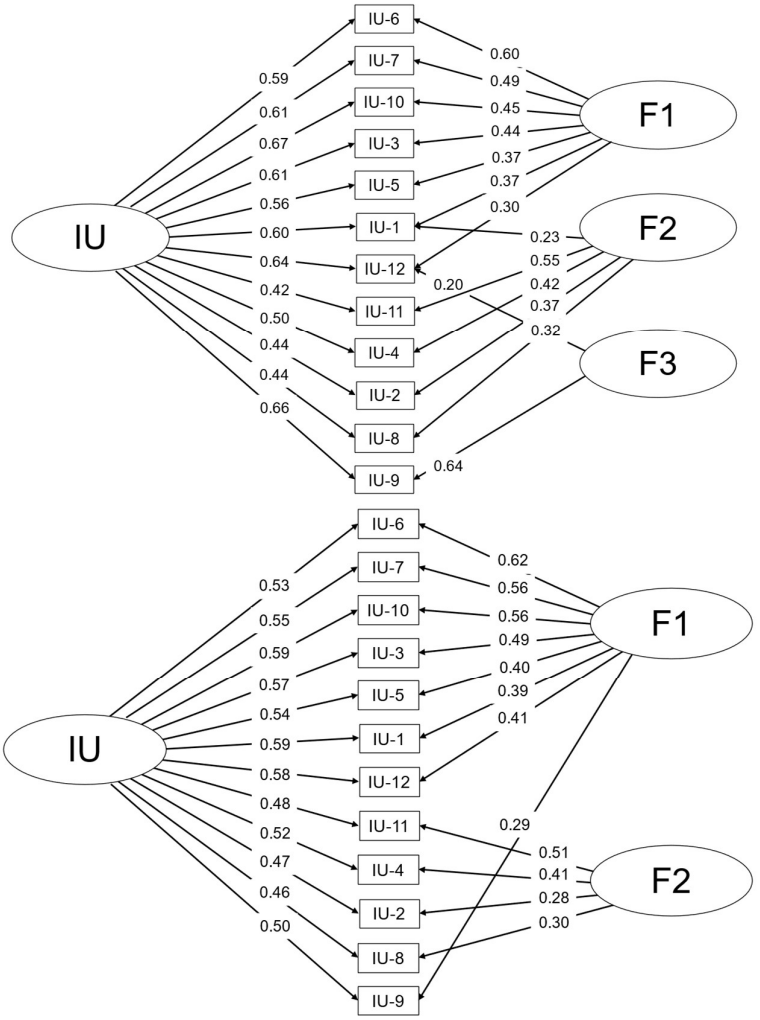


Figure 3. Exploratory bifactor models of the IU-SF with three and two group factors specified. Numbers on lines indicate item loadings.

However, the third factor of the first exploratory bifactor model contained only two items from the IU-SF scale (items 9 and 12), one of which had a poor loading ($\lambda = 0.20$).

Given the available empirical evidence suggesting a two-factor structure of the IU-SF, a second exploratory bifactor model was estimated with two group factors with no items prespecified as belonging to a particular subscale. The combined general and two group factors displayed similarly high reliability to the three factor model (ω_h = 0.91), with a general factor ω_h estimate of 0.60. The two factor model retained good fit statistics (χ^2 = 60.98, *p* = ns, SRMR = 0.05, RMSEA = 0.05 [90% CI = 0.01 – 0.08]) but these were poorer relative to the three-factor bifactor model. However, this may be due to difficulties estimating omega in models with only two group factors in exploratory bifactor models (Zinbarg et al., 2007). A summary of the results comparing the 3-group versus 2-group factor models are shown in Table 4, with both models displayed in Figure 3.

	3-Group Factor Exploratory Bifactor Model				2-Group Factor Exploratory Bifactor Model		
IU-SF Scale Item	g	F1	F2	F3	g	F1	F2
1.	0.60	0.37	0.23		0.59	0.39	
2.	0.44		0.37		0.47		0.28
3.	0.61	0.44			0.57	0.49	
4.	0.50		0.42		0.52		0.41
5.	0.56	0.37			0.54	0.40	
6.	0.59	0.60			0.53	0.62	
7.	0.61	0.49			0.55	0.56	
8.	0.44		0.32		0.46		0.30
9.	0.66			0.64	0.50	0.29	
10.	0.67	0.45			0.59	0.56	
11.	0.42		0.55		0.48		0.51
12.	0.64	0.30		0.20	0.58	0.41	
ECV	0.59				0.57		
ω_T	0.92	0.89	0.71	0.85	0.91	0.90	0.70
ω General	0.67	0.60	0.38	0.44	0.60	0.53	0.43
ω Group	0.18	0.30	0.32	0.41	0.24	0.37	0.26

Table 4. Summary of the exploratory bifactor models, with item loadings for both the three-group and two-group factor estimations.
g = General factor, F1 = Factor 1, F2 = Factor 2, F3 = Factor 3, ECV = Explained Common Variance, ω_T = Omega Total, ω General = Omega for the general IU factor, ω Group = Omega for the group factors.

Finally, a confirmatory bifactor model of IU-SF using the pre-determined Prospective Anxiety and Inhibitory Anxiety group factors was evaluated. Although historically bifactor

models typically require the general and group factors to be orthogonal, relaxing this assumption for group factors is also acceptable (Lorenzo-Seva & Ferrando, 2019). The confirmatory bifactor model had excellent fit statistics (χ^2 = 45.42, p = ns, CFI = 0.99, TLI = 0.99, SRMR = 0.03, RMSEA = 0.03 [90% CI = 0.00 – 0.07], Yuan-Bentler Correction = 1.37), and was a significant improvement from the confirmatory two-factor model ($\chi^2\Delta$= 33.95, dfΔ = 12, AICΔ = 34.90, $p < 0.001$). Comparisons of the confirmatory one-factor, two-factor, and bifactor model fit indices are shown in Table 5. The group factors Prospective Anxiety and Inhibitory Anxiety, however, did not contribute statistically unique variance in the confirmatory bifactor model. Although a bifactor model converged, the standard errors of the group factors were large suggesting inadequate power to accurately estimate a confirmatory bifactor model (Rindskopf, 1984), and therefore any interpretation of this model should be done with caution and replicated in larger samples.

In summary, the two-factor structure of the IU-SF in ABI provides the most reasonable option for assessment, but fit indices are still not ideal. Further evaluation in larger samples using confirmatory bifactor models would be of benefit.

Model	χ^2	*df*	CFI	TLI	SRMR	RMSEA (90% CI)
One-factor	98.05***	54	0.93	0.92	0.06	0.08 (0.05 – 0.11)
Two-factor	85.15**	53	0.95	0.94	0.06	0.07 (0.04 – 0.09)
Bifactor[a]	45.42	41	0.99	0.99	0.03	0.03 (0.00 – 0.07)

Table 5. Comparison of a confirmatory one-factor, two-factor and bifactor models of the IU-SF with robust parameter estimates.
[a] Due to elevated standard errors of the group factors, the confirmatory bifactor model is to be interpreted with caution with the current sample size.
CFI = Comparative Fit Index, TLI = Tucker-Lewis Index, SRMR = Standardised Root Mean Square Residual, RMSEA = Root Mean Square Error of Approximation, CI = Confidence Interval.
***p <0.001, ** $p < 0.01$

Study 2 – Reliability and Validity of the IU-SF

The aim of Study 2 was to investigate the reliability and validity of the IU-SF. As Study 1 results indicate that a two-factor structure is the better fitting model, IU-SF subscale results are presented here.

Data Collection

The data collection procedure for Study 2 is presented in Table 6. As in Study 1, participants took part either in person or online, depending on preference, recruitment source, and timeframe (before or during COVID-19). After completing a demographics form, participants received the below battery of questionnaires in a counterbalanced order at the first data collection time point (Time 1). All participants were contacted approximately 4 weeks later (range 28 to 42 days, $M = 31$ days) to complete the IU-SF a second time (Time 2) to collect test-retest data. Participants who completed Time 1 at any point after the onset of the first UK COVID-19 lockdown (March 23 2020) were re-invited to complete the IU-SF, a custom COVID questionnaire, and measures of generalised anxiety, depression, social phobia and activation/avoidance. Time 3 data collection took place approximately 20 weeks post-Time 1 (range 140 to 154 days, $M = 143$ days).

Time 1 **Week 0**	**Time 2** **4 weeks post T1**	**Time 3** **20 weeks post T1**
• Demographics • IU-SF • PHQ-8 • GAD-7 • SPIN • BADS-SF • EBIQ-S • BMQ-S	• IU-SF	• IU-SF • PHQ-8 • GAD-7 • SPIN • BADS-SF • COVID-Q

Table 6. Data collected at each time point.
IU-SF = Intolerance of Uncertainty Scale-Short Form, PHQ-8 = Patient Health Questionnaire-8, GAD-7 = Generalised Anxiety Disorder-7, SPIN = Social Phobia Inventory, BADS-SF = Behavioural Activation for Depression Scale-Short Form, EBIQ-S = European Brain Injury Questionnaire-Self, BMQ-S = Brain Injury Rehabilitation Trust Motivation Questionnaire-Self, COVID-Q = COVID-19 Questionnaire

Study Measures

The *Intolerance of Uncertainty Scale – Short Form* (IU-SF; Carleton et al., 2007) is a 12-item measure of responses to uncertainty, ambiguous situations, and the future (see Study 1 for detailed description).

The *European Brain Injury Questionnaire-Self* (EBIQ-S; Teasdale et al., 1997) is a 63-item measure developed to assess the subjective experience of brain injury and its associated symptoms. Participants rate the frequency of each symptom in the past month on a 3 point Likert scale (1 "Not at all", 2 "A little" and 3 "A Lot"). The EBIQ-S can be used to assess overall ABI symptom frequency, with possible scores ranging from 63 to 189, or subscale scores can be calculated. Though the original EBIQ-S had some subscales with poor internal consistency (Teasdale et al., 1997) in the present study Cronbach's alpha for the subscales ranged from acceptable to good (αs = 0.64 to 0.89) and are subsequently used in analysis. These subscales represent common functional categories in ABI, entitled Somatic, Cognitive, Impulsivity, Depression, Physical, Isolation, Motivation, and Communication.[6]

The *Patient Health Questionniare-8* (PHQ-8; Kroenke et al., 2009) is a 9-item measure of depression. The scale contains 8 items assessing depression symptoms in the past two weeks (e.g., "Little interest or pleasure in doing things"), with ratings including 0 ("Not at all"), 1 ("Several days"), 2 ("More than half the days") and 3 ("Nearly every day."). A final item asks participants to rate the extent to which any endorsed symptoms impeded daily functioning, with options "Not at all difficult", "Somewhat difficult", "Very difficult" and "Extremely difficult" scored from 0 to 3. Total scores on the PHQ-8 range from 0 to 24, with the functioning item scored separately. The PHQ-9 has good internal consistency and test-retest reliability in adults with and without ABI (Kroenke et al., 2010; Fann et al., 2005). A

[6] The proposed EBIQ subscales by Bateman et al. (2009) resulted in multicollinearity issues in the regression analyses due to some subscales using the same items across multiple subscales. Hence, the original Teasdale et al. (1997) subscales were retained.

cut score of at least 5 symptoms, including 1 cardinal symptom, has the best sensitivity and specificity in adults with TBI (Fann et al., 2005). The PHQ-8 was used here in preference due to institutional safeguarding policies prohibiting direct questions about suicidal ideation for anonymous online participants to whom we cannot offer immediate support.

The *Generalised Anxiety Disorder-7* (GAD-7; Spitzer et al., 2006) scale indexes generalised anxiety via 7 items assessing symptoms in the past two weeks (e.g., "Worrying too much about different things"). An additional item asks participants to rate the extent to which any endorsed symptoms made daily functioning difficult. The symptomatology items are rated from 0 to 3, with options including "Not at all", "Several days", "More than half the days" and "Nearly every day." The item assessing function is rated from 0 to 3, with options "Not at all difficult", "Somewhat difficult", "Very difficult" and "Extremely difficult." Total scores range from 0 to 21, with the functioning item scored separately. The GAD-7 has demonstrated excellent internal consistency and good test-retest reliability, with cut scores of 10 representing optimal sensitivity and specificity outside of ABI (Kroenke et al., 2010).

The *Social Phobia Inventory* (SPIN; Connor et al., 2000) is a 17-item measure of social anxiety. The SPIN consists of subscales assessing fear (e.g., "Parties and social events scare me"), avoidance (e.g., "I avoid activities in which I am the centre of attention"), and physiological symptoms (e.g., "Heart palpitations bother me when I am around people") experienced in the past week. Items are rated on a 5-point Likert scale, ranging from 0 (Not at all) to 4 (Extremely), with total scores ranging from 0 to 68. A cut score of 19 on the SPIN total has good sensitivity and specificity in distinguishing social anxiety compared to controls (Connor et al., 2000). The SPIN has demonstrated good internal consistency, convergent validity and test-retest reliability outside of ABI (Connor et al., 2000).

The *Behavioural Activation for Depression Scale-Short Form* (BADS-SF; Kanter et al. 2007, 2009) is a 9-item, shortened version of the original 25-item BADS. The scale

measures avoidance and activation behaviours considered central to depression. Participants are instructed to respond based on the previous week. The BADS-SF consist of 2 subscales: Activation (e.g., "I engaged in many different activities"), and Avoidance/Rumination (e.g., "I spent a long time thinking over and over about my problems"). Items are rated on a 7-point Likert scale, ranging from 0 (Not at all) to 6 (Completely). Here, subscale scores were used independently. Possible Activation scores ranging from 0 to 36, with higher scores indicating better activation. Possible Avoidance/Rumination scores ranging from 0 to 18, with higher scores indicating worse avoidance and rumination. The BADS has good factor structure, internal consistency, test-retest reliability, and construct validity outside of ABI (Kanter et al., 2007; 2009).

Brain Injury Rehabilitation Trust Motivation Questionnaire-Self (BMQ-S; Oddy et al., 2008): The BMQ-S is a 34-item questionnaire designed to measure difficulties with motivation in ABI. Items are rated on a 4-point Likert scale, with response options including Always, Often, Sometimes, and Never. Total scores range from 34 to 136, with higher scores indicating greater *problems* with motivation (i.e., not motivated). Examples of items include "It's hard to get started, even when I know I've got something to do" and "I feel satisfied when I've finished something" (reverse scored). The BMQ-S has good internal consistency, test-retest reliability (Kusec et al., 2018) and high split-half reliability (Oddy et al., 2008).

A *COVID-19 Questionnaire* (COVID-Q) was custom-developed to assess the potential impact of the pandemic on IU-SF responses. Participants were asked whether they have had COVID-19, and if yes, how recently, if they had any acute or persistent (> 3 months) symptoms, and how severe their symptoms were. The COVID-Q also asked whether and when participants had been vaccinated, and if they had experienced any negative (e.g., finances, physical and mental health) or positive changes (e.g., sense of community, more time with family) due to the pandemic (see *Appendix* for COVID-Q).

Data Cleaning Procedures

See Study 1 for a detailed account of cleaning procedures. For Study 2 specifically, to account for missingness at the item level, total scores for each measure were imputed using mean responses to available items. If a participant that was not excluded above had more than 20% of items missing at the subscale or scale total level, these cases were also excluded. Due to greater than 20% of missing data at the item level, Study 2 had empty cases for the GAD-7 (n=2), EBIQ-Communication (n=2), and EBIQ-Fatigue (n=1).

Statistical Analyses

All analyses were conducted using R statistical software version 4.0.3 (R Core Team, 2020). The results were first analysed irrespective of the phase of the COVID-19 pandemic during data collection and individuals' status with respect to the pandemic (i.e., vaccination status, concern over COVID-19, etc.).

A Shrout & Fleiss (2,1) intraclass correlation coefficient (ICC) was used to estimate test-retest reliability for IU-SF subscales at Time 1 and Time 2 (Shrout & Fleiss, 1979). In comparison to a Pearson correlation that measures *association,* the ICC measures *agreement* of items across assessments (Shrout & Fleiss, 1979). Though both Pearson correlation and ICC assess magnitude of a relationship, ICC uniquely requires scores to be additively similar. ICC estimates were obtained using the psych R package (Revelle, 2021). Both complete cases analysis and maximum likelihood estimation for missing cases were conducted. Cichetti's (1994) guidelines for evaluating good clinical significance (ICC $\geq$ 0.60) were used to guide interpretation of the ICC. To determine the standard error of measurement (SEM) of the IU-SF, the following formula was used:

$$SEM = \sigma \, x \, \sqrt{1 - r}$$

Where σ is the standard deviation of the IU-SF, and r is its reliability. The standard deviation of the IU-SF per subscale at Time 1 was used to calculate the SEM. Spearman's

rho correlations were additionally estimated to examine the rank-order stability of IU-SF scores across all time points. This was done to detect whether individuals scoring within a certain rank at Time 1 continued to do so at Time 2 and Time 3 despite any time-related factors that may cause changes in rank (e.g., illness).

Full and partial correlation matrices of the relationship of the IU subscales to EBIQ-S, PHQ-8, GAD-7, SPIN, BMQ-S and BADS-SF scores were estimated to assess concurrent validity. Linear regressions were conducted to assess whether IU-SF subscale scores related to PHQ-8, GAD-7, and SPIN scores. To estimate predictive validity, scores on the IU-SF at Time 1 were used to predict scores on the PHQ-8, GAD-7, and SPIN at Time 3. I examined the effect of removing cases with high levels of influence (as defined by a Cook's distance of greater than 4 divided by the sample size; Cook, 1977). Inclusion or exclusion of highly influential cases made little to no difference and hence the full sample was used in all analyses.

An exploratory analysis was conducted on whether IU-SF subscale scores contributed unique variance to PHQ-8, GAD-7, and SPIN scores above ABI symptoms as reported on the EBIQ-S using Time 1 data.

Exploratory analyses on the potential impact of COVID-19 on IU were conducted. These included correlating IU-SF scores and other study measures to negative and positive changes during the pandemic; and summarising IU-SF scores based on whether or not individuals had been infected with COVID-19. A more in depth account of COVID-19 analyses are in the *Appendix*.

Study 2 Results

Demographics

A total of 118 participants participated at Time 1 (demographics shown in Table 7). Eighty-two participants took part at Time 2, and 48 participants completed Time 3.

Participants (N=118)		Min - Max
Gender – *n* (%)		
Male	62 (52.50%)	
Female	56 (47.50%)	
Age – Mean (*SD*)	48.07 (14.17)	24 – 78
Ethnicity – *n* (%)		
White British	108 (91.50%)	
Mixed Ethnicity	5 (4.20%)	
White Other	3 (2.50%)	
Black British	2 (1.80%)	
Highest Level of Education – *n* (%)		
Primary	1 (0.80%)	
Secondary	5 (4.20%)	
GCSE/O-Level	15 (12.70%)	
A-Levels	17 (14.40%)	
College Diploma	21 (17.80%)	
Bachelor's Degree	34 (29.80%)	
Postgraduate Degree	23 (19.50%)	
Other	2 (1.70%)	
Living Situation – *n* (%)		
Living with Partner	57 (48.30%)	
Living with Family	37 (31.40%)	
Living Alone	24 (20.30%)	
Work Status – *n* (%)		
Full Time	52 (44.10%)	
Part Time	18 (15.30%)	
Retired (including Medical retirement)	22 (18.60%)	
Unemployed	15 (12.70%)	
Other	11 (9.30%)	
Type of ABI – *n* (%)		
Traumatic Brain Injury	66 (55.90%)	
Stroke	23 (19.50%)	
Tumour	25 (21.20%)	
Other	4 (3.40%)	
Years Post-ABI – Mean (SD)	11.01 (8.73)	0.20 – 40.80
Reported Duration of Loss of Consciousness in Minutes – Median[a]	30	0 – 20,160
Recruitment Source – *n* (%)		
Prolific	57 (48.30%)	
CCNRP	33 (28.00%)	
Social Media	23 (19.50%)	
ABI Charity	5 (4.20%)	
Method of Assessment – *n* (%)		
Online	96 (81.40%)	
In Person	22 (18.60%)	

Table 7. Participant Characteristics with data collected at Time 1. Of note, 58 participants (49.2% of the sample) completed the study prior to the first COVID lockdown in the UK (before March 2020) and the remaining 60 participants (50.8%) during COVID (post March 2020).
ABI = Acquired brain injury, CCNRP = Cambridge Cognitive Neuroscience Research Panel
[a] Only collected for individuals reporting a "head injury" or "traumatic brain injury."

Test-Retest Reliability

Prospective Anxiety scores did not differ between time points ($F_{2, 245} = 0.91$, $p = 0.41$), nor did Inhibitory Anxiety scores ($F_{2, 245} = 0.54$, $p = 0.59$). For the Prospective Anxiety subscale, rank-order stability was high from Time 1 to Time 2 (*rho* = 0.57), Time 1 to Time 3 (*rho* = 0.72), and Time 2 to Time 3 (*rho* = 0.71). For the Inhibitory Anxiety subscale, rank-order stability was high from Time 1 to Time 2 (*rho* = 0.74), Time 1 to Time 3 (*rho* = 0.74), and Time 2 to Time 3 (*rho* = 0.81). Complete case subscale scores from Time 1 to Time 2 and at Times 1, 2, and 3 are presented in Figure 4.

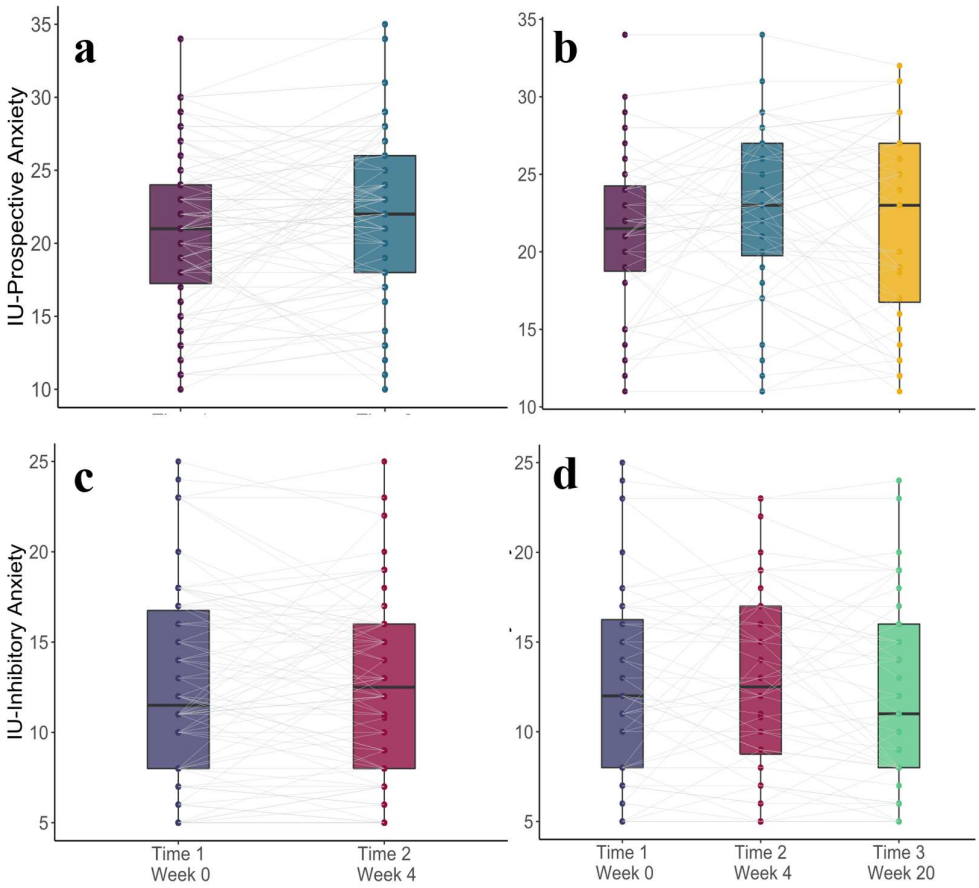


Figure 4. Complete case IU-SF subscale scores across study time points with time intervals. Plots a and b show Prospective Anxiety scores, and plots c and d show Inhibitory Anxiety scores. Eighty-two participants provided data from Time 1 to Time 2, and 48 participants provided data at Times 1, 2, and 3.

In general, 2,1 intraclass correlation coefficients using data from all time points were excellent (ICCs ≥ 0.75). A summary of ICC estimates is presented in Table 8. The standard

error of measurement (SEM) for the Prospective Anxiety subscale was 2.84 using Time 1 and Time 2 data, and was 2.20 using data from Times 1 to 3. For the Inhibitory Anxiety subscale, the SEM was 1.94 for Time 1 to Time 2 data, and 1.47 for Times 1 to 3 data. In summary, whether the absolute scores are considered, or individuals' rank order, the IU-SF showed excellent test-retest reliability in ABI.

IU-SF	Time 1 to Time 2 (*N* = 82)	Times 1, 2 and 3 (*N* = 48)	ICC Estimate With Missing Cases (*N* = 118)
Prospective Anxiety	0.75 (0.64 – 0.83)	0.85 (0.78 – 0.91)	0.85 (0.81 – 0.89)
Inhibitory Anxiety	0.86 (0.80 – 0.91)	0.92 (0.88 – 0.95)	0.91 (0.88 – 0.93)

Table 8. Average 2,1 intraclass correlation coefficients (ICC) with 95% confidence intervals for IU-SF subscale scores. The first column provides estimates for complete cases at Time 1 to Time 2, with the second column estimates for complete cases at Times 1, 2, and 3. The third column provides an estimate of the ICC given the missing data using maximum likelihood estimation.

Exploratory Analysis – Test-Retest Reliability of the IU-SF relative to other Study Measures

IU is proposed to be a stable trait that is a risk factor for mood disorders and subsequent activation and avoidance behaviours. Mood and levels of activation and avoidance, in contrast, are considered to be less stable *states*. Thus, IU-SF scores should produce higher test-reliability. Accordingly, the relevant questionnaires ask participants to rate the frequency of particular experiences over the past week (BADS-SF, SPIN) or two weeks (PHQ-8, GAD-7), whilst the IU-SF instructs participants to rate items in general. An exploratory analysis investigating the test-retest reliability of the BADS-SF PHQ-8, GAD-7, and the SPIN compared to IU-SF subscale scores was therefore conducted using repeated measures data from Time 1 and Time 3. Type 2,1 ICCs were estimated across all measures, with results presented in Table 9. The PHQ-8, GAD-7, and SPIN showed similar levels of reliability to the IU-SF over these intervals, whilst the BADS-SF was less reliable.

N = 48	Average 2,1 ICC (95% CI)
IU-SF	
Prospective Anxiety	0.80 (0.68 – 0.88)
Inhibitory Anxiety	0.87 (0.79 – 0.82)
PHQ-8	0.93 (0.89 – 0.96)
GAD-7	0.87 (0.77 – 0.92)
SPIN	0.95 (0.92 – 0.97)
BADS-SF	
Activation	0.67 (0.47 – 0.80)
Avoidance	0.74 (0.58 – 0.84)

Table 9. ICC estimates for study measures across 5 months (Time 1 to Time 3). These estimates did not include Time 2 IU-SF data in order to compare ICC estimates across all measures.

Concurrent Validity

Alpha-adjusted full correlation and partial correlation matrices of Time 1 variables is presented in Figure 5. In the full partial correlation matrix, the effect of all variables were partialled from all other correlations (Revelle, 2021). The Prospective Anxiety and Inhibitory Anxiety subscales correlated with depression, generalised anxiety, social phobia scores, greater difficulties with motivation, lower activation, greater avoidance, and greater frequency of brain injury symptoms (*p*s <0.01).

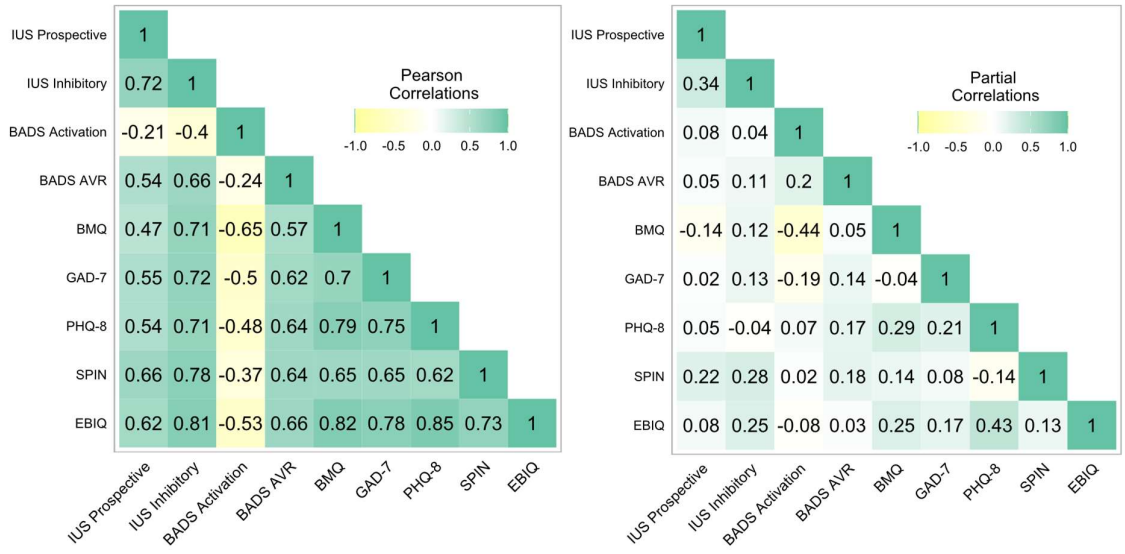


Figure 5. Full and partial correlations of study variables.
IUS = Intolerance of Uncertainty Scale-Short Form, BADS = Behavioural Activation for Depression Scale, BADS AVR = BADS Lack of Avoidance/Rumination, BMQ = Brain Injury Rehabilitation Trust Motivation Questionnaire, GAD-7 = Generalised Anxiety Disorder-7, PHQ-8 = Patient Health Questionnaire-8, SPIN = Social Phobia Inventory, EBIQ = European Brain Injury Questionnaire.

After controlling for shared variance through partial correlations, scores on the Prospective Anxiety subscale were correlated with SPIN scores ($p < 0.05$), and Inhibitory Anxiety scores were correlated with SPIN ($p < 0.05$) and EBIQ-S ($p < 0.05$) scores.

In a series of linear regressions, only Inhibitory Anxiety was associated with PHQ-8 scores ($F_{2, 115} = 58.02$, $\beta = 0.66$, Adj $R^2 = 0.51$, $p < 0.001$) and GAD-7 scores ($F_{2, 113} = 61.73$, $\beta = 0.67$, Adj $R^2 = 0.51$, $p < 0.001$). Both Prospective Anxiety ($\beta = 0.21$, $p < 0.01$) and Inhibitory Anxiety ($\beta = 0.63$, $p < 0.001$) were associated with SPIN scores ($F_{2, 115} = 98.02$, Adj $R^2 = 0.62$). Visualisations of the distributions of IU-SF subscales per clinical cut-off scores are shown in Figure 6.

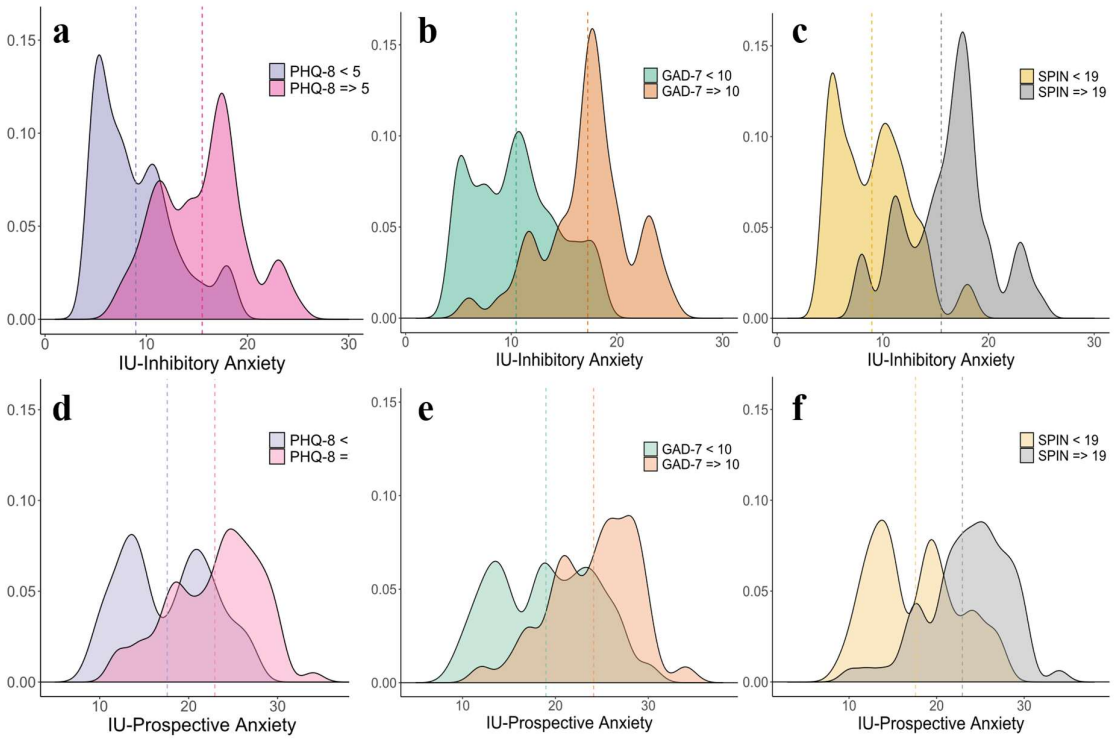


Figure 6. Distribution of IU-SF Inhibitory Anxiety and Prospective Anxiety scores to depression (PHQ-8, plots a and d), generalised anxiety (GAD-7, plots b and e) and social phobia (SPIN, plots c and f) separated by clinical cut-off scores for each measure (see *Methods*) using Time 1 data ($N = 118$). Group means are visualised along the dotted lines.

Predictive Validity

A series of linear regressions were estimated using IU-SF subscale scores at Time 1 predicting Time 3 PHQ-8, GAD-7, and SPIN scores. Only Inhibitory Anxiety was

significantly predictive of Time 3 scores on the PHQ-8 ($F_{2, 43} = 17.64$, $\beta = 0.50$, Adj $R^2 = 0.43$, $p < 0.01$), the GAD-7 ($F_{2, 43} = 19.16$, $\beta = 0.58$, Adj $R^2 = 0.45$, $p < 0.01$), and the SPIN ($F_{2, 43} = 21.97$, $\beta = 0.80$, Adj $R^2 = 0.48$, $p < 0.01$).

Exploratory Analysis – Relationship of IU to ABI symptoms

As previously highlighted, ABI places individuals at increased risk of mental health difficulties, and it is likely that this is in part due to the effects of the injury itself (Juengst et al., 2017; Shi et al., 2017). To determine whether IU-SF scores added unique variance to depression, generalised anxiety, and social phobia symptoms above self-reported ABI symptoms on the EBIQ-S, three hierarchical multiple regressions were conducted predicting PHQ-8, GAD-7, and SPIN scores. The EBIQ-S subscales were organised into blocks representing physical function (Physical and Somatic subscales), cognitive function (Cognitive and Motivation subscales), and social function (Impulsivity, Isolation, and Communication subscales)[7]. Each block was entered in order into the regression models first, then in the last block, the Prospective Anxiety and Inhibitory Anxiety scores were added. The Depression subscale of the EBIQ-S was not included due to its obvious conceptual overlap with the mood measures. An overview of regression results are shown in Table 10.

[7] My organisation of EBIQ-S subscales into blocks was based on conceptual associations between specific items on subscales. Example items demonstrating conceptual overlap are:
Physical Function Block:
Physical item: "Problems with household chores", "Needing help with personal hygiene";
Somatic items: "Headaches" , "Lack of energy or being slowed down"
Cognitive Function Block:
Cognitive items: "Being unable to plan activities", "Failing to get things done on time"';
Motivation items: "Feeling unable to get things done", "Lack of interest in hobbies outside the home"
Social Function Block:
Impulsivity items: "Reacting too quickly to what others say or do", "Being 'bossy' or dominating"';
Isolation items: "Others do not understand your problems", "Mistrusting other people";
Communication items: "Difficulty participating in conversations", "Losing contact with your friends"

	PHQ-8		GAD-7		SPIN	
	β	*p*	β	*p*	β	*p*
Block 1: Physical Function						
Physical	-0.07	0.41	-0.19	0.04*	0.33	<0.001***
Somatic	0.19	0.01*	0.35	<0.001***	-0.04	0.62
Block 2: Cognitive Function						
Cognitive	0.19	0.07	0.03	0.79	0.00	0.99
Motivation	0.42	<0.001***	0.05	0.63	-0.04	0.69
Block 3: Social Function						
Impulsivity	0.17	0.08	0.27	<0.01**	-0.22	0.03*
Isolation	0.01	0.95	0.06	0.55	0.15	0.10
Communication	-0.07	0.53	0.14	0.22	0.13	0.26
Block 4: Intolerance of Uncertainty						
Inhibitory Anxiety	0.15	0.13	0.33	<0.01**	0.39	<0.001***
Prospective Anxiety	-0.01	0.87	-0.10	0.26	0.28	<0.01**

Table 10. Full hierarchical regression with standardized coefficients (β). Brain injury symptoms as measured via the EBIQ-S.
PHQ-8 = Patient Health Questionniare-8, GAD-7 = Generalised Anxiety Disorder-7, SPIN = Social Phobia Inventory.

In the PHQ-8 model, only EBIQ-Motivation scores (β = 0.42) and EBIQ-Somatic scores (β = 0.19) had the strongest unique associations with PHQ-8 scores, with the full model accounting for 71% of the variance ($F_{9, 103} = 31.61$, $p < 0.001$).

The full GAD-7 model accounted for 66% of the variance ($F_{9, 103} = 24.99$, $p < 0.001$). EBIQ-Somatic scores had the strongest contribution (β = 0.35), followed by Inhibitory Anxiety (β = 0.33), EBIQ-Impulsivity (β = 0.27) and EBIQ-Physical (β = -0.19) scores.

In the SPIN model, Inhibitory Anxiety scores had the greatest contribution (β = 0.39), followed by EBIQ-Physical (β = 0.33), Prospective Anxiety (β = 0.28), and EBIQ-Impulsivity (β = -0.22) scores, account for 67% of the variance ($F_{9, 103} = 26.25$, $p < 0.001$).

Taken together, the regression results demonstrate that the Inhibitory Anxiety subscale of the IU-SF shares unique variance in generalised anxiety and social phobia above self-reported ABI symptoms, but IU does not make a unique contribution to depression.

Exploratory Analysis – Effect of COVID-19 on IU and Mood in ABI

As discussed, IU is considered a relatively stable trait, rather than the degree of uncertainty that they face. Though no prior hypotheses were made regarding how the COVID-19 pandemic may affect IU, there is evidence suggesting IU modulates responses to the pandemic, particularly in mental health difficulties (Akbari et al., 2021; Rettie & Daniels, 2021). A brief summary of the effects of COVID-19 on IU-SF and mood measures is presented here. Further details are reported in the *Appendix.*

Of the 48 participants who completed Time 3, 10 reported having confirmed (through a medical test) or suspected COVID-19 (no test taken). Descriptive statistics are in Table 11. Those with confirmed or suspected COVID had higher PHQ-8 ($W = 80.5$, $p < 0.01$) and GAD-7 scores ($W = 100.5$, $p = 0.03$), otherwise there were no differences between groups.

M (*SD*)	**Confirmed or Suspected COVID (*n* = 10)**	**No COVID (*n* = 38)**
IU-SF		
Prospective Anxiety	23.0 (5.76)	21.2 (6.37)
Inhibitory Anxiety	13.6 (5.10)	11.6 (5.32)
PHQ-8	12.9 (6.01)	6.81 (6.48)
GAD-7	11.2 (5.63)	5.80 (6.08)
SPIN	32.1 (20.3)	22.9 (16.9)
BADS-Activation	15.4 (3.97)	20.6 (8.39)
BADS-Avoidance/Rumination	8.11 (4.68)	5.25 (4.68)
Negative Changes Due to Pandemic	20.7 (9.04)	14.6 (9.48)
Positive Changes Due to Pandemic	8.5 (5.57)	7.9 (3.78)

Table 11. Mean scores of study measures at Time 3 in those with confirmed or suspected COVID versus those without COVID.

Full and partial pairwise correlations of study variables at Time 3 were estimated, with Bonferroni-adjusted comparisons (see Figure 7). Only the Inhibitory Anxiety subscale correlated with greater negative changes due to COVID-19, with small partial correlations between lower positive changes in Prospective Anxiety and Inhibitory Anxiety subscales (ps < 0.05). Negative changes due to COVID-19 still correlated with GAD-7 scores and lower avoidance, though were smaller associations to PHQ-8, SPIN scores, and activation (ps < 0.05).

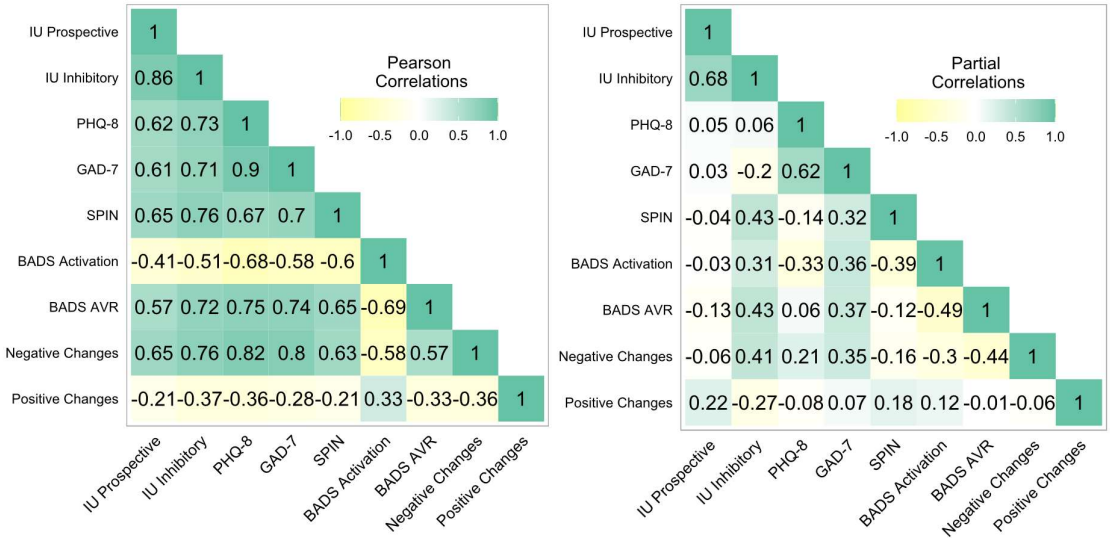


Figure 7. Full and partial correlations of study measures to negative and positive changes due to COVID-19 in participants at Time 3 ($N = 48$).
IUS = Intolerance of Uncertainty Scale-Short Form, BADS = Behavioural Activation for Depression Scale, BADS AVR = BADS Lack of Avoidance/Rumination, GAD-7 = Generalised Anxiety Disorder-7, PHQ-8 = Patient Health Questionnaire-8, SPIN = Social Phobia Inventory.

In summary, contracting COVID-19 does not seem to influence IU-SF scores in this sample. The Inhibitory Anxiety subscale in particular seem to be related to negative changes due to COVID-19, however direction of causality cannot be established here.

Discussion

The purpose of this chapter was to evaluate the factor structure, reliability and validity of the Intolerance of Uncertainty Scale-Short Form (IU-SF; Carleton et al., 2007) in ABI. The results show that while a two-factor structure of the IU-SF is acceptable, further factor analysis of the IU-SF in ABI would be beneficial. The IU-SF can be used reliably over time, and is arguably more impressive given the "natural experiment" in levels of uncertainty due to COVID-19. Similar to those without ABI, IU is associated with depression, anxiety, and social phobia. While Inhibitory Anxiety seems to play a key role in anxiety in ABI, aspects of the COVID-19 pandemic may have affected IU and mental health scores.

IU-SF Internal Consistency in ABI

The IU-SF demonstrated excellent internal consistency as measured by Cronbach's alpha, both for the scale total and for the Prospective and Inhibitory subscales. However,

Cronbach's alpha has been criticised for having unrealistic statistical assumptions, chiefly that scale items are unidimensional (Graham, 2006). Using McDonald's omega estimates of internal consistency, the general and group factors of the bifactor IU-SF model display excellent internal consistency. However, in this study, multidimensionality of the IU-SF is likely (Explained Common Variance = 0.57 to 0.59). Given the ongoing questions surrounding what exactly the factor structure of the IU-SF is (Birrell et al., 2011; Bottesi et al., 2019, 2020), selection of which subscales are best to use is yet to be determined.

IU-SF Factor Structure in ABI

A two-factor model using the Prospective Anxiety and Inhibitory Anxiety subscales of the IU-SF had significantly better fit relative to a one factor model in ABI. However, exploratory bifactor models in our study revealed differential item loadings on the IU-SF. Similarly, Saulnier and colleagues (2019) report that the Prospective Anxiety subscale had items that did not have strong factor loadings, suggesting that reworking this subscale is necessary. Rather than a bifactor structure, the interaction of several types of responses to uncertainty may give rise to a general IU trait. Network analysis approaches (Bottesi et al., 2020) suggest that the IU-SF has three subscales representing behavioural reactions to uncertainty, emotional reactions to uncertainty, and negative beliefs about uncertainty, which work in tandem to generate changes in IU.

From a conceptual standpoint, in ABI, responses on the Inhibitory Anxiety and Prospective Anxiety subscales may not uniquely stem from individual differences in tolerating uncertainty. Difficulties understanding ABI-related changes and perceiving that not enough information was provided in acute care services are common experiences post-ABI (Snell et al., 2020), and thus even those low in IU may be high in information seeking tendencies. In both exploratory bifactor analyses, items 2 ("it frustrates me not having all the information I need"), 4 ("one should always look ahead so as to avoid surprises"), 8 ("I

always want to know what the future has in store for me"), and 11 ("I should be able to organise everything in advance") loaded onto the same factor, which could all represent information seeking tendencies. The influence of COVID-19 on Prospective Anxiety scores cannot be ignored, due to varying amounts of health-related information throughout the pandemic (Brown et al., 2021). Of course, information seeking may interact with IU; for example, IU has been shown to moderate the relationship between repeatedly checking the internet for health-related information and health anxiety (Fergus, 2013).

IU-SF Reliability in ABI

The IU-SF Prospective Anxiety and Inhibitory Anxiety subscales demonstrated good test-retest reliability across 4 weeks (ICC = 0.75 and 0.86, respectively) and 20 weeks (ICC = 0.85 and 0.92), despite the variations in sample recruitment, assessment method, time of pandemic, and type of ABI. Research in non-ABI populations reported strong IU-SF correlations over 2 weeks (r = 0.77; Khawaja & Yu, 2010) and an ICC of 0.87 was estimated in a non-ABI clinical sample over 12 weeks (Wilson et al., 2020). This suggests that the IU-SF is similarly stable in adults with ABI. Although ABI can have ongoing effects, our sample only included adults in the chronic stages of their injury. It is possible that test-retest reliability would change within the first year of ABI, as this is a period of marked instability, especially in the development of mental health difficulties (Gould et al., 2011; Ouellet et al., 2018). Further work in the acute stage of ABI is required and the current results should be interpreted as pertaining to the chronic stages of ABI.

Given its proposed role as a "trait", it is surprising that test-retest reliability of the IU-SF was not higher (albeit not majorly so) than "state" measures (PHQ-8, GAD-7, and SPIN). Potentially, the PHQ-8, GAD-7, and SPIN do not measure "mood state" in the study context. Though over shorter time points, similar ICC estimates have been reported outside of ABI for the PHQ-9 (ICC = 0.91, Pinto-Meza et al., 2005), GAD-7 (ICC = 0.83; Spitzer et al., 2006),

and the SPIN (ICC = 0.94, Chen et al., 2011). The PHQ-8, GAD-7, and SPIN may be easier to consistently respond to given the greater specificity of items such as "Poor appetite or overeating" – the IU-SF, with statements such as "I always want to know what the future has in store for me" may have greater subjective interpretation and thus lower agreement. Further work using Item Response Theory approaches assessing item difficulty would be beneficial.

IU-SF Concurrent and Predictive Validity in ABI

IU-SF subscales both correlated with greater difficulties with motivation, decreased activation, increased avoidance, and with PHQ-8, GAD-7 and SPIN scores. Only Inhibitory Anxiety was predictive of PHQ-8, GAD-7, and SPIN scores at 20 weeks post-Time 1. However, when accounting for self-reported ABI symptoms, Inhibitory Anxiety was only uniquely associated with generalised anxiety and social anxiety, suggesting IU may be a stronger correlate of anxiety disorders in ABI than depression.

The finding that IU is not uniquely associated with depression is somewhat surprising given the common co-occurrence of depression and anxiety, though this result aligns with IU research outside of ABI (McEvoy et al., 2019). Possibly, motivation fully mediates any relationship between inhibitory anxiety and PHQ-8 scores. As many items on the EBIQ-S Motivation subscale denote a lack of interest in engaging in activities, it may be this finding represents increased apathetic behaviour often seen post-ABI (Marin & Wilkosz, 2005).

The finding that Prospective Anxiety does not uniquely relate to generalised anxiety is contrary to research in clinical and nonclinical samples (Carleton, 2012; McEvoy & Mahoney, 2011; 2012). Inhibitory Anxiety however, remained a unique correlate. Previously "normal" amounts of uncertainty may become inhibiting due to difficulties attending to and retrieving relevant information and a disorganised approach to problem-solving uncertainty. Anxiety disorders are associated with impaired processing speed, flexible thinking, attention and working memory, and executive function in TBI and stroke (Faulkner et al., 2020;

Whiting et al., 2014; Gould et al., 2013) – similarly, adults without ABI with anxiety (Gualtieri et al., 2008; Moran, 2016) and those high in IU (Berenbaum et al., 2008; Flores et al., 2018) display difficulties in these domains.

Both the Prospective Anxiety and Inhibitory Anxiety subscales significantly contributed to social phobia scores. After ABI, individuals often report social challenges, such as change or loss of friendships, or interpersonal difficulties (Salas et al., 2018). Perceived stigma has been found to be the only unique predictor of social anxiety post-TBI, even when controlling for demographic factors, depression and cognitive difficulties (Curvis et al., 2018). This relationship may be moderated by IU – someone high in Prospective Anxiety may be more likely to worry over perceived stigma, whilst Inhibitory Anxiety may in part explain any resultant avoidance of social situations.

Another line of research to explore is the extent to which IU relates to motivation, activation and avoidance in ABI. Both Prospective Anxiety and Inhibitory Anxiety related to avoidance (*r*s 0.55 and 0.66, respectively) and to lowered activation (*r*s -0.21 and -0.40). In ABI, there may be an increased tendency to view potentially pleasurable events as challenging due to the uncertainty around whether one's impairments may inhibit enjoyment, thus reducing motivation for an activity (e.g., "I may have difficulty remembering the bus route, so getting outside of the house will be unpleasant"). Exploring how IU affects motivational processes for future activities may be useful in reducing avoidance in ABI.

Clinical and Theoretical Implications

Although this is the first study to quantitatively investigate IU in ABI, a key translational question is "*to what degree is it useful to directly address intolerance of uncertainty in rehabilitation?*" Progressive neurological conditions, for example, are often wrought with uncertainty – at high levels of uncertainty, individual differences in IU may be less relevant. However, in multiple sclerosis, high IU is related to maladaptive coping

strategies (Alschuler & Beier, 2015). Though IU may be more obviously relevant to a *condition* that is highly uncertain, those with non-progressive ABIs may face similar challenges about rehabilitation outcome due to high uncertainty in prognoses.

Rather than assessing IU by condition, "domains" of uncertainty may be more relevant to assess, such as self-uncertainty around one's identity, uncertainty about perceived functional capacity, future uncertainty of injury recurrence or changing frequency of impairments, or uncertainty surrounding one's social circumstances. Outside of ABI, disorder-congruent situations (e.g., social situations for social anxiety, contamination concerns in obsessive-compulsive disorder) relate more strongly to IU than disorder-incongruent situations (Jensen & Heimberg, 2015). Qualitative themes of uncertainty in ABI (e.g., Salter et al., 2008) may be useful sources for developing IU measures that are sensitive to "uncertainty domains" post-ABI.

There is promise in modifying IU in neurological populations. An IU-focused intervention has been piloted in multiple sclerosis, with reduced IU correlating with increases in diagnosis acceptance (Molton et al., 2019). Outside of ABI, modifying IU using cognitive behavioural treatments has been successful (Bomyea et al., 2015; Hebert & Dugas, 2019). However, in ABI, behavioural approaches are desirable (Gallagher et al., 2019). Encouraging behavioural experimentation in activities with uncertain outcomes may challenge uncertainty-related beliefs. Alternatively, "third-wave" approaches such as Acceptance and Commitment Therapy may be useful for individuals learning to accept the inherent unknowns of post-ABI life.

From a theoretical perspective, the much more challenging question is to what extent IU fits within models of psychological distress in ABI. It is not yet clear what the distinction is (if any) between increases in *amount* of uncertainty, changes to neurological *processing* of uncertainty, the *personal relevance* of sources of uncertainty, and *individual differences* in

ability to cope with uncertainty. Processing of uncertain threat has been linked with functional abnormalities in the anterior insula, anterior cingulate cortex, and dorsolateral prefrontal cortex, and with grey matter volume in the right superior temporal pole and striatum (Kim et al., 2017; Tanovic et al., 2018). Functional or structural changes to these areas may be relevant to theoretical accounts of IU in ABI. Finally, whether IU is a fundamental aspect of mood disorders, rather than an independent construct, is still under discussion (Carleton, 2016).

Limitations

The study was conducted with participants with chronic ABI, hence patterns of responses may differ in an acute sample or in groups with progressive neurological conditions. For practical reasons, the study included those who self-report an ABI without requesting evidence of diagnosis, and sampling methods in medical settings may produce different results. The current study was adequately powered to evaluate factor analyses, reliability, and validity, but a larger sample size is required to exhaustively test bifactor models of the IU-SF. Whilst the results suggest that the IU-SF is reliable despite potential influences of recruitment source and effects of COVID-19, it possible that these have unknown effects on the data.

Conclusions

The IU-SF is a reliable measure in ABI. The relationship of IU to the GAD-7 and SPIN appears clinically informative, in particular Inhibitory Anxiety seems to be relevant to anxiety in ABI. A two-factor structure is superior to a one-factor structure for use in ABI research. However, more research is needed to explore other scale structures, namely bifactor modelling. Further work is necessary to disentangle the relationship between IU and cognitive changes following ABI and their relation to depression, generalised anxiety, and

social phobia, and critically, precisely evaluate how IU contributes to outcomes in rehabilitation.

Chapter Three

Discrepancies in Estimations of Abilities following Acquired Brain Injury and its Relationship with Participation and Mood

This chapter describes a secondary data analysis on routinely collected outcome assessment data from two NHS acquired brain injury community-based rehabilitation centres in the UK. The data were collected by staff members at each NHS site, and I am grateful for their collaboration and support in using this data as part of my thesis. I was responsible for developing a research question suitable for a secondary data analysis, analysing the data, and writing the thesis chapter. For the data used from the first NHS site, I was responsible for coalescing the data into a master data file.

Introduction

In the ABI literature, it has been long recognised that self-awareness into the extent of one's disability is central to successful rehabilitation. Impaired self-awareness, where one is unable to recognize the presence or extent of impairments following ABI and their impact on everyday life, is thought to reduce motivation to engage in therapy, disrupt family systems, and negatively affect return to work and long-term participation (Tate et al., 2014; Leung & Liu, 2011; Schönberger et al., 2006). In line with the overall aims of this thesis, here I discuss self-awareness as it relates to mood and activity participation.

Impaired self-awareness is often operationalised as the discrepancy between ratings from the person with an ABI and an informant (e.g., relative, partner, clinician; Brown et al., 2021). Self-ratings can also be measured against performance measures, though this can be complex for more abstract skills such as performance on executive function tasks (Burgess et al., 1998). Crosson and colleagues (1989) proposed a three-tiered model of self-awareness in which *intellectual awareness* (the ability to recognise an impairment) is a pre-requisite for *emergent awareness* (the monitoring of impairments as they occur) – with both leading to *anticipatory awareness* (the ability to make predictions as to when a problem will occur as a result of impairment). By definition, discrepancies assess *intellectual awareness.* As such, when an informant endorses a difficulty but the individual with the ABI does not (i.e., a positive discrepancy), this "overestimation" is considered impaired intellectual self-awareness, with likely knock-on effects for emergent and anticipatory awareness.[8]

What might be reasons for overestimation? Previous studies have linked impaired self-awareness with injury severity, such as through duration of post-traumatic amnesia (PTA) and depth of loss of consciousness (via Glasgow Coma Scale scores) following

[8] Some have challenged whether this is the case. Toglia & Kirk (2000) and Mograbi & Morris (2013) distinguish between explicit and implicit forms of awareness. In the latter, behavioural adaptation to a deficit might occur even in the absence of conscious report.

traumatic brain injury (Dromer et al., 2021b). The literature on whether structural changes to particular brain regions (e.g. right vs. left hemisphere, anterior temporal regions) causes impairments in awareness has been mixed (Anderson & Tranel, 1989; Ranseen et al., 1990; Sherer et al., 2005; Ham et al., 2014); however, this may be influenced by difficulties making inferences about localisation in TBI especially, as widespread damage (i.e., axonal shearing and disconnection) are likely to occur in addition to discrete lesions. Emerging evidence has supported the notion that brain network dysfunction may be related to impaired self-awareness (Dromer et al., 2021b). For example, Ham et al. (2014) compared resting state connectivity in TBI survivors with relatively good or poor self-awareness. Whilst location of focal lesion or amount of axonal injury did not relate to impaired self-awareness, abnormal activity in the frontoparietal control network distinguished those with impaired self-awareness from those with good self-awareness.

Impaired self-awareness has also been posited to be due to executive dysfunction. Some characterisations of executive functions *include* self-awareness (e.g. Stuss, 1991) hence, a priori, there will be a relationship. Newman et al. (2000) examined the relationship between performance-based measures and self-awareness in a TBI sample (n = 37) and found *no* significant relationship between a variety of executive function tasks (e.g., Wisconsin Card Sorting Test, Trails and Verbal Fluency) and patient-clinician rating discrepancies. Other studies examining *individual* test-awareness relationships have similarly often failed to find significant correlations (Prigatano & Altman, 1990; Lanham et al., 2000). In contrast, *aggregated* neuropsychological test scores have more reliably predicted impaired awareness (Dromer et al., 2021b; Steward & Kretzmer, 2021). Of course, it could be that self-awareness is more likely to be captured across a wider range of cognitive tests than a single measure, though a relationship between self-awareness and executive impairments may vary on particular definitions used (Hart et al., 2005).

Reasons for overestimation may further have psychological correlates. For example, a distinction has been drawn between impaired self-awareness and denial of disability, in which the latter is an unconscious mechanism to protect oneself from distress (Prigatano & Sherer, 2020). Premorbid tendencies may further complicate assessment of impaired self-awareness – outside of ABI, adults tend to have only moderate insight into their abilities, with meta-analytic evidence across 22 studies resulting in only a modest correlation between self-evaluations of ability and objective performance ($r = 0.29$; Zell & Krizan, 2014). However, if such psychological factors are indeed protective of mood, some inference may come from examining awareness-mood relationships. An important caveat here is that, as discussed, reduced self-awareness is linked with greater ABI severity which, in turn, may be linked with greater psychological distress (Shi et al., 2017). This means that it is important to take severity into account. When that is done, better self-awareness may indeed link with reduced self-esteem (Cooper-Evans et al., 2008; Carroll & Coetzer, 2011; Ownsworth, 2014).

Of course, discrepancies in reports of disability may not strictly reflect overestimation – poor self-awareness can also be considered an *underestimation* of one's abilities. In contrast to overestimation, underestimation seems to be related to mood status. Smeets and colleagues (2017) reported that adults with ABI undergoing intensive neurorehabilitation who were underestimators had higher levels of depression relative to accurate estimators and overestimators. If individuals with depression are experiencing low self-worth, it could be that underestimation reflects a negative awareness bias. Whether or not underestimators are a distinct clinical group and have different outcomes relative to overestimators and accurate estimators is not well-understood.

Investigation of how over and underestimation of abilities may differ from those who accurately estimate their abilities is of interest, as either group may have differential outcomes in participation following rehabilitation and hence implications for the support

network of those with an ABI such as spouses or relatives. If a relative lack of awareness relates to greater confidence to engage in pre-injury activities, for example, this could be of benefit to mood and hence overall outcome. Conversely, if attempts to increase self-awareness result in greater distress, this could negatively impact participation outcomes. Thus, whilst there is a general consensus that self-awareness may be altered by an ABI, differences in mood, executive function, self-esteem, caregiver strain, participation between those who overestimate, accurately estimate, and underestimate their abilities relative to an informant requires further clarification, in particular whether there are longitudinal differences in participation. Here, I look at self-awareness in the context of community-based neurorehabilitation services using routine outcome assessment data from two separate NHS sites. Large clinical datasets with relevant measures completed for clinical reasons provide a potentially rich source of such information, and importantly provide data from individuals who may normally not engage in University-organised research studies.

Chapter Aims

This chapter reports on three separate investigations of the relationship of self-awareness to participation, executive function, self-esteem, depression and anxiety, and caregiver strain in those who overestimate, accurately estimate, and underestimate their abilities relative to an informant in ABI both cross-sectionally and longitudinally. The first analysis uses a moderate ($N = 88$) sample from an NHS community neurorehabilitation site ("Site 1") for adults with ABI to investigate cross-sectional and longitudinal differences. The second analysis aims to replicate the analyses of Site 1 in a larger ($N = 153$) dataset from outcome assessments from a second NHS community neurorehabilitation site ("Site 2") for adults with TBI. Analysis 3 then combines the data from both sites ($N = 241$) to gain greater precision of estimates.

Methods

As a retrospective analysis of anonymised clinical data, this project did not require formal ethical approval. The study received informal permission from the relevant NHS Trust to conduct the analysis as a service evaluation project. This analysis was preregistered on January 10th 2019 (https://osf.io/65zx3/). Formal permission to include the results in my PhD thesis was granted by the Medical Director of the relevant NHS Trust on June 10th 2021. Although the service users of these sites were not participants *per se*, here I refer to them as participants for simplicity.

Study Design and Sample Size

This study is a secondary data analysis of observational longitudinal data. Sample size was determined by whether there was both a self- and informant-rated measure of ABI symptoms (the European Brain Injury Questionnaire; see *Study Measures*) available to create estimation groups.

Data Collection

An overview of the assessment timeline in each NHS site, and the data structure used for analyses, are presented in Table 12. At Site 1, self-report measures were routinely collected at Assessment, Weeks 1, 6, and 18 of their programme, and repeated at 3, 6, and 1-year follow-up post-rehabilitation. At Site 2, self-report measures were only collected at Assessment and at a 1-year follow up appointment. For longitudinal analyses, Assessment and Week 1 data at Site 1 was collapsed into a *Time 1* variable, 6 and 18 week data was collapsed as *Time 2*, and any data point at 3, 6, or 12 month follow up was collapsed as *Time 3*. If a participant had multiple Time 1, 2, or 3 assessments, the last available data point (e.g., 1 Year Follow Up) was used. Site 2 data was analysed as initially structured within site records. This restructuring was undertaken for ease of analysis and to ensure an adequate number of participants at each time point. However, within NHS Site 1, Week 6 represents a

key period in change in the intervention offered (i.e., a shift from intervention delivered predominantly on site versus individuals using skills gained within their home, social and work environment). Thus, there may be key differences between these time points that are not examined here.

	Site 1	Site 2	Data Structure
Initial Assessment	X	X	Time 1
Week 1 – Pre-Rehabilitation	X		
Week 6 – Mid-Rehabilitation	X		Time 2
Week 18 – Post-Rehabilitation	X		
3 Month Follow Up	X		Time 3
6 Month Follow Up	X		
1 Year Follow Up	X	X	

Table 12. Assessment timeline at each NHS site and data structure for analysis.

Study Measures

The below self-report measures were routinely collected at both NHS sites, with the exception of the Dysexecutive Questionnaire which was collected at Site 1 only. Where appropriate, an informant (e.g., caregiver or family member) completed measures of caregiver strain and ABI symptoms (plus an informant version of the Dysexecutive Questionnaire at Site 1). Clinicians at both NHS sites completed a measure of participation.

The *European Brain Injury Questionnaire – Self and Carer Versions* (EBIQ-S and EBIQ-C; Teasdale et al., 1997) is a 63-item measure developed to assess the subjective experience of brain injury and its associated symptoms. The EBIQ is described in detail in Chapter 2 of this thesis. Parallel self and informant versions are available, with informant versions rating items about the individual with an ABI. Discrepancies between the EBIQ-S and EBIQ-C were used to estimate self-awareness (see *Creation of Estimation Groups*).

The *Dysexecutive Questionnaire-Revised – Self and Carer Versions* (DEX-R-S and DEX-R-C; Burgess et al., 1996; Simblett et al, 2017) is a 37-item measure of dysexecutive difficulties in everyday life following ABI. Items are rated on a 5-point Likert scale, with endpoints 0 “Never” to 4 “Very Often”, with possible totals ranging from 0 to 148. Higher

scores represent greater difficulties with executive function. Self and informant versions of the DEX-R are available. DEX-R items align with Stuss' (2007) theoretical model of domains of frontal lobe function. The DEX-R scales have demonstrated good reliability and internal validity in ABI, with subscales demonstrating good model fit (Simblett et al., 2017).

The *Hospital Anxiety and Depression Scale* (HADS; Zigmond & Snaith, 1983) is a 14-item self-report measure of symptoms of anxiety (7 items) and depression (7 items). Participants rate items on a 4-point Likert scale, from 0 (Not at all) to 3 (Most of the time). Examples of items are "I have lost interest in my appearance" and "I feel restless as if I have to be on the move." Total scores can range from 0 to 21 on each subscale, with greater scores indicating greater anxiety or depression. The HADS two-factor structure has been supported in ABI (Dawkins et al., 2006; Schönberger & Ponsford, 2010), alongside excellent internal consistency and strong convergent validity with other measures of depression and anxiety (Dahm & Wong, 2013; Whelan-Goodinson et al., 2009).

The *Rosenberg Self-Esteem Scale* (RSES; Rosenberg, 1965) is a 10-item self-report measure of self-esteem, specifically an evaluation of judgments of self-worth or self-value. Items are rated on a 4-point Likert scale from 1 (strongly disagree) to 4 (strongly agree). Higher scores indicate greater self-esteem. Example items include "On the whole, I am satisfied with myself" and "I wish I could have more respect for myself" (reverse coded). The RSES has demonstrated good internal consistency and validity in ABI (Anson & Ponsford, 2006; Carroll & Coetzer, 2011).

The *Caregiver Strain Index* (CSI; Robinson, 1983; Onega, 2008) is a measure of carer strain completed by an informant (e.g., spouse, relative). Items cover areas of potential distress, including family adjustments, changes in personal plans, and financial strain. The CSI has demonstrated good reliability and validity in ABI (Visser-Meily et al., 2004). The CSI was adapted in both NHS sites to include three additional items on worry about the

future, strain on relationship, and feeling tired. This version of the CSI instructs informants to rate items from 0 to 10, with 10 indicating greater strain. Total scores range from 0 to 160.

The *Mayo-Portland Adaptability Inventory-4th Edition* (MPAI-4; Malec, 2005) is a 31-item clinician-rated measure of community integration in adults with ABI. Scale items reflect a range of physical, cognitive, emotional, behavioural, and social difficulties that may affect community integration. Clinicians rate to what degree each item affects daily activities of the person with the ABI: 0 (None), 1 (Mild problem but does not interfere with activities), 2 (Mild problem that interferes with activities), 3 (Moderate problem that interferes with activities) or 4 (Severe problem that interferes with activities). The MPAI-4 consists of three subscales, Participation (e.g., "Leisure and recreational activities"), Abilities ("Verbal communication"), and Adjustment ("Irritability, anger, aggression"). The MPAI-4 has demonstrated excellent reliability when rated by a clinician or informant, and good concurrent and predictive validity with self-report measures of disability and neuropsychological assessments of cognitive performance (Malec, 2005). Only the Participation subscale is used here.

Along with the above measures, severity information about those with TBI was collected from both sites using the below measure.

The *Glasgow Coma Scale* (GCS; Teasdale & Jennett, 1974) is a measure of depth of loss of consciousness following TBI performed on site immediately following an injury, acute care settings, or both. The scale is based on three different aspects of response following TBI – eye opening (scored 1 to 4; "none", "to pressure", "to speech", or "spontaneous"), verbal response (scored 1 to 5; "none", "sounds", "words", "confused", or "oriented"), and best motor response (scored 1 to 6; "none", "extension", "abnormal flexion", "normal flexion", "localising" or "obeying commands"). GCS scores are typically used to classify TBI severity, with scores 13 – 15 indicating a mild TBI, 9 – 12 indicating moderate

TBI, and 3 – 8 indicating severe TBI. The GCS has shown good validity with length of post-traumatic amnesia, structural damage on CT scans, and blood biomarkers, and good inter-rater reliability (Teasdale et al., 2014).

Data Cleaning Procedures

As only total scores on the above measures and their subscales were available for analysis, data cleaning was managed at the observation level. Missing data were common as some measures were administered only when deemed clinically appropriate or relevant to care. To ensure that overestimation, accurate estimation, and underestimation groups could be created, all participants included in the final analysis were required to have both EBIQ-S and EBIQ-C scores available at Time 1. For any participant who had at least these two measures, scores on the HADS, RSES, DEX-R-S, DEX-R-C, CSI, MPAI-4 Participation subscale and GCS scores were included, where available.

Statistical Analyses

All data were analysed using R statistical software version 4.0.3 (R Core Team, 2020). The same analysis procedure was used across all three studies, with the aim of attempting to replicate the results of Site 1 in a larger sample.

Handling of Missing Data

Missing data at the observation level for cross-sectional analyses were imputed using predictive mean matching (PMM) via the mice package in R (van Buuren & Groothuis-Oudshoorn, 2011). Essentially, PMM uses the distribution of the observed data to estimate *M* number of datasets containing plausible values for missing observations. Analyses were then re-conducted on each imputed dataset and the pooled imputed datasets, and were compared to the observed data. This can be considered equivalent to a sensitivity analysis approach, where differing estimates of analyses across an imputed datasets are used to determine if interpretation of the observed results would change based on theoretically plausible data.

Multiple imputation is increasingly preferred for analysing datasets with missing data (Wulff & Ejlskov, 2017) and has been found to outperform listwise deletion and simple imputation in datasets with small to large amounts of missing data (Janseen et al., 2010; Knol et al., 2010), including datasets with greater than 50% of data missing (Marshall et al., 2010).

For longitudinal analyses, missing data were handled using maximum likelihood estimation via a mixed-effects modelling approach. Maximum likelihood works through estimating the most likely model parameters that best fit the observed data. Maximum likelihood estimates provide unbiased estimates for longitudinal studies with missing data, and performing multiple imputation prior to mixed-effects modelling has not been shown to affect accuracy of inferences (Peters et al., 2012; Twisk et al., 2013). Given that I was interested in group-level estimates rather than observation-level data, mixed-effect modelling approaches were selected as an appropriate choice for managing missing longitudinal data.

Prior to conducting multiple imputation or mixed-effects modelling on any dataset, visual inspections and Hawkins test of Normality and Homoscedasticity were used to determine if data were Missing Completely at Random, Missing at Random, or Missing Not at Random (see *Appendix* for full details).

Creation of Estimation Groups

I created estimation groups to determine whether there were differences between groups at Time 1 and whether estimation group at baseline was predictive of participation outcomes at follow up. Given that all participants received rehabilitation input, I additionally used discrepancy scores as a continuous variable in an exploratory longitudinal analysis to detect if changes in self-awareness were relevant to participation outcomes.

In previous research of self-awareness in ABI (e.g., Prigatano & Altman, 1990; Smeets et al., 2017), creation of overestimation, accurate estimation, and underestimation groups was based on *discrepancy scores* between self-rated and informant-rated functional

capabilities on *items* on the Patient Competency Rating Scale (Prigatano et al., 1986), a measure intended to calculate impaired self-awareness. As item-level scores were not available here, a standard deviation approach was adopted using the EBIQ-S and EBIQ-C. As higher scores on the EBIQ indicate more severe ABI symptoms, a positive discrepancy therefore indicates overestimation.

In each sample (Site 1, Site 2, and combined), estimation groups were based on whether discrepancy scores between the EBIQ-S and the EBIQ-C were half a standard deviation (SD) lower (underestimation group), half SD higher (overestimation group), or within a half SD (accurate estimation group) of the mean discrepancy. The choice of this 0.5 SD categorisation is pragmatic. One or two SDs would create more extreme over/under estimator groups (i.e., potentially clinically more significant) but the numbers in the groups would be very small to detect differences in predictor variables. Of note, using the SD approach resulted in similarly proportioned groups to those previously reported in ABI (Boosman et al., 2014; Smeets et al., 2017). Though there are methodological limitations to categorising a continuous variable, I present results using an SD approach here, in line with my pre-registered analysis. As mentioned above, discrepancy scores were additionally used continuously in longitudinal analyses as a means of mitigating this limitation.

Cross-Sectional Analyses

Correlation analyses were conducted between EBIQ discrepancy scores, demographic characteristics and study variables. A series of one-way ANOVAs were conducted to determine differences in self-rated variables (depression, anxiety, self-esteem, and executive function), informant-rated variables (caregiver strain, executive function) and clinician-rated participation between estimation groups on both the observed and imputed datasets. Bonferroni adjustments were made per analysis (alpha of 0.05 divided by 9 tests). Tukey-adjusted post-hoc tests were conducted for any significant differences between groups.

Longitudinal Analyses

Linear mixed-effects models investigating differences in participation were estimated using the lmerTest R package (Kuznetsova et al., 2017). Participants were modelled as a random effect in each analysis, with the independent variables (Time, Discrepancy Group) modelled as fixed effects. Source (Site 1 vs Site 2) was additionally used as a random effect in the combined analysis. For each model, adjusted intraclass correlation coefficients (ICC_{adj}) were calculated to estimate the amount of variance attributable to random effects (Nakagawa et al., 2017), with higher ICC_{adj} indicating that a higher proportion of the variance can be accounted for by the random effects.

Analysis 1 Results – Estimation of Abilities in ABI

Site 1 comprised 88 participants from an ABI community neurorehabilitation NHS service. Adults referred to this service are provided holistic neuropsychological rehabilitation. Services offered include family and couples therapy, vocational rehabilitation, speech and language therapy, occupational therapy, clinical psychology, and cognitive rehabilitation, or a bespoke rehabilitation programme, depending on individual need.

Site 1 Participant Characteristics

Demographic characteristics of Site 1 participants are provided in Table 13. EBIQ discrepancy scores did not differ by gender (t = -0.23, p = 0.82), type of ABI ($F_{1,86}$ = 0.44, p = 0.78), by relationship of the informant to the participant ($F_{1,86}$ = 0.75, p = 0.66), or correlate with age (r = -0.11, p = 0.34) or time post-injury (rho = -0.14, p = 0.20).

Participants (*N* = 88)		Min – Max
Gender – *n* (%)		
Male	62 (72.9%)	
Female	23 (27.1%)	
Age – *M* (SD)	37.92 (12.7)	18 – 69
Type of ABI – *n* (%)		
Traumatic Brain Injury	48 (56.5%)	
Stroke	25 (29.4%)	
Brain Tumour	6 (7.1%)	
Other	6 (7.1%)	
Time Post-ABI (Days) – *Median*	888	25 – 8603
GCS Score (TBI only) – *n* (%)		
3 – 8 (Severe)	21 (23.8%)	3 – 8
9 – 12 (Moderate)	4 (4.54%)	10 – 12
13 – 15 (Mild)	7 (7.95%)	13 – 14
Informant Relationship to Participant – *n* (%)		
Wife	23 (28.4%)	
Mother	20 (8.60%)	
Partner	13 (16.0%)	
Husband	7 (8.60%)	
Sibling	6 (7.40%)	
Parent – Relationship not specified	4 (4.90%)	
Other	8 (9.10%)	
Unknown	7 (8.60%)	

Table 13. Participant characteristics. ABI = acquired brain injury; TBI = traumatic brain injury, GCS = Glasgow Coma Scale.

Site 1 Cross-Sectional Analysis Results

The mean discrepancy on the EBIQ-S and EBIQ-C at Time 1 was 3.09 points, with a standard deviation of 20.93 (Figure 8). Scores on the EBIQ-S and EBIQ-C were not significantly different from each other (t = -0.86, p = 0.38), a remarkable degree of concordance between self- and carer-ratings on a scale that could potentially differ by 126 points. However, there was considerable variability in discrepancy scores, consistent with more extreme overestimators being balanced by more extreme underestimators.

Participants with discrepancy scores less than -7.37 were thus classified as underestimators (UE, n = 25), participants with discrepancy scores greater than 13.56 overestimators (OE, n = 24), and the remainder accurate estimators (AE, n = 39).

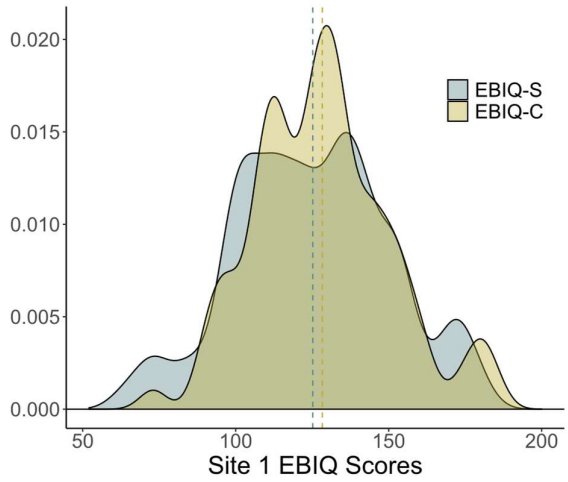


Figure 8. Site 1 density plots of EBIQ scores provided by the individual with an ABI (EBIQ-S) and those provided by an informant (EBIQ-C). Dashed lines indicate group means.
EBIQ=European Brain Injury Questionnaire.

Figure 9 shows alpha-adjusted pairwise correlations of discrepancy scores to study variables. Higher discrepancy scores were significantly correlated ($p < 0.05$) with greater self-rated anxiety, lesser difficulties with executive function, and higher caregiver strain. Worse participation was correlated with greater caregiver strain and higher informant-rated executive function difficulties.

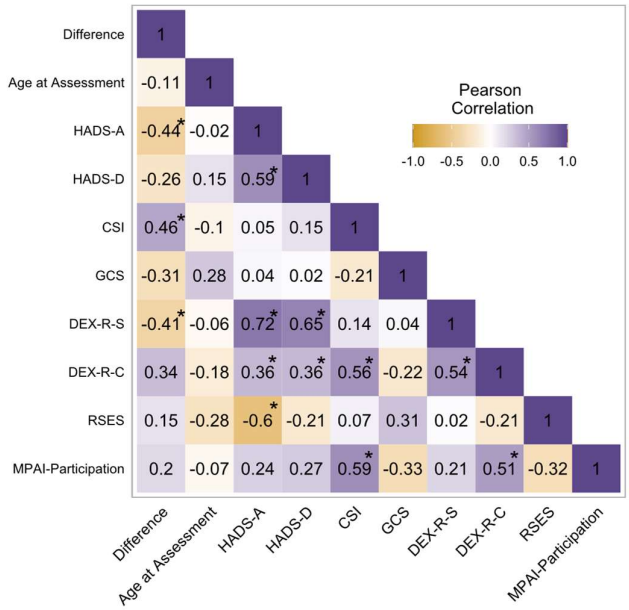


Figure 9. Correlation of Site 1 variables. Starred correlations are significant at the $p < 0.05$ level after adjusting for multiple comparisons.
HADS-A = Hospital Anxiety and Depression Scale-Anxiety; HADS-D = HADS-Depression; CSI = Caregiver Strain Index; GCS = Glasgow Coma Scale, DEX-R-S = Dysexecutive Questionnaire-Revised-Self; DEX-R-C = Dysexecutive Questionnaire-Revised-Carer; RSES = Rosenberg Self Esteem Scale; MPAI = Mayo Portland Adaptability Inventory.

When comparing the 3 estimation groups, there were significant differences in self-rated depression ($F_{2,73} = 3.68$, $p < 0.05$), anxiety ($F_{2,73} = 8.64$, $p < 0.001$), executive function scores ($F_{2,70} = 6.91$, $p < 0.01$), levels of caregiver strain ($F_{2,80} = 10.42$, $p < 0.001$), and on GCS scores for those with TBI ($F_{2,29} = 5.73$, $p < 0.001$). There were no group differences on levels of self-esteem, informant-rated executive function and clinician-rated participation. When correcting the probability value for multiple statistical tests, ($p < 0.005$ indicates a significant difference), only differences in self-reported depression did not reach significance.

In Tukey-adjusted post-hoc tests, the UE group had less severe GCS scores compared to the AE ($p < 0.01$) and OE groups ($p < 0.01$). Those in the UE group self-reported higher depression ($p < 0.05$), anxiety ($p < 0.001$), and executive function difficulties ($p < 0.001$) compared to the OE group, though the UE group did not differ from the AE group on these measures. The OE group did, however, self-report less anxiety relative to the AE group ($p < 0.05$). With regards to informant-rated carer strain, the AE and OE groups did not differ, but the UE group had lower levels than the AE ($p < 0.001$) and OE ($p < 0.001$) groups.

Cross-Sectional Results with Multiple Imputation

As discussed, multiple imputation can be considered a method of testing the robustness of complete-case results against imputed datasets. For space, a brief account of multiple imputation procedures is presented here, with full details in the thesis *Appendix*.

Cross-sectional imputation was conducted setting a total of 5 imputed datasets and maximum number of 50 iterations. The RSES and GCS were not imputed due to the large amount of missingness of the RSES relative to other study variables (i.e., limited range of values to sample in multiple imputation), and imputation of GCS scores for non-TBI participants injuries considered not appropriate.

The imputed datasets had visually similar distributions to the non-imputed dataset. A summary of analyses using complete cases and pooled estimates of the five imputed datasets

is shown in Table 14. Self-rated depression (F range = 3.29 – 4.04), anxiety (F range = 7.76 – 12.57), and difficulties with executive function (F range = 5.83 – 9.06) were consistently shown to differ between groups across all imputed datasets. The UE only differed from the OE group in self-reported depression (ps < 0.05). The OE group demonstrated lower self-reported anxiety compared to the UE (ps < 0.001) and AE group (ps < 0.05) across all imputed datasets, but the UE group differed from the AE group in only one imputed dataset (p < 0.05). The dominant pattern in self-reported executive function was that the UE group tended to report greater difficulties only compared to the OE group (ps < 0.001).

***N* = 88**	**Without Imputations**				**With Imputations for Variables with Missing Cases**			
	UE	AE	OE	*F*	UE	AE	OE	*F*
Injury Variables								
GCS	11.57 (3.91)	6.33 (4.03)	6.00 (3.02)	5.73**				
Self-Rated Variables								
HADS-D	10.19 (4.64)	8.79 (4.26)	6.64 (4.19)	3.68*	10.22 (4.71)	8.88 (4.22)	6.86 (4.19)	3.59*
HADS-A	11.43 (3.76)	9.30 (3.97)	6.23 (4.69)	8.64***	11.32 (3.83)	9.19 (4.05)	6.13 (4.55)	7.70***
RSES	16.12 (3.40)	17.29 (5.19)	17.67 (4.84)	0.23				
DEXR-S	82.51 (24.57)	67.38 (27.27)	51.15 (28.94)	6.91**	82.99 (25.89)	68.98 (27.56)	52.75 (29.43)	6.15**
Informant-Rated Variables								
DEXR-C	65.95 (24.64)	73.77 (26.70)	82.94 (21.16)	2.17	63.32 (24.81)	72.81 (25.84)	82.11 (23.37)	2.98
CSI	61.43 (40.54)	97.91 (36.47)	106.04 (33.42)	10.42***	61.43 (39.88)	97.74 (35.80)	103.67 (35.25)	9.26***
Clinician-Rated Variables								
MPAI-4 Participation	14.00 (6.36)	16.00 (5.70)	16.96 (5.92)	1.61				

Table 14. Site 1 summary of cross-sectional results with and without imputations. Variables that are blank on the imputation columns either already had complete cases for all participants (MPAI-4), or were not imputed (RSES, GCS). Note that imputed values are pooled estimates of five separate imputations.
* p < 0.05, ** p < 0.01, *** p < 0.001
HADS-A = Hospital Anxiety and Depression Scale-Anxiety; HADS-D = HADS-Depression; CSI = Caregiver Strain Index; GCS = Glasgow Coma Scale, DEX-R-S = Dysexecutive Questionnaire-Revised-Self; DEX-R-C = Dysexecutive Questionnaire-Revised-Carer; RSES = Rosenberg Self Esteem Scale; MPAI = Mayo Portland Adaptability Inventory.

There was no difference in informant-rated executive function in two of five imputed datasets (F range = 2.57 – 4.37, ps = 0.02 – 0.08). Differences in caregiver strain between groups occurred in all five imputed datasets (F range = 8.95 – 11.12, ps < 0.001), with post-hoc tests indicating that the UE group has lower levels of caregiver strain relative to both the AE group (ps < 0.001) and OE group (ps < 0.001), but the AE and OE group did not differ from each other (ps = 0.69 – 0.94).

Overall, the pattern of results on variables with missing data imputed was similar, though variation in informant-rated executive function across the imputed datasets may indicate that interpretation of these particular results should be viewed with caution. The most robust results in differentiating estimation groups in Site 1 were therefore anxiety and caregiver strain.

Longitudinal Analysis of Participation Outcomes

The key question for the longitudinal analysis was whether a tendency to over, under, or accurately estimate ABI symptoms at Time 1 had any predictive value for clinician-rated participation at follow up. Please see *Appendix* for further details on determining missingness.

The dataset had large amount of missing data on all variables at Time 2 and Time 3 (50% to 80% of data missing on study variables). Although maximum likelihood is robust with even 75% of data missing (Marshall et al., 2010), and is preferable to excluding even small amounts of observed data from analysis (Janssen et al., 2010), results here should be interpreted with caution.

A linear mixed-effects model with participant set as the random effect was conducted. The model included only Time (Time 1 vs Time 2 vs Time 3) and Group Status (UE vs AE vs OE group) as fixed effects. There was a main effect of Time ($F_{2,39}$ = 9.16, p < 0.001), with participation scores at Time 2 and Time 3 being significantly improved from Time 1. There

was additionally significant variance due to participant-level random effects (21.29, *SD* = 4.61, $\chi^2 = 14.19$, $p < 0.001$, $ICC_{adj} = 0.61$). There was no time by group interaction ($p = 0.55$).

In summary, whilst the cross-sectional analysis of Time 1 data indicates differences in anxiety and caregiver strain between estimation groups, longitudinal data from Site 1 does not provide any evidence that there are differences in participation outcomes between those who overestimate, underestimate, and accurately estimate their abilities. However, even with mixed-effects modelling, due to the large amount of missing longitudinal data, no definitive conclusions could be drawn about long-term participation outcomes here.

Analysis 2 Results – Cross-Validation

The second analysis examined a dataset comprising 153 participants from a TBI community neurorehabilitation NHS service ("Site 2"). Those referred to this service are provided holistic assessments to determine rehabilitation goals, are offered one-to-one or group therapy sessions, speech and language therapy, occupational therapy, return to work support, and family work or carer training, depending on individual need. This site collected the same measures as those from Site 1, with the exception of the DEX-R-S and DEX-R-C. As Site 2 provided services to only those with TBI, GCS scores were available for most (n = 116 of 153) individuals. Data were routinely collected at Site 2 for initial assessment (Time 1) and 1-year follow up (Time 2).

Site 2 Participant Characteristics

Demographic characteristics of participants from Site 2 are provided in Table 15. EBIQ Discrepancy scores did not differ by gender ($t = -1.92$, $p = 0.16$), by informant relationship to the participant ($F_{12,124} = 1.52$, $p = 0.13$), and were not correlated with age (r = 0.07, $p = 0.39$) or time post-injury ($rho = -0.12$, $p = 0.14$).

Participants (*N* = 153)		Min – Max
Gender – *n* (%)		
Male	105 (68.6%)	
Female	48 (31.4%)	
Age – *M* (SD)	42.22 (16.13)	17 – 82
Type of ABI – *n* (%)		
Traumatic Brain Injury	153 (100%)	
Time Post-ABI (Days) – *Median*	245.5	30 – 11843
GCS Score – *n* (%)		
3 – 8 (Severe)	41 (26.8%)	3 – 8
9 – 12 (Moderate)	25 (16.3%)	9 – 12
13 – 15 (Mild)	50 (32.7%)	13 – 15
Missing	37 (24.2%)	
Informant Relationship to Participant – *n* (%)		
Wife	42 (30.7%)	
Mother	31 (22.6%)	
Partner	18 (13.1%)	
Husband	14 (10.2%)	
Friend	6 (4.40%)	
Daughter/Son	5 (3.60%)	
Other	16 (10.5%)	
Unknown	21 (13.7%)	

Table 15. Site 2 participant characteristics. ABI = acquired brain injury; GCS = Glasgow Coma Scale.

Site 2 Cross-Sectional Analysis Results

The mean discrepancy on the EBIQ-S and EBIQ-C at Time 1 was 2.59 points, with a standard deviation of 19.41. Density plots of EBIQ scores are shown in Figure 10. As with Site 1, these scores did not significantly differ (t = -0.85, p = 0.39). Participants with a discrepancy score less than -7.12 were classified underestimators (UE, n = 43), participants with discrepancy scores greater than 12.29 overestimators (OE, n = 39), and the remainder accurate estimators (AE, n = 71).

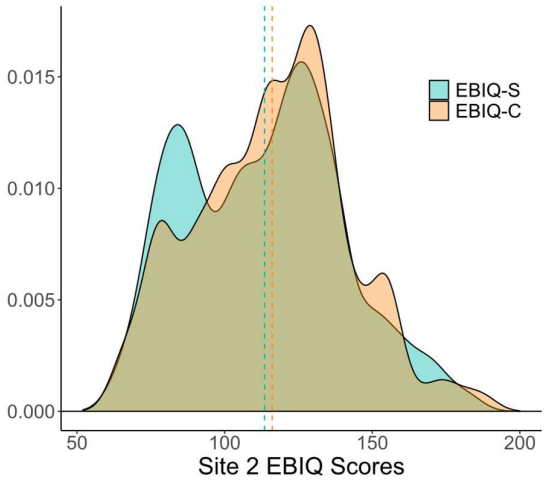


Figure 10. Density plots of EBIQ scores provided by the individual with a TBI (EBIQ-S) and those provided by an informant (EBIQ-C). Dashed lines indicate group means.
EBIQ=European Brain Injury Questionnaire.

Alpha-adjusted pairwise correlations of EBIQ discrepancy scores to study variables are shown in Figure 11. As in Site 1, higher difference scores were significantly correlated ($ps < 0.05$) with lower self-rated anxiety and depression, higher caregiver strain, and worse participation. Worse participation correlated with higher depression and caregiver strain.

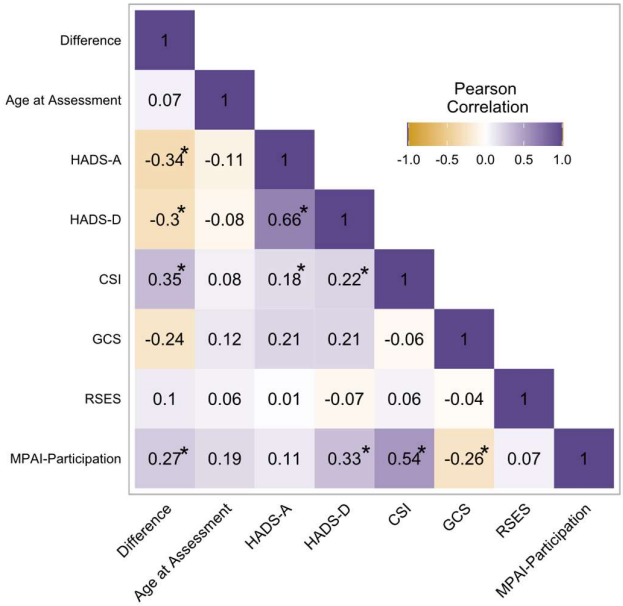


Figure 11. Pairwise correlations of study variables from Site 2. Starred correlations are significant at the $p < 0.05$ level after adjusting for multiple comparisons.
HADS-A = Hospital Anxiety and Depression Scale-Anxiety; HADS-D = HADS-Depression; CSI = Caregiver Strain Index; GCS = Glasgow Coma Scale, RSES = Rosenberg Self Esteem Scale; MPAI = Mayo Portland Adaptability Inventory.

A group difference was found for GCS scores between estimation groups ($F_{2,113}$ = 4.72, p = 0.01), with the UE group having less severe GCS scores compared to the OE group ($p < 0.01$). As in Site 1, there were significant group differences in self-rated depression ($F_{2,144} = 4.89$, $p < 0.01$) and anxiety ($F_{2,146} = 7.29$, $p = 0.001$). The UE group had greater levels of depression ($p < 0.01$) compared to the OE group. The OE group reported less anxiety compared to both the AE ($p < 0.01$) and the UE group ($p < 0.001$). There were no differences between estimation groups on levels of self-esteem. Further, after correcting for multiple statistical tests ($p < 0.005$), differences in self-reported depression and GCS scores did not reach significance in Site 2 analyses.

There were group differences in caregiver strain ($F_{2,136} = 9.24$, $p < 0.001$), but contrary to Site 1, the OE group had higher levels of caregiver strain relative to both UE ($p < 0.001$) and the AE ($p < 0.01$) groups. Further, there were differences in clinician-rated participation ($F_{2,149} = 6.12$, $p < 0.01$), unlike Site 1. The OE group had worse levels of clinician-rated participation compared to the AE ($p < 0.01$) and UE ($p < 0.01$) groups.

Site 2 Cross-Sectional Results with Multiple Imputation

As in Site 1, data were imputed to determine robustness of results (see *Appendix*). GCS scores were considered suitable to impute given Site 2 comprised only those with TBI.

A summary of analyses using complete cases and pooled estimates of the five imputed datasets are shown in Table 16. As in Site 1, self-rated depression (F range = 3.93 – 5.13, ps < 0.05) and anxiety (F range = 6.88 – 8.09, ps < 0.001) differed between groups across all imputed datasets. There were no differences in self-esteem between groups in any imputed datasets (F range = 0.55 – 1.09, ps = 0.34 – 0.58). The UE group only differed from the OE group in depression (ps < 0.05), though the OE group had significantly lower anxiety compared to the UE (ps < 0.001) and AE groups (ps < 0.01) across all datasets, replicating the results from Site 1.

Clinician-rated participation (F range = 5.99 – 6.23, ps < 0.01) and caregiver strain (F range = 7.51 – 9.53, ps < 0.001) differed between groups in all imputed datasets. The dominant pattern across all imputations was that the UE and AE groups did not differ in levels of caregiver strain and clinician-rated participation, rather that the OE group had greater levels of caregiver strain and worse participation relative to these two groups (ps < 0.001). Finally, GCS scores significantly differed between groups in 4 of 5 imputed datasets (F range = 2.83 – 5.19, ps = 0.01 – 0.06), with the UE group having higher GCS scores relative to AE (ps < 0.05) and OE groups (ps < 0.05).

Overall, the results of the imputed datasets were similar to complete case analyses, and replicated Site 1 results on differential depression and anxiety levels between estimation groups. However, participation levels differed between groups in Site 2 only, and group differences in caregiver strain were opposite to Site 1 results. Further, when correcting for multiple statistical tests, only self-reported anxiety, levels of caregiver strain, and clinician-rated participation differed between groups.

N = 153	Without Imputations				With Imputations for Variables with Missing Cases			
	UE	AE	OE	*F*	UE	AE	OE	*F*
Injury Variables								
GCS	11.62 (4.07)	10.64 (3.91)	8.55 (4.37)	4.72*	11.13 (4.13)	10.54 (3.99)	8.65 (4.29)	3.33*
Self-Rated Variables								
HADS-D	9.14 (4.66)	7.24 (4.48)	6.12 (4.12)	4.89**	9.14 (4.61)	7.34 (4.51)	6.22 (4.19)	4.28*
HADS-A	9.91 (4.98)	8.94 (4.54)	6.11 (4.57)	7.19***	9.91 (4.93)	8.99 (4.53)	6.10 (4.49)	7.34***
RSES	15.04 (2.94)	15.63 (2.59)	15.70 (2.22)	0.85	15.04 (2.92)	15.64 (2.64)	15.73 (2.23)	0.84
Informant-Rated Variables								
CSI	51.55 (41.67)	63.85 (38.86)	90.43 (39.41)	9.24***	52.40 (41.70)	63.66 (38.72)	88.50 (39.24)	8.38***
Clinician-Rated Variables								
MPAI-4 Participation	10.21 (5.90)	10.87 (6.96)	14.92 (7.01)	6.12**	10.21 (5.85)	10.90 (6.89)	14.92 (6.94)	6.11**

Table 16. Site 2 summary of cross-sectional results with and without imputations. Note that imputed values are pooled estimates of five separate imputations.
* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$
HADS-A = Hospital Anxiety and Depression Scale-Anxiety; HADS-D = HADS-Depression; CSI = Caregiver Strain Index; GCS = Glasgow Coma Scale, RSES = Rosenberg Self Esteem Scale; MPAI = Mayo Portland Adaptability Inventory.

Site 2 Longitudinal Analysis Results

A detailed account of missingess for Site 2 longitudinal data is present in the *Appendix*. For Site 2, the CSI had the largest amount of data missing at Time 2 (32%). Approximately 20% to 30% of data overall was missing at Time 2.

A linear mixed-effects model was conducted with participant set as the random effect and clinician-rated participation as the dependent variable. The first model included only Time (Time 1 vs Time 2) and Estimation Group status (UE vs AE vs OE group) as fixed effects. There was a main effect of Time ($F_{1,85} = 52.71$, $p < 0.001$) and Group ($F_{2,151} = 3.57$, $p = 0.03$) but no Time by Group interaction effect ($F_{2,85} = 1.94$, $p = 0.14$). This model additionally had significant variance due to participant-level random effects (29.26, $SD = 5.41$, $\chi^2 = 39.47$, $p < 0.001$, $ICC_{adj} = 0.68$). As Time 1 participation scores were significantly

different between groups (see above), baseline differences in participation were then used as a covariate, resulting in the Time by Group interaction becoming significant ($F_{2,227} = 4.33$, $p = 0.01$). However, this resulted in singular fit and thus random effects could not be reliably estimated. Further, when adjusting for number of statistical tests within Site 2 data (adjusted $p < 0.005$), the Time by Group interaction did not retain significance.

In summary, there seemed to be differences in longitudinal participation outcomes between estimation groups, but these effects were only found in Site 2. When adjusting for multiple statistical tests across the dataset, however, longitudinal differences between groups did not retain significance, suggesting further investigation is warranted.

Analysis 3 Results – Combined Sample Estimates

Analysis 3 combined the data from Sites 1 and 2 ($N = 241$) to obtain more precise estimates. To ensure similar data structure across studies, only Time 1 (assessment) and Time 3 (1 year follow up) data were used from Site 1. The DEX-R-S and DEX-R-C were not included in analyses due to Site 2 not using these measures in routine outcome assessment.

Combined Sample Participant Characteristics

Demographic characteristics of the combined sample are shown in Table 17. Data from Site 1 and Site 2 did not differ by proportion of men and women ($\chi^2 = 0.30$, $p = 0.58$) but individuals from Site 1 were younger than those from Site 2 ($t = -2.11$, $p = 0.03$).

Participants (*N* = 241)		Min – Max
Gender – *n* (%)		
Male	167 (70.2%)	
Female	71 (29.8%)	
Age – *M* (SD)	40.69 (15.10)	17 – 82
Type of ABI – *n* (%)		
Traumatic Brain Injury	201 (83.4%)	
Stroke	25 (10.4%)	
Brain Tumour	6 (2.5%)	
Other	6 (2.5%)	
Time Post-ABI (Days) – *Median*	426	25 – 11843
GCS Score (TBI only) – *n* (%)		
3 – 8 (Severe)	62 (25.7%)	3 – 8
9 – 12 (Moderate)	29 (12.0%)	9 – 12
13 – 15 (Mild)	57 (23.7%)	13 – 15
Missing	93 (38.6%)	
Informant Relationship to Participant – *n* (%)		
Wife	65 (26.9%)	
Mother	51 (21.2%)	
Partner	31 (12.8%)	
Husband	21 (8.71%)	
Friend	6 (2.50%)	
Sibling	6 (2.50%)	
Daughter/Son	5 (3.60%)	
Parent – Relationship not specified	4 (2.10%)	
Other	24 (9.96%)	
Unknown	28 (11.6%)	

Table 17. Combined sample participant characteristics. ABI = acquired brain injury; TBI = traumatic brain injury, GCS = Glasgow Coma Scale.

Site 1 participants with TBI had lower GCS scores ($t = -3.52$, $p < 0.001$) than participants from Site 2. Site 1 participants additionally had worse levels of clinician-rated participation ($t = 4.49$, $p < 0.001$), greater levels of caregiver strain ($t = 3.76$, $p < 0.001$), and higher frequency of self-rated ($t = 3.32$, $p < 0.01$) and informant-rated ($t = 3.69$, $p < 0.001$) ABI symptoms as measured via the EBIQ compared to those from Site 2. Participants from both Sites did not differ in self-rated depression ($t = 0.75$, $p = 0.46$), anxiety ($t = 1.63$, $p = 0.10$), or self-esteem (Welch's $t = 1.54$, $p = 0.14$).

Cross-Sectional Analysis Results

The mean discrepancy on the EBIQ-S and EBIQ-C at Time 1 was 2.78 points, with a standard deviation of 19.94 (see Figure 12). EBIQ-S and EBIQ-C scores did not differ from

each other in the combined sample (t = -1.17, p = 0.24). Participants with a discrepancy score less than -7.19 were classified as underestimators (UE, n = 68), greater than 12.74 overestimates (OE, n = 69), and the remainder accurate estimators (AE, n = 104).

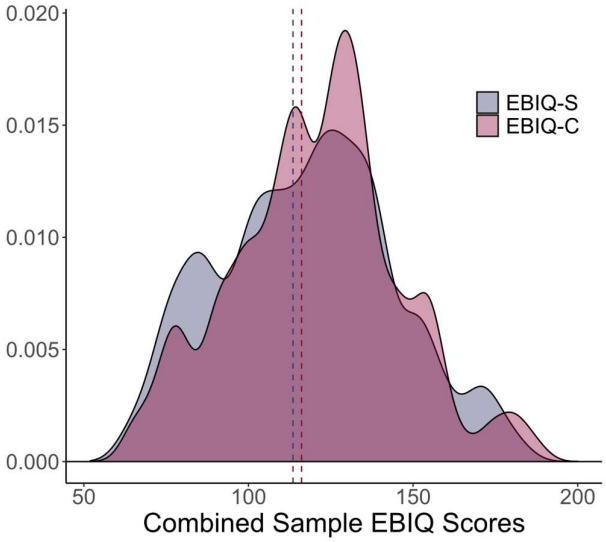


Figure 12. Combined sample density plots of EBIQ scores provided by the individual with an ABI (EBIQ-S) and those provided by an informant (EBIQ-C). Dashed lines indicate group means.
EBIQ=European Brain Injury Questionnaire.

Pairwise correlations of discrepancy scores to study variables are shown in Figure 13. After adjusting for multiple comparisons, higher discrepancy scores correlated with lower self-rated anxiety and depression, higher GCS scores, higher caregiver strain, and worse clinician-rated participation (ps < 0.05). Lower clinician-rated participation correlated with worse self-rated depression (but not anxiety), lower GCS scores, and greater caregiver strain (ps < 0.05).

After accounting for shared variability across measures through partial correlations (see Figure 13), greater discrepancy scores only correlated with higher levels of caregiver strain and lower self-reported anxiety.

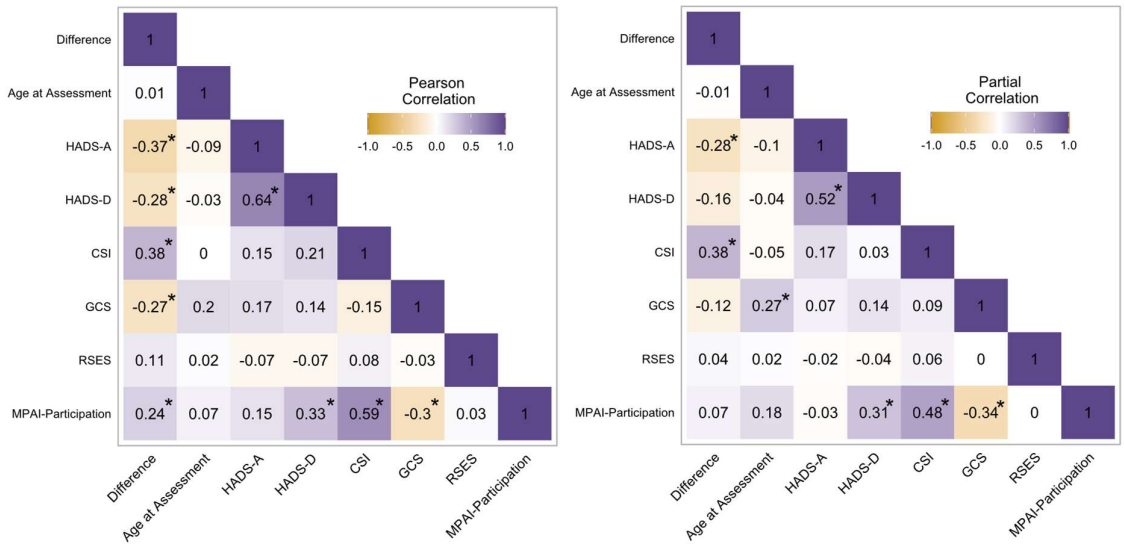


Figure 13. Combined sample pairwise Pearson and partial correlations of the combined datasets (N = 241). Starred correlations are significant at the $p < 0.05$ level after adjusting for multiple comparisons. HADS-A = Hospital Anxiety and Depression Scale-Anxiety; HADS-D = HADS-Depression; CSI = Caregiver Strain Index; GCS = Glasgow Coma Scale, RSES = Rosenberg Self Esteem Scale; MPAI = Mayo Portland Adaptability Inventory.

There were no differences between estimation groups in self-esteem ($F_{2,166} = 0.99$, $p = 0.38$). There were group differences on GCS scores for those with TBI ($F_{2,145} = 7.81$, $p < 0.001$), with only the UE group differing from the OE group ($p < 0.001$).

The groups differed on self-rated depression ($F_{2,220} = 8.77$, $p < 0.001$) and anxiety ($F_{2,222} = 16.36$, $p < 0.001$), with the UE group having greater levels of depression than the OE group ($p < 0.0001$). The OE group reported less anxiety compared to both the AE ($p < 0.001$) and the UE group ($p < 0.001$).

There were differences in levels of caregiver strain ($F_{2,219} = 17.42$, $p < 0.001$), with the OE group having higher caregiver strain compared to the UE ($p < 0.001$) and AE ($p < 0.001$) groups. In Tukey-adjusted post-hoc tests, the UE group had lower caregiver strain relative to the AE group ($p = 0.02$). Groups differed in participation ($F_{2,237} = 6.48$, $p < 0.01$), with both the UE group ($p < 0.01$) and AE group ($p = 0.02$) having better levels of participation relative to the OE group, though participation did not differ between the AE and UE groups ($p = 0.58$).

When correcting for multiple statistical tests (adjusted $p = 0.005$), all above differences between groups remained significant.

Combined Sample Cross-Sectional Results with Multiple Imputation

As with Analyses 1 and 2, a detailed account of missingness and imputation is presented in the *Appendix*. GCS scores were not imputed in the combined sample due to Site 1 containing participants with non-TBI brain injuries.

A summary of analyses using complete cases and pooled estimates of the five imputed datasets are shown in Table 18. Across the imputed datasets of the combined data, there were no differences between groups in levels of self-esteem (F range = 0.48 – 2.64, ps = 0.07 – 0.83). All five imputed datasets demonstrated group differences in clinician-rated participation (F range = 6.33 – 6.52, ps < 0.01), self-rated depression (F range = 8.66 – 9.89, ps < 0.001) and anxiety (F range = 16.65 – 19.18, ps < 0.01), and informant-rated caregiver strain (F range = 11.62 – 19.00, ps < 0.01). In Tukey-adjusted post-hoc tests, the pattern of results followed that of the non-imputed cross-sectional Analysis 3 results reported above.

In summary, lower levels of anxiety, and higher levels of caregiver strain seem to distinguish overestimators relative to *both* underestimators and accurate estimators. It is interesting that, despite an ostensibly more severe injury (for those with TBI) and worse participation levels, overestimators seem to fare better emotionally – however, there is no evidence that may be due to better self-esteem.

***N* = 241**	**Without Imputations**				**With Imputations for Variables with Missing Cases**			
	UE	AE	OE	*F*	UE	AE	OE	*F*
Injury Variables								
GCS	11.62 (3.99)	9.73 (4.25)	7.95 (4.27)	7.81***				
Self-Rated Variables								
HADS-D	9.49 (4.64)	7.87 (4.48)	6.23 (4.03)	8.77***	9.48 (4.63)	7.99 (4.56)	6.29 (4.01)	8.39***
HADS-A	10.41 (4.64)	9.23 (4.34)	6.08 (4.46)	16.36***	10.45 (4.65)	9.21 (4.38)	6.08 (4.35)	17.05***
RSES	15.21 (3.01)	15.75 (2.93)	16.01 (2.72)	0.38	15.42 (2.86)	15.76 (2.91)	16.07 (2.65)	0.15
Informant-Rated Variables								
CSI	55.53 (41.17)	73.82 (41.36)	97.27 (36.76)	17.42***	56.46 (41.08)	73.15 (41.69)	96.04 (37.13)	15.19***
Clinician-Rated Variables								
MPAI-4 Participation	11.60 (6.30)	12.64 (15.54)	15.54 (6.62)	6.48**	11.60 (6.26)	12.67 (6.96)	15.54 (6.58)	6.46**

Table 18. Combined sample summary of cross-sectional results with and without imputations on study variables. Note that imputed values are pooled estimates of five separate imputations. Blank columns on the right-hand side indicate that a variable was not imputed.
* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$
HADS-A = Hospital Anxiety and Depression Scale-Anxiety; HADS-D = HADS-Depression; CSI = Caregiver Strain Index; GCS = Glasgow Coma Scale, RSES = Rosenberg Self Esteem Scale; MPAI = Mayo Portland Adaptability Inventory.

Combined Sample Longitudinal Analysis Results

A detailed account of missingness is in the thesis *Appendix*. A linear mixed-effects model, with participants nested by source (NHS Site 1 vs NHS Site 2) as random intercepts, was conducted. Clinician-rated participation was set as the dependent variable. The first model included only Time (Time 1 vs Time 2) and Group status (UE vs AE vs OE group) as fixed effects. There was a main effect of Time ($F_{1,105} = 66.97$, $p < 0.001$), but only a borderline effect of Group ($F_{2,268} = 2.99$, $p = 0.05$). There was no Time by Group interaction effect ($F_{1,109} = 1.31$, $p = 0.27$). The random effects of the model were significant (26.84, $SD = 5.18$, $\chi^2 = 44.77$, $p < 0.001$, $ICC_{adj} = 0.71$), with modelling participant intercepts nested by source providing a better fit to the data compared to modelling by source alone ($\chi^2 = 46.58$, $p < 0.001$) or participant alone ($\chi^2 = 11.72$, $p < 0.001$).

Given Time 1 differences in participation, these were entered as a covariate in a second mixed-effects model. In this model, the Time by Group interaction became significant ($F_{2,328} = 5.38$, $p = 0.005$). However, this resulted in a singular fitting model, suggesting the random effect structure (participants nested by NHS site) was too complex to be supported by the observed data. Modelling random effects by source or participant alone did not resolve model singularity, resulting in random effects estimates not being reliable.

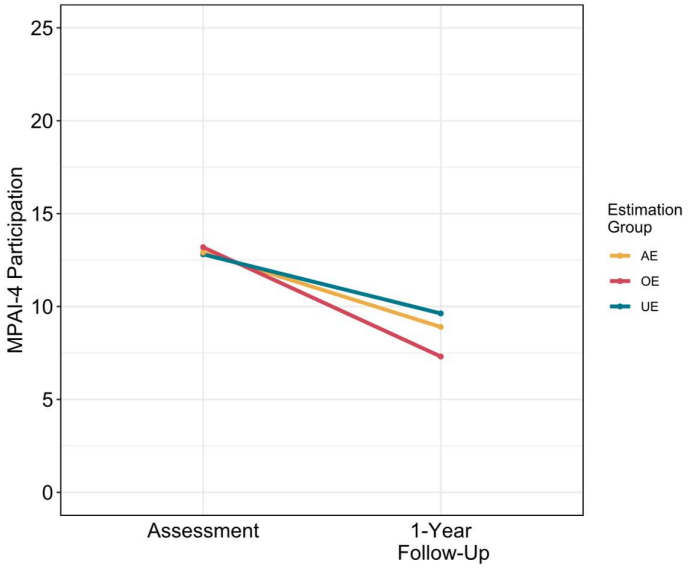


Figure 14. Changes in participation between estimation groups from assessment to 1-year follow up, when controlling for baseline differences in participation.
MPAI-4 = Mayo-Portland Adaptability Inventory; AE = Accurate Estimators; OE = Overestimators; UE = Underestimators.

In Tukey-adjusted post-hoc tests, all groups showed improvements in clinician-rated participation at Time 2 (all *p*s < 0.001). At Time 2, the UE and AE group did not differ in levels of participation, but the OE group had significantly better participation compared to both the UE ($p = 0.005$) and the AE groups ($p = 0.04$). Changes in participation by group are shown in Figure 14.

In summary, it does not seem to be the case that those who are overestimators when beginning community-based ABI neurorehabilitation have worse participation outcomes in the long-term following rehabilitation; it may be that they have slightly better outcomes.

Combined Sample Exploratory Analysis – Covariates of Changes in Participation over Time

While I find no evidence to suggest that impaired self-awareness *at baseline* affects changes in long-term participation, it is likely that this is in part due to staff at the NHS sites mitigating any difficulties due to impaired self-awareness throughout rehabilitation. Potentially, *changes* in differences between self- and informant-rated ABI symptoms over time may better explain changes in participation. To evaluate this, an exploratory mixed-effects model predicting clinician-rated participation, with time point (Time 1 vs Time 2) and discrepancy scores set as covariate, was first conducted. Participants nested by Source (Site 1 vs Site 2) were set as random effects. In this model, there was a significant interaction of discrepancy scores over time (b = -0.07, SE = 0.03, p = 0.03). Random effects estimates accounted for a large portion of the variance (27.36, SD = 5.23 χ^2 = 40.09, $p < 0.001$, ICC_{adj} = 0.74), suggesting differences between sites on model intercepts. The fixed effects on their own only accounted for approximately 11% of the variance (Marginal R^2 = 0.11), suggesting that further exploration of contributors to changes in participation is warranted.

Secondly, GCS scores were included in the model under the assumption that more severe injuries would have adverse effects on long-term participation. There was a main effect of GCS scores (b = -0.35, SE = 0.12, $p < 0.01$). There was a marginally non-significant interaction between discrepancy scores and Time (b = -0.07, SE = 0.04, p = 0.05). Random effects estimates maintained a significant contribution (26.97, SD = 5.19, χ^2 =30.69, $p <$ 0.001, ICC_{adj} = 0.68). Marginal R^2 improved, accounting for 18.3% of the variance.

Next, self-rated variables (depression, anxiety, self-esteem) were entered into the model under the assumption that changes in mood and self-esteem may contribute to participation outcomes. Nesting participants by NHS site resulted in singular fit, and thus the random effects were reduced to model random effects at the participant level only. There were main effects of discrepancy scores (b = 0.13, SE = 0.03, $p < 0.001$), GCS scores (b = -0.41, SE = 0.12, $p < 0.001$), and self-rated depression (b = 0.81, SE = 0.15, $p < 0.001$), but

not self-rated anxiety or self-esteem. There were no significant interactions in this model. Random effects estimates maintained a significant, but lower, contribution (15.89, $SD = 3.99$, $\chi^2 = 11.68$, $p < 0.001$, $ICC_{adj} = 0.51$), with a marginal R^2 accounting for 36.1% of the variance.

Finally, caregiver strain was included in the model, with participant-level random effects remaining. There was a main effect of caregiver strain ($b = 0.06$, SE = 0.01, $p < 0.001$) and GCS scores ($b = -0.33$, SE = 0.11, $p < 0.001$), and interaction effects in discrepancy scores ($b = -0.12$, SE = 0.05, $p < 0.001$) and depression scores ($b = -0.67$, SE = 0.26, $p < 0.001$) across time points, with *higher* discrepancy scores and *lower* depression scores over time contributing to better participation outcomes. The marginal R^2 improved, explaining 45.3% of the variance. The contribution of random effects remained significant, though lower than all previous models (13.87, $SD = 3.72$, $\chi^2 = 9.25$, $p < 0.001$, $ICC_{adj} = 0.51$).

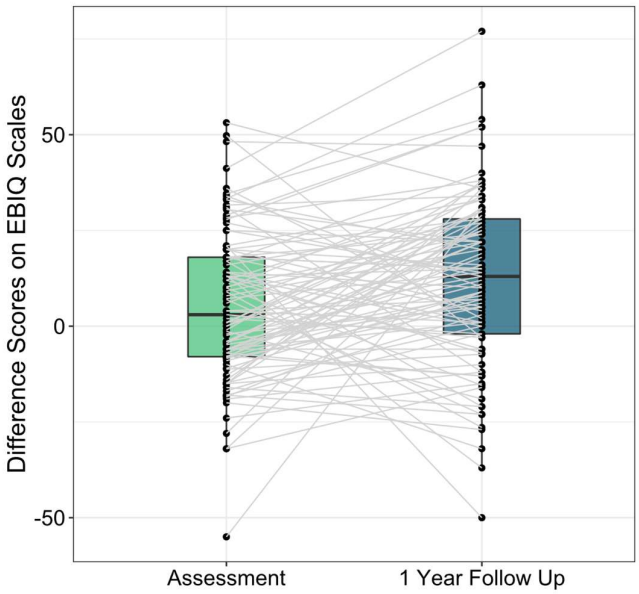


Figure 15. Combined sample discrepancy scores at assessment (Time 1) and at 1 year-follow up (Time 2). EBIQ = European Brain Injury Questionnaire.

Discussion

The purpose of this chapter was to investigate differences in injury severity, self-rated mood, executive function, self-esteem, and caregiver strain in those who overestimate,

accurately estimate, and underestimate their abilities following ABI, relative to an informant. The study further sought to detect whether discrepancies in estimation of abilities contributed to long-term participation outcomes.

It is first worth noting that, on the EBIQ scales, average discrepancies across analyses were non-significant. Though interpretation of null findings using frequentist statistics is not possible, it is surprising that the degree of agreement is high in this community rehabilitation ABI sample, given the literature discussed in the introduction between those with ABI and informants.[9] It is possible that the greater number of items and the narrower response range (3- vs 5-point Likert scales) of the EBIQ relative to measures like the Patient Competency Rating Scale (Prigatano et al., 1986) or the Awareness Questionnaire (Sherer et al. 2004) accounts for this, though both measures enquire about the effects cognitive, motor etc. symptoms on everyday activities. It may be that a general tendency to overestimate may be stronger in acute settings. However, as there were no performance-based measures to compare self-report results to, it remains an open question as to how the results here would differ with such information. As individuals who overestimate and underestimate themselves relative to an informant may simply be a result of a general tendency to rate themselves better or worse, respectively, the results here are discussed in the context in which over and underestimators differ from accurate estimators.

Overestimation of Abilities

Consistent with previous research, where GCS scores were available overestimators in general had more severe injuries, suggesting that the tendency to be discrepant from informants may in part stem from residual difficulties recognising impairments. Further, overestimators had lower levels of depression and anxiety relative to both accurate estimators

[9] Given the non-significant findings, a Bayesian t-test was conducted comparing EBIQ scores between those with ABI and informant across the three analyses demonstrated very little evidence in favour of the alternative hypothesis that a difference exists (*BF* range = 0.19 – 0.23), suggesting the null hypothesis of no difference between raters is credible.

and underestimators – in line with this, impaired self-awareness has been conceptualised as independent from an emotional reaction to one's ABI (e.g., Prigatano & Sherer, 2020) which may explain better mood scores. Despite its association with lower levels of depression and anxiety, overestimation was not reflected in generally higher self-esteem; prior research has consistently demonstrated the association of self-esteem to mood in ABI (Cooper-Evans et al., 2008; Vickery et al., 2008; Ponsford et al., 2014). If overestimation is truly independent from emotional self-evaluation, then potentially individuals with impaired self-awareness do not recognise their self-worth, but are not emotionally invested in the consequences of this to everyday life.

It is worth further exploring how overestimation of abilities relates to informant-rated caregiver strain. In Site 1, informants of overestimators did not have greater levels of caregiver strain relative to accurate estimators; rather, informants of underestimators reported less strain. In Site 2, however, informants of overestimators had the greatest levels of strain, consistent with previous research (e.g., Goodwin et al., 2016). In the combined sample, the relationship between caregiver strain and discrepancy scores remained even when controlling for GCS scores – this could potentially reflect concern that overconfidence will lead to failure, greater informant effort to avoid risk or hazards, or distress around lack of self-awareness of the consequences of ABI on the informant's life (Richardson et al., 2015). Again, it may be important to balance the benefits of increasing awareness (in terms of rehabilitation engagement and relationships) against the apparent benefits of overestimation for mood. It is also worth exploring why there were no differences between estimation groups in informant-rated executive function in Site 1 despite these differences in caregiver strain, though objective measures of executive function should be used in future research.

Underestimation of Abilities

Whilst the results were consistent with mood benefits for overestimators, there was no evidence for underestimators reporting significantly worse depression or anxiety relative to accurate estimators. This joins the rather mixed findings on the (less well-studied) effects of underestimation on mood (Smeets et al., 2017; Hoofien et al., 2005).

Underestimators in the current study with TBI generally had less severe injuries and thus likely fewer salient physical difficulties that may be more obvious to others. Prior research has consistently demonstrated that emotional and behavioural items are more likely to have poorer agreement relative to physical items (Seel et al., 1997; Sherer et al., 1998; Fleming & Strong, 1999; Brown et al., 2021). This may additionally account for informants of underestimators reporting the least amount of caregiver strain – physical disabilities may simply require more "hands on" support (e.g., for transport, responsibilities around the house) or be more likely to affect occupational status and reduce income, whereas support required for those with predominantly behavioural or emotional difficulties may be more sporadic. Further exploration into causes of underestimation, especially in the context of theoretical accounts of impaired self-awareness, is needed.

Participation Outcomes

One of the key questions in this data was whether overestimation had benefits for participation as it may be another factor underpinning improved mood. Despite differences in participation between estimation groups cross-sectionally, long-term participation outcomes do not seem to suffer – in the combined sample analyses, those who were overestimators at Time 1 had better participation outcomes at follow up; similarly, a greater tendency toward overestimation at Time 2 was associated with better participation. This aligns with previous research demonstrating that impaired self-awareness does not affect community integration outcomes (Sander et al., 1997), does not correlate with ability to apply compensations due to disability (Sohlberg et al., 1998), or outcomes in cognitive or behavioural interventions

(Ownsworth et al., 2017; Bieman-Coplan & Dywan, 2000). It is possible that increased discrepancies at 1-year follow-up represent less self-focused attention, rather than increases in impaired self-awareness, especially given the relationship of depression scores to participation. Of course, the lack of an awareness-engagement relationship may be a testament to the efficacy of the respective rehabilitation programmes (e.g., in encouraging greater engagement in those who view themselves as more impaired). Further research in samples without intervention is required.

Future Directions

A limitation for many studies in this area is that we assume that reports of those with an ABI are more prone to inaccuracy than those of an informant because of salient cases of reduced self-awareness following injury, the increased probability of cognitive impairment, and the possibility that it may be psychologically preferable to avoid coping with ABI-related changes. At the same time, there may be many instances where an informant is simply less aware of a problem keenly felt by the person with the ABI. In datasets like the ones used here, there are probably many cases where the informant and person with an ABI broadly agree but have different tendencies on using scales, and so appear discrepant. So while there may be participants within these datasets with a profound lack of self-awareness, they may be difficult to identify using only discrepancy ratings. When using self-report measures to determine levels of self-awareness, improving item specificity on scales may be helpful (e.g., "forgets to take medicine each day" vs "has memory difficulties"; Seel et al., 1997; Brown et al., 2021). Of course, agreement between an individual and an informant may simply represent that both are overestimating or underestimating the person with the ABI relative to absolute ability, or potentially greater agreement post-rehabilitation is the result of both the person with the ABI and an informant (e.g., a family member) involvement in rehabilitation. Given the subjectivity involved in self-reported discrepancy ratings, where possible, using

more objective assessments to determine self-awareness may be preferred. It is worth noting that no "gold standard" exists for assessing self-discrepancies, and likely a combination of self-report and objective measures is more informative than either alone (see Brown et al., 2021, for a detailed review). Distinguishing agreement, self-focused attention, and self-awareness may further be of benefit in development of measures of impaired self-awareness in ABI.

Limitations

Although using clinical records allows for greater generalisability of results due to enhanced representativeness of the sample, only self-report measures were available in sufficient numbers to conduct analyses. Whilst combining objective task performance and subjective ratings is complex (Steward & Kretzmer, 2021, Burgess et al., 1998) it may have supplemented interpretation of the self-reported data. No ethnicity data were available, restricting generalisability. Though mixed-effects models are robust at managing missing data, the large amounts of missing cases, particularly for Site 1, may have affected estimations of outcomes in longitudinal analyses. This is further compounded by sample size for analyses; based on a post-hoc power analysis, Site 1 analyses had only 69.4% power to detect differences between groups, though analyses for Site 2 and the combined sample were sufficiently powered to detect differences. Additionally, the large number of statistical tests can increase Type I error rates. Though core study results remain unchanged after using a Bonferroni-adjusted p-value, findings should be replicated using prospectively collected data. Finally, given that this chapter uses retrospectively collected data, there may be additional variables that contribute to outcomes not measured here.

Conclusion

In summary, traditionally classified impaired self-awareness ("overestimation") was associated with a more severe injury, worse participation, and, conversely, better mood upon

beginning community ABI rehabilitation. Underestimators, by contrast, had less severe injuries and worse mood than overestimators, but mood did not differ from those who accurately estimate their abilities. Discrepancies in estimations of abilities were not related to self-esteem, and its relationship to caregiver strain varied across sites. Longitudinal participation outcomes were best predicted by higher initial GCS scores, lower informant-rated caregiver strain, decreases in self-rated depression, and increases in discrepancy scores over time.

Chapter Four

Developing Behavioural Activation Therapy for Individuals with Acquired Brain injury: A Qualitative Interpretive Description Study

This chapter describes a qualitative exploration into barriers and facilitators of activity engagement following acquired brain injury. For this study, I was responsible for the conceptualisation and development of study questions and materials. I was primarily responsible for data collection and analysis, with primary qualitative analysis support from Dr Abigail Methley. Further analysis support was provided by my supervisory team (Dr Tom Manly, Dr Fionnuala Murphy, and Dr Polly Peers). Ms Estela Carmona-Gonzalez provided support in transcribing interviews. I was responsible for writing the thesis chapter.

Introduction

As discussed in the Introduction, ABI is associated with marked increases in depression. More recent research has shown promise using Behavioural Activation (BA) in adults with stroke (Thomas et al., 2019) suggesting its potential for broader ABI populations. An attractive feature of BA is that it can be delivered effectively without extensive therapeutic training (Ekers et al., 2011; Thomas et al., 2019). However, there are many variants of BA – aside from "hallmark" BA techniques such as activity scheduling and mood monitoring, BA has historically comprised additional techniques such as goals and values assessments, relaxation training (e.g., progressive muscle relaxation), contingency management (e.g., self-reward procedures), procedures targeting verbal behaviour (e.g., positive reframing), and procedures targeting avoidance (e.g., identifying and mitigating avoidance patterns). Longer courses of BA have included psychoeducational topics such as mindfulness, communication skills, and social skills to facilitate greater activity engagement (Kanter et al., 2010). It is worth considering what components are perceived as useful in ABI to best prepare therapists delivering BA who may not have extensive training or experience with ABI. In a mixed-methods review of knowledge of ABI among UK health care professionals, there was a general lack of understanding of ABI from acute care to community-based services (Norman et al., 2020). A lack of research on use of BA in ABI may prohibit effective delivery. Given the potential of BA for widespread use in ABI, and the benefits of increased knowledge of how therapists can support clients with an ABI, exploring typical experiences of activity engagement in ABI and perceptions of BA components is necessary.

Here, I utilise qualitative methodology to obtain an in-depth understanding of contributors to activity levels and perceptions of BA components from both those living with an ABI and their family members. Specifically, this study uses interpretive description methodology, a constructivist approach to qualitative data to develop practical information

for health care settings (Thorne et al., 1997, 2004; Thorne, 2016). In constructivist epistemology, meaning is generated through an interaction between one's beliefs and experiences, thus reality is subjective. Importantly, interpretive description aims to capture subjective experiences of individuals whilst framing researcher experience and knowledge as useful in analysing data. In this chapter, I aim to provide information that may be useful to therapists working with individuals with an ABI and to inform the development of BA interventions that may be suitable for those with an ABI. Further, much of my thesis involved working directly with adults with ABI, including in intervention delivery. Thus, interpretive description is an epistemologically-aligned approach for myself as a researcher and for conducting this study.

Study Purpose

The purpose of this study is to collect perceptions from adults with ABI and their family members on 1) barriers to engaging in meaningful or enjoyable activities; 2) facilitators of such engagement, and 3) the likely utility of BA techniques and psychoeducational topics in fostering engagement. A secondary purpose of this study was to use responses to inform the development of a BA intervention in ABI (see Chapter 5).

Methods

Research Team Characteristics

The research team consisted of neuropsychological rehabilitation specialists. I have experience conducting qualitative research in ABI (Kusec et al., 2020) including a Master's degree in Rehabilitation Science. The supervisory team consisted of two registered clinical psychologists and researchers with extensive expertise in neuropsychology and intervention development. The authors and I believe, based on available evidence and personal experience, that a reduction of activity levels can cause low mood and depression, and that sustained engagement in reinforcing activities contributes to a positive mood.

Ethical Approval

This study was given ethical approval from the University of Cambridge Psychology Research Ethics Board Committee (2018.059) and was preregistered on August 18th 2018 (https://osf.io/gmabq).

Interview Development

I developed the semi-structured interview based on the Kanter et al. (2010) review of BA components and BA clinical guides (Martell et al., 2013), BA theory (Lewinsohn, 1974; 1985a), self-determination theory (Deci & Ryan, 1985), my own experience, as well as my supervisors' experience, working with neurological populations (Murphy et al., 2019, Peers et al. 2020, Gracey et al, 2016).

The interview covered experience in everyday activities, such as hobbies and socialising. I additionally included questions on the helpfulness on 10 different components that may be used in BA (see Table 19 for included components; refer to Results for definitions). For a review of each component, see Kanter et al. (2010). Two additional components concerned a) the balance between activities seen as predominantly functional (e.g., grocery shopping, chores) and activities where reward or satisfaction are the main aims (e.g., hobbies, entertainment, socialising), and b) managing uncertainty in planning activities. These components were included based on the relationship of both routine and enjoyable activities' to mood (Renner et al., 2019), the robust association of intolerance of uncertainty to mood (McEvoy et al., 2019), as well as personal interest.

Topic	Example Question
Experiences in Day to Day Activities	"We are going to talk about day to day activities, such as chores, work, appointments, and so on. Can you tell me what gets you motivated to complete these activities?"
Experiences in Enjoyable Activities	"Would you say that taking part in enjoyable or pleasant activities is important to you? Why or why not?"
BA Techniques *Mood Monitoring* *Activity Scheduling* *Active Engagement* *Alternative Solutions* *Self-Rewards* *BA Psychoeducational Topics* *Social Skills* *Communication Skills* *Mindfulness* *Routine vs. Enjoyable Activities* *Managing Uncertainty*	"Some people find it useful to keep a diary and plan in pleasant activities to look forward to. Do you think this would be helpful for you? Why or why not?" (Activity Scheduling)

Table 19. Interview topics and example questions for each category. See thesis *Appendix* for full interview script.

Participant Recruitment

Members of the Cambridge Cognitive Neuroscience Research Panel (CCNRP) were invited to participate. The CCNRP is a panel of community-dwelling adults with stroke and resected brain tumours recruited via review of radiological scans who have expressed interest in participating in research. CCNRP members complete a basic battery of cognitive and emotional measures.

I purposively sampled CCNRP members based on Patient Health Questionnaire-9 scores (PHQ-9; Spitzer, Kroenke, & Williams, 1999), a brief depression measure. Participants were categorised as either having no low mood (<5 symptoms on the PHQ-9) or low mood (>4 symptoms present plus at least depressed mood/anhedonia present; see Fann et al., 2005). The aim was to increase the variety of possible combinations of activity level to mood to explore a range of experiences. Additional inclusion criteria were 1) age over 18, 2)

ability to speak and comprehend English, and 3) sufficient capacity to consent to and tolerate the interview (based on previous CCNRP evaluation). My aim was to interview an approximately equal number of men and women. Once recruited, I asked participants whether an adult family member (e.g., partner, child, sibling) could be approached for a separate interview for data triangulation, thus enhancing credibility of constructed themes. Not having such a person, or not consenting to their contact, did not preclude participation. For family members that were approached, I asked them to provide feedback on each interview topic with regards to the individual with the ABI.

Interviews

After providing informed consent, I conducted one-to-one interviews either in a private testing space within the University, the participant's or family member's home, or over the telephone, depending on individual preference and circumstance.

Interviews took approximately 30 to 60 minutes and were audio recorded with participant consent. Participants selected pseudonyms for the interviews which are used to present the results. I used prompts to encourage elaboration and clarifying remarks (e.g., "What I am hearing is that you have a hard time beginning an activity – is this correct?"). Field notes were taken throughout to capture non-verbal and contextual information. Reflexive journaling, where I reviewed the interview and potential conceptualisations of the data, were completed within 24 hours of interview.

The interview was iteratively developed throughout data collection and analysis to better communicate interview questions. Commonly, qualitative research concludes once saturation is reached (i.e., when there are no new themes in the data). However, the assumption that one can know all aspects of an area of inquiry in a single study, and hence reach saturation, has been challenged in interpretive description (Thorne, 2016). Thus, my

aims were pragmatic in interviewing enough participants to build a practical framework that may have utility when increasing activity levels in ABI.

Data Analysis

An overview of the analysis procedure is shown in Figure 16. I transcribed all participant interviews, and family member interviews were transcribed by a research assistant. Personally identifiable information was removed upon transcription. I conducted analyses using the constant comparative method (Glaser, 1965), a process of concurrent data collection and analysis. Within interpretive description, the interviewer's knowledge and experiences are thought to provide valuable insight to the data, thus analysis primarily being conducted independently is typical (Hunt, 2009, Thorne, 2016). Data interpretation was inductive, that is, giving precedence to participant responses irrespective of my views on their merits. Early stages of analysis focused heavily on big picture questions such as "What am I learning about this?" (Thorne, 2016). I sorted transcript data into discrete categories using *open coding*, consisting of initial labelling of transcript text (e.g., "planning as a motivator"). I then considered potential links between all open codes and collapsed these into broader categories, a process termed *axial coding*. Referring back to the transcripts, field notes, and reflexive journal entries, these axial codes were then further refined and constructed into an initial *interpretive thematic summary* (Thorne, 2016; Braun & Clarke, 2006). Throughout analysis, the social skills and communication skills questions were eliciting similar responses from participants, and subsequently resulted in similar construction of themes. Hence, I analysed them and present them below as a single component.

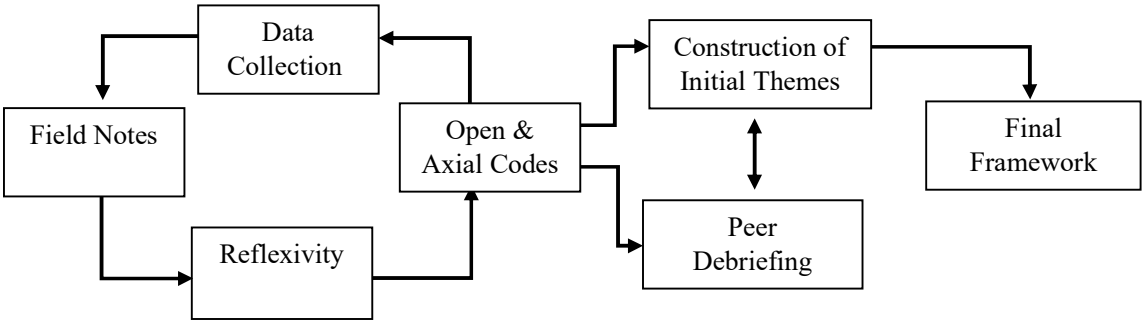


Figure 16. Qualitative analysis procedure. Upon finishing data collection, I wrote field notes, or general observations during the data collection process. Reflexivity, completed within 24 hours, is an evaluation of my beliefs and conceptualisations of the data and interview process. Open codes refer to the smallest discrete unit of data from transcripts that are provided a label. Axial codes refer to categories labelled by linking open codes together. I then further linked these themes into a construction of themes, used for reviewing the data with peers (peer debriefing).

I engaged in a peer debriefing session with my supervisory team and discussed collective impressions of the initial thematic summary and review of transcripts from those with and without self-reported depressive symptoms. Themes that were felt to require further elucidation included addressing how results vary according to mood, the notion of "one step at a time", emphasising cognitive and affective elements of an ABI, and self-expectations within participants. I incorporated this feedback into subsequent analyses by considering their fit within the initially constructed themes, re-examining the transcripts, and reconstructing the framework. We agreed that greater description (i.e., more discrete subthemes) in the results would be of more use to therapists when delivering BA in ABI than combining the data into a smaller number of themes. Thus, I decided to present barriers and facilitators per BA component, and construct central themes that relate to activity level overall. The final framework received general acceptance from the supervisory team.

Results

Sixteen participants and 7 family members participated in this study (see Table 20 for full details). Participants varied widely in education, ABI aetiology, and occupational status, however there was no diversity in ethnicity.

ABI Demographic Information (*N* = 16)	
Gender	
Male	9
Female	7
Age – M (*SD*)	62.82 (10.54)
Ethnicity	
White British	16
Highest Level of Education	
Primary School	1
Secondary School	1
GCSE/O-Level	4
A-Level	1
Undergraduate Degree	3
Postgraduate Degree	6
Aetiology	
Meningioma	6
Stroke	5
Other brain tumour	4
Brain scarring due to head trauma	1
Current Living Situation	
Living with Spouse	8
Living with Family	8
Current Work Status	
Retired	7
Working full-time	4
Working part-time	4
Unemployed	1
PHQ-9 Status	
Low Mood	7
Without Low Mood	9
Family Members (*N* = 7)	
Gender	
Male	2
Female	5
Age – M (*SD*)	55.17 (20.51)
Ethnicity	
White British	7
Relationship to Participant	
Husband	1
Wife	4
Adult Child	2

Table 20. Participant Characteristics.

Framework for Development of BA in ABI

The following sections present the constructed framework for considering themes relevant to developing BA for adults with ABI. The first section, entitled *Adapting to the*

Individual Context, comprises four central themes (Table 21). The second section addresses barriers and facilitators to BA components. A visualisation of themes is shown in Figure 17.

Adapting to the Individual Context

It was apparent that interview responses were not just about the activities or components themselves but rather person-specific aspects that could be barriers or facilitators to activity engagement. ABI in particular is associated with highly variable outcomes in severity and effects of ABI (such as poor memory), opportunities to engage in activities (e.g., access to transport), support and encouragement from family, and other factors such as having dependents, all of which may affect decision-making in planning activities.

Theme	Subtheme	Example Quotes
Right Tool at The Right Time	Is This Tool For Me	*"It doesn't matter to me where I improve [my communication skills] or not. I don't need it at my age."* Participant Cory
	Coping with Early Stages	*"At the time [of his stroke], he was very frustrated with not being able to do things himself but he also would blame mum for a whole lot of things"* Family Member Rose
	Chronic Changes to Abilities	*"I did get diagnosed with chronic fatigue last year…I kind of get to about 11 o'clock, 12 o'clock and I just hit a brick wall and I just can't function."* Participant Linda
Perceived Effort	Willingness to Work for Others	*"[The activity] is for somebody else. So I'm prepared to get up at silly o'clock and get myself organised."* Participant Charles
	Resisting Passivity	*"I might meet somebody, and then it'll become nothing after that. I will not follow it through and I might even not keep in touch with some friends with whom I should have. And then friendships would die. And I know I need to make an effort but that effort to maintain is hard."* Participant Alice
	Success Sustains Effort	*"I think [completing an activity] kind of gives you a spur – you know that you've achieved something and therefore you can go forward and do it again."* Participant David

	Increased Prioritising and Planning	*"I do need to sleep in the afternoon, so therefore I would go from one to five, which [activity] is more important?"* Participant Sophia
	Activities as a Habit	*"Well, you have your routine and it has to be done. He's very strict with the routine."* Family Member Sandy
Emotional Impact	Managing Self-Criticism	*"Occasionally [I'm] self-critical that I think things have not worked out the way I want them to. Sometimes I think that things will work out better than they do, and you know sometimes they just don't. And I do think then that it's usually, I think I must have done something wrong, to have done that, but really it should have worked but it didn't"* Participant Kelly
	Recognising How Activities Affect Me	*"[Enjoyable activities] lift my heart. Life, for everybody regardless of your circumstances is full of challenges, and some of those are difficult and wear you down. So I need, I need those sort of therapeutic uplifts."* Participant Bella
	Gaining Confidence	*"I'm always very wary [about trying new things]. I just don't know enough about it, it worries me."* Participant James
	Coping with Failed Activities	*"If [an activity] doesn't work out we can find something else. I'm very much a 'Let's not worry about it' person."* Participant Sophia
	Aversion to Confronting Emotions	*"For [communication skills], I don't like arguments and everything and I get upset easily"* Participant Alice
	Changes in Social Circle	*"I said to the members of my family, I said 'look, you've got to appreciate that someone in my position, it's too much expecting me to do everything'…think about things that I might want doing."* Participant Merlin
	External Praise	*"You have to encourage him all the time…'you've made a lovely job with that, well done!' That kind of thing."* Family Member Sandy
Relation to Values	I Do What I Value	*"If it's anything to do with family, that comes first."* Participant Roy
	New Perspective on Life	*"Since I had my brain tumour…nothing really bothers me that much. I just take every day as it comes…you know people would understand what I'm saying,*

		who's actually been through the same thing, they would know exactly 100 percent" Participant Cory
	Closeness to Others	*"Everybody when you get older have got their own jobs on their own with their own family their own way. When we were single we had loads of time to say hello to people. We didn't have [time] so much anymore and so it has be certain people, you know. And so there is the little key nucleus."* Participant Sophia

Table 21. Four central themes of *Adapting to the Individual Context* and its subthemes. All subthemes are illustrated by relevant participant quotes.

Individual Context – The Right Tool at the Right Time

An important theme was whether it was the "Right Time" for participants to increase activity level. Time-related barriers included age (e.g., "too late in life to change"), occupational status ("no time") and perceived social roles (e.g., caretaking responsibility). Whether or not a BA component was the "Right Tool" was based on preference, experience, and post-ABI ability – simply not perceiving the need or relevance for the BA component could be a barrier.

> *"I've never even thought about [scheduling something enjoyable]….we keep ourselves busy, I wouldn't think that would do anything."* (Participant 8, Fred)

Some described how the early stages of ABI could be emotionally distressing, and formerly "easy" tasks were now difficult due to chronic impairments – as such, there was little scope for thinking about increasing activity level. Establishing new habits was seen as time consuming, and could disrupt routine, increase risks (e.g., injury, fatigue) and expose limitations due to ABI such as speech issues or slowed information processing. Family members generally were hesitant about attempts to increase activities post-ABI, with some components perceived as irrelevant.

Facilitators to increasing activity engagement included recognising how impairments affected activity levels, wanting to exceed expectations of others, and regularly engaging in

activities to maintain recovery. Simpler BA components were thought as especially valuable in early stages of ABI.

> *"[Mood monitoring is] such a simple thing…during the early stages [of my ABI], I think I could have done with the simplicity of that sort of structure."* (Participant 9, Bella)

Individual Context – Perceived Effort

A recurring barrier to increasing activity level was the amount of effort required, a limited commodity perhaps better expended on necessary activities. As a result, participants reported engaging in greater prioritisation and planning of activities, and were less likely to complete activities perceived to be too difficult or irrelevant. One participant described needing time for mental preparation prior to a task.

> "*I have to, I have to know what I'm doing…I have to know in advance so that I can get it clear in my head what I'm doing."* (Participant 15, Linda)

For highly valued activities, expending limited effort was worthwhile, especially if others were involved. Some wished to reduce *wasted* effort, making sure that invested energy paid off. For example, when discussing an upcoming trip a participant said:

> *"I want to achieve what I set out to do that day. So it is important to plan. I don't want to be left in a situation where I arrive and there's nothing happening. It's not every day we're doing things."* (Participant 7, Roy)

Completing an activity helped motivate effort for other activities. As one participant noted "*Once you're successful in one thing then you're feeling 'well okay I'll try other things as well'"* (Participant 2, Sophia). The subjective effort required for new activities diminished once they became habitual.

Individual context – Emotional Impact

Participants highlighted a variety of emotional responses to activities and BA components. Recognition of the positive emotions associated with enjoyable activities could, of course, be a strong facilitator.

> *"I can't imagine how miserable life would be without [enjoyable activities]. It really would be miserable without them. If they didn't happen I think I'd just go downhill, curl up, and die."* (Participant 7, Roy)

Others, however, struggled with self-critical thoughts, and felt frustrated if ABI impairments such as poor memory interfered with activities. Low confidence became a barrier and negatively affected mood. Changes to relationships after ABI, and the emotional responses of others, affected activity levels.

> "*I got to the point where my physical lack of ability to do all these things was such that … my wife was no longer enjoying what was going on, and she was concerned, frightened beyond belief that I was going to do something stupid and I did a couple of times. And I thought, I had to just think about it for the weekend and I said to my wife 'I don't think this is going to work for me, I'm going to give it up'…I feel that I'm too much of a burden upon these, the staff that are running [the swimming programme]"* (Participant 13, Charles)

Anticipated emotional responses acted as a barrier - when discussing mood monitoring, one participant felt that rating how activities made her feel would be distressing.

> *"I have to live with myself every day and I don't want to write [my mood] down, I would have to see it."* (Participant 15, Linda)

Successfully overcoming self-critical thoughts, including not perceiving a failed activity to have negative implications and retaining confidence, were facilitators to completing an activity. Others benefitted from external praise.

Individual Context – Relation to Values

This theme represents how an activity relates to the values of the individual. For some, simply enjoying an activity was perceived as valuable. Others placed value on experimentation with new activities following ABI. Some placed greater emphasis on satisfaction, or even sense of duty, for activities completed for others, regardless of how enjoyable the activity was perceived to be. For those with a brain tumour, the potential for recurrence seemed to prompt critical reflection on valued aspects of one's life, acting as a facilitator to engagement. When describing his mother, one family member noted:

> *"She can't know that [her brain tumour] won't take a turn for the worse, and you know unless she's had an MRI yesterday she could wake up tomorrow and she could be close to death. I think she has an amazing ability to put that aside, and I think her faith helps with that…it allows her to keep a positive mindset and she feels she's doing her best."* (Family Member 1, Clark)

The activities that participants continued to engage in were ones they valued most. In particular, a sense of belonging and closeness to others, as well as a desire to be understood and appreciated, acted as facilitators.

> *"I feel alive, I feel who I am [when I do something enjoyable]. I feel that other people need me as much as I need them. I feel like I can do something for other people and make them happy."* (Participant 11, Alice)

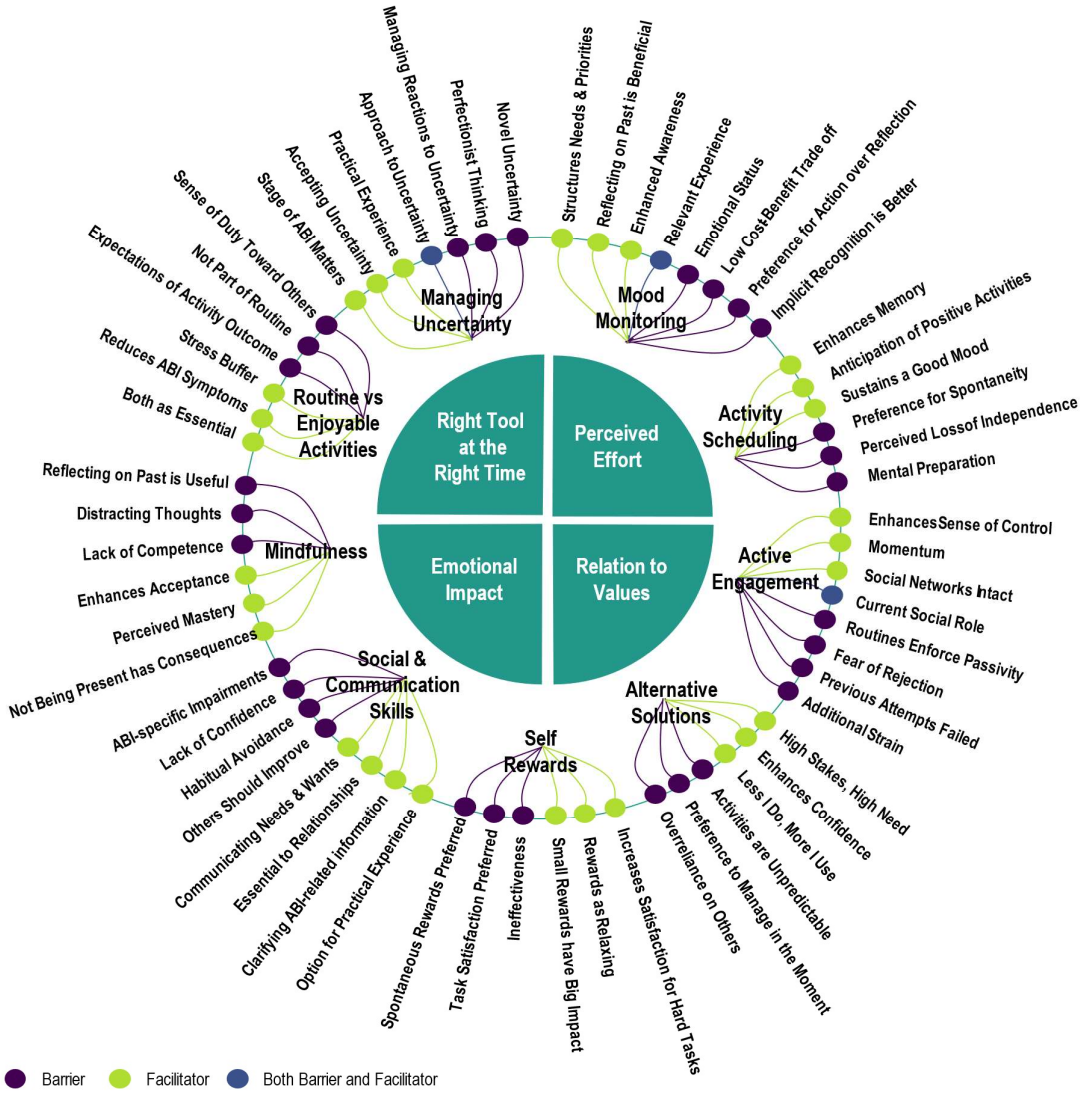


Figure 17. The final constructed framework entitled *Adapting to the Individual Context* based on participant interviews. The central quadrants represent the four core themes of the framework, with component-specific (e.g., mood monitoring, activity scheduling) facilitators and barriers in the outer circle. It may be useful to consider the fit between particular BA components and the stage of the client's ABI (The Right Tool at the Right Time); individual differences in perceptions of how effortful an activity is based on current capabilities (Perceived Effort), what emotional responses the client may have to BA (Emotional Impact), and how therapeutic targets link to the client values (Relation to Values). Component-specific facilitators and barriers are considered secondary to the central quadrants in considering how ways to deliver BA therapy.

Barriers and Facilitators for Specific BA Components

The second set of themes presents responses to BA components; in particular, aspects that may be a barrier or facilitator to their adoption. Of course, as most participants had no

direct experience of BA these are anticipated responses based on similar experience, self-knowledge, and speculation on how they are likely to respond to the proposed components.

BA Technique – Mood Monitoring

Mood monitoring requires individuals to think about and record how they feel before, during, and/or after activities. It is a technique designed to increase awareness of the links between activities and reinforcement. Facilitators included recognising that this enhanced awareness, using mood monitoring to provide structure and evaluate needs and priorities, and evaluating whether novel activities were mood-enhancing.

> *"I think [mood monitoring] might help him generally assess areas in his life and help him focus on the things that do improve his mood."* (Family Member 6, Rose)

Others, though recognising its value, perceived regular monitoring as too effortful to maintain, or felt resistant to exploring how activities made them feel. Some preferred implicitly evaluating the activity-mood relationship rather than explicitly writing it down. Mood monitoring was viewed as unnecessary when in a good mood, and could become aversive in a low mood. Some had experience with similar formats of monitoring activities, which were either a barrier or facilitator.

> "*I tried to keep a happiness diary. I kept going for a week and then I stopped. Because it simply meant I had to discipline myself into doing yet another activity at the end of each day… as long as I later became aware of these things and just, stopping and thinking 'Aha, I'm having a happy moment now' I don't feel the need to write it down."* (Participant 11, Alice)

There was a general sense from participants and family members that they were already aware of what they enjoy, and hence mood monitoring was at best irrelevant, and at worst patronising and "*a total waste of time"* (Family Member 3, Sandy).

BA Technique – Activity Scheduling

In activity scheduling, clients are encouraged to identify and schedule potentially mood-enhancing activities, the premise being that explicit plans are more likely to be enacted. This rationale was broadly accepted, with facilitators including memory benefits and sustaining a good mood. Participants emphasised the importance of having something to look forward to, and mitigating stress.

> *"Absolutely useful…it restrains stress levels, and you just get out and do something."* (Participant 16, Bonnie)

Barriers highlighted by participants were related to physical, cognitive, and financial constraints, rather than scheduling *per se.* Consequently, some felt they had reduced independence. Needing a sense of "readiness" was a barrier, especially for something unexpected or complex. Some expressed a distaste for planning activities in advance and preferred engaging in activities spontaneously. This related both to the effort involved in planning, and uncertainty about how they would feel the day of the activity.

> *"I just like to take things as they come naturally…say you block out Saturday morning to do something in particular. I don't like to do that because I might not feel like doing that on the day, you see. So, for example, this weekend my husband wanted to go to Chilton, and we were planning, but now, I don't feel like doing it now, so we're not going. I don't feel things are set in stone and I have to do them."* (Participant 14, Adriana)

BA Technique – Active Engagement

BA treatment manuals (e.g., Martell et al., 2013) distinguish between the *process* of engaging in a potentially reinforcing activity and the activity itself, in particular whether the activity was initiated by the individual – termed here as "active engagement." Participants felt that initiative and agency were important, yet expressed difficulties reducing passivity. An

important facilitator was the desire to actively contribute to wellbeing rather than be a passive recipient of care.

> *"When I was first diagnosed one thing that really frustrated me was that I was given no options for how I could help myself. I was just told to watch and wait, and that wasn't good enough for me. I needed to be doing something. And all the medical people I spoke to, including a GP at the surgery I went to, told me to just keep up with the drugs and that would be enough. And that wasn't enough. I needed to actually be involved in trying to make myself better."* (Participant 9, Bella)

Once an activity was successfully initiated, the resultant "momentum" was a facilitator to initiate further activities. For some, especially in early stages of ABI, the input of family and friends in helping maintain this momentum in activity levels, easing the transition to greater self-initiation in chronic stages of ABI. Some participants noted previous attempts to self-initiate had gone poorly, or had concerns that self-initiating would be too straining. A fear of rejection from others when initiating an activity was a barrier.

> *"I'm not very good at [taking initiative] and sometimes I don't call friends enough. I kind of sit back and wait for them to call me which I know is wrong…there's always a slight doubt in your mind…sometimes you'll be rebuffed or that person will not be as enthusiastic as you are and therefore you kind of feel you shouldn't"* (Participant 1, David)

Perceived social role could be a barrier or facilitator, with some family members stating it was their role to initiate activities rather than the participant's.

BA Technique – Alternative Solutions

One technique to reduce avoidance involves generating alternative solutions in anticipation of barriers that may arise to a planned activity. Perceived value of this technique depended on the complexity and/or rarity of the activity, involvement of others, and any

potential consequences of failure. Alternative solutions were thought to increase confidence in executing plans, and provide reassurance.

> *"Only for complicated things…where other people are involved in the end result. If it was just me and I was making a very complicated meal and it went wrong I'd just say 'I'll do without it then' but I put more expectations on myself if I'm doing something for somebody else and that's when I need that plan."* (Participant 6, Kelly)

However, some participants felt that generating alternative solutions was not always a good use of time. Given the inherent unpredictability of future activities, some expressed a preference for managing barriers as they occur, rather than in advance. For others, generating alternative solutions was the role of family members, not the person with the ABI.

> *"It would be good to think of that, but as I say I have [my wife] to help me do that. I don't have to think that way."* (Participant 13, Charles)
>
> *"He really wouldn't worry about it….that'd be me who'd panic."* (Family Member 3, Sandy)

BA Technique – Self-Rewards

Whilst BA generally encourages engagement in activities that are inherently rewarding, additional rewards (e.g., a cup of tea) can be used to supplement reinforcement. Participants felt that self-rewards increased task satisfaction, particularly for complicated or difficult activities, or found small self-rewards relaxing. Some viewed self-rewards as essential to daily life.

> *"I believe it's really important that we all learn to congratulate ourselves. Even just, and I say this to my students a lot, you know you work hard at something and you see yourself achieve something and you must when you get to the end say 'Well done me!' and give yourself a pat on the back because we live in a world that doesn't encourage*

that. I think they're essential to everything, and there shouldn't be a single day that goes by without some sort of self-praise or reward." (Participant 9, Bella)

Others were divided over the use of self-rewards, and found them too indulgent or preferred task satisfaction.

"I don't think I'm that sort of person. It just doesn't appeal to me…the amount of effort and time you put into something is a reward in itself without any sort of tangible thing at the end." (Participant 1, David)

Others felt that self-rewards could be ineffective or overused, and preferred to have spontaneous celebration of achievements.

Psychoeducational Topic - Social & Communication Skills

Longer courses of BA have included skills training to foster positive relationships and maintain social reinforcement (Kanter et al., 2010). Participants acknowledged the importance of social and communication skills, especially in communicating personal needs and wants to others, but perceived them as difficult to develop. In particular, effectively conveying ABI-related information was a facilitator.

"People make assumptions if you don't communicate things…and they can treat you in a different way when they, if they think they're making allowances for you or whatever. I mean it was definitely difficult telling people about my, my meningioma. I was doing a 'wait and see' and see what happened with it and there didn't seem to be any point in telling my children because it would have worried them. But I did learn from that, I think you have got to talk to people about health problems" (Participant 6, Kelly)

Participants stated that practicing difficult social situations and creating positive social atmospheres were desirable. However, implementing these skills were thought to be hindered

by ABI-related impairments such as speech difficulties, habitual avoidance of social situations, and decreased confidence when socialising with others.

> *"I don't believe in myself that I can. I'm so concerned that I can't, um, put words in my mouth properly like I used to."* (Participant 16, Bonnie)

A notable barrier was feeling that others should improve their social and communication skills instead of themselves, specifically when inquiring about ABI impairments. For example, when describing her eye being permanently shut following her ABI, one participant stated "*an issue is I meet new people and they're focusing on my eye rather than me. I'd rather people asked me about it than just look at me"* (Participant 15, Linda).

Psychoeducational Topical – Mindfulness

Borrowing from mindfulness, BA has encouraged individuals to stay "in the moment" when engaging in activities to enhance reinforcement. Participants generally interpreted staying "in the moment" as a broad philosophy rather than a specific "experience savouring" technique. Some found this message to enhance acceptance of post-injury life, and reduce focus on concerns about how they might change as a consequence of their ABI in the future. When asked why staying in the moment is useful for her, one participant stated:

> *"Well, it's, you can't change the past. And there's no point in revisiting that because you can't change it. And the future, well nobody knows what going to happen from one day to the next. Just because you've had a brain injury, that's, you know, I don't believe anything to do with my brain is any more likely to happen to me than anybody else."* (Participant 6, Kelly)

Some saw the merits of mindfulness, but were unsure of how to implement it or became easily distracted by negative thoughts. Some were not receptive to mindfulness, as they found it beneficial to reflect on the past.

"It's just, it's quite important, it's quite important to think of life, any mistakes previously so that you don't actually repeat them." (Participant 10, Cory)

Psychoeducational Topic – Balancing Routine vs Enjoyable Activities

Within BA, the level of positive reinforcement that activities afford is important (Martell et al., 2013). Although "routine" activities can be reinforcing (e.g., high level of mastery), here I use "routine vs enjoyable" as shorthand for activities that are perceived as repetitive or arduous but necessary, and activities where there is an explicit expectation of enjoyment. Like self-rewards, beliefs around dedicated time for enjoyment seemed to affect responses. Some found this "balance" to act as a "stress buffer" and helped manage the effects of an ABI, while others viewed regular engagement in both types of activities as essential.

"Every individual has got their own life to live. And I feel that my life is unique, and I want to live it on my terms. There are certain things to me that are important to me and I need to make space for those things in my life. It's essential for me to do things that I enjoy, as well as responsibilities that other people need." (Participant 11, Alice).

Some had difficulties prioritising enjoyable activities, especially if there were many competing routine demands or if they had expectations of the outcomes of activities that weren't met. Others implied that seeking out personal enjoyment would be not be a useful habit to develop, or that a duty toward others was more important.

"I don't have time for relaxation…everybody else comes before I do. So I have to make sure that my son is catered for, cooked for, clean, all the rest of it. And then my husband, I have to sort his tea and what have you. I don't give a thought to me as long as everybody else is happy." (Participant 15, Linda)

"I do think [planning both types of activities] would be helpful. But I keep referring back to [my wife] because she does everything. So I'm very fortunate I don't have to worry about things like that." (Participant 13, Charles).

Psychoeducational Topic – Managing Uncertainty

There is evidence linking "intolerance of uncertainty", or difficulties managing uncertainty, to depression (McEvoy et al., 2019). Increasing activity levels may result in increases in uncertainty, therefore an important element of BA may be managing responses to uncertainty. Facilitators to learning how to manage uncertainty included being in early stages of ABI, and an awareness of the futility of entirely predicting the future. Having support from others who have experienced similar health difficulties was viewed as helpful.

"It would have been helpful to have had some help with that…in a normal life if you're not challenged by an illness you still have those uncertainties and you work out ways, or you get help working out ways to deal with them. When an illness, a serious illness is thrown at you often times you can't get that help from your friends or your family because they haven't experienced what you're going through." (Participant 9, Bella)

Participants had distinct approaches to uncertainty, such as becoming fatalistic about their future, relying on religious faith to cope with uncertainty, or concerns about situation-specific rather than general uncertainty. These approaches were either a barrier or facilitator. Barriers included finding the sudden increases in uncertainty post-ABI too overwhelming to manage, negative reactions to uncertainty such as fears of injuring oneself again, and perfectionist thinking.

"For the brain injury, wondering what that really means, is that event going to occur again, and what really controls that event, and why did it happen in the first place? And how, what influences it. You know certain things influence it, you need to take

your medication, control your blood pressure, but then how do you control your blood pressure? And is the medication really doing what it should do? There's all those sorts of aspects to it. So I think there is an anxiety associated with having a stroke that I never really thought of before I had it." (Participant 1, David)

Discussion

The purpose of this study was to explore experiences of activity engagement in ABI, and identify barriers and facilitators to adopting potential BA components. In my study, there was variability in responses driven by individual differences in abilities, beliefs, experiences, and contexts. The framework *Adapting to the Individual Context* posits that, whilst there may be a *general* evidence base for the benefits of increasing activity, or for specific BA components in helping to achieve this, the fit to an individual is likely to be a primary determinant of success in any *specific* instance. Post-ABI, clients may experience a lack of autonomy (Kusec et al., 2020) and thus it may be particularly important to involve them in treatment decisions.

Right Tool at the Right Time, Perceived Effort, Emotional Impact, and Relation to Values

The theme Right Tool at the Right Time is perhaps unsurprising given variable outcomes in activity levels post-ABI (Forslund et al., 2019). Only half of individuals with TBI return to pre-injury leisure activities, even at 10 years post-injury (Ponsford et al., 2014), suggesting the "Right Time" to intervene may not uniquely occur in early stages of ABI. Beyond preference, selecting the "Right Tool" (and increasing activity engagement more broadly) was linked to the effort (both perceived and actual) required to execute it. Consistent with recommendations to modify CBT in ABI (Gallagher et al., 2019), there was a view that simpler techniques would have been especially preferable in early ABI. However, participants noted that if an activity became habitual, it required less effort. There is evidence that recurrent, compared with one-off activities, had greater success in BA case studies in

ABI (Gertler & Tate, 2019). Of course, given that the sample was in chronic stages of their ABI, any ongoing impairments may have influenced perceptions of BA components and therefore their adoption.

The "Right Time" likely does not only relate to amount of time post-injury but a readiness to confront emotional difficulties, increasing activity level, and navigating changes to social relationships – something participants both with and without low mood found challenging. In a study investigating changes in competency post-TBI, van Walsem and colleagues (2020) found that participants report lowest competency in emotional and cognitive capabilities. The "Right Time" may therefore be when one recognises a "gap" in one's skillset. Positively, many participants in my study recognised the benefit of enjoyable activities and how a lack thereof would be detrimental. However, those with low mood may especially struggle with maladaptive coping patterns to failed activities (Katz et al., 2020) and may find therapy aversive. It may be useful to evaluate whether encouraging planning in *valued* activities can overcome maladaptive coping patterns in BA, rather than encouraging planning *enjoyable* activities.

Participant Views on BA Components

The literature on efficacy of BA in ABI is limited, and even further so the suitability and preference of BA components. In a systematic review (Oates et al., 2020) only four studies explored use of BA in ABI. The components included psychoeducation to carers, mood monitoring and activity scheduling, graded task assignment and problem solving. With the exception of activity scheduling, Oates and colleagues (2020) have not reported on the specific success of each component, nor acceptability of components from participants, though this was stated to be due to inconsistencies in reporting how content was adapted for ABI and data on fidelity assessments of what was delivered.

BA Techniques: Mood Monitoring & Activity Scheduling

Mood monitoring and activity scheduling are hallmarks of BA, often included in brief BA therapy (e.g., Leujez, Hopko, & Hopko, 2001). Conceptually, both techniques were perceived as useful by participants, but there were challenges that it could be too effortful, unnecessary, and/or counterproductive. Similarly, in Thomas and colleagues' (2019) BA trial in stroke, there was mixed feedback on mood monitoring, with some valuing its reflective purpose but others finding it repetitive or difficult. Although the degree to which mood monitoring's effectiveness relies on explicit vs implicit recognition is yet to be determined, caution is warranted as expectations of use may differ from practical experience – especially as, outside of ABI, mood monitoring on its own can decrease depressive symptoms and increase activity (Harmon et al., 1980, O'Hara & Rehm, 1979, Reaven & Peterson, 1985). The less-than-optimal feedback to mood monitoring could be due to those with low mood finding it aversive or too effortful, while for those without low mood explicit monitoring provides no new information. In ABI specifically, poor memory for one's mood at the time of reporting it or the amount of effort required to regularly record mood may be too demanding.

Conversely, there was greater endorsement of activity scheduling by participants for enforcing a structure on one's week, providing cognitive benefits such as enhanced memory, and helping sustain a good mood. Anticipatory benefits of enjoyable activities were noted to be mood enhancing, consistent with research demonstrating that individuals with ABI with depression have a reduced positive bias in prospective cognition (Murphy et al., 2019). Despite its benefits, some participants preferred spontaneously engaging in activities, and were hesitant about activity scheduling because of the difficulty of anticipating whether they would be in the "right mood" at the time. Possibly, spontaneously engaging in tasks is protective – that is, the person may feel less emotionally invested in activities they have not spent effort in planning, and reduces any negative impact of failed activities. Whether

encouraging spontaneity in BA increases activity level in ABI, relative to concretely scheduled activities, is yet to be determined. Too much spontaneity may be ineffective if the individual has a lack of support at home to help prevent spontaneous actions turning into impulsive behaviours. No participants in this study live alone, which may partially explain preference for spontaneity; likely any excessive spontaneity would be mitigated by family.

BA Techniques: Active Engagement, Alternative Solutions, and Self-Rewards

BA techniques to increase the likelihood of reinforcement included supporting active engagement, generating alternative solutions to planned activities, and self-rewards. Though alternative solutions could be perceived as too effortful, a noteworthy result was that participants made use of this technique if activities involved others. Possibly, this is representative of the Relation to Values theme, where participants felt that connecting with, or responsibility to, others was important even when effortful. Generating alternative solutions has been used in CBT in ABI as a means of improving flexible thinking (Gallagher et al., 2019) but for BA, which is predominantly behavioural, regular use of alternative solutions for activities could make activities burdensome in general, and increase avoidance. Additionally, mood may impact uptake of more complex BA techniques; in a systematic review, mood disorders and passive personality traits were related to poor uptake of goal-setting in stroke (Plant et al., 2016).

Participants generally found learning how to self-initiate activities and reduce avoidance as beneficial. By contrast, there was less endorsement of likely value of self-rewards. This may reflect beliefs about compassion toward oneself. Chywl and colleagues (2020) report that those who viewed self-compassionate actions as irresponsible, indulgent, or leading to complacency were less likely to demonstrate care toward themselves in hypothetical emotionally challenging scenarios. Whether or not preference for self-rewards and its effect on reinforcement is determined by these beliefs is unclear. Additionally, the

type of activity rewarded may be important – historically, self-rewards have been used for necessary activities that are not highly intrinsically reinforcing (e.g., conflict resolution; Kanter et al., 2010). Further, both severe depression and ABI may lead to reduced ability to experience pleasure (Katz et al., 2020; Husain & Roiser, 2018), thus even if an individual is receptive toward using self-rewards, it may not be effective. Exploration on whether self-rewards improve behaviour change in ABI is warranted.

Psychoeducational Topics: Mindfulness and Social & Communication Skills

In adults without ABI, extensions of BA with social and communication skills have been delivered successfully (Mazzucchelli et al., 2009; Kanter et al., 2010). Participants in my study perceived social and communication skills to be important - as these skills may be felt to be lacking post-ABI (Rousseaux et al., 2010, Struchen et al., 2008), more explicit incorporation of these skills into BA could be useful.

Mindfulness, though perceived as useful, was viewed as difficult in practice. Mazzucchelli and colleagues (2009) noted mixed feedback on the mindfulness component of their BA intervention, concluding that encouraging mindfulness toward activities that are already in one's routine is preferable, rather than encouraging scheduling new reinforcing activities *and* learning to savour these new activities. More broadly, the concept of "staying in the moment" was thought by participants in my study to enhance acceptance of post-ABI changes. Incorporating therapeutic options that facilitate acceptance such as Acceptance and Commitment Therapy into BA may be beneficial; a previous trial of BA in stroke noted that many struggled with accepting their post-injury life and were not ready to focus on increasing activity level (Thomas et al., 2019). It is interesting to consider whether either training individuals to attend to the present moment during specific activities, or encouraging a more general mantra of staying "in the moment" would have differential effects in post-ABI adjustment.

Psychoeducational Topics: Routine vs Enjoyable Activities and Managing Uncertainty

Other potential additions to BA include encouraging a balance between non-reinforcing but necessary ("routine") and potentially reinforcing ("enjoyable") activities, and managing responses to uncertainty in planning. Some participants were not inactive – indeed, some felt overwhelmed by activities in their week. Like self-rewards, prioritising enjoyable activities may be considered indulgent – possibly even more so in those with depression (Neilissen & Zeelenberg, 2009). Potentially, given the increase in prioritising and planning activities reported by my participants, the limited cognitive capacity for activities is dedicated to those that "must" be completed. It is interesting to consider whether increasing pleasurable activities for individuals who view enjoyable activities as too indulgent would be beneficial, or if challenging such beliefs would be better suited to other therapeutic approaches.

When reducing avoidance in BA, individual responses to uncertainty may be relevant. Greater amounts of uncertainty are common post-ABI and often leads to significant distress (Salter et al., 2008; Connolly et al., 2021). This risks setting off a chain of worry that participants recognised as something to reduce. Though adaptations of BA for anxiety exist (e.g., Chen et al., 2013), the degree to which incorporating uncertainty management would increase activity levels is unknown. Graded exposure to activities with varying levels of perceived uncertainty may result in a client with ABI requiring additional reassurance, and in this instance alternative solutions and self-rewards for the activity may become useful.

Though all BA components were received positively by at least some participants, in general, it is not clear whether the use of a technique or a general reframing of attitude toward activities is what "sticks" in BA. Potentially, ongoing use of a technique provides greater effects, but general concepts are more enduring lessons from BA.

Clinical Implications

Given the variety of components that can be used in BA, tailoring the intervention to the client's circumstances and preferences post-ABI may enhance outcomes (Plant et al., 2016; Terry & Kayes, 2020). It may be worth assessing whether more effortful techniques such as alternative solutions are necessary. For participants in early stages of ABI, activities with fewer steps or shorter duration may be useful to prioritise. In longer courses of BA, using value-based approaches may be useful in early sessions to establish a routine, with later sessions introducing more complex topics such as social and communication skills. Some clients may be averse to explicit consideration of how activities affect their mood, or may not have accepted changes as a result of their injury, in which case other therapeutic approaches may be preferred in combination with or instead of BA.

Limitations

Though the strength of qualitative research is its focus on the individual perspective, it does not allow for estimates of how frequently these themes would occur beyond this sample. The degree to which responses align with practical experience of BA is unknown. Participants largely had tumours or strokes, thus exploration of BA components in other ABIs is warranted. Although I purposively sampled those with and without low mood to enhance variety of responses, studies looking only at participants without low mood, or only with low mood, may produce additional themes. There additionally was no diversity in ethnicity. Finally, many participants had a postgraduate degree and lived in an affluent area, thus public health contributors to depression such as poverty may be relevant in other samples.

Conclusion

This study adds to the sparse literature relevant to delivering BA in ABI. The stage of one's ABI, how prepared they are to engage in a mood-focused intervention, the amount of effort needed, and the perceived value of planned activities are recommended aspects to consider when delivering BA in ABI.

Chapter Five

Mood, Activity Participation, and Leisure Engagement Satisfaction (MAPLES): A Randomised Controlled Pilot Feasibility Trial for Low Mood in Acquired Brain Injury

Part of this chapter has been published as a randomised controlled trial study protocol:

Andrea Kusec, Fionnuala C. Murphy, Polly V. Peers, Cara Lawrence, Emma Cameron, Claire Morton, Andrew Bateman, Peter Watson, & Tom Manly (2020). Mood, Activity Participation, and Leisure Engagement Satisfaction (MAPLES): A randomised controlled pilot feasibility trial for low mood in acquired brain injury. *BMC Pilot and Feasibility Studies, 6, 135.* https://doi.org/10.1186/s40814-020-00660-8

The above published paper describes the original protocol where the study was set to run entirely in person. The below chapter is modified to incorporate changes that were made to implement the intervention remotely via videoconferencing and is written following the CONSORT reporting standards for pilot randomised controlled trials.

Though I use first-person pronouns in this chapter, this study is the result of combined effort and support from my research team, clinical collaborators, and steering committee members. My contributions included trial conception and design, creation of study materials, drafting ethics approval and amending the protocol, overseeing all study procedures and scheduling assessments, organising and facilitating the group sessions, transcribing and cleaning both quantitative and qualitative data, analysing the data, and writing the chapter. Ron Bennett provided service user input in developing study materials. Estela Carmona-Gonzalez and Aleksandra Korbacz conducted blinded outcome assessments, fidelity assessments, and supported interview transcription. Blinded outcome assessment was further supported by Verity Smith, Silvana Mareva, Sinead O'Brien, Nadene Dermody and Jamie Stefaniak, with Wiktoria Wiatrowska providing additional transcription support. Input on analysis was provided by Drs Tom Manly, Fionnuala Murphy, Polly Peers, and Peter Watson.

Introduction

ABI is associated with increased risk of mood disorders and decreases in overall activity levels. Though existing therapies for depression such as CBT have a strong evidence base in the general population, they place heavy demands on skills often compromised in ABI, such as comprehension, memory, and mental flexibility. This may account for the mixed outcomes for CBT in ABI (Waldron et al., 2013). A promising alternative with lower cognitive demands and established efficacy in the non-ABI population is BA therapy. In BA therapy, individuals are encouraged to plan and engage in reinforcing activities and overcome barriers to their occurrence. BA has shown strong effects both individually (d = 0.78) and in group (d = 0.74) settings in the non-ABI population (Dimidjian et al., 2006; Cuijpers et al., 2007; Ekers et al., 2008) as well as preliminary support (d = 0.24 to 1.17) in one-to-one therapy in stroke (Thomas et al., 2019; Oates et al., 2020). This is the first *group* BA evaluation, of which I am aware, in a wider ABI population. There are clear economic advantages to groups, as well as greater efficiency in reducing waitlist time, compared with individual therapy (Tucker & Oei, 2007; Morrison, 2001; Vinogradov & Yalom, 1994). When groups work well, the supportive dynamics of groups of people with similar challenges can enhance therapeutic effects (Morris & Morris, 2012, Lewinsohn & Clarke, 1999).

An important issue given the mixed efficacy of other psychological interventions for mood in ABI is whether the cognitive demands of BA, although notably lower than other approaches, may still undermine its effectiveness. Difficulties in planning, in recalling and executing the plan at the correct time, and in subsequently recalling positive aspects of the experience may preclude any benefit from BA therapy. Accordingly, in developing a BA intervention suitable for ABI I incorporated features that are efficacious in interventions designed to support executive function in ABI (e.g. Levine et al., 2000; Miotto et al., 2009; Gracey et al., 2016; Spikman et al., 2010). These included ideas such as breaking complex

goals down into a series of smaller steps ("task splitting"), identifying and mitigating causes of distraction, and preventing automatic behaviours interfering with activity completion.

There is a risk that, despite the inclusion of goal management techniques, individuals with marked cognitive impairments may still struggle to engage in planned activities and experience feelings of failure. As such, here I compared a "Traditional" BA group (Activity Planning Group, "AP") described above, with a more "Experiential" BA group (Activity Engagement Group, "AE"). In the latter, participants engaged in positive activities *within* sessions (crafts, games, discussions), removing the need for planning, engaging in, and reporting back on activities from everyday life.

It is possible that both groups are beneficial in different ways by participants. A Traditional BA group may for some feel too structured, too much like a classroom, too much like "hard work" and with not enough time to socialise; while for others it may meet their expectations of "proper therapy." Similarly, the Experiential BA group may provide greater levels of social reinforcement, or feel like "pointless activities" and "just chat" to some. Further, Traditional BA has a number of features likely to better foster longer-term maintenance and generalisation of gains (e.g., experience of applying strategies in everyday life). However, positive experiences in Experiential BA might implicitly challenge underlying counter-productive beliefs and lead to *increased* seeking of such experiences in everyday life, possibly even more so than with the more didactic Traditional BA approach. As activity-based peer support and social groups are offered by a number of ABI charities and non-NHS community-based settings (Salas et al., 2020), it could be argued that we should already be aware of any such generalised benefits that could follow. As has been noted previously (Morris & Morris, 2012), such groups are rarely if ever evaluated relative to another or no intervention. Exploring differences between the two types of groups are therefore key aims of this trial.

Objectives

The primary objective of the Mood, Activity Participation, and Leisure Engagement Satisfaction (MAPLES) trial is to determine the feasibility and acceptability of two activity-based group interventions in individuals with an ABI with low mood and/or activity levels delivered both online and in person. Feasibility and acceptability will be based on participant retention from baseline to 1-month post-intervention, acceptability of the proposed skills in the group sessions and assessments, and participant feedback from qualitative interviews. Although the original protocol was set to deliver all group sessions in person, the COVID-19 pandemic and resulting social distancing regulations meant that the study pivoted to online delivery in March 2020. This offered the opportunity to compare the two forms of delivery. Therefore, this study reports both the combined results and, where appropriate, in-person and online results separately.

The secondary objective of the MAPLES trial is to explore whether *either* traditional or experiential Behavioural Activation potentially leads to changes in mean activity level and related outcomes including depression, anxiety, post-traumatic stress, motivation, participation, and sense of control, compared to a Waitlist Control (WL) condition at the group level in individuals with an ABI.

Methods

Trial Design

The MAPLES trial is a parallel arm randomised controlled trial with nested qualitative research. Participants were allocated on a 1:1:1 ratio.

Research Ethics Approval and Consent

This trial received ethical approval from the Health Research Authority of the UK National Health Service (East of England – Cambridge Central, REC reference: 18/EE/0305). The trial was registered at clinicaltrials.gov on 12 Mar 2019 (NCT03874650) where the

protocol can be accessed. All participants were taken through an informed consent process prior to beginning participation. Approval to conduct the groups online was obtained on June 5th 2020.

Study Setting

Participants were recruited from two NHS sites within the Cambridgeshire region in the UK. In person sessions were held in NHS sites or at the MRC Cognition and Brain Sciences Unit, depending on participant availability and preference. Following the onset of COVID-19 in the UK, non-COVID research was halted across all NHS Trusts, thus recruitment expanded to department research panels, ABI charities such as Headway and the Stroke Association, and self-referrals via social media. These sessions were delivered online using videoconferencing software. Differences between these samples (e.g., experience with similar groups, differences in abilities across recruitment sources) are considered in the discussion.

Eligibility Criteria

Participants were included in the trial if they met the below criteria:

1) Have a diagnosis of an ABI[10]
2) Were 18 years of age or older
3) Spoke and comprehended English
4) Were a minimum of 3 months post-ABI
5) Were identified as having low mood/reduced activity level. These were identified by either:
    a. A score of at least 7 on the depression subscale of the Hospital Anxiety and Depression Scale (HADS-D; Zigmond & Snaith, 1983), or

[10] This included traumatic brain injury, stroke, anoxia/hypoxia, encephalitis and other brain infections, and resected brain tumours.

b. Clinician report (i.e., through the clinician's own administration of the HADS-D within the past 3 months of screening date or clinical interview that has indicated a client has low mood/would benefit emotionally from increased activity level).

Participants were excluded from the trial if they:

1) Were incapable of attending to and/or understanding the intervention materials. This was based on clinical judgment from the referrer (i.e., has receptive aphasia, does not have capacity to consent, is unable to live independently)
2) Had a diagnosis of dementia or other neurodegenerative disorder
3) Unstable psychotropic medication (i.e., started/changed medications in past 6 weeks)
4) Active suicidality (i.e., had attempted suicide in the past 3 months, currently self-harming, and/or had suicidal intentions for the near future)

Interventions

Both groups met once weekly for approximately 1.5 hours over 8 weeks. Group sizes ranged from 3 to 6 individuals. Participants in the WL Group, who received standard care for 8 weeks between baseline and the second assessment, were re-randomised to either the AP or AE Group (see *Methods – Sequence Generation* for details on allocation). An overview of the core components of each intervention is shown in Table 22.

Therapist Training and Characteristics

I facilitated both the Activity Planning and Activity Engagement groups. I received training on the intervention (approximately 6 hours) and regular clinical supervisions from a registered clinical psychologist and from senior members of the research team.

Activity Planning Group	Activity Engagement Group	Waitlist Control Group
• Activity scheduling and monitoring	• Participant autonomy	• No contact with research team during wait period
• Identifying avoidance patterns	• Direct experience of selected activity in session	• No in-depth information about either study group
• Problem solving barriers to activation	• Focus on social engagement	• Not discouraged from continuing other forms of care
• Step-by-step activity planning	• Non-linear group structure	
• Enhancing planning through goal management	• No explicit planning of activities	

Table 22. Core components of each group.

Activity Planning (AP) Group

The AP group was designed in line with typical BA interventions (for a review, see Kanter et al., 2010). The design of the intervention was informed by interviews with participants with ABI and their family members, as discussed in Chapter 4 of this thesis.

AP Group sessions centred on increasing engagement in meaningful and positive activities. When planning activities, participants were instructed to "task split" and break down the activities into steps. Participants were instructed to monitor their mood and participation in these activities to help identify the connection between the two (Lewinsohn, 1976; Lewinsohn et al., 1985a). Participants also identified counter-productive patterns of avoidance, including distraction and goal neglect, and practiced strategies that may help to overcome these patterns (Levine et al., 2000; 2011). The AP Group covered 8 overarching topics, described below. A more detailed topic discussion guide is in the thesis *Appendix.*

1) Introduction to Group Therapy

- Overview of BA and the relationship of activity level to mood
- Psychoeducation on why planning activities can be difficult after ABI
- Introduction to mood monitoring and monitoring lapses in attention

2) Identifying Enjoyable Activities

- Discuss monitoring homework
- Identify activities that align with personal goals and values
- Schedule first activity using task splitting

3) Changing Habits and Planning Pleasurable Activities

- Review planned activity homework and discuss impact on mood (henceforth "Review homework")
- Psychoeducation on how activities become habitual
- Identify personal triggers that interfere with activity completion
- Schedule an activity using task splitting

4) Goal Review and Balancing Enjoyable and Routine Activities

- Review homework
- Review Session 2 values and goals
- Reflect on whether current activities negatively contribute to mood and whether these can be altered
- Schedule an activity using task splitting

5) Identifying Solutions to Goal Attainment

- Review homework
- Psychoeducation on identifying avoidance patterns to activities
- Psychoeducation on preventing task distraction
- Schedule an activity using task splitting

6) Increasing Mastery and Managing Fatigue

- Review homework
- Discuss benefits of consistently increasing activity levels
- Psychoeducation on warning signs of fatigue when increasing activity levels

- Schedule an activity using task splitting, encouraged to raise activity level further

7) Active Approaches to Engagement

- Review homework
- Psychoeducation on importance of social relationships to a good mood
- Identify barriers to taking initiative to plan activities with other people
- Role play sessions practicing initiating activities with other people
- Schedule an activity using task splitting

8) Relapse Prevention

- Review homework
- Review content from past 7 sessions and list "take home" messages
- Identify personal triggers for relapse and create strategies to overcome triggers
- Schedule an activity using task splitting, encouraged to continue engaging in activities beyond group end

Activity Engagement (AE) Group

The AE Group took a "hands on" approach to increasing activity level. Individuals randomised to this arm engaged in various potentially rewarding activities such as board games and crafts. Participants in this group did not receive specific training on increasing activity level outside of weekly sessions or overcoming barriers to participation.

At the start of the 8 weeks, participants were told that one approach to increasing activity level is to "learn by doing" and that as part of the group they will take part in potentially interesting/creative activities. Participants were offered suggestions by myself, such as board games, painting, and "pub quizzes." Session activities were selected based on those typical of ABI charities. Participants were also encouraged to suggest activities within the group. There was no requirement to choose a different activity for each session; e.g.,

participants could have played board games for all 8 sessions if they wished. This somewhat paralleled the AP group in which individuals choose their own activities to schedule.

Waitlist (WL) Control Group

To control for repeated exposure to the assessments, and as a baseline of general variability in activity levels and mood against which to compare groups, approximately one third of participants were first assigned to the WL Group. At the end of the 8 week waiting period, participants completed a second baseline assessment, and were then immediately re-randomised into either AP or AE groups.

Intervention Fidelity

All group sessions were audio recorded to allow coding for intervention fidelity. Two research assistants not conducting the intervention retrospectively listened to 25% (approximately 42 hours) of sessions to determine protocol adherence. Fidelity in the AP Group was assessed by identifying whether the therapist covered the components outlined in the Fidelity Checklists (see *Appendix*) in a suitable manner (i.e., not skimmed). Given the inherently flexible nature of the AE Group, general principles (e.g. not discussing planning activities outside of the sessions) rather than specific content was used to evaluate fidelity.

Primary Objective

Feasibility and acceptability were determined based on 1) ability to meet recruitment targets; 2) attrition levels across the three groups; 3) group attendance; 4) a post-study questionnaire where participants were asked to rate aspects of their group, and 5) qualitative data from a post-study questionnaire and exit interview, which included questions about participants' experience within each group. These outcomes were evaluated based on the following targets for each objective:

Quantitative Targets

1) For each set of trial arms conducted, a minimum of 9 people and maximum of 18 participants recruited (i.e., minimum of three people in the AP, AE, and WL groups in parallel)
2) Attrition levels less than 20% across the three arms of the trial
3) Each participant attending at least 5 of 8 sessions within the AP and AE Groups

Mixed-Methods Targets

4) Sufficiently positive ratings of group aspects in the Post-study Questionnaire
5) Minimal barriers to attendance and engagement in groups reported relative to benefits discussed in the qualitative data.

Participant Timeline

Participants were recruited for approximately 18 months, and enrolled on a rolling basis into 7 successive cohorts or "waves". Figure 18 presents the participant timeline.

Sample Size

Although typically power calculations are conducted for definitive trials, the primary objective of the MAPLES trial was to determine the feasibility and acceptability of the intervention. Approximately 20 participants per arm (a total of 60 participants) was considered sufficient to give a reasonable balance between determining feasibility and exploring effect on outcome between the groups.

Recruitment

Participants recruited through any source were first given invitation letters, providing a brief summary of the study. Individuals expressing interest were screened by myself to determine eligibility. If eligible, an appointment was made to take informed consent (either written or electronic) and conduct a baseline assessment using the measures specified below.

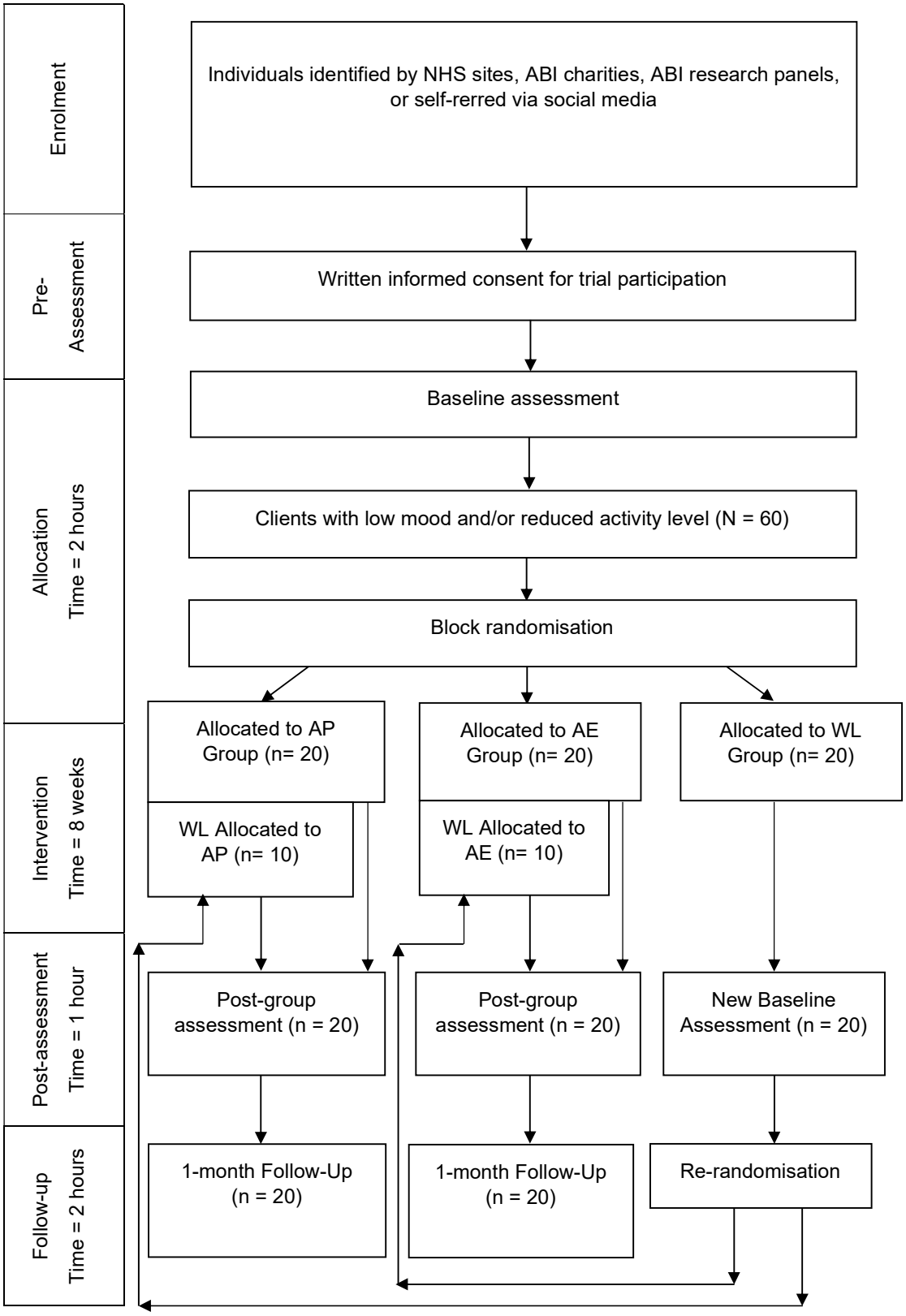


Figure 18. Participant flow diagram with expected numbers.

AP = Activity Planning, AE = Activity Engagement, WL = Waitlist Control

Allocation – Sequence Generation

The trial used pre-determined block randomisation. The trial statistician conducted a computer-generated, pseudo-random allocation prior to beginning recruitment. Blocks were of varying length to reduce likelihood of guessing the allocation sequence, unknown to all researchers with the exception of the trial statistician. Participants first assigned to the WL Group were re-randomised again using pre-determined block randomisation.

Allocation Concealment Mechanism, Blinding and Implementation

The statistician placed the condition allocation for each prospective participant into a separate sealed opaque envelope. Envelopes were taken in sequence to each initial assessment and opened after the assessment was complete (i.e., the first assessment was therefore blind to condition). This process was repeated for the re-randomisation of WL group participants. Quantitative assessments at Time 2 and 3 were conducted by research assistants blinded to condition. However, it was impossible that the researchers conducting qualitative assessments (that discussed specific group experiences) could be blinded.

Data Collection Methods

Depending on COVID-19 restrictions, participants gave informed consent in person or online via videoconferencing. Participants were also asked if they consented to researcher access to medical records for details of the ABI. Consenting to such access was not a condition of participation. Demographic information, such as age, gender, ethnicity, and occupational status, were then recorded. Participants then completed the baseline assessment (Time 1).

Secondary Objective – Outcome Measures

The *Behavioural Activation for Depression Scale* (BADS; Kanter et al., 2007; 2009) was the primary outcome measure used to estimate the therapeutic benefit of the groups. Additional exploratory analyses of secondary outcome measures were also conducted. The

secondary measures were selected based on their direct relevance to BA theory (measures of mood or activity levels), to internal processes associated with mood state (behavioural inhibition, internal and external motivation, anhedonia), and secondary processes that may mediate response to the intervention (sense of control, intolerance of uncertainty). Measures of inductive reasoning and expectations of the intervention were used only at Time 1 to characterise the sample and to assess perceived credibility of the groups, respectively.

The BADS is a 25-item measure of activation and avoidance behaviours considered to underlie depression. A description of the short-form version of this measure is in Chapter 2. This longer version consists of 4 subscales: Activation ("I was an active person and accomplished the goals I set out to do"), Avoidance/Rumination ("I did things to avoid feeling sadness or other painful emotions"), Work/School Impairment ("My work/schoolwork/chores/responsibilities suffered because I was not as active as I needed to be"), and Social Impairment ("I was not social, even though I had opportunities to be"). Items are rated on a 7-point scale, ranging from 0 (Not at all) to 6 (Completely). Total scores can either be summed per subscale, or the scale total can be used. Total scores range from 0 to 150. Higher scores indicate greater behavioural activation. The BADS has good factor structure, internal consistency, test-retest reliability and construct validity outside of ABI (Kanter et al., 2007; 2009).

Secondary Outcome Measures

The *Hospital Anxiety and Depression Scale* (HADS; Zigmond & Snaith, 1983) is 14-item self-report measure of symptoms of anxiety and depression (7 items each). See Chapter 3 for a full summary of this measure.

The *Behavioural Inhibition Scale/Behavioural Activation Scale* (BIS/BAS; Carver & White, 1994) is a 20-item measure that assesses behavioural approach or avoidance motivational tendencies that underlie behaviour. The BAS portion contains 3 subscales: Drive

("I go out of my way to get things I want"), Fun Seeking ("I crave excitement and new sensations"), Reward Responsiveness ("When I get something I want, I feel excited and energised"), whilst the BIS is a single subscale ("I worry about making mistakes"). Items are rated on 4-point Likert scale, ranging from 1 (Strongly Agree) to 4 (Strongly Disagree). Scores on the Drive and Fun Seeking subscales range from 4 to 16, and Reward Responsiveness from 5 to 20, with higher scores indicating greater activation. The BIS scale ranges from 7 to 28, with higher scores indicating greater inhibition. The BIS/BAS subscales have good internal consistency and factor structure, adequate test-retest reliability, and convergent and discriminant validity outside of ABI.

The *Intolerance of Uncertainty Scale – Short Form* (IU-SF; Carleton et al., 2007) is a 12-item measure of responses to uncertainty, ambiguous situations, and the future. The IU-SF has two subscales: Prospective Anxiety and Inhibitory Anxiety. For a full summary of details on this measure, see Chapter 2.

The *Impact of Events Scale-Revised* (IES-R; Weiss et al., 2007) is a 22-item measure that assesses post-traumatic symptoms within the past week via three subscales: Intrusion ("Any reminders brought back feelings about [traumatic event]"), Avoidance ("I tried not to talk about [traumatic event]"), and Hyperarousal ("I was jumpy and easily startled"). Items are scored on a 5-point Likert scale ranging from 0 (Not at All) to 4 (Often). Scores on Intrusion and Hyperarousal range from 0 to 35, and scores on Avoidance range from 0 to 40. Total scores range from 0 to 110, with higher scores indicating greater post-traumatic stress. The IES-R has good internal consistency (Sveen et al., 2010; Baumert et al., 2004), and acceptable discriminative, convergent, divergent, and concurrent validity outside of ABI (Beck et al., 2008).

The *Brain Injury Rehabilitation Trust Motivation Questionnaire-Self* (BMQ-S; Oddy et al., 2008) is a 34-item questionnaire that measures difficulties with motivation after ABI. See Chapter 2 for a full description of this measure.

The *Motivation for Traumatic Brain Injury Rehabilitation Questionnaire* (MOT-Q; Chervinsky et al., 1998) is a 31-item measure of motivation for rehabilitation activities in ABI. It consists of four subscales: Lack of Denial ("I have always had the problems I am having now" [reverse scored]), Interest in Rehabilitation ("Rehabilitation is very useful"), Lack of Anger ("Rehabilitation therapists can't help me with my problems" [reverse scored]) and Reliance on Professional Help ("I rely on doctors to help me with my problems"). It uses a 5-point Likert scale rated from -2 to +2 (Strongly Disagree to Strongly Agree). Total scores range from -62 to +62, with higher scores indicating greater motivation for rehabilitation. The MOT-Q subscales have shown good internal consistency (Chervinsky et al., 1997) and has been found to have good test-retest reliability (Kusec et al., 2018).

The *Modified Outcome Measure – Participation Objective, Participation Subjective* (MOM-POPS; Brown et al., 2004) is a shortened version of the original POPS scale, a measure of community integration post-TBI. In the MOM-POPS, participants are asked to 1) provide an estimate of the amount of household, occupational, and social activities engaged in within the past week (Participation Objective); 2) whether they would like to do more, less, or the same amount of these activities (Participation Subjective) and 3), and whether these activities are the most, very, moderate, a little, or not at all important to their satisfaction with life. Participants then select from a list of options (e.g., cleaned the house, volunteering) which activities they have engaged in within the past week, and report any additional activities. The original POPS has shown acceptable internal consistency, good test-retest reliability and ecological validity.

The *Snaith-Hamilton Pleasure Scale* (SHAPS; Snaith et al., 1995) is a 14-item measure of hedonic capacity within the past few days. Items are rated from Strongly Disagree to Strongly Agree. If a participant responds to a Disagree category, they receive a score of 1, and if they respond to an Agree categories, they receive a score of 0. Hence, the scale total range is 0 to 14, with higher scores representing greater hedonia. Example items include "I would enjoy a warm bath or a refreshing shower" and "I would be able to enjoy a beautiful landscape or view." The SHAPS has high convergent and discriminant validity and test-retest reliability (Snaith et al., 1995; Franken et al., 2007; Nakonezny et al., 2010).

The *Sense of Control Scale* (SCS; Lachman & Weaver, 1998a; 1998b) is a 12-item measure of an individual's perceived ability to exert control over their life, comprising two subscales, Personal Mastery ("I can do just about anything I really set my mind to") and Perceived Constraints ("There are many things that interfere with what I want to do"). Items are rated on a 7-point Likert scale, ranging from Strongly Disagree to Strongly Agree. Total scores range from 12 to 84. Factor analysis has supported its two-factor structure, with good internal consistency.

The *Verbal and Spatial Reasoning Test* (VESPAR; Langdon & Warrington, 1995) is a neuropsychological test of inductive reasoning, comprising of six subtests with three word- and picture-based tests each. There are 25 items in each subtest, each beginning with 5 practice items, with answers in multiple choice format. In the practice items of each subtest, participants are instructed to select which multiple choice option is correct, and feedback is given if necessary to help clarify test demands. If a participant fails both of the last 2 practice items of a subtest, then the participant does not move on to the main 25 items. In this study, I used the Verbal Odd One and Spatial Odd One subtests, where participants were asked to select which multiple choice option is the "odd one out." Raw scores were transformed to age-standardised inductive reasoning scores per subtest. This test was only given at Time 1.

The *Credibility/Expectancy Questionnaire* (CEQ) is a 6-item measure of participant expectations and perceived credibility of the treatment (Devilly & Borkovec, 2000). Example items include "How much improvement in your symptoms do you really *feel* will occur?" and "How logical does the therapy offered to you seem?" The CEQ has high internal consistency and test-retest reliability. This measure was only given at Time 1.

I designed the *Post-Study Questionnaire* (PSQ) to obtain general feedback on the MAPLES trial. Participants provided responses to questions focused around enjoyment of the group and factors involved in group attendance, such as "Do you see any benefits to being part of group sessions?" Participants were encouraged to provide any additional comments to support their answers, or comment on any topic that was not specifically addressed in the PSQ. A copy of the PSQ can be found in the thesis *Appendix.*

The Exit Interview

Twenty participants were randomly selected to take part in an exit interview at Time 3. This comprised a series of in-depth questions to gain more specific feedback about participants' experiences in the groups. Examples and prompts were used to facilitate recall. If participants took part in the AP group, they were asked to comment specifically on the content and materials. Participants were asked about practical aspects that may have affected their participation, such as a relationship with a partner, or transport or health difficulties. A copy of the Exit Interview is in the *Appendix.*

Participant Remuneration

Individuals who took part in-person received travel reimbursement for each session attended (Time 1, 2, 3, and group sessions) as well as £50 compensation at the Time 3 assessment. Participants who took part online received the £50 compensation at the Time 3 assessment only.

Data Management

Any outcome measures with less than 20% of missing items had their total scores imputed by using averaged responses from answered items. Any participant with more than 20% of items missing from any of the above measures (e.g., more than 2 items missing on a 10-item scale) at any time point was treated as a missing value.

Time 2 assessments from the WL group served two purposes. These were used as Time 2 data for comparison with Time 2 data from those initially randomised to AP or AE. They were also used as pre-group attendance baseline scores (i.e. effectively "Time 1") to then examine any changes post AP or AE group in these former WL participants.

Quantitative and Qualitative Data Analysis

A CONSORT flow diagram was created to visualise the participant pathway throughout the study. Percent attrition rates, at what point attrition occurred, and number of sessions attended per participant, along with ratings of helpfulness and enjoyableness of each group, were calculated to inform conclusions about the acceptability of the trial. Missing data points, as well as reasons for drop-out and non-attendance are additionally reported.

Quantitative data were analysed using R statistical software version 4.0.3 (R Core Team, 2020). Demographic variables of the participants allocated to each group are reported (see Table 23). Data were analysed using an intention-to-treat analysis by including all randomised participants. Exploratory analyses were conducted to estimate the effectiveness of the AP and AE groups and determine effect size estimates for a power analysis for a definitive trial. A linear mixed-effects model using the primary outcome measure, the BADS, across the multiple assessment points was used. Linear mixed-effects models are a superior method to analysing trial data relative to a repeated measures ANOVA for two reasons. First, linear mixed-effects models provide the most likely estimate of effect given incomplete longitudinal data through maximum likelihood estimation (i.e., providing parameter estimates

that are most probable based on the observed data). Repeated measures ANOVA, by contrast, perform listwise deletion of missing data, potentially resulting in less accurate estimates. Second, mixed-effects models allow for modelling of the impact of random effects on the dependent variable that are not explicitly modelled as a fixed effect (e.g., time point, group allocation). For example, participants within a group may have higher levels of variability due to the timeline in the trial at which data was collected (i.e., study "wave"). As only those in the WL Group were re-randomised, there are unlikely to be carry-over effects that influence treatment effects in the subsequent group allocation. Thus, treatment effects of these individuals were not expected to differ from participants initially allocated to the AE and AP. The Minimal Clinical Important Difference (MCID; see *Results* for details on calculation) of the BADS and the secondary outcome measures were additionally estimated to inform interpretation of clinically meaningful change.

Qualitative data from the PSQ and Exit Interview were considered in relation to the acceptability of the AP and AE Groups. Data were analysed using an interpretive description framework, a methodology developed to identify clinically relevant information in complex health care populations (Thorne et al., 1997; 2004). As described in more detail in Chapter 4, qualitative data were approached with a constructivist epistemological stance and are presented here as a thematic summary (Thorne et al., 2016). As all participants received the PSQ, and approximately 30% of participants received the Exit Interview, pre-specifying saturation was not possible. Potential themes of importance were discussed in a peer debriefing session among myself and my supervisory team using selected transcripts of participants who had positive and negative experiences of group participation.

Harms

The management and reporting of adverse events were conducted as per Medical Research Council protocol. Although participants may have experienced heightened negative

affect (e.g., in discussing difficulties with engaging in meaningful activities) this was considered a normal aspect of psychological therapies. Precautions were taken to reduce the probability of adverse events (e.g., not recruiting participants reporting active suicidal intent). Any cases of adverse events or harms are reported in the results.

Results

A CONSORT flow diagram of the study outcomes is shown in Figure 19. Sixty participants were randomised, with 25 randomised pre-COVID and 35 randomised during COVID. Due to the re-randomisation design, for the last wave of the intervention (Wave 7, February to March 2021), participants who were first randomised to the WL Group (4) based on the predetermined randomisation sequence, were immediately re-randomised by opening the second randomisation envelope, and assigned to either the AP or AE group. This was done to ensure all participants could take part in one of the two active interventions. This resulted in 22 participants in total for the AP and AE Groups each, and 16 in the WL Group.

The main reason for exclusion was not meeting study eligibility criteria (n = 37). A detailed summary of reasons for exclusion are shown in Table 23.

Reason Excluded (N = 74)	In Person	Online	Total
Did not Meet Eligibility Criteria			
No Low Mood/No Low Activity Level	11	12	23
Incapable of Attending to Study Materials	5	1	6
Current Psychotherapy	4		4
Suicidality/Risk of Immediate Harm to Self	2		2
Does not speak English	1		1
Recent Change in Psychotropic Medication	1		1
Declined Participation/No Longer Interested	12	10	22
No Response after Expression of Interest	7	3	10
Other			
Mobility Issues Affecting Participation	1		1
Client Wants Limited Input in Services	1		1
Due to Move away from Study Location	1		1
Lives Outside of UK		1	1

Table 23. Summary of reasons for exclusion from the trial. Of note, current psychotherapy was no longer an exclusion criteria following a protocol amendment approved December 2019.

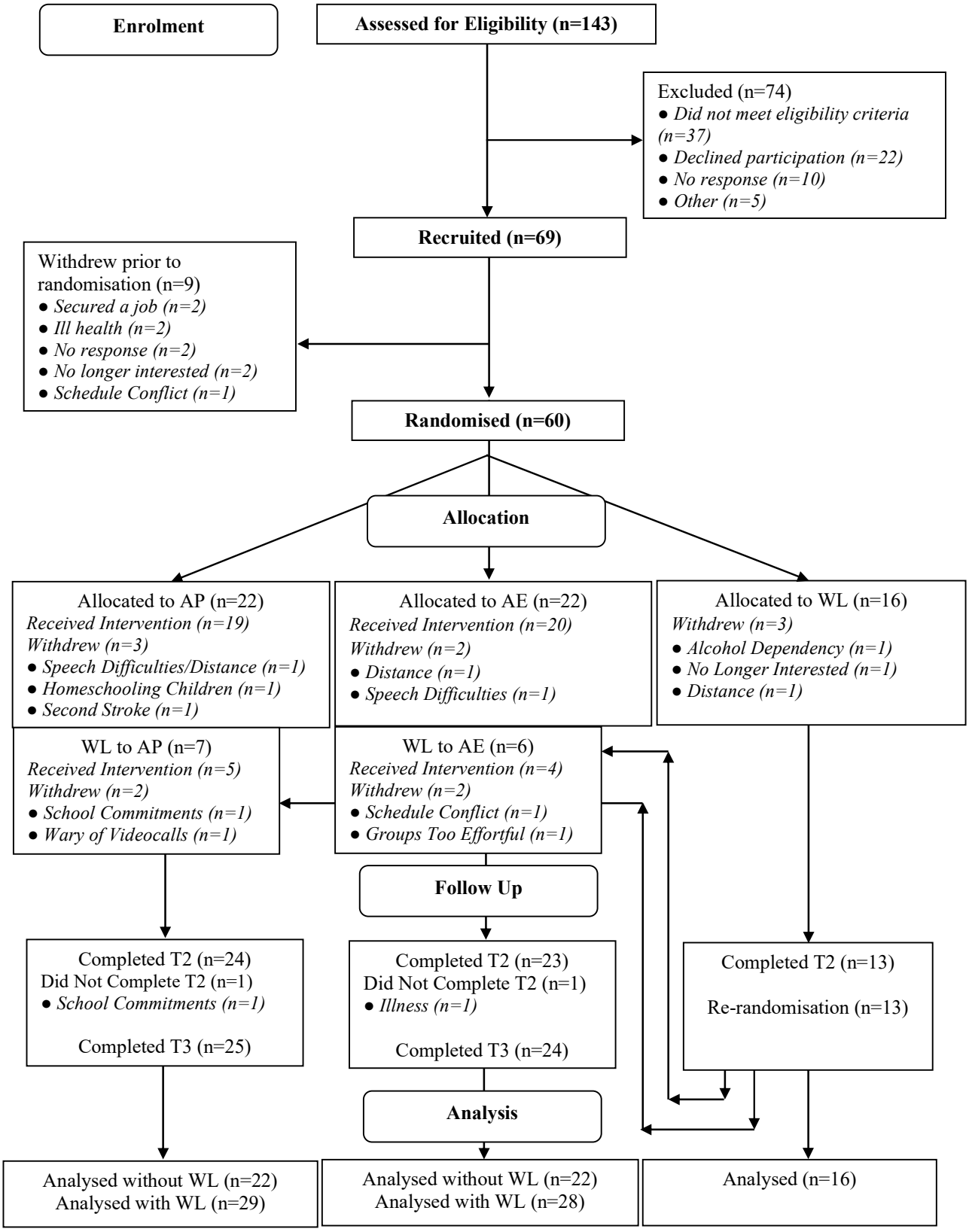


Figure 19. CONSORT Flow Chart of recruitment into the MAPLES study.
AP = Activity Planning Group, AE = Activity Engagement Group, WL = Waitlist Controls.

Participant demographics of the 60 randomised participants are presented in Table 24. There were no statistically significant differences between groups at baseline on these characteristics. The sample was majority White British, with the WL Group comprising only White British participants.

	Activity Planning (n = 22)	**Activity Engagement** (n = 22)	**Waitlist Controls** (n = 16)	**Group Differences**
Age – M (*SD*)	52.45 (11.03)	53.59 (12.41)	54.94 (11.89)	$p = 0.81$
Gender (*n*, %)				
Male	12 (54.5%)	12 (54.5%)	7 (43.8%)	$p = 0.45$
Female	10 (45.5%)	10 (45.5%)	9 (56.2%)	$p = 0.97$
Ethnicity (*n*, %)				
White British	21 (95.5%)	18 (81.8%)	16 (100%)	$p = 0.71$
White Other		2 (9.10%)		$p = 0.14$
Black British		2 (9.10%)		$p = 0.14$
Asian British	1 (4.50%)			$p = 0.37$
Type of ABI (*n*, %)				
Traumatic Brain Injury	9 (40.9%)	6 (27.3%)	6 (37.4%)	$p = 0.65$
Stroke	8 (36.4%)	13 (59.1%)	5 (31.3%)	$p = 0.15$
Other	5 (22.7%)	3 (13.6%)	5 (31.3%)	$p = 0.74$
Years Post-ABI – M (*SD*)	7.92 (9.44)	5.91 (7.48)	7.93 (7.28)	$p = 0.67$
Employment Status (*n*, %)				
Full Time	3 (13.6%)			$p = 0.05$
Part Time	1 (4.50%)	3 (13.6%)	2 (12.5%)	$p = 0.61$
Unemployed	7 (31.8%)	5 (22.7%)	2 (12.5%)	$p = 0.26$
Medical Retirement	6 (27.3%)	9 (40.9%)	5 (31.2%)	$p = 0.52$
Retirement	3 (13.6%)	3 (13.6%)	2 (12.5%)	$p = 0.88$
Student	1 (4.50%)		1 (6.03%)	$p = 0.61$
On Leave		2 (9.10%)	4 (25.0%)	$p = 0.14$
Psychotropic Medication (*n*, %)				
Antidepressant	8 (36.3%)	8 (36.3%)	5 (31.2%)	$p = 0.65$
Antianxiety	3 (13.6%)	5 (22.6%)	3 (18.8%)	$p = 0.70$
No psychotropic medication	11 (50.0%)	9 (40.1%)	8 (50.0%)	$p = 0.78$
Mental Health Diagnosis (*n*, %)	7 (31.2%)	11 (50.0%)	7 (43.8%)	$p = 0.53$
Current Clinical Input (*n*, %)				
None	17 (77.3%)	18 (81.8%)	14 (87.5%)	$p = 0.77$
Clinical Psychology	3 (13.70%)	2 (9.10%)	1 (6.20%)	$p = 0.61$
Occupational Therapy	1 (4.50%)	2 (9.10%)		$p = 0.37$
Physiotherapy	1 (4.50%)			$p = 0.37$
Other			1 (6.20%)	$p = 0.36$
Inductive Reasoning – M (*SD*)				
Verbal	101.56 (10.46)	102.48 (6.67)	109.48 (8.81)	$p = 0.08$
Spatial	103.31 (5.02)	103.57 (6.33)	105.59 (7.39)	$p = 0.63$

Table 24. Participant Characteristics. ABI = Acquired Brain Injury

Primary Objective – Feasibility Outcomes

Due to the COVID-19 pandemic requiring all research to be conducted remotely, feasibility data was summarised for intervention sessions conducted in person separately from sessions attended remotely via videoconferencing.

Recruitment Outcomes

In general, recruitment targets were met only when including participants re-randomised from the WL group; otherwise, the minimum target recruitment was only met for Wave 1 and Wave 4 (see Table 2 for an overview).

Protocol Target	**Actual**						
Minimum 9, Maximum 18 participants recruited per wave	Wave 1 Jun–Jul 2019	Wave 2 Sep–Nov 2019	Wave 3 Feb–Apr 2020	Wave 4 Jun–Jul 2020	Wave 5 Sep–Nov 2020	Wave 6 Oct–Dec 2020	Wave 7 Feb–Mar 2021
	9	8 (+3 WL)	8 (+1 WL)	11 (+2 WL)	8 (+4 WL)	7 (+0 WL)	8 (+2 WL)

Table 25. Total number of new participants recruited per wave, with participants re-randomised to an active intervention (Activity Planning or Activity Engagement) included in brackets. Recruitment for solely online adaptations of the active interventions began in Wave 4.
WL = Waitlist Controls.

Prior to the first COVID-19 lockdown in the UK (March 23 2020), the majority of participants recruited were from NHS ABI rehabilitation services (19 of 25), and during COVID-19 the majority of participants were recruited from ABI charities (22 of 35). A summary of participants assessed for eligibility versus those randomised by recruitment source is shown in Table 26.

Assessed (Randomised)	**NHS ABI Services**	**Research Panel**	**Self-referral via Social Media**	**ABI Charity Groups**
In Person	58 (19)	28 (3)	0	3 (3)
Online	0	5 (3)	21 (14)	30 (18)
Total	58 (19)	31 (6)	21 (14)	33 (21)

Table 26. Participants assessed ($N = 143$) versus those randomised ($N = 60$) per recruitment source.

Study Withdrawal

A summary of study withdrawal rates across groups is shown in Table 27. When including participants who were re-randomised to one of the two active intervention groups, attrition was less than 20% across the three arms. Not including those who were re-randomised, withdrawal rates were 13.6%, 9.1%, and 18.8% in the AP, AE, and WL Groups, respectively.

Protocol Target	Actual			
Attrition Less than 20% Across All Trial Arms		Activity Planning Group (n = 29)	Activity Engagement Group (n = 28)	Waitlist Controls (n = 16)
	In Person	n = 2	n = 1	n = 2
	Online	n = 3	n = 3	n = 1
	Total	n = 5 (17.2%)	n = 4 (14.8%)	n = 3 (18.8%)

Table 27. Summary of attrition between the Activity Planning and Activity Engagement Groups.

Reasons for study withdrawal are visualised in Figure 20. The most common reason for withdrawal across all arms was difficulties travelling to the study location (n = 3), followed by speech difficulties within group sessions (n = 2).

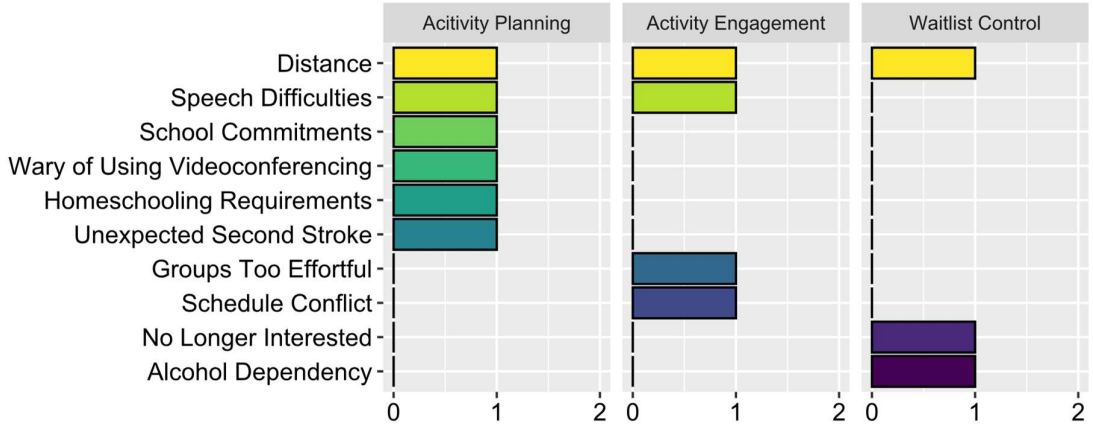


Figure 20. Reasons for study withdrawal across all three arms of the trial. The number on the x-axis indicate how many participants withdrew per reason, per group. Of note, one participant withdrew due to both travel distance and speech difficulties in the Activity Planning Group thus contributed to two categories in the figure.

Intervention Session Attendance

A summary of attendance by intervention group is shown in Table 28. Including participants who withdrew, average attendance did not differ between the AP and AE Group (t = -0.38, p = 0.70). However, the mode number of sessions attended in person rose from 7

to 8 when delivered online. Attendance did not differ whether conducted in person or online for the AP group (t = -1.25, p = 0.22) or the AE group (t = -0.55, p = 0.59).

Protocol Target	**Actual**		
At least 5 out of 8 sessions attended		Activity Planning Group	Activity Engagement Group
	In Person	5.90 (Mode = 7)	6.50 (Mode = 7)
	Online	6.89 (Mode = 8)	6.88 (Mode = 8)

Table 28. Summary of average attendance between the Activity Planning and Activity Engagement Groups, including those who withdrew.

An overview of session attendance per wave is shown in Figure 21. The pattern of session attendance across study waves was variable, most notably for Wave 3, which was halfway completed when the first UK COVID-19 lockdown was announced (March 23 2020). In the AP group, this resulted in no attendees for Week 5 (the first week following the onset of lockdown) and a participant withdrawing due to security concerns about videoconferencing. In the AE Group, this resulted in only one person in attendance for Weeks 5 and 6 and another group member, who did not wish to attend the group online for Week 5, was hospitalised due to COVID-19 but opted to complete the Time 3 assessment.

Figure 21. Total group session attendance per recruitment wave in the AP Group (above) and the AE Group (below). X-axes denote session number, and y-axes number of participants. Waves 1, 2, and the first half of Wave 3 were conducted in person. Waves 4 to 7 were conducted remotely via videoconferencing.

The most commonly missed session was Session 5 in the AP Group (n = 7), and Session 7 in the AE Group (n = 5). A full list of reasons for non-attendance is shown in Figure 22. Generally, the majority of reasons were independent of study factors or group content.

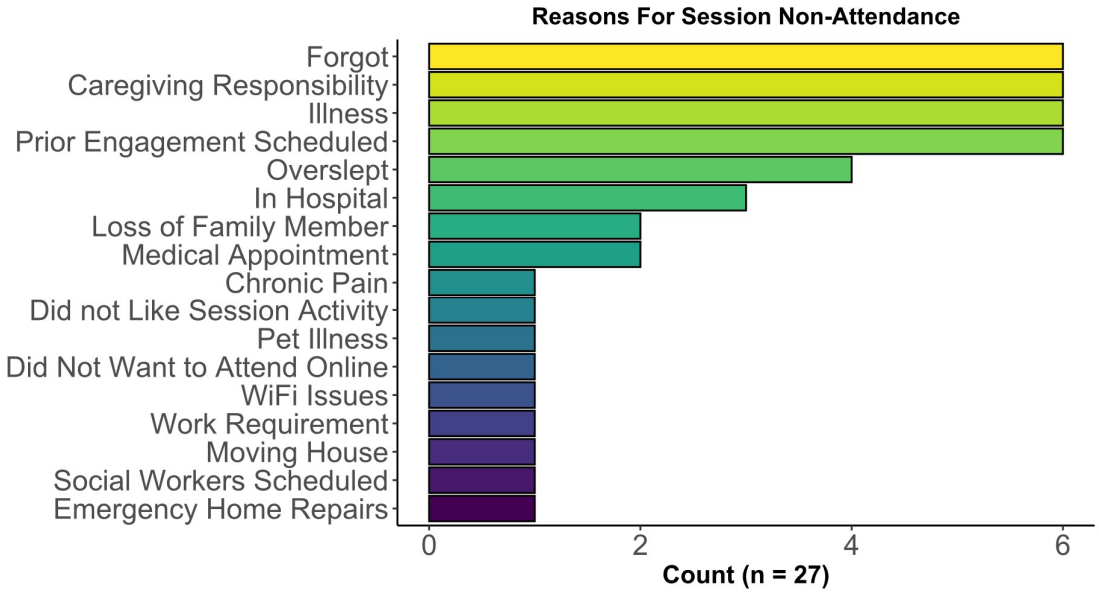


Figure 22. Reasons for session non-attendance in the AP and AE Groups. Number on the x-axis indicate the total number of times a reason for non-attendance occurred. A total of 44 sessions were missed across 27 participants.

Acceptability Outcomes

Credibility and Expectations of the Interventions

Before beginning the intervention, the AP group approach was perceived by participants to be slightly more "logical" than the AE group ($t = 1.98$, $p = 0.05$). There was no difference in perceptions of how effective each group would be in increasing activity level ($t = 1.79$, $p = 0.08$) or in the reported likelihood that either group would be recommended to a friend ($t = 0.87$, $p = 0.39$). Participants assigned to either group were as likely to report feeling that their activity levels would improve ($t = 1.35$, $p = 0.18$).

Post-Study Questionnaire – Quantitative Data

Overall, responses on the PSQ were positive for both groups. An overview of the quantitative PSQ data is shown in Table 29.

PSQ Item	Activity Planning		Activity Engagement	
	In Person	Online	In Person	Online
Focus on Activity Levels is Beneficial - % Agree	100%	100%	100%	100%
Group Sessions are Beneficial - % Agree	100%	100%	91.7%	100%
Regular Contact From Research Team is Helpful % Agree	100%	94.4%	91.7%	100%
Helpfulness of Group – M (SD), Min – Max	8.33 (1.12) 7 – 10	8.31 (1.58) 5 – 10	6.82 (2.36) 3 – 10	7.69 (1.93) 2 – 10
Enjoyableness of Group – M (SD), Min – Max	8.56 (1.59) 6 – 10	8.75 (1.73) 4 – 10	7.73 (2.37) 3 – 10	9.23 (1.01) 7 – 10
Barriers to Attendance – M (SD), Min – Max	1.75 (1.67) 0 – 4	3.31 (2.41) 0 – 9	1.45 (1.57) 0 – 4	2.54 (1.85) 0 – 7

Table 29. Summary of responses to Post-Study Questionnaire (PSQ) per group for participants who attended in person versus online.

Across in person and online versions, both the AP and AE Groups were rated as similarly enjoyable ($t = 0.27$, $p = 0.79$), though the AP Group was rated as marginally more helpful than the AE Group ($t = 2.15$, $p = 0.04$). The AP group was rated as similarly helpful ($t = 0.03$, $p = 0.97$) and enjoyable ($t = -0.28$, $p = 0.78$), whether delivered in person or online. The AE group was similarly helpful both online and in person ($t = -0.99$, $p = 0.33$), though was rated marginally more enjoyable when delivered online ($t = -2.08$, $p = 0.04$).

Barriers to Attendance

An overview of barriers to attendance is presented in Figure 23. The average number of barriers per person for the AP (M = 2.88) and AE Groups (M = 2.04) did not significantly differ ($t = 1.43$, $p = 0.16$). There appeared to be variations in which barriers were present,

though only fatigue being less frequently reported as a barrier in the AE group was statistically significant ($t = 2.99$, $p < 0.01$).

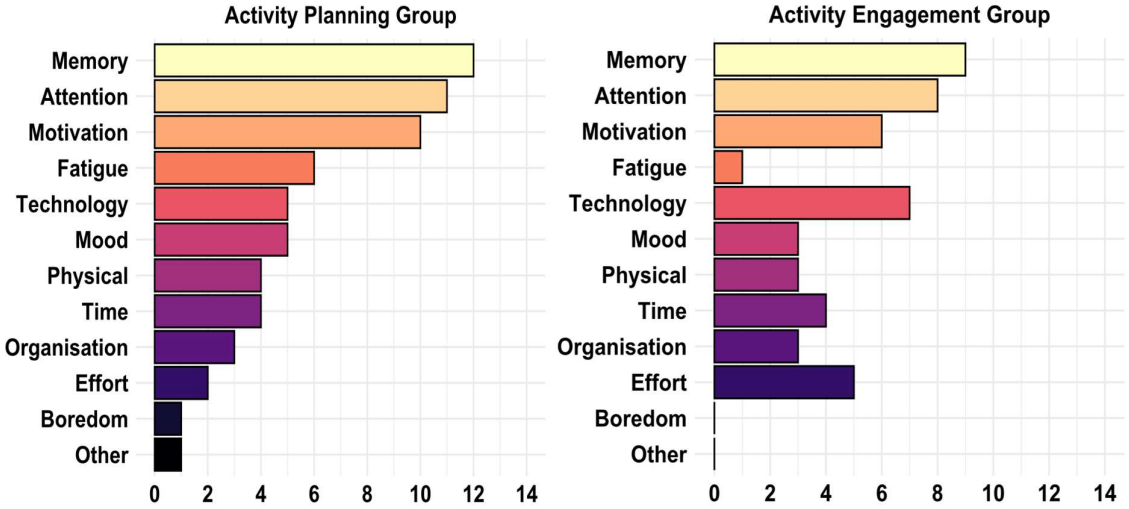


Figure 23. Frequency of each barrier to attendance across all participants in the AP Group (left) and AE Group (right).

Number of barriers reported for the AP group was similar when attending online compared to attending in person ($t = -1.78$, $p = 0.09$). Similarly, there were no statistically significant differences in number of barriers when attending the AE Group online relative to in person ($t = -1.53$, $p = 0.14$). Regardless of group, attending online was associated with more reported barriers than in person groups in the areas of attention, fatigue, technology and organisational problems (ts = -2.89 – -3.78, ps < 0.01).

For the AP group specifically, technology, fatigue, and attention barriers were more frequently reported when attending online versus in person (ts = -2.58 – -4.24, ps < 0.05). For the AE group specifically, organisational barriers were more frequently reported when attending online ($t = -2.28$, $p = 0.04$).

Acceptability Outcomes – Qualitative Feedback on Groups

Qualitative data from the PSQ and Exit Interview were used to explore participant perspectives of acceptability of the groups, specifically aspects that positively or negatively contributed to helpfulness, enjoyableness, and overall benefit from study participation.

Pseudonyms are used to present the data. The first part of this section summarises overall participant-reported views of the groups, highlighting common and divergent themes. The second part summarises how practical aspects of the study design and implementation contributed to participant experiences. As speech difficulties were a common reason for study withdrawal, the final part of this section discusses qualitative data from those with aphasia and provides a summary of recommendations for including those with aphasia into future group BA interventions.

Participant Views on Groups – Activity Planning Group

Space of Shared Progress and Commitment

In discussing planning between-session activities, knowing what others were planning, and hearing about progress of others seemed to foster a sense of shared commitment toward individual and study goals.

> "*I think the group session just made it seem like [completing activities] would be more possible because I'd have to keep up with the group"* Luisa, AP Group
>
> "*We all had tasks that we had to do, we had to achieve something more or less at each session, and so that pushed us to make sure that we did those tasks before we went to the next session."* Oliver, AP Group

Discussing barriers to activities facilitated a sense of shared progress, especially when activities did not go as expected. Emphasising achievable goals within sessions was important.

> "*I've participated in NHS groups before, and because they were setting me goals which weren't achievable, they were making me feel bad about myself. I failed because of that. But with the activities that we just did, it didn't matter if you didn't get to your goal. If you took steps and you understood why you didn't reach that goal, that was OK."* Amy, AP Group

Participants noted that it was difficult to sustain motivation if not all group members appeared to be putting forth equivalent effort.

> *"There's always a challenge when you're working with a group that not everybody is participative or continues with the session. And that's one of the things that happened…so to improve the group…commitment is key, it's so important."* Joe, AP Group

Adapting to New Demands, Taking Steps, and Challenging Negative Thoughts

It took some time to get used to the effort associated with attending weekly AP sessions and remembering to complete between-session activities, and avoidance could occur. This was a source of frustration for group members if it became an ongoing challenge.

> "*I would have to remember this is not something which is the norm, is also meant to be happening in the following week…it's a bit uncomfortable having to remember something as that was new."* Luisa, AP Group

Once the ongoing pattern of the group was established, however, the perceived effort associated with the group reduced.

> "*The first few sessions were quite difficult, and it took me I think to about week three to finally get into, finding maybe discipline, to do my homework and not let other things get in the way. But after that, once I started doing it, I thought, 'no, you can do this.'"* Gemma, AP Group

An aspect of the AP group was perceived to be particularly helpful was learning to take smaller, manageable steps toward activities. The process of breaking down planned activities into steps was something that many participants commented on as beneficial and helped increase the success of planned activities.

> "*Without [the steps], you wouldn't have anything to move on to or to be able to use as a daily achievement, basically. Because it, it split into multiple things that would help*

you achieve what you were trying to achieve in the first block. So it just made everything a little bit easier for you to work your way through them." Leo, AP Group

"*I've taken away this idea of one of the weeks, it was like the kind of homework we got was kind of like plan an activity, um, a guide to breaking it down. And that's something that I've kind of taken forward, that I'm using in like day-to-day."* Phoebe, AP Group

At its most successful, the AP group challenged negative pre-conceptions that a participant couldn't complete a task, enhanced recognition of the potential benefits of attempting activities, and reframed negative thoughts into positive ones.

"*Something which has become a lot more prevalent in my thinking is the importance of doing stuff, to try, and even though you don't want to you can see some sort of benefit in this."* Frank, AP Group

"*[The group] has helped me change from being 'oh God I can't be bothered.' I'm, I'm planning things rather than [my husband] saying to me 'right we're going to do this,' I'm going to him now and saying 'right we're going to do this and that.'"* Joan, AP Group

"Taking care of myself, I've not seen that as selfish. I think it was something [the therapist] said, she used the words self-help instead of selfishness. And I thought, what if I put that selfishness word in there? I thought, who taught me that? Where have I have been carrying this from, and for how long? And the fact that [the therapist] and the group, all those people saying 'well, it's not selfishness, it's self-help.' I thought, 'oh yeah, that's true.' And I had a revelation that way, that I wasn't being lazy or inefficient. I was just unable to do stuff. And I should stop beating myself up about it." Ellen, AP Group

Participant Views on Groups – Activity Engagement Group

Space for Teamwork and Enjoyment

Responses that were specific to the AE group included a sense of teamwork, and within-session activities facilitating conversation. The enjoyment from engaging with others often appeared greater than inherent pleasure/satisfaction with the activities themselves.

> "*I particularly enjoyed the discussion that went around the activities, rather than the activities themselves…I think the best, the ones I enjoyed the most were the sessions where you sort of spontaneously talked about things, as, um, whilst in theory doing other, doing other things. So the activities provided the sort of background level of involvement around which we could talk about."* Arnold, AE Group

Though enjoyment seemed to derive primarily from social interactions, the selection of activities did matter, especially in terms of perceived relevance, interest, and achievability.

> "*Most of the activities I wasn't keen on, I thought they were a bit childish or for older people. They were sort of, the sort of things that were, you know, not particularly useful to me. There was a couple that I liked, but you know a lot of the other stuff I doubt, there was just, I thought it was such a waste of time for me to travel so long to do that."* Ryan, AE Group

Testing Boundaries of Activities and Experiencing Autonomy

Other reasons included cited for positive experiences in the AE group included finding it helpful to try out new activities in a structured environment and testing personal limits.

> "*I think the course showed me that I could put in an hour or two into a solid task. Because I think before then I was little bit too scared to start something because I wasn't sure how far I would get through it."* Gillian, AE Group

The focus on group autonomy and being able to provide input on group content was particularly valued by some.

> "*I think, [the therapist] was not um, it, it didn't really force us to do anything that people didn't want to do, and we were always given the choice of the activities, and we decide which activity we wanted to do."* Don, AE Group

> "*This is the thing why it's good, you are asking me, see you are asking me 'what do you think would be better' that's why it would be better, because you are asking my advice, and that's why I like the group. It weren't just like 'we're doing this and that and that and you got to do it.' It wasn't like that. It was, everything was, it's like you [the interviewer], you actually asked me how I think the group would be better, so straight away you're including me in the conversation rather than asking me a question, 'do you reckon it would be better with that and that or that.'"* George, AE Group

Participant Views on Groups – Experiences Common to Both Groups

The Therapeutic Milieu

Responses that equated to "positive group dynamics" and "sharing experiences of ABI" were common endorsements of both groups. Aspects such as a sense of safety, mutual trust, and respect between group members and the therapist were felt to lead to openness in discussion. Having an ABI-specific "space" in which participants could empathise with, and learn from, each other's experiences was valued and linked with reduced feelings of isolation.

> "*We just got along really well. And the therapist… and me and the two other [group members], we kind of encouraged each other as well, and it was just nice to have that support. When I came away from the group, I felt really good and that feeling carried on."* Gemma, AP Group

"*When I first done the group, you're obviously unsure how it's going to be, but within, within ten minutes, it's almost like I knew I should be there, and I felt like, I don't know…it was, it'd just lift you, going to the group, it does lift you."* George, AE Group

However, a positive group experience could be negatively affected by group members overtaking session time, too much focus on group discussion, or no perceived similarities between group members.

"There is a strong tendency when somebody says they have a difficulty with this for the other people in the group to say 'well I got over that by doing this' or 'I have been in that' and I don't think that's a necessary part of the course…and I think that every time people went there, including myself, because we all want to help, and it's a very natural thing. But it just took a hell of a lot of time. It just took a lot of time. And I don't think it was beneficial." Shirley, AP Group

"*I always thought I had nothing in common with [my group], which made it difficult to strike up a conversation."* Arthur, AE Group

Practical Aspects of Delivering the Study across Both Groups

Group Size, Session Frequency and Duration, and Session Content

Group size was generally recognised to be an important factor. In smaller groups (2 to 4 people), absences or members leaving had a greater negative effect.

"*Our group was supposed to be larger and then we ended up with two in last few [sessions]…A bigger group would definitely had made it better."* Oliver, AP Group

"*We had one participant who was struggling slightly more with the group, and it made me quite sad because she decided to not, not continue with it…I just thought it was a shame, that, it made me sad that she was missing out."* Miranda, AE Group

Larger groups were also thought to increase chances of meeting people with similar interests, impairments, or type of ABI, but they carried the perceived risk of more arguments between members, reduced time for any given participant, and potentially feeling less personal.

"*I kind of understand why [there weren't more people in the groups], because that's where the arguments start, doesn't it."* Don, AE Group

"Smaller groups, I think, are better than larger groups. I've been on courses where there's sort of about 20 of you, and you don't really get to know the other people, but um, with a smaller group, I think there's more, um, the word, I think I'm looking for is companionship." Amy, AP Group

Participants generally found that 8 sessions with a duration 1.5 hours per group was acceptable, however this varied with group size and attendance. Some participants thought that increasing the number of sessions would reduce the impact of missed sessions for an individual and give members more time to gain confidence. There was diversity of views on the relative trade-offs of more/longer sessions (give more time for discussion/activities) and issues such as fatigue, the need for breaks and level of interference with other activities.

"*For me personally, it took a few sessions to be able to have enough confidence to contribute and be part of the group, but then once you got to that point, you know, you knew it was coming to an end so, having more would have been good for me."* Nelson, AP Group

"*I think if it'd gone on for longer, it would be more helpful…I think some of the activities that we all had ideas for took longer than we kind of planned."* Miranda, AE Group

Though generally group content was found to be useful and informative, participants in both groups reported wanting more session time to have been given to participants sharing

details of their ABI and how it had affected them. Although such an invitation to share was included in the first session in both groups, a view was that more opportunities for such exchanges would have been of benefit in later sessions, when members had come to know each other better.

> "*[The therapist] did say, would you like to [talk about your brain injury at the first session], but I actually chose not to because I didn't know these people…maybe by week four or five when we got to know each other a bit better then I would have felt confident to say that."* Colleen, AE Group

Study procedures, Method of delivery, and Participant support

Overall, study procedures were acceptable to participants, however schedule conflicts could become a barrier. In one instance, a participant originally scheduled to participate in an earlier wave ended up participating in a subsequent wave due to schedule conflicts.

> "*Obviously when you're in a group they have to choose you know how to um, like what days would suit people and that sort of stuff, so that became a little bit of an issue, and I know I had to wait because originally I was due to start the [the group] sooner because my times wouldn't match up with everyone else's on the last one."* Lindsay, AE Group

The research design mean that, for those in the WL group, there was a delay between initial assessment and actually starting the groups. For some, this meant that their circumstances had so changed that they could no longer commit the time, and this was one factor in drop out from this arm.

Some participants felt that the similarity of group members (e.g., in age, gender, type of ABI, and/or level of disability) was likely to be an important factor in efficacy.

"*Depending on where you are with your brain injury, I think that makes a huge difference…if you're in a group with people who are, who have more energy than you, then that is probably a disadvantage."* Alison, AE Group

As discussed, both in-person and online groups were generally considered useful and effective. Particularly for those who were unable to travel independently, had long trips on public transport, and/or found travel fatiguing, online sessions were preferable.

"*You've got to work out, you know, how far I've got to go, how long is it going to take me, do I need money for a parking meter, or have I got to catch a bus? All of those things take up all that mental capacity before you go, which will leave you exhausted when you get there."* Shirley, AP Group

For others, however, online conversations were perceived as awkward or artificial.

Therapist training and expertise, Understanding ABI, and Group facilitation style

Participants noted that any therapist facilitating the group would need sufficient training in clear and accessible communication and in keeping sessions suitably focused. If sessions became rushed or too tangential, this was perceived as detrimental.

"I found some of the…the way it was presented. To me, I've just finished an undergrad in psychology so I kind of understand it. I found it was a little bit um confusing because I noticed some of the other members sometimes would go a little bit off tangent, as if they didn't really understand what exactly was asked of them" Phoebe, AP Group

Participants emphasised the important of tailoring group contents to the individuals present (e.g., in terms of understanding, nature of disabilities), and that there is no "one size fits all" for interventions in ABI.

"*It's trying to, trying to deal with a group of people who all have different needs. So, for example, if you was to go to a group where one person's broke their arm, one*

person's broke their leg, and one person's broke their spine, you wouldn't lump them all together, talking about general stuff. So with the brain it's pretty much the same."

Ryan, AE Group

The importance of the therapist as a motivator was emphasised.

"*If you had somebody who was a bit more, um, aggressive or forceful, it could, it could change the way you feel about the group and the work that you're doing. [The therapist] was easy-going, but at the same time forceful, but you never felt pressured."* Amy, AP Group

If emotionally taxing or distressing events occurred in session, it was viewed as important for the therapist to directly address what happened, and check in with other group members, while ensuring that group content was still given sufficient time and attention.

Table 30 synthesises key areas of perceived strengths of the groups or areas for improvement derived from the qualitative data. It is, however, important to keep in mind the variety of views that were expressed, and as such, recommendations should be considered within any local context of recreating the groups described here.

	Activity Planning Group	Activity Engagement Group	Both Groups
Group Factors	• Paced information • Time limits for group discussion relative to session content • Share group materials ahead of each session • Provide summary of session content following each session	• Prioritise group discussion • Regular offers to discuss ABI • Variety of activities on hand suited for different types of ABI	• Dedicated time for group members to interact without therapist • Day before and day of reminders of sessions • Group materials explicitly adaptable to different types of ABI
Study Factors	• Incorporate explicit session material on sharing medical history of ABI • Reduce content per session, or • Increase session duration	• Increase session duration • Clearer rationale for potential benefits of group	• Increase minimum group size • Consider ways to facilitate group cohesion with wide variety of group characteristics • Dedicated tech support for online sessions • Dedicated transport support/reimbursement for in person
Therapist Factors	• Communicate session topics using clear language • Sufficient training delivering session materials • Emphasise routine formation	• Regularly offer choice in selecting activities • Group protocol specifies adaptation to feedback from participants	• Acknowledge individuality of ABI • Ensure equal participation from group members • Engaging but not forceful facilitation

Table 30. Recommendations for important areas to maintain or modifications of the groups, based on qualitative data.

Supporting Participants with Aphasia

To evaluate the potential suitability of the groups for people with language difficulties, qualitative data from these participants is summarised below. Three of six participants with aphasia withdrew. One of these three completed a bespoke interview, recorded using contemporaneous notes, whilst the 3 participants that continued completed all assessments. This resulted in data from two participants with fluent aphasia (who provided feedback independently), and two with non-fluent aphasia (who were supported by carers in providing feedback). A summary of recommendations based on this data is in Table 31.

Overall, participants with fluent aphasia found their group to be positive and generally did not find their speech to be a major barrier to participation. One participant made no reference to their speech prohibiting enjoyment of the AE group within the PSQ. The second participant noted that the AE Group was preferable given their difficulties with their speech.

> *"For me, because my brain injury is quite recent, I think the activity was better for me... because with my speech, I know it sounds OK at the moment, but I'm really conscientious, conscious of the um, the speaking and the group members. But that was fine, um, so there was not a lot, there was um, doing the activities, was relaxing for me."* Maya, AE Group

However, if other participants spoke rapidly or were perceived to dominate conversation, this was detrimental.

> "*I would, I did find really difficult, because my words and the thinking was difficult...it was difficult when people speak over you when you're talking, I know it's difficult online with that anyway, but um, I just feel that little bit, it makes me feel quite small when, when that happens."* Maya, AE Group

For those with non-fluent aphasia, however, taking part in either group was effortful and individual therapy was preferred. This was influenced by feeling "like a charity case" for requiring communication support, smaller group sizes increasing pressure to contribute, and difficulties engaging in activities with verbal components. One carer noted that the main reason to participate was to contribute to research, rather than any perceived direct benefits.

> "*[The participant] joined in, it's because it can be of some use, their difficulties could be of some use to somebody, you know...I thought, well, it's all extra practice for him, but he finds it upsetting, but he will do it because it's useful to somebody"* Carer of Mason, AE Group

Positive comments from those with non-fluent aphasia and carers related mainly to a welcoming atmosphere and friendly group members, with structured turn-taking perceived as useful. Learning how people struggle internally after ABI in comparison to external difficulties like aphasia was viewed as beneficial. Online sessions were preferable due to fatigue associated with travel in person. However, this was not sufficient to improve mood.

> "*We have a communication group that [he] has been to a few times before the lockdown and everything happened, which I used to drop him off and leave him there. But no matter how caring they are, he felt left out and couldn't contribute and because they were a group of people – this will come up [for MAPLES] as well - but he doesn't go anymore because of that, and also they do it online now. But he can't join in with that either. That's a good point [for MAPLES], so it was much more ordered. It wasn't just a general everybody chat at any random time. It was much more go round the group, which is much easier for him, but still frustrating. So he doesn't join in with the communication group we have anymore at all because it is more harmful than good. He's come home upset, you know, and struggling and like, 'what's the point, I can't get anything out anyway.'"* Carer of Mason, AE Group

The two carers of those with non-fluent aphasia felt it beneficial to be present to support communication and one felt it should be mandatory for carers to attend. For the AP group specifically, the carer noted that for study materials to be accessible, they would need to be mainly visual and in point form. Further, planning only small and non-verbal activities was important. For the AE Group specifically, the carer felt that interest-based groups only for people with communication difficulties would help reduce stigma. Carers noted that it was beneficial for therapists to have knowledge of the ways aphasia affects a person, and explicitly confirm that they have understood what participants are trying to say.

	Activity Planning Group	Activity Engagement Group	Both Groups
Both Fluent and Non-Fluent Aphasia	• Group slides short with small amount of information • Avoid academic language • Beginning with small non-communication-based activities	• Selection of visual activities (e.g., colouring, painting) or activities adapted for single-word responses • Less time spent solely on conversation	• Therapist proficient in understanding variety of effects due to aphasia • Therapist checks to ensure they have correctly understood what participant has said • Structured turn-taking • Bigger group size to reduce pressure to speak • Group rules for other group members to speak slowly • Online delivery preferable
Non-Fluent Aphasia	• All study materials in point-form or picture-based • All participants with similar level of communication difficulties • Audio dictated homework options available	• Interest-based groups for those with communication difficulties only	• Family member or carer involved in at least two group sessions • Additional one-to-one support if other group members do not have communication difficulties

Table 31. Summary of recommendations for adapting the MAPLES intervention groups to support those with aphasia based on *n = 4* participants and two carers.

Secondary Objective – Clinical Outcomes

The secondary objective of the MAPLES trial was to provide estimates of effect on the primary objective outcome measure, not least to help determine the sample size for a subsequent trial. Below, I summarise missing data on outcome measures, fidelity assessment results of the AP and AE Groups, and estimations of effect on the primary outcome measure between all groups.

Fidelity Assessment Results

Fidelity was assessed separately for the AP and AE Groups (see *Appendix* for Fidelity Assessment checklists). To standardise the method, the research assistants followed the below steps in order (similar to Robbins-Welty et al., 2018):

1) Raters listen to an audio recording together and assess fidelity together;
2) Raters listen to an audio recording together and assess fidelity separately;
3) Raters listen to an audio recording separately and assess fidelity separately.

Following point 2 and 3, the raters compared their scores and resolved any discrepancies in fidelity assessments, if any. Sufficient agreement was considered to be reached once raters had fewer than 10% of discrepant items, following point 3. After this, raters scored audio recorded sessions independently.

To obtain percent estimates of fidelity of each group, all fidelity checklist items were summed and given percent scores per checklist per group. The percent scores were then averaged for a total percent estimate. Overall, both the AP Group and the AE Group was delivered as intended, with percent fidelity estimates of 95.06% and 99.17%, respectively.

Missing Data

Generally, participants who did not withdraw had complete data sets. One participant did not complete the SHAPS at any time point due to discomfort with the measure.

At Time 1, two participants did not complete the MOT-Q, one due to discomfort about giving opinions on rehabilitation staff and another due to its accidental omission from the questionnaire battery. One response each was missing on the BMQ-S and MOM-POPS at Time 1 due to a technical error with online data collection.

At Time 2, two participants did not provide responses to any questionnaires, as one participant was ill and declined participation, and the second formally withdrew earlier in the study, but both opted to provide outcome assessment data at Time 3. One participant at Time 2 did not complete the MOT-Q for unknown reasons (left blank by participant).

At Time 3, one participant did not complete the SCS, possibly accidentally, but this was not noted in time to collect this data within a reasonable time window (i.e., greater than 1 month past Time 3 assessment date).

Baseline Outcome Measures

A summary of baseline scores by group is presented in Table 32. Despite randomisation occurring before initial assessment (i.e. blind to these scores), group allocation nevertheless produced well matched groups on these variables. Note, the WL participants who were re-randomised do *not* contribute to the AP and AE table values.

Efficacy of Intervention on Primary Outcome Measure

A mixed-effects linear model was conducted using total BADS scores as the dependent variable was used to examine potential efficacy using the lmerTest package in R (Kuznetsova et al., 2017). As pre-specified in my protocol (Kusec et al., 2020), participants were initially modelled as a random effect. However, when adding BADS baseline scores as a covariate, this resulted in a singular fitting model (i.e., modelling participants as a random effect *and* including baseline scores as a covariate was too complex to be supported by the observed data). Throughout my trial, participants were recruited in "waves" where the AP, AE, and WL Groups ran in parallel. This was considered important to address in analysis because a) this period included the onset of the COVID-19 pandemic and the resultant fluctuating restrictions on socialising, mood, and activity levels, b) COVID-19 dramatically affected recruitment and c) in the last wave, those first sent to WL were immediately re-randomised. Whilst randomisation should protect against potential systematic differences, study wave (Waves 1 – 7) was modelled as a random effect in order to account for this.[11] This was a statistically better fitting model ($\chi^2 = 129.84$, AIC$\Delta = 127.80$, $p < 0.001$).

[11] Participants nested by study wave was also modelled as a random intercept structure, but this resulted in the model being overparameterised (i.e., too many parameters to be reliably estimated by the observed data).

	Activity Planning (n = 22)	Activity Engagement (n = 22)	Waitlist Control (n = 16)	Group Differences
BADS				
Total	94.30 (27.18)	80.55 (31.42)	93.44 (20.39)	$F = 1.68$, $p = 0.20$
Activation	22.36 (8.38)	19.18 (8.93)	19.00 (8.59)	$F = 0.99$, $p = 0.38$
Lack of Avoidance/Rumination	31.48 (11.87)	26.55 (12.37)	30.06 (10.04)	$F = 1.04$, $p = 0.36$
Lack of School/Work Impairment	18.59 (6.25)	16.55 (8.10)	20.44 (5.68)	$F = 1.52$, $p = 0.23$
Lack of Social Impairment	21.73 (8.72)	18.27 (8.11)	23.94 (4.82)	$F = 2.68$, $p = 0.08$
HADS				
Depression	9.14 (5.21)	11.50 (4.33)	8.31 (4.77)	$F = 2.37$, $p = 0.10$
Anxiety	8.14 (5.44)	9.14 (5.90)	7.81 (5.26)	$F = 0.31$, $p = 0.74$
BMQ-S	83.51 (13.88)	87.96 (16.23)	81.39 (15.81)	$F = 0.94$, $p = 0.39$
MOT-Q				
Lack of Denial	6.86 (5.96)	10.24 (4.98)	6.07 (6.02)	$F = 2.97$, $p = 0.06$
Interest in Rehabilitation	8.09 (5.23)	8.52 (4.02)	5.93 (5.91)	$F = 1.29$, $p = 0.29$
Lack of Anger	8.91 (6.04)	9.14 (5.82)	8.27 (6.94)	$F = 0.09$, $p = 0.92$
Reliance on Professional Help	6.14 (3.50)	4.24 (3.45)	3.40 (3.94)	$F = 2.90$, $p = 0.06$
IES-R				
Total	27.82 (14.51)	33.27 (23.40)	25.63 (15.24)	$F = 0.89$, $p = 0.41$
Avoidance	10.77 (5.51)	11.91 (8.01)	7.81 (4.64)	$F = 1.98$, $p = 0.15$
Hyperarousal	7.50 (5.23)	9.32 (6.93)	7.40 (6.01)	$F = 0.65$, $p = 0.53$
Intrusions	9.55 (6.61)	12.05 (9.47)	10.48 (5.90)	$F = 0.60$, $p = 0.55$
BIS/BAS				
Inhibition	20.36 (4.10)	20.59 (5.10)	21.44 (4.59)	$F = 0.27$, $p = 0.77$
Fun Seeking	10.02 (2.44)	9.20 (2.52)	9.19 (2.59)	$F = 0.54$, $p = 0.59$
Reward Responsiveness	16.45 (3.74)	15.41 (3.02)	16.20 (3.10)	$F = 0.75$, $p = 0.48$
Drive	10.09 (3.62)	10.45 (2.77)	10.40 (3.29)	$F = 0.07$, $p = 0.93$
SCS				
Perceived Mastery	20.27 (3.07)	18.27 (5.42)	20.08 (5.60)	$F = 1.15$, $p = 0.33$
Perceived Constraints	32.59 (10.91)	36.77 (10.33)	34.00 (9.01)	$F = 0.95$, $p = 0.39$
MOM-POPS				
Number of Weekly Activities	10.76 (4.82)	10.32 (4.38)	10.38 (3.86)	$F = 0.06$, $p = 0.94$
SHAPS	12.26 (2.91)	11.46 (2.32)	12.42 (2.28)	$F = 0.81$, $p = 0.45$
IU-SF				
Prospective Anxiety	21.50 (6.41)	21.86 (6.19)	20.75 (7.33)	$F = 0.13$, $p = 0.88$
Inhibitory Anxiety	14.81 (5.02)	16.36 (4.30)	13.05 (4.74)	$F = 2.32$, $p = 0.11$

Table 32. Scores on all outcome measures at baseline by group. Type 3 ANOVAs were conducted to detect any statistical differences, with no measures differing significantly across groups.
BADS=Behavioural Activation for Depression Scale, HADS=Hospital Anxiety and Depression Scale, BMQ-S = BIRT Motivation Questionnaire-Self, MOT-Q = Motivation for Traumatic Brain Injury Rehabilitation Questionnaire, IES-R = Impact of Event Scale-Revised,, BIS/BAS = Behavioural Inhibition/Behavioural Activation Scales, SCS = Sense of Control Scale, MOM-POPS=Modified Outcome Measure-Participation Objective, Participation Subjective, SHAPS=Snaith-Hamilton Pleasure Scale, IU-SF =Intolerance of Uncertainty Scale-Short Form

For all analyses, missing data was estimated using restricted maximum likelihood estimation. *F*-statistics with effective degrees of freedom were estimated using Satterthwaite's method in lmerTest. For each model, adjusted intraclass correlation coefficients were used to estimate the amount of variance attributable to the random effects

structure (Nakagawa et al., 2017). Tukey-adjusted post-hoc tests were conducted using estimated marginal means.

In the model estimating differences in BADS scores, there was a main effect of Time ($F_{2,167} = 3.82$, $p < 0.05$), Group ($F_{2,170} = 3.33$, $p < 0.05$) and baseline scores ($F_{2,172} = 479.43$, $p < 0.001$) but no Time by Group interaction. Random effects estimates were low (14.44, $SD = 3.80$, $\chi^2 = 5.54$, $p = 0.02$, $ICC_{adj} = 0.07$), indicating the variation in participant intercept due to study wave likely only had a minor influence. In post-hoc tests, only the AP group demonstrated improvements on BADS scores from Time 1 to Time 2 ($t = -2.76$, $p = 0.01$). Change between Time 1 and Time 2 across all three arms is shown in Figure 5.

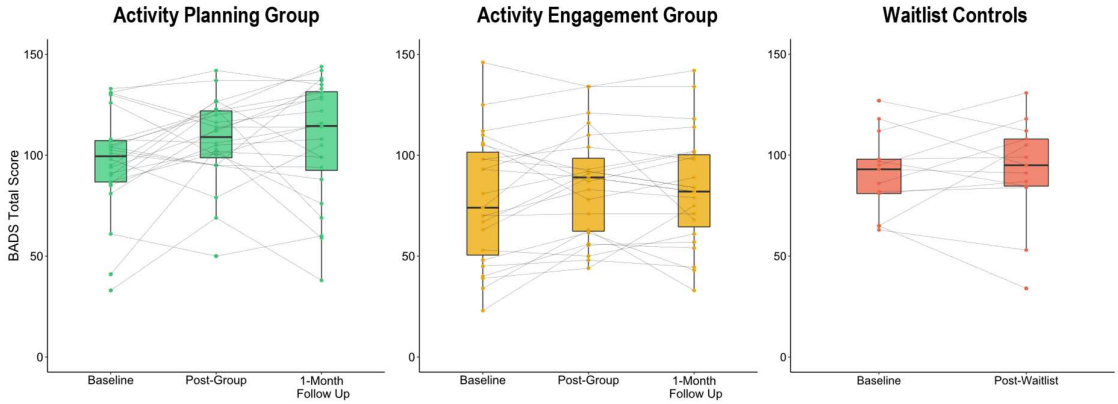


Figure 24. Visualisation of individual change between the three groups on the Behavioural Activation for Depression Scale (BADS) across each time point. Visualisations include those who were re-randomised into either the AP or AE Group.

At Time 3, within-group AP scores were still significantly different from Time 1 ($t = -2.68$, $p = 0.02$). Scores between Time 2 and Time 3 did not differ within the AP group ($t = 0.10$, $p = 0.99$). At Time 3, there was a difference in BADS scores between the AP and AE Groups ($t = 2.11$, $p = 0.04$) with higher scores in the AP group. In summary, significant increases in BADS scores were only observed in the AP group and these were well maintained at Time 3. At Time 3, the BADS gains in the AP group relative to AE were marginal but statistically significant. The groups did not differ from each other at Time 2.

Exploratory Analyses - Efficacy of Intervention on Secondary Outcome Measures

To determine the potential effect of the interventions on secondary outcome measures, exploratory analyses of changes on the HADS, BMQ-S, the SCS and IU-SF were conducted. These measures were selected on the basis of the Minimal Clinically Important Difference results (presented below). For ease of exposition they are reported here because the same mixed-effects model analyses (used above on the BADS) were applied. In each case, the baseline levels of the measure in question was entered as a covariate.

There was a significant time by group interaction on the HADS-Depression subscale at Time 2 ($F_{3,167} = 5.96$, $p < 0.001$). Random effects estimates for this model were minimal (0.31, $SD = 0.56$, $\chi^2 = 3.95$, $p = 0.04$, $ICC_{adj} = 0.06$). In post-hoc contrasts, both the AP ($t = -4.30$, $p < 0.001$) and AE ($t = -4.60$, $p < 0.001$) groups demonstrated *reduced* HADS-Depression scores relative to WL at Time 2, whilst the AP and AE Groups did not differ from each other ($t = 0.41$, $p = 0.91$), nor did these two groups differ at Time 3 ($t = -0.84$, $p = 0.48$). Improvements in HADS-Depression scores were maintained from Time 2 to Time 3 for both the AP group ($t = 0.01$, $p = 1.00$) and the AE group ($t = -1.25$, $p = 0.43$)

Similarly, for HADS-Anxiety scores, there was a significant Time by Group interaction ($F_{3,167} = 4.04$, $p < 0.01$). Random effects estimates were non-significant (0.15, $SD = 0.38$, $\chi^2 = 0.98$, $p = 0.32$, $ICC_{adj} = 0.03$). At Time 2, the AP Group showed significantly greater *reductions* in anxiety than both the AE ($t = -3.98$, $p < 0.001$) and WL Groups ($t = -4.13$, $p < 0.001$) whilst the AE Group did not significantly differ from the WL Group ($t = -0.78$, $p = 0.72$). At Time 3, the AP Group still demonstrated reductions in HADS-Anxiety scores relative to the AE Group ($t = -2.55$, $p = 0.03$). Reductions in HADS-Anxiety scores within the AP Group were maintained from Time 2 to Time 3 ($t = -0.83$, $p = 0.69$).

There was a significant Time by Group interaction on BMQ-S ($F_{3,164} = 3.66$, $p < 0.05$), with marginally non-significant random effects (2.98, $SD = 1.73$, $\chi^2 = 3.56$, $p = 0.06$, $ICC_{adj} = 0.06$). Only the AP Group demonstrated significant reductions in difficulties with

motivation as measured via the BMQ-S relative to the AE Group (t = -2.91, p < 0.01) and WL (t = -3.99, p < 0.001) at Time 2. The AE Group did not differ from WL at Time 2 (t = -1.54, p = 0.27). At Time 3, the AP Group still had lesser difficulties with motivation compared to the AE Group (t = -2.59, p = 0.03). Reductions in BMQ-S scores within the AP Group were maintained from Time 2 to Time 3 (t = 0.49, p = 0.87). Changes in HADS-Depression and Anxiety, and in BMQ-S scores, are shown in Figure 25.

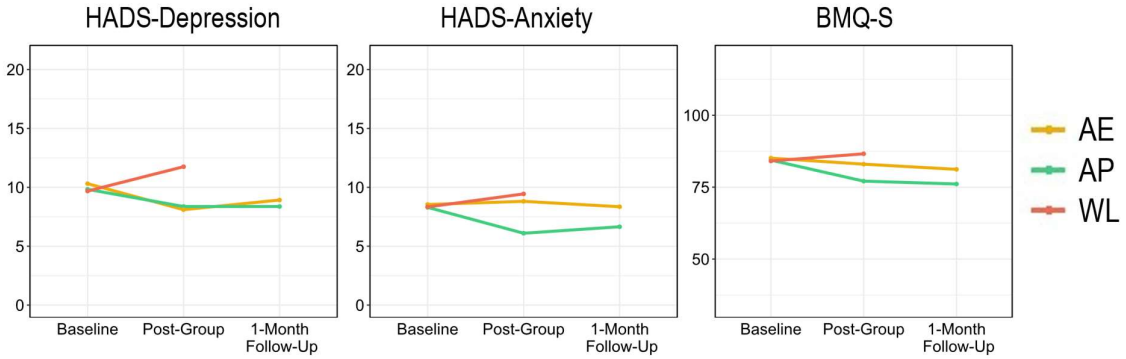


Figure 25. Changes in depression, anxiety, and motivation between the three groups at baseline, post-group, and one-month follow-up.
AP = Activity Planning, AE = Activity Engagement, WL = Waitlist Controls; HADS = Hospital Anxiety and Depression Scales, BMQ-S = Brain Injury Rehabilitation Trust Motivation Questionnaire.

There were no main effects, nor Time by Group interactions, on scores on the Perceived Constraints (p = 0.77) and Perceived Mastery (p = 0.17) subscales of the SCS; further the random effects estimates on both models were non-significant (ps = 0.99).

On the Inhibitory Anxiety subscale of the IU-SF, there was a significant Time by Group interaction ($F_{3,167}$ = 3.27, p = 0.02) with non-significant random effect estimates (0.27, SD = 0.53, χ^2 = 0.80, p = 0.37, ICC_{adj} = 0.03). At Time 2, the AP Group had greater reductions in Inhibitory Anxiety relative to the AE Group (t = -2.64, p = 0.02) and WL (t = -3.86, p < 0.001), with the AE group and WL not differing from each other (t = -1.63, p = 0.24). The AP Group maintained reductions from Time 2 to Time 3 (t = -0.30, p = 0.95). There was no Time by Group interaction on the Prospective Anxiety subscale of the IU-SF,

though random effects estimates were marginally significant (0.95, $SD = 0.98$, $\chi^2 = 4.26$, $p = 0.03$, $ICC_{adj} = 0.06$).

Taken together, the results suggest that the AP group was associated with a wider range of improvements in activity levels, symptoms of depression and anxiety, difficulties with motivation and the inhibiting effects of uncertainty, which persisted for at least a month after the end of the group (Time 3). There were also reductions in depressed mood in the AE group that were, again, well maintained. These outcomes did not seem to be affected by study wave, though further modelling for random slopes due to study wave in a larger trial would be beneficial.

Caution is clearly needed in exploratory analyses in terms of likely false positive findings over a large number of comparisons. For this reason, I selected to analyse secondary measures based on Minimal Clinically Important Difference estimates. In addition, the *pattern* of results is important. Where a set of conceptually related measures (anxiety, low mood, low motivation) show *consistent* patterns across the groups, the likelihood that it reflects a true underlying pattern is increased.

Estimation of the Minimal Clinically Important Difference

In pilot trials, statistical inference is done typically in an exploratory way in order to determine relevant outcomes for a definitive trial. There may be an overall change in an outcome of interest, but some individuals may not change and others may have worse outcomes. Therefore, the minimal clinically important difference (MCID), or the smallest unit of change that indicates value to a participant, is a marker of clinically meaningful change that, in a "real world" setting, indicates change in an individual's health care management (Guyatt et al., 2002). Though a conceptually important construct, multiple methods of calculating the MCID have been developed. Any particular MCID is typically selected depending on the study population and context (Mouelhi et al., 2020). Generally,

MCID estimates can be determined using anchor-based methods such as self-reported global ratings of change due to the intervention or clinician opinion of improvement, distribution-based methods such multiples of standard deviations or the standard error of measurement (SEM), or Delphi methods to reach expert consensus on a study-specific MCIDs. Generally, anchor-based methods are recommended over distribution-based and Delphi methods as they better capture the participant perspective of meaningful change (see Mouehli et al., 2020, for a review). Here, the MCID was calculated by estimating the SEM, a distribution-based method. Though distribution-based methods do not directly address clinically important change as separate from statistically significant change, no anchor-based MCID was pre-established in my trial protocol, therefore retrospectively establishing an anchor-based method may be difficult to interpret. MCID results here should therefore be taken into conjunction with the PSQ and qualitative data presented above, which gives insight into the degree to which participants found the intervention helpful and beneficial.

For all outcome measures, the MCID was calculated based on the below formula:

$$SEM = \sigma \, x \, \sqrt{1 - r}$$

The sigma value (σ) was the standard deviation of each measure of interest at Time 1 across all participants, and the reliability (r) was calculated using internal consistency estimates at Time 1. Data from Time 1 to Time 2 were used to provide percent estimates so as to compare both the AP and AE Groups to WL, including those who were re-randomised. For the BADS, the MCID was estimated as 8.28 points. Missing data at Time 2 was imputed using predictive mean matching (PMM) via the mice package in R (van Buuren & Groothuis, 2011). In essence, PMM creates *M* number of datasets containing plausible data based on the distribution of the observed data. A total of 5 imputed datasets were created. The number of participants who had improvements greater than 8.28 points on the BADS using only

complete case data, *and* the range of the total number of participants who had improvements across the 5 imputed datasets, are reported.

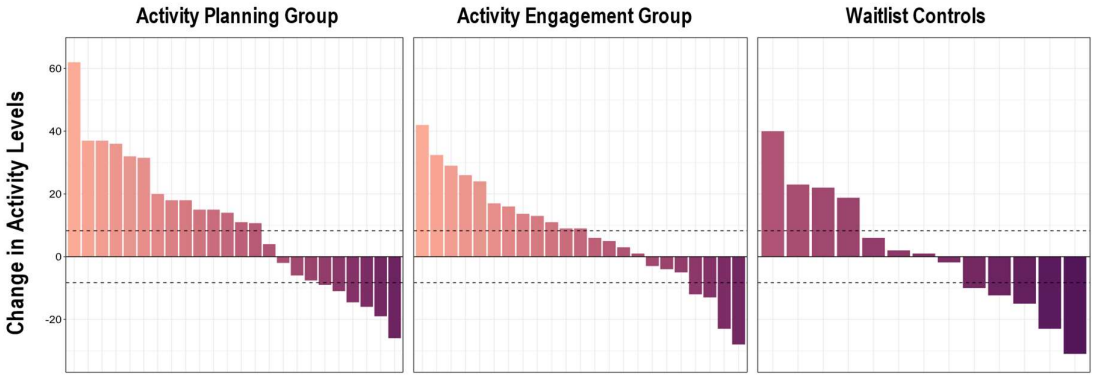


Figure 26. Visualisations of participant-level change scores from Time 1 to Time 2 on the Behavioural Activation for Depression Scale (BADS), not including those who withdrew. Dashed lines indicate the minimal clinically important difference (8.28) in either direction. Higher change scores indicate greater improvements in activity levels.

Visualisations of MCID change on the BADS, the primary outcome measure, between groups with complete data (including those re-randomised) are presented in Figure 26. Using only complete data (including re-randomised participants), 58.33% of participants in the AP group showed BADS improvements at or above this level. The rate was 50% in the AE Group and 38.5% in the WL Group. Across the 5 imputed datasets, the AP Group had a percent MCID improvement range of 51.72% – 65.52%. The AE group had a range of 46.43% – 57.14%, and the WL Group had a range of 25% – 43.75%.

From the above BADS results there is a sense that the AP and AE Groups had positive effects on activity levels, relative to WL. However, 25% in the AP Group demonstrated clinically meaningful *reductions* in activity levels (imputed range 14.29% – 28.57%), relative to 16.67% in the AE Group (imputed range 20.69% – 31.03%) and 30.77% in the WL Group (imputed range 31.25% – 43.75%).

Exploratory Analysis – MCID of Secondary Outcome Measures

Changes in MCID in secondary outcome measures were explored to determine which variables may be useful to include or exclude as outcome measures in a main trial. MCID changes on the HADS subscales is visualised in Figure 27.

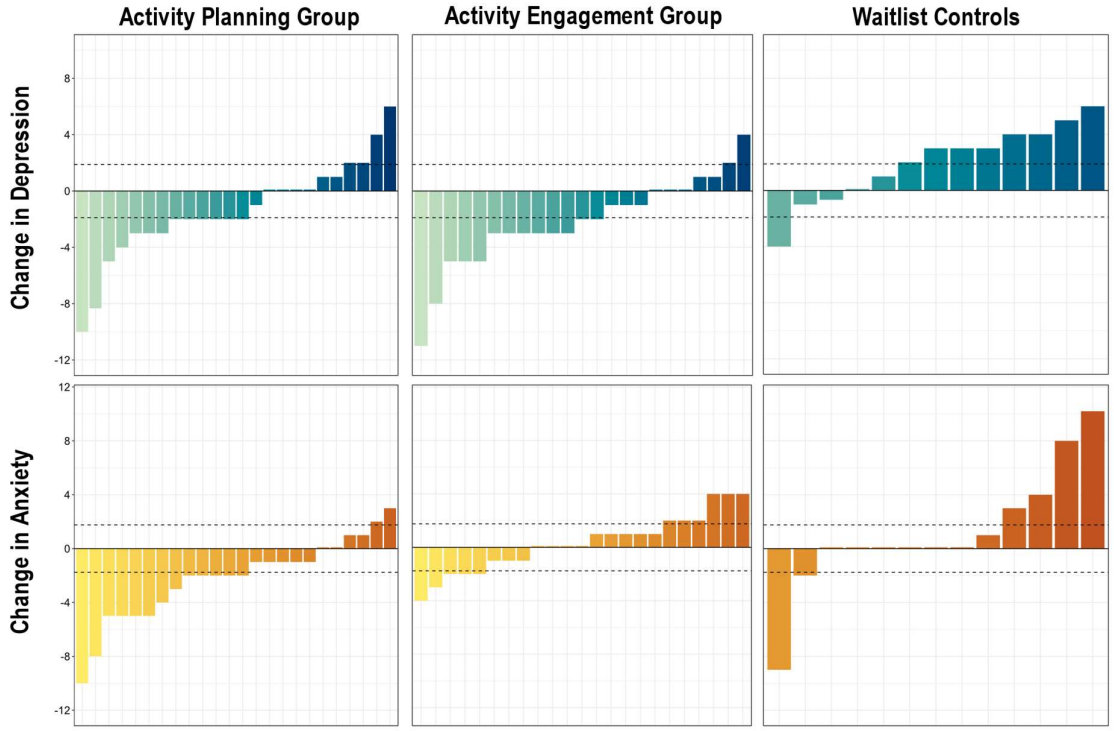


Figure 27. Visualisations of participant-level change scores from Time 1 to Time 2 on the Hospital Anxiety and Depression Scale (HADS), not including those who withdrew. HADS-Depression change scores are on the top row, and HADS-Anxiety scores are in the bottom row. Dashed lines indicate the minimal clinically important difference (HADS-Depression = 1.96, HADS-Anxiety = 1.75) in either direction. Lower change scores indicate greater reductions in depression and anxiety.

An overall summary of number of individuals demonstrating clinically meaningful improvements from Time 1 to Time 2 for those who provided Time 2 data is presented in Table 33. MCID estimates were not calculated for the MOM-POPS due to it measuring activity levels categorically, nor for the Reliance on Professional Help subscale of the MOT-Q and the Fun Seeking subscale of the BIS/BAS due to poor internal consistency estimates ($\alpha < 0.60$). Overall, the measures that seemed most responsive to either of the interventions were the HADS, the BMQ-S, the SCS, and the IU-SF.

MCID Change – *n* (%)	Activity Planning Group (*n* = 24)	Activity Engagement Group (*n* = 24)	Waitlist Controls (*n* = 13)
HADS			
Depression	13 (54.17%)	13 (54.17%)	1 (7.69%)
Anxiety	13 (54.17%)	5 (20.83%)	2 (15.38%)
BMQ-S	14 (58.33%)	9 (37.5%)	3 (23.08%)
MOT-Q			
Lack of Denial	6 (25.00%)	3 (12.50%)	4 (30.77%)
Interest in Rehabilitation	4 (16.67%)	5 (20.83%)	5 (38.46%)
Lack of Anger	11 (45.83%)	4 (16.67%)	3 (23.08%)
IES-R			
Avoidance	7 (29.17%)	5 (20.83%)	5 (38.46%)
Hyperarousal	10 (41.67%)	6 (25.00%)	3 (23.08%)
Intrusions	10 (41.67%)	5 (20.83%)	5 (38.46%)
BIS/BAS			
Inhibition	7 (29.17%)	6 (25.00%)	4 (30.77%)
Reward Responsiveness	6 (25.00%)	7 (29.17%)	2 (15.38%)
Drive	4 (16.67%)	7 (29.17%)	4 (30.77%)
SCS			
Perceived Mastery	11 (45.83%)	9 (37.5%)	1 (7.69%)
Perceived Constraints	10 (41.67%)	4 (16.67%)	4 (30.77%)
SHAPS	5 (20.83%)	8 (33.33%)	4 (30.77%)
IU-SF			
Prospective Anxiety	7 (29.17%)	6 (25.00%)	7 (53.85%)
Inhibitory Anxiety	12 (50.00%)	9 (37.5%)	3 (23.08%)

Table 33. Summary of the number of participants in each arm of the MAPLES trial that showed improvements by at least the scale-specific minimal clinically important difference (MCID). Percentages were calculated based on those who had provided data at Time 2 (i.e., did not withdraw prior to this point).
BADS=Behavioural Activation for Depression Scale, HADS=Hospital Anxiety and Depression Scale, BMQ-S = BIRT Motivation Questionnaire-Self, MOT-Q = Motivation for Traumatic Brain Injury Rehabilitation Questionnaire, IES-R = Impact of Event Scale-Revised, BIS/BAS = Behavioural Inhibition/Behavioural Activation Scales, SCS = Sense of Control Scale, SHAPS=Snaith-Hamilton Pleasure Scale, IU-SF =Intolerance of Uncertainty Scale-Short Form

Power Analysis

Effect size estimates on the BADS were obtained using estimated marginal means from the emmeans package for R (Lenth et al., 2021). In comparison to computing effect size estimates based on the raw data, using estimated marginal means allow for adjustment of a covariate, in this case baseline scores on the BADS. Cohen's *d* estimates between each group at Time 2 were calculated. Given its relevance to BA theory, Cohen's *d* estimates were also calculated for the HADS-Depression subscale.

At Time 2, the estimated effect sizes on the BADS for the AP Group compared to the AE Group was 0.48 (95% CI = -0.12 – 1.09), and was 0.79 (95% CI 0.08 – 1.50) against WL.

The estimated effect size for the AE Group compared to WL was 0.31 (95% CI = -0.40 – 1.02).

At Time 2, the estimated effect sizes on the HADS-Depression subscale for the AP Group compared to the AE Group was 0.18 (95% CI = -0.42 – 0.79), and was -1.63 (95% CI -2.36 – -0.89) against WL. The estimated effect size for the AE Group compared to WL was -1.82 (95% CI = -2.56 – -1.07).

Power analyses were conducted using both the raw estimates on the BADS and HADS-D from study data, and a range of effect size estimates. A range of effect size estimates were used to account for likely changes in estimates of effect in a definitive trial, especially in consideration of the wide confidence intervals reported above. BA has only been compared to passive control groups in neurological populations, therefore typical effect size estimates between BA and other active interventions are unknown. Thus, the smallest effect size of interest for detecting an effect between any two of the three groups (whether AP to AE, AP to WL, or AE to WL) was a Cohen's *d* of 0.30. This value was chosen based on Oates and colleagues' (2020) systematic review of effect size estimates of BA interventions in neurological populations. Range of effect sizes used were in increments of 0.10 from 0.30 to 1.00.

All power analyses were two-tailed with an alpha of 0.05. To account for the likelihood of inflated estimates of effects in small samples, a conservative beta of 0.90 was used. Power analyses were conducted to determine the sample size required for all possible primary comparisons of interest (i.e., whether a future trial is powered to detect and effect between only the AP and AE groups, the AP and WL groups, or the AE and WL groups). Sample size estimates are presented without correcting for multiple comparisons and without accounting for expected attrition.

Results of the power analysis are shown in Table 34. If the primary comparison of interest is the AP vs the AE group, and a main trial replicates a re-randomisation design using an allocation ratio of 1:1:1, the total number of participants required across all three arms would always equal that of the total N specified in Table 34. For example, to detect an effect on the BADS between the AP and AE group, 186 participants are required (62 AP, 62 AE, 62 WL). As 31 participants each in the WL group would be re-randomised, this would result in the 93 data units in the AP and AE groups, with an overall total of 248 data units (93 AP, 93 AE, 62 WL). If the primary comparison of interest is the AP or AE group compared to WL on the BADS, using a re-randomisation design and a 1:1:2 allocation ratio, this would require 70 participants (17 AP, 18 AE, 35 WL), with 18 of the 35 WL participants re-randomised to AP and 17 re-randomised to AE (35 AP, 35 AE, 35 WL), for a total of 105 data units.

Depending on the primary comparison of interest and primary outcome measure used, sample size estimates varied widely. For example, detecting a difference between the AE and WL groups on the BADS would require a much higher number of participants than detecting an effect between the AP and WL groups. Similarly, detecting a difference on the HADS-D between the AP and AE Groups would require an unobtainable number of participants, though detecting a difference between either group and the WL group is feasible with relatively low numbers, based on the raw data estimates.

Raw Effect Size Estimates			
Measure	**AP vs AE**	**AP vs WL**	**AE vs WL**
BADS Total	*N* = 186 (93 per group)	*N* = 70 (35 per group)	*N* = 440 (220 per group)
HADS-D	*N* = 1300 (650 per group)	*N* = 18 (9 per group)	*N* = 16 (8 per group)
Range of Estimates of Effect			
Estimate	**AP vs AE**	**AP vs WL**	**AE vs WL**
d = 0.30	*N* = 470 (235 per group)	*N* = 470 (235 per group)	*N* = 470 (235 per group)
d = 0.40	*N* = 266 (133 per group)	*N* = 266 (133 per group)	*N* = 266 (133 per group)
d = 0.50	*N* = 170 (85 per group)	*N* = 170 (85 per group)	*N* = 170 (85 per group)
d = 0.60	*N* = 120 (60 per group)	*N* = 120 (60 per group)	*N* = 120 (60 per group)
d = 0.70	*N* = 88 (44 per group)	*N* = 88 (44 per group)	*N* = 88 (44 per group)
d = 0.80	*N* = 68 (34 per group)	*N* = 68 (34 per group)	*N* = 68 (34 per group)
d = 0.90	*N* = 54 (27 per group)	*N* = 54 (27 per group)	*N* = 54 (27 per group)
d = 1.00	*N* = 44 (22 per group)	*N* = 44 (22 per group)	*N* = 44 (22 per group)

Table 34. Sample size calculations based on effect size estimates using trial data on the BADS and HADS-D, as well as a range of possible effect size estimates. Estimates do not include expected attrition. Power analyses were conducted based on the primary two-group comparison of interest. An alpha of 0.05 and a beta of 0.90 was used.

Harms

Harms were operationalised as worsening scores on mood measures throughout the trial, reporting of suicidality, and miscellaneous reported concerns. Below, I report and discuss each separately. It is important to note that participants were not insulated from other events (e.g., effects of COVID-19) and one would expect fluctuations in mood in both directions. The statistical tests attempt to detect intervention signal above this noise.

However, if an intervention had a beneficial effect for a majority of participants, but a substantially detrimental effect for a minority, this would be important to report and would be primarily evidenced by negative impacts on mood greater than the WL Group.

Harms – Worsening on Mood Measures

Changes in the HADS-Depression and HADS-Anxiety subscales by the MCID across the three groups for those that provided Time 2 data is shown in Table 35. The MCID value for HADS-Depression was 1.96 points, and was 1.75 points for HADS-Anxiety.

	MCID Change – *n* (%)	Activity Planning Group (*n* = 24)	Activity Engagement Group (*n* = 24)	Waitlist Controls (*n* = 13)
HADS-Depression	Improved	13 (54.2%)	12 (50.0%)	1 (7.69%)
	No Change	6 (25.0%)	10 (41.7%)	4 (30.7%)
	Worsened	5 (20.8%)	2 (8.33%)	8 (61.5%)
HADS-Anxiety	Improved	13 (54.2%)	4 (16.7%)	2 (15.4%)
	No Change	9 (37.5%)	14 (58.3%)	7 (53.8%)
	Worsened	2 (8.33%)	6 (25.0%)	4 (30.7%)

Table 35. Summary of change as measured by the minimal clinically important difference (MCID) on the HADS-Anxiety and HADS-Depression subscales using complete-case data from Time 1 to Time 2 only.

In the AP and AE Group, generally the proportion of those improved is better than WL, suggesting that overall there is likely no disproportionate harm. From an intention-to-treat perspective, if I take a "worst case scenario" sensitivity analysis approach (Jadad & Enkin, 2008) and assume that all those with missing data in the AP and AE Groups worsened, and participants with missing data in the WL Group improved, improvements in both active intervention groups are still proportionally higher, particularly in HADS-Depression scores (Table 36). Of note, under this approach, the proportion of participants with worsening HADS-Anxiety levels is of potential concern in the AE Group.

	MCID Change – *n* (%)	Activity Planning Group (*n* = 29)	Activity Engagement Group (*n* = 28)	Waitlist Controls (*n* = 16)
HADS-Depression	Improved	13 (44.8%)	12 (42.9%)	4 (25.0%)
	No Change	6 (20.7%)	10 (35.7%)	4 (25.0%)
	Worsened	10 (34.5%)	6 (21.4%)	8 (50.0%)
HADS-Anxiety	Improved	13 (44.8%)	4 (14.3%)	5 (31.3%)
	No Change	9 (14.3%)	14 (50.0%)	7 (43.7%)
	Worsened	7 (24.2%)	10 (35.7%)	4 (25.0%)

Table 36. Summary of change as measured by the minimal clinically important difference (MCID) on the HADS-Anxiety and HADS-Depression subscales, assuming that participants in the AP and AE Group who withdrew from study worsened as a result of the intervention, and Waitlist participants who withdrew improved.

Given the above reported benefits on mood of either group, potentially using a WL condition, where participants are ensured access to an intervention, is more ethical than a treatment-as-usual control condition without subsequent treatment allocation.

Harms – Reporting of Suicidality

Though participants who were at immediate risk of self-harm/suicidality were excluded at recruitment, participants who reported thoughts such as "I would be better off dead" but with no stated intent to self-harm were not. Including those re-randomised, such thoughts were reported by 13 participants at Time 1 (AP = 3, AE = 6, WL = 4), 9 at Time 2 (AP = 2, AE = 5, WL = 2) and 9 at Time 3 (AP = 4, AE = 5). For the most part these were reported as abstract thoughts rather a goal. However, it is worth noting that one participant, who had not reported thoughts of suicide at Times 1 or 2, reported suicidal ideation at Time 3 in the AP group. According to the report, this occurred in response to a personal event in the previous week that had brought back memories of a former self-harm attempt. This participant was followed up individually with a phone call to further assess immediate risk and a detailed list of resources was provided.

In general, there was no evidence that participation had a particular influence on this kind of thinking. Only one contact had to be made with a GP according to the self-harm

safeguarding protocol. This participant was not excluded from the trial or from analyses due to a stated wish to continue participating, and it was agreed in clinical supervision that inclusion in the study may be of benefit.

Harms – Miscellaneous

Based on the PSQ data, there were small numbers of participants who reported a worsening in self-perceived ability/capacity/coping. Potential reasons were explored using qualitative data from the PSQ (see Table 37). These were often attributable to external factors such as health issues, COVID-19 restrictions and personal events.

Ability Reported as Worsened	**Activity Planning Group**	**Activity Engagement Group**
Concentration (*n* = 1)	• Extra effort needed to remember session dates and homework	
Spatial Awareness (*n* = 2)	• Accidentally walking into things due to attempting to initiate activities	• Eyesight strain worsening due to comorbid health issue
Motivation (*n* = 1)		• Decreased due to Time 3 assessment coinciding with moving house and resultant fatigue
Mood (*n* = 2)	• No reason reported	• Decreased due to Time 3 assessment coinciding with moving house and resultant fatigue
Social Interactions (*n* = 5)	• COVID-19 social distancing requirements (*n* = 2)	• COVID-19 social distancing requirements (*n* = 3)

Table 37. Reasons for reported worsening of abilities on the Post-Study Questionnaire at Time 3.

In summary, participation did not appear associated with significant harm, nor systematic worsening in self-reported abilities. However, given the "worst case scenario" sensitivity analysis MCID results, it is worth exploring whether HADS-Anxiety scores show reliable increases in settings like the AE group and whether, for example, heightened anxiety in this novel social setting is balanced by improvements in mood relative to a WL Group.

Challenges in Trial Implementation

This section provides a brief overview of challenges in implementing the trial from my own and the steering committee's perspective. For space, a more detailed account is in the dissertation *Appendix*.

Recruitment

- Recruiting participants who were active users of NHS services was challenging, with reasons including clinician concerns about interactions with their own input, and not enough time for clinicians to review cases for study referral. Service user groups were better sources of recruitment.
- There was merit in recruiting from ABI charities and through social media, particularly for online intervention delivery.

Delivering Sessions in Person vs Online

- Delivery of the didactic aspects of the AP group online was broadly similar to in-person. The AE group was more challenging due to having to post materials, and stilted interactions between group members due to the videoconferencing setup.
- Technical issues interfered with online delivery for both groups. Distractions in the home and, for some, lack of private space in which to participate affected conversation. Conversations that may occur before/after in-person groups were effectively absent and including time not structured by the therapist in subsequent online groups may be useful.
- Advantages of online groups included no travel time, participants who may have forgotten groups being able to joining quickly if prompted, and safety in terms of the pandemic.

Mixed-Methods Data Collection

- Collecting both quantitative and qualitative data collection proved challenging when methodologies were at odds with each other (e.g., purposively sampling participants to interview could affect blinded outcomes for quantitative data)
- Collecting qualitative data at both Time 2 and Time 3 may help reduce difficulties with recall in those with ABI.

Participant Preference in Groups

- Some participants had preferences for either the AP or AE Group prior to enrolment – potentially, more participants could be recruited if benefits of either group were made clear in study advertising.

Impact of COVID-19

- The COVID-19 pandemic and resulting lockdowns, social distancing etc. had a huge impact on the range of activities that participants could undertake. The ways in which this affected the results (e.g. less reinforcement from activities/greater social benefits from the online groups in contrast to other aspects of life) are hard to gauge.

Discussion

This study examined the feasibility and acceptability of two types of BA therapeutic groups for people with an ABI. In line with "traditional" BA, the AP Group emphasised learning about the relationship between activity and mood, planning activities and reflecting on changes in mood, alongside strategies to mitigate difficulties in planning due to ABI. The AE Group, or "experiential" BA, emphasised actively engaging in pleasurable activities within group time with the possibility that this might implicitly challenge negative expectations/avoidant tendencies. The results show that both groups are feasible and acceptable, even when transitioning online due to COVID-19, and were assessed to have high levels of fidelity. Qualitative data from participants included benefitting from both a positive group environment, enhancing confidence, and challenging negative thoughts.

Approximately 58.33% of individuals in the AP Group have clinically meaningful improvements in activity levels, compared to 50% in the AE Group and 38.5% in the WL Group. There was no overall statistically significant differences between the three groups on activity levels as measured by the Behavioural Activation for Depression scale. On secondary outcome measures, both the AP and AE group had significantly lower depression scores at Time 2 compared to WL, though only the AP Group demonstrated reductions in anxiety, difficulties with motivation, and the inhibiting effects of uncertainty. These improvements in both groups were retained at 1-month follow up.

Interpretation

Comparison with Previous BA Research

The current study is in line with previous interventions delivering BA one-to-one in ABI and in neurological populations more broadly (Thomas et al., 2019; Oates et al., 2020), with Cohen's *d* estimates ranging from 0.24 to 1.17 in adults with stroke. Such benefits have not, however, been reported in all previous studies (Gertler & Tate, 2019, Hart et al., 2020; see Chapter 1). Given that the majority of evidence is in stroke populations, it is a strength of the current study to show positive effects in a wider variety of ABI diagnoses.

Potential Mechanisms of BA - Group Effects

To my knowledge, this is the first study that has investigated group BA in ABI, and the first to compare "Traditional" BA to an alternative method of delivery. The results are consistent with literature on positive effects of groups, including in ABI (Wilson, 2018; Salas et al., 2020; Yalom & Leszcz, 2020; von Mensenkampff et al., 2015; see Chapter 1). The use of group formats may reduce perceived effort associated with homework in BA, or increase motivation to complete homework, and therefore increase the likelihood of increased reinforcement. In my qualitative data, participants discussed having a sense of commitment not just to the research study, but to each other and wishing to complete homework "for the

group." Similarly, in the AE group, a sense of teamwork among group members was thought to facilitate enjoyment.

Groups like the AE group that have no explicit therapeutic agenda and no direction to reflect on thoughts or behaviour patterns, are far less well-understood and investigated than conventional therapeutic groups. Salas and colleagues (2020) have proposed that such groups are a method of social rehabilitation that provide a safe and predictable milieu, a space where identity can be reconstructed, where one can be cognitively and socially active, and which offer a network of continuous support. Others have emphasised the potentially de-stigmatising importance of meeting other people with ABI experiencing similar difficulties to oneself (Patterson et al., 2019). An interesting issue is whether such groups have benefits only for as long as they are running, or whether they produce effects that generalise to other situations – here I find that improvements in mood were maintained at 1-month follow up, suggesting that such groups can have some lasting impact. Based on the qualitative data, potential mechanisms for changes in mood in settings like the AE group are that it offered a "safe training ground" where individuals could practice and improve social skills that are of benefit more broadly. Similarly, it may have offered a place where self-categorisation and social identity could develop ("people listened to me despite my injury"; "I was competent at the task"; Jones et al., 2012; Ownsworth, 2014). Social cognition difficulties are becoming of increasing interest in ABI rehabilitation (McDonald, 2013; Nijsse et al., 2019), and the potential of AE-style groups to foster positive change requires further exploration.

Activity Levels, Mood, or Something Else?

The Behavioural Activation for Depression Scale (BADS) was selected as the primary efficacy outcome measure for the study because it assesses activity levels. BA therapy is generally predicated on the idea that improvements in activity levels will *precede* improvements in mood. However, whilst the highest proportion of participants showing

improvements in BADS scores at or above the level for the Minimal Clinical Important Difference were in the AP Group (58.33%), there was no overall statistically significant interaction between groups on this measure. Despite this, significant improvements in mood in both the AP and AE Groups were observed. There are a number of possible accounts of this. First, it may be attributable to measurement difficulties; there was a greater increase in activity levels in the AP Group that was enough to alter mood but which was insufficient in itself to cross a statistical threshold or was diluted by items that require some interpretation (e.g. "I did things to avoid feeling sadness or other painful emotions"). Alternatively, it could be that attending the AP Group, as with the AE Group, itself acted to improve mood. In fact, in an early characterisation of BA, exactly this priming of the mood-activity cycle was posited – an increase in "energy levels" was a necessary prerequisite for increases in activity level (Lewinsohn, 1974). Whilst it cannot be directly established, the results here are certainly consistent with a "mood boost" within the AP Group starting to potentiate increases in activity that amplified its mood effects relative to the initially similar "mood boost" in the AE Group that generalised less well to between-session activity.

Of course, it may be the case that cognitive mediators of change are responsible for mood improvements in BA, as evidenced in the qualitative data. The rationale for BA therapy over cognitive therapeutic approaches was never that maladaptive beliefs did *not* relate to mood, but rather these beliefs could be equally or *better* modified via behavioural experimentation than explicit cognitive restructuring (Zeiss et al., 1979; Jacobson et al, 1996; Gortner et al., 1998). In this study, improvements in reported motivation, reductions in anxiety and the inhibiting effects of uncertainty occurred in the "traditional BA" AP Group, and qualitatively, participants expressed increased confidence post-intervention. Outside of ABI, the only robust reported cognitive mediators of change in depression symptoms in BA is self-belief in coping efficacy and crediting oneself for self-improvement (Moradveisi et al.,

2015). It may be that self-reported changes in motivation, anxiety, and coping with uncertainty seen in the AP Group are reflective of changes in negative beliefs about the outcome of future activities due to the therapeutic content.

Changes in Executive Management or Activity Levels?

The AP group not only emphasised increasing activity levels, but also involved discussion of goal management techniques that can facilitate activity planning and execution. It is possible that the greater improvements to mood in this group were, in part, related to this. It is not difficult to imagine how everyday memory lapses or slips of attention could undermine a good mood. It is harder to imagine, however, that the necessarily brief portion of each AP session given to these issues over 8 sessions could so dramatically reduce these problems so as to enhance mood. Nevertheless, perhaps even the anticipation of gaining greater mastery in executing activities could have mood benefits. Interestingly, in a study comparing the executive skills training intervention Goal Management Training (GMT) to a psychoeducational control group in ABI, Tornås and colleagues' (2019) reported that a better ability to identify and organise steps needed to implement an intention predicted lower levels of psychological distress across both groups. Likely, there are a range of factors in addition to a simple "increase in activity leads to better mood" that account for the greater improvement in the AP group compared to the AE group. It is quite likely these different factors interact to a degree in producing gains.

Potential Sources of Bias

As with all psychological intervention research, interventions can only be single-blinded and therefore a completely unbiased estimate of effect is impossible to ascertain. As I delivered both interventions, this minimised the issue of whether apparent "therapy differences" may be attributable to "therapist differences" (e.g., confidence, experience). However, this inevitably raises the issue of how the therapist's beliefs about likely efficacy of

the two approaches played a role. I certainly hold beliefs about the veracity of BA theory in everyday life and for those with ABI. From a research and personal perspective I genuinely believe that less fixed, external factors such as the group setting and a positive social atmosphere are beneficial. Whilst the evidence in favour of "traditional" BA certainly affected my beliefs on what *might* work, from personal experience I felt I equally believed in the value of more "experiential" approaches. The groups were therefore both designed to be as effective as possible, were discussed in detail with a clinical supervisor, and were delivered in the knowledge that recordings would be independently assessed for fidelity – which were assessed to be very high. An important issue for any subsequent trial would be in maximising therapist "buy-in" to both approaches.

There is some risk of population choice bias for the online portion of the study because self-referrals in particular hinge upon individuals with ABI who are able to understand recruitment materials and contact the research team independently. As volunteering for research studies does not occur randomly in general, greater efforts would need to be made to sample across a wider range of individuals with an ABI.

Generalisability

Potential generalisability of this study has benefitted from the use of a mixed-methods design, in accordance with MRC recommendations for complex interventions (Moore et al., 2015). The combination of both methods allows for richer data on acceptability and feasibility outcomes, insights into *why* changes on outcome measures may have occurred, and highlights potential additional areas to assess (e.g. from participant interviews).

A strength of the study, in terms of generalisability, is that circumstances necessitated a variety of recruitment routes, from direct clinician referrals of current service users, through charity contacts and from social media self-referrals. Whilst underpowered to examine quantitative differences in outcome, the qualitative data at least suggest that both

interventions were well-received. Importantly, the blocked randomisation ensured that, whatever differences between participants recruited in the different study waves, these would not have had a disproportionate impact on feasibility/efficacy on either group.

Participants were mainly in the chronic stages of ABI, leaving open the question of whether similar benefits would be observed in acute stages. Earlier stages are associated with greater frequency of impairments and impact on function, which can limit engagement in interventions (Smania et al., 2013). In addition, some may be less "ready" to accept emotionally-focused interventions in early stages when any lasting effects of the injury may be uncertain (e.g., Thomas et al., 2019). Whether BA interventions at this stage may have value, perhaps as an "inoculation" against subsequent reduced activity/mood cycles, remains an interesting question.

Further, with a mild to moderately depressed sample, it is unknown to what degree the results here extend to those with severe depression. In interviews, some participants felt that discussing highly personal and significantly emotionally challenging content was not well-suited to the group setting. It is possible that one-to-one support may be preferred by a greater proportion of people with more severe depression (Roback, 2000).

Based on data from participants with aphasia, it seems reasonably clear that dedicated groups for those with non-fluent aphasia are likely to have greater acceptability (Tregea & Brown, 2013; Wray & Clarke, 2017). Including those with non-fluent aphasia into a group of individuals with ABI without speech difficulties should be done with caution and in discussion with the participant in question. In contrast, it appears that people with fluent aphasia, given appropriate support and availability of suitable materials, can be included in both group approaches, though further piloting would be beneficial.

The generalisability of the feasibility and acceptability data must be considered in light of in-person vs. remote delivery. For the former, transport across the East Anglia region

was a considerable barrier for many participants. Transport and access-related barriers have long been identified as important to community integration and wellbeing in ABI (Kettle & Chamberlain, 1989) and are in part responsible for reductions in activity levels (Rapport et al., 2008; Risser et al., 2012). Therefore, the in-person study results may only be generalizable to those capable of travelling to the study location independently.

For online sessions, trading-off the limitations (e.g. in creating a cohesive group atmosphere online) against the increased ease of attendance was viewed as worthwhile by many participants in the qualitative data. Participants with greater physical disabilities and those who found travel too cognitively demanding/tiring particularly benefited. Some online participants, due to service provision differentiating across regions, could *only* access groups similar to those here via videoconferencing. It is worthwhile to consider, however, whether there would be differences in recruitment numbers (and in outcomes) if the study was replicated online in a few years' time, where there are (hopefully) no restrictions preventing greater out-of-home socialisation and travel. Possibly, the online recruitment numbers are reflective of participants wanting to have "something to do" rather than reflect genuine recruitment rates. However, hybrid formats of intervention delivery (e.g., Chumbler et al., 2012) may become more common, particularly as surmounting evidence supports use of telerehabilitation (Ng et al., 2013; Tsaousides et al., 2014; Lawson et al., 2020).

Limitations

The results relating to the primary aims of this study, on feasibility and acceptability, are relatively robust *in the current sample.* As the regional and online recruitment produced a sample without much ethnic diversity, generalisation of results to samples more representative of the UK population, or particular cultural groups, should not be assumed. In terms of the results from standardised outcome measures, again these were generally positive. However, it must be noted that estimates of effect have wide confidence intervals, making it

difficult to interpret a true effect of either intervention group. Due to restraints in collecting trial data in a PhD timeframe, collecting follow-up data at only 1-month post-intervention limits any potential investigation of longer-term effects. Finally, not being able to recruit from NHS sources for the entirety of the trial limits the conclusions and recommendations made when implementing the groups in NHS settings, though a detailed account of implementing individual BA therapy in stroke is available (Thomas et al., 2019).

Summary of Recommendations

Based on both the quantitative and qualitative study results, changes in aspects of the trial design, recruitment methods, data collection, intervention design, and study outcomes may be beneficial in supporting participants and ensuring efficient delivery of a main trial. The main recommendations of moving the intervention to a definitive trial are outlined in Table 38. Whilst these recommendations require further review and discussion, utilising these recommendations may help facilitate a definitive trial and provide a rigorous evaluation of effectiveness with informed outcomes.

Protocol Aspect	Recommendations	Further Review Required Before Implementation?	Type of Review Recommended
Trial Design	• Retain Waitlist Control design • Include additional participant support check-ins for Waitlisted participants • Retain online delivery	Yes	Staffing Costs Review, Steering Committee Review
Recruitment	• Target between acute and community services • Enhance social media recruitment and self-referrals • Clearer advertisement of potential benefits of both BA groups • Identify methods to enhance sample representativeness	Yes	PPI consultation, Clinician consultation
Data Collection	• Include further measures to characterise cognitive ABI symptoms in baseline assessment • Include 3 month follow up • Remove Exit Interview and include additional questions in PSQ • Qualitative Data collected at all follow-up time points	Yes	Staffing Costs Review, Literature Review
Interventions	• Retain 8 sessions • Review suitability of AP group content • Adapt training manual for therapists on ways to create therapeutic milieu online • Consider additional co-therapist	Yes	PPI consultation, Staffing costs review, Steering Committee consultation
Outcomes	• Include measures of group cohesion • Include measures of positive and negative self-beliefs • Consider executive function measures • Review choice of primary outcome measure (activity levels versus mood)	Yes	Literature Review, Steering Committee consultation

Table 38. Recommendations based on pilot feasibility data when implementing a main trial.

Conclusion

In summary, I demonstrate that two methods of delivering Behavioural Activation therapy are feasible and acceptable, and both show promise in improving mood relative to Waitlist Controls in a high-quality randomised controlled design. Benefits of the interventions generally outweighed reported harms. "Traditional" BA seems to affect motivational processes and enhance confidence relative to "Experiential" BA. Further delineating how group processes contribute to activity levels and mood, and methods of facilitating group cohesion in future intervention studies, is warranted.

Chapter Six

Thesis Summary, Limitations, and Future Directions

Summary of Thesis Findings

This thesis investigated the clinical application of Behavioural Activation (BA) theory in adults with a variety of acquired brain injuries (ABI) such as traumatic brain injury, stroke, encephalitis, and brain tumours. I evaluated the relationship of responses to uncertainty and self-awareness to mood and activity levels in ABI, and developed and tested two activity-based interventions to improve mood. The research presented here integrated both quantitative (e.g., structural equation modelling, mixed-effects models) and qualitative (e.g., interpretive description) methodology to enhance the person-centeredness of my research whilst conducting statistically rigorous evaluations of my thesis aims. Below, I summarise the main findings from each empirical chapter.

Chapter 2 – Factor Structure, Reliability, and Validity of the Intolerance of Uncertainty Scale-Short Form in Adults with Acquired Brain Injury

The first empirical chapter evaluated whether intolerance of uncertainty (IU), or negative beliefs about uncertainty and its implications, can be reliably assessed in ABI and whether it relates to depression, generalised anxiety, and social phobia using longitudinal observational data. In a sample of 176 adults with ABI, I demonstrate that the IU-SF demonstrates good test-retest reliability and internal consistency, despite any potential influence from the COVID-19 pandemic and a range of recruitment sources, (e.g., research panels, ABI charities, and online recruitment). I find that a two-factor structure is acceptable for use in ABI populations; however, a bifactor structure may be more accurate, suggesting that IU may be "both unitary and divisible" (Harsch, 2014). Exploratory bifactor modelling

resulted in differential subscale item loadings to that of established evidence of the IU-SF outside of ABI, potentially representing the relatively common need for, and increased tendency to, seek relevant health-care information following ABI (Snell et al., 2020).

Though I find no unique relationship of IU to depression above ABI symptoms, of particular interest is the consistently strong relationship of difficulties with the inhibitory effects of uncertainty to generalised anxiety and social phobia in ABI. Further, IU was strongly associated with increases in avoidance and rumination. Potentially, the increases in uncertainty following ABI, coupled with lowered functional capabilities and confidence thereof, are interpreted as too unpredictable for those high in IU, resulting in avoidance and lowered activity levels. Managing uncertainty is certainly commonly discussed in qualitative accounts of ABI (Salter et al., 2008; Connolly et al., 2021; Cubis et al., 2018) – and this chapter, which to my knowledge is the first quantitative investigation of IU in ABI, suggests further work exploring IU's contribution to changes in activity levels and mood may be a fruitful avenue of research.

Chapter 3 – Discrepancies in Estimation of Abilities Following Acquired Brain Injury and its Relationship with Participation and Mood

The second empirical chapter uses longitudinal anonymised outcome assessments from a sample of 241 adults from two NHS ABI neurorehabilitation sites to investigate differing levels of self-awareness and their association with mood and participation. In ABI, self-awareness is typically assessed using individual-informant discrepancy scores, with impaired self-awareness typically corresponding to an individual having higher self-ratings of their abilities relative to the ratings of an informant ("overestimation"). In Chapter 3, I used discrepancies in individual-informant ABI symptoms as measured by the European Brain Injury Questionnaire to investigate differences between overestimators, accurate estimators, and underestimators. In line with previous research, overestimators had more severe injuries

as measured by GCS scores, and worse clinician-rated participation. However, they had better overall self-reported mood relative to those who accurately estimate and underestimate their abilities. Underestimators, by contrast, had less severe injuries and worse mood than overestimators, but severity and mood status of underestimators do not differ from those who accurately estimate their abilities.

There was no evidence that discrepancy scores at baseline assessment significantly correlated with clinician-rated participation outcomes at 1 year post-rehabilitation. Longitudinal participation outcomes were instead best predicted by initial GCS scores, changes in self-rated depression, and caregiver strain. Importantly, however, levels of caregiver strain differed between the two NHS sites; whereas Site 1 informants of overestimators did not report more strain relative to accurate estimators, this was not replicated at Site 2, where informants of overestimators reported significantly more strain. Potentially the extent of involvement of caregivers in rehabilitation varies by site, as does support for addressing any discrepancies between the individual with an ABI and their caregiver, which in turn may facilitate better levels of participation. Interestingly, I find that all estimation groups have similarly low levels of self-esteem despite differences between groups in self-rated depression and anxiety. Perhaps for accurate estimators and underestimators, lower levels of self-esteem are emotion-driven, but for overestimators, lower endorsements of statements of self-worth are driven by other processes.

Chapter 4 – Developing Behavioural Activation Therapy for People with Acquired Brain Injury: A Qualitative Interpretive Description Study

Chapter 4 describes an in-depth qualitative exploration of experiences of engaging in activity in adults with ABI. It additionally provides details of barriers and facilitators of 10 different components that could be included as part of BA therapy. Four individual-level themes that were relevant to attempts to engage in activities and uptake of BA components

were constructed. For participants in my study, motivation to plan and engage in activities was affected by whether a BA component was perceived to be the *Right Tool at the Right Time* – specifically, whether it was suitable for them given individual circumstances. Engaging an activity, as well as whether a BA component was perceived to beneficial, was tied to the *Perceived Effort* involved. This was influenced by the fact that participants noting that total amount of effort was a limited commodity post-ABI, which led to increased prioritisation of which activities to take part in. However, effort was worth expending if it *Related to the Values* of the participant, or if the activity involved other people, or if BA component facilitated better relationships with others. The *Emotional Impact* of activities, whether positive or negative, affected choice to continue engaging in or disengaging from an activity, but these decisions could also be influenced by the emotional responses of close others post-ABI.

Chapter 5 – MAPLES: A Randomised Controlled Pilot Feasibility Trial for Low Mood in Acquired Brain Injury

Chapter 5 outlined the development and evaluation of a randomised controlled pilot feasibility study of two types of BA therapeutic groups compared to waitlist controls in 60 adults with an ABI. Specifically, a "traditional" BA group, in which participants planned and engaged in enjoyable activities and were provided with strategies to mitigate executive function difficulties, was compared to an "experiential" BA group, where participants engaged in enjoyable activities *within* group time. It was hypothesised that the experiential BA group alone might implicitly challenge participants' negative beliefs about activities and reduce avoidance. I demonstrate that, whether delivered in person or online, both groups were feasible and acceptable. Online delivery of both groups came with higher rates of attendance, and was found to be similarly helpful and enjoyable to in person sessions.

However, attention, fatigue, technology, and organisational barriers were more frequently reported by individuals attending online.

In qualitative interviews, participants noted benefits from a positive group environment, with perceived similarities between group members and group size being important determinants of group cohesion and thus outcome. Participants from the "traditional" BA group seemed to benefit particularly from splitting planned activities into smaller steps and challenging negative preconceptions about initiating activities. Participants in the "experiential" BA group, on the other hand, benefited from social discussions with each other, and valued the opportunity to provide input on group content. In evaluating efficacy, 58.33% of individuals in the "traditional" BA group had clinically meaningful improvements in activity levels, compared to 50% in the "experiential" BA Group and 38.5% of waitlist controls. Interestingly, both "traditional" and "experiential" BA significantly lowered depression scores compared to waitlist controls, which was maintained at 1-month follow up. However only "traditional" BA resulted in lowered anxiety, reduced difficulties with motivation, and the inhibiting effects of uncertainty.

Thesis Limitations

Though study-specific limitations have been discussed in the relevant chapters, below I outline more general limitations of this dissertation.

Participant Sampling Procedures

An important aim for future research using BA theory in ABI will be to expand the results presented here to a broader variety of individuals with ABI. Throughout my thesis, the majority of my participants were in the chronic stages of their ABI. Further, my recruitment sources were convenience samples such as the Cambridge Cognitive Neuroscience Research Panel, and partly due to COVID-19, there were fewer numbers recruited through NHS settings. Whilst it may be reasonable to conclude that the thesis results are generalizable to

community-based ABI rehabilitation settings, it is possible that, for example, the BA interventions described in Chapter 5 would need to be modified further to specifically suit adults with ABI within their first 6 months to 1 year of injury.

The research presented here benefits from its inclusion of different types of ABIs, an equal proportion of men and women, and a wide age range across all chapters. However, despite online sampling methods which might have served to increase diversity, across all thesis chapters there were disproportionately more participants who were White British (range 91.50% – 100%) relative to the UK population (86%; UK Census of England and Wales, 2018). Possibly, the NHS site participants used for the retrospective analysis in Chapter 3 are more representative, though ethnicity was not recorded and no conclusions can be made in this regard.

Selection of Study Measures

As the aim of this thesis was to investigate the clinical application of BA theory in ABI, in particular in its relevance to activity levels and mental health outcomes, I did not thoroughly measure neuropsychological variables that may have affected interpretation of the thesis results. For example, in a randomised-controlled trial of cognitive-only versus behavioural-only therapy in adults with depression without ABI, Murphy and colleagues (2021) report that those with greater self-reported cognitive skills at baseline had better outcomes in the behavioural-only arm, while this was not the case in the cognitive-only arm. In ABI specifically, better cognitive flexibility is thought to be an important aspect of behaviour change in therapy, and impaired problem solving can lead to poor problem solving in activities (Whiting et al., 2017).

Further, assessment of depression is often done through diagnostic interview, whereas here I rely on self-report questionnaires. Arguably, self-report is a more inclusive method of assessing mood relative to a more time-intensive diagnostic interview process. Evidence

suggests that self-report measures of low mood and depression do not perform worse than diagnostic interview in ABI populations (Berg et al., 2009; Dahm et al., 2013). However, measurement of activity level through self-report may be particularly challenging, and future research would benefit using more objective measures such as GPS trackers or pedometers. It is important, however, that objective level of overall activity may not fully align with measuring engagement in *reinforcing* activities, which BA theory posits to be a key aspect of improved mood. Potentially, incorporating experience-sampling methods throughout interventions can supplement self-report activity level data, and provide information that is less likely to be affected by recall bias, though this could be an intervention in and of itself.

Analysis Methods

Quantitative data analysis was limited by sample size in particular for the randomised controlled trial presented in Chapter 5, specifically when modelling for random effects in mixed-effects models. Of particular interest in interventions is not only *whether* people change, but by *how much*, and what is driving greater changes in some over others. As the qualitative data indicated that many group factors such as level of similarity and group size affects cohesion and to a degree outcomes, formally testing this hypothesis through modelling the slope of change in self-reported depression per group would be of benefit. Further, in Chapter 2, exhaustively testing different types of structural equation models was limited by the study sample size especially. Achieving large sample sizes sufficient to test more complex models is often time-consuming in ABI research, and prevents analyses that can inform conclusions about the quantitative data reported here.

The selection of interpretive description as a qualitative analysis method was driven by personal experience, as well as its focus on developing knowledge for use in clinical settings. Interpretive description is often used as a methodology that drives study design rather than analysis alone (such as the qualitative study on activity levels and BA components

in Chapter 4), though when analysing the qualitative data from the randomised controlled trial in Chapter 5, I did not use commonly-used interpretive description design and analysis methods (e.g., constant comparative analysis). This decision was taken for pragmatic reasons that allowed blinding for the quantitative assessments and, important for a PhD thesis, this allowed me to analyse the qualitative data largely on my own. However, as interpretive description is meant to be inherently flexible and atheoretical (Thorne, 2016), departing from these methods is not a limitation *per se,* rather an adaptation of interpretive description to be made suitable for the thesis aims. As I was blind to all outcomes until data collection had ended, potentially the questions asked in the qualitative interviews could have been expanded as issues arose throughout the trial. As recommended in Chapter 5, ongoing analysis of qualitative data throughout a future trial would be beneficial. It is also worth considering whether analysing the data without clinical goals in mind would result in additional constructed themes; data generated through qualitative interviews that may not be directly clinically applicable or useful may still be of use for other means.

Theoretical Implications and Future Directions

"Predisposing Characteristics" in Behavioural Activation – Which one(s) matter?

An important question for all intervention research is determining at the outset what specific vulnerabilities or immunities will inform response to therapy, and which of these are essential to explicitly address within an intervention session. It is interesting that in Chapter 2, the inhibiting effects of uncertainty were strongly associated with increases in generalised and social anxiety, whilst in Chapter 5, a BA-focused intervention decreased both anxiety and the inhibiting consequences of uncertainty, despite no explicit material addressing uncertainty or anxiety reduction. Perhaps uncertainty-anxious responses cause avoidance, rather than a better ability to manage uncertainty causing greater activation. Of course, a therapeutic group environment may simply be a place to discuss unknowns out loud, or implicitly learn how

others cope with uncertainty. It would be interesting to explore, for example, whether the relative increases in uncertainty following ABI lead to a heightened sensitivity to uncertainty, or whether changes in problem-solving uncertainty due to poor executive function capabilities give rise to greater anxiety and avoidance. Though only using cross-sectional data, in Chapter 3 greater levels of self-reported executive function problems had the strongest relationship to anxiety of all study variables.

Of course, psychology is especially vulnerable to "construct redundancy" (Le et al., 2010) in which "novel" constructs are highly conceptually similar to, or share unacceptable levels of variance with, extant constructs. When selecting the most relevant constructs in BA and ABI, identifying constructs that have sufficient scope to explain a set of associated behaviours ("breadth"), but are unidimensional enough to be sensitive to change in an intervention ("depth") relative to other similar constructs, may be the best measurement targets. Further structural equation modelling, especially in research focusing on construct validity work, could help identify constructs with sufficient depth and breadth that would be of particular benefit in rehabilitation research where time and resources are often limited.

Self-focused attention versus self-awareness

Impaired self-awareness research in ABI has been considered to be independent from emotional evaluations of capabilities (Prigatano & Sherer, 2020), as is evidenced by its consistent association with lower levels of depression and anxiety, and greater levels of apathy and emotional indifference (Bivonia et al., 2019). When considering how BA theory may be applied in ABI, it would be useful to disentangle how "self-focused attention" or a "hyper awareness" on oneself differs from self-awareness, and whether changes in both contribute to successful outcomes in rehabilitation. It is interesting to ask, however - can one be fully self-aware without being self-focused? Presumably, in any intervention, reflecting how new knowledge relates to the self serves to increase self-awareness ("I am now

knowledgeable of why I have a hard time completing tasks") *and* self-focused attention ("I am discussing difficult emotions and the negative ways it has impacted me"). Thus, both are necessary components of successful rehabilitation. Some individuals, when attempting to increase self-awareness, may instead engage in self-focused attention and this may become detrimental to progress. Perhaps all self-awareness is self-focused attention, but not all self-focused attention is self-awareness.

Which BA component works for whom?

The central aim of BA has commonly been to enhance reinforcement through increases in activity level. Methods to achieve this have been substantially varied throughout the years (Kanter et al., 2010). Lewinsohn (1975) himself stated that the choice of specific BA techniques will ultimately depend on individual circumstances. Despite this, the techniques of activity scheduling and mood monitoring have become almost synonymous with BA – but are these the only techniques in BA that might drive improvements in mood? It would be interesting to conduct a series of single-case experimental design studies where participants and researcher select a discrete BA component (e.g., mood monitoring, self-rewards, social skills training) that is of mutually agreed benefit, and whether this would produce equivalent gains in mood, or reductions in depression. To my knowledge, an investigation comparing different BA components has not been conducted. Maybe just trying *any* component is what is important in challenging preconceptions that attempts will fail; indeed in Chapter 5 just group effects alone can have a substantial impact on mood.

Do More, Feel Better, or Feel Better, Do More?

BA therapy has been used throughout the years under the premise that increases in activity levels lead to improvements in mood. Yet, therapy is predicated on an atmosphere of openness, empathy, and trust. Flexibility in adapting therapy to those with ABI is particularly important (Judd & Wilson, 2005), and as such, perhaps for ABI, focusing on creating such a

space is more important than it might be outside of ABI, where there might be fewer barriers to activity completion. In BA theory, the consequences of failing to cope with a "depression evoking event" are cyclical, with the most amenable point in the cycle to intervene being activity levels. But perhaps instead BA therapy (and potentially other therapies) works by first providing the "milieu" needed to ease the immediate emotional responses of coping with an ongoing "depression evoking event" – in this case, chronic effects of ABI that can be experienced daily. Providing knowledge of the effects of ABI and strategies serve to enhance "rehabilitation readiness" or preparedness (van den Broek, 2005; O'Callaghan et al., 2012) that serve to motivate attempts at initiating activities, and to continue self-motivating attempts to engage in activities past intervention, as modified in Figure 28 below. Rather than solely modifying internal abilities, BA theory in ABI may benefit from explicitly incorporating how external influences can contribute to improved outcomes.

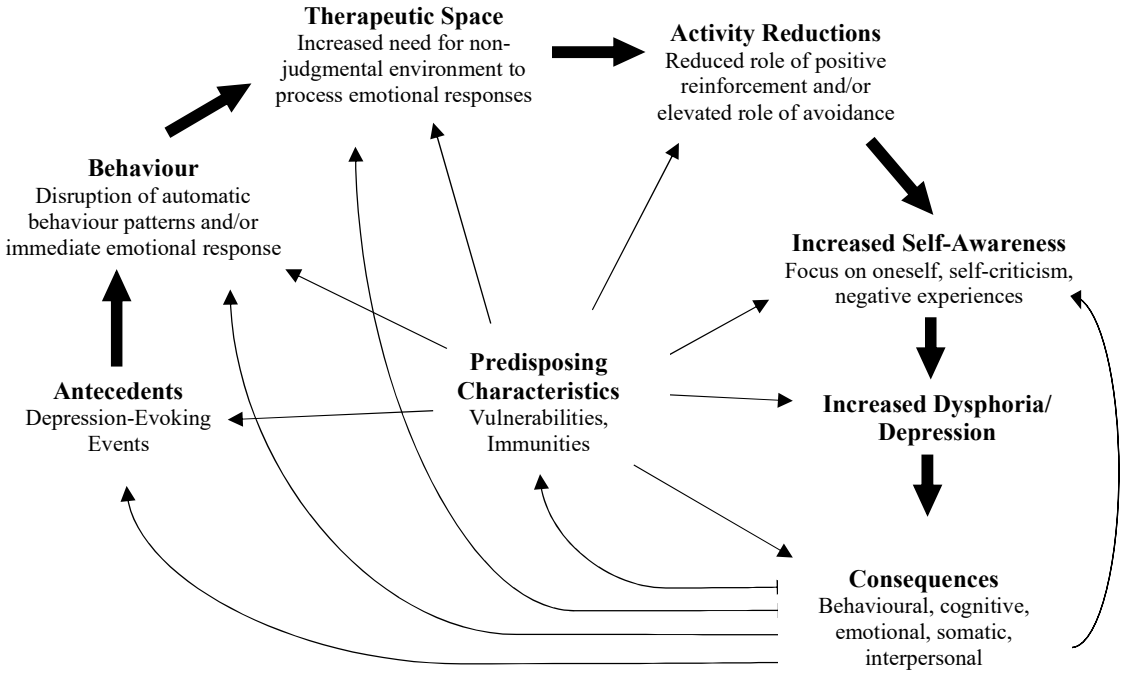


Figure 28. Lewinsohn's integrative model of depression, with a modification to include need for therapeutic spaces following ABI. (Adapted from Lewinsohn et al., 1985a). Reproduced with permission.[12]

[12] This article was published in *Theoretical Issues in Behavior Therapy,* 1, Reiss. S. & Bootzin, R.R. *An integrative theory of depression*, 331 – 359. Copyright Elsevier (1985a).

Sitting in the "Middle Chair" – Embracing Objectivity and Subjectivity

In coming to understand effective assessment and intervention for those with acquired brain injury, evaluating different ways of integrating both objective and subjective knowledge is necessary. Johnson & Onwuegbuzie (2004) visualise such an integrative approach as representing a third, middle chair, with rich and nuanced qualitative methods sitting on the left side, and categorical, generalizable quantitative methods sitting on the right. This pluralistic approach to developing knowledge is becoming increasingly used, with novel methods of both quantifying qualitative data and "qualitizing" quantitative data being developed (Tashakkori & Teddlie, 2011) that can be of benefit in ABI research.

Psychological research more generally will always experience difficulties in quantitative replication, as both participants and researchers will change in response to contextual and time-bound variables. In turn, the tools with which we conduct research must account for these changes too. Identifying and establishing robust patterns, and *describing* in our research the particular context with which these patterns occur and how participants engage with and experience the research at hand, are both invaluable. Thus, we can enhance our understanding of who our results apply to, and under what conditions, in an attempt to firmly distinguish what is truly "generalizable" to all populations and what is "transferable" to subsets of individuals.

Thesis Appendix

Chapter 2 Appendices

Appendix items for Chapter 2 include the custom-developed COVID-19 questionnaire when examining whether intolerance of uncertainty as rated by the Intolerance of Uncertainty Scale-Short Form were affected by the pandemic, and a more detailed exploration of potential ways intolerance of uncertainty could be affected. All analyses here are purely exploratory and were conducted to determine if there was *any* indication that reliability of the Intolerance of Uncertainty Scale-Short Form was affected by COVID-19, and as such, any results here should be treated with caution.

COVID-19 Questionnaire

The following set of questions are about your experiences during the COVID-19 pandemic. We are asking these questions to help us make sense of people's answers on questionnaires completed during this time. Your answers are not linked with your name and you do not have to answer any question with which you are not comfortable.

1. **Have you had COVID-19?** Please indicate which of the following best applies to you.

I have had COVID-19 and this was confirmed with a positive test result	☐
I think that I did have COVID-19, but didn't get a positive test result (because result was negative or I didn't take the test)	☐
I have not had COVID-19	☐

2. If you answered yes to having had COVID-19, or think you might have had it, please enter below about when this was, and any symptoms that you had.

Less than 2 weeks ago	2-4 weeks ago	Within last 3 months	Within last 6 months	Within the last year	More than a year ago

Please choose any of the following that describe the symptoms that you had when you had COVID-19.

	Yes	No		Yes	No
No symptoms			Headache		
Fever (high temperature) or chills			Change in ability to taste or smell		
Cough			Sore throat		
Shortness of breath or difficulty breathing			Congestion or runny nose		
Fatigue			Stomach problems (nausea/ diarrhoea)		
Muscle/body aches			Confusion/ disorientation		

3. Please indicate any symptoms from COVID-19 that persisted **for more than 3 months** after you were infected.

	Yes	No		Yes	No
No symptoms			Sore throat		
Fever (high temperature) or chills			Congestion or runny nose		
Cough			Stomach problems (nausea/ diarrhoea)		
Shortness of breath or difficulty breathing			Confusion/ disorientation		
Fatigue			Neurological (brain) problems		
Muscle/body aches			Low Mood		
Headache			Anxiety		
Change in ability to taste or smell			Any other symptoms?		

4. If you had, or may have had, COVID-19, please select one of the following that best describes its severity.

I had mild symptoms for less than a week and didn't go to hospital ☐
I had mild symptoms for more than a week but didn't go to hospital ☐
I felt very ill for less than a week but didn't go to hospital ☐
I felt very ill for more than a week but didn't go to hospital ☐
I was so ill that I was admitted to hospital ☐
I was so ill that I was admitted to an intensive care unit ☐
I was so ill that I was medically sedated and placed on a ventilator ☐

5. COVID-19 Vaccination

	Yes	**MM/DD/YYYY**
I have had the first part of a two-part COVID-19 vaccination		
I have had the second part of a two-part COVID-19 vaccination		
I have had a COVID-19 vaccination that only requires one dose		
I have not had a COVID-19 vaccination		

6. Thinking back to March 2021, please indicate to what extent you were experiencing each of the following at THAT time, and then NOW, using the 5-point scale.

	March 2021					**Now**				
	Very little				A lot	Very little				A lot
1. Worry about your own health	1	2	3	4	5	1	2	3	4	5
2. Worry about family or friends' health and/or general situation	1	2	3	4	5	1	2	3	4	5
3. Worry about not having enough food or essential supplies	1	2	3	4	5	1	2	3	4	5
4. Worry about your own/your family's financial situation	1	2	3	4	5	1	2	3	4	5
5. Loneliness/ isolation	1	2	3	4	5	1	2	3	4	5
6. Boredom	1	2	3	4	5	1	2	3	4	5
7. Low mood	1	2	3	4	5	1	2	3	4	5
8. Anxiety	1	2	3	4	5	1	2	3	4	5
9. Lack of exercise	1	2	3	4	5	1	2	3	4	5
10. Increased caring demands (e.g., for relatives or children not at school)	1	2	3	4	5	1	2	3	4	5

7. Some people experienced positive aspects of changes related to COVID-19. Thinking back to March 2021, please indicate to what extent you were experiencing each of the following at THAT time, and then NOW, using the 5-point scale.

	March 2021					**Now**				
	Very little				A lot	Very little				A lot
1. Positive changes to my work situation (e.g., not having to travel/commute)	1	2	3	4	5	1	2	3	4	5
2. Having time for other activities such as exercise, reading, hobbies, or catching up with people	1	2	3	4	5	1	2	3	4	5
3. Spending more time with my partner	1	2	3	4	5	1	2	3	4	5
4. Feeling part of bigger purpose/ greater sense of community	1	2	3	4	5	1	2	3	4	5
5. Made me think about what is important in life	1	2	3	4	5	1	2	3	4	5

Exploration of the Effects of COVID-19 on IU-SF

This section provides further detail on the potential impact of COVID-19 on assessment of IU. Overall, the results in Chapter 2 suggest that there was no general increase in low mood, anxiety and social phobia symptoms between the time points collected. However it is important to remember that, for many of the participants *all* time points occurred *during* the COVID-19 pandemic. To draw some, albeit exploratory, inferences on these issues I therefore focused on *differences* in experience during the pandemic, such as whether or not participants had been vaccinated or infected at the time of measure completion, whether they had experienced symptoms and whether these had persisted, and positive/negative experiences of the pandemic such as social isolation, financial concerns etc.

I investigated any potential differences in IU and mood measures between those who have been ill with COVID-19, and whether self-reported negative or positive changes due to COVID-19 related to IU, and mental health outcome measures used in the present study. Due to small number of those who have contracted COVID-19, results are largely descriptive. A summary of self-reported medical details is shown below.

Confirmed or suspected COVID (*n* = 10)	
COVID Status – *n*	
Confirmed	2
Suspected	8
COVID Recency – *n*	
Less than 2 weeks ago	1
Within the last year	4
Greater than 1 year ago	5
COVID Severity – *n*	
Mild symptoms for less than 1 week	2
Mild symptoms for more than 1 week	2
Very ill for less than 1 week	2
Very ill for more than 1 week	4
Number of symptoms – M (*SD*)	
Acute COVID symptoms	8 (1.89)
Long COVID symptoms	3.1 (3.31)

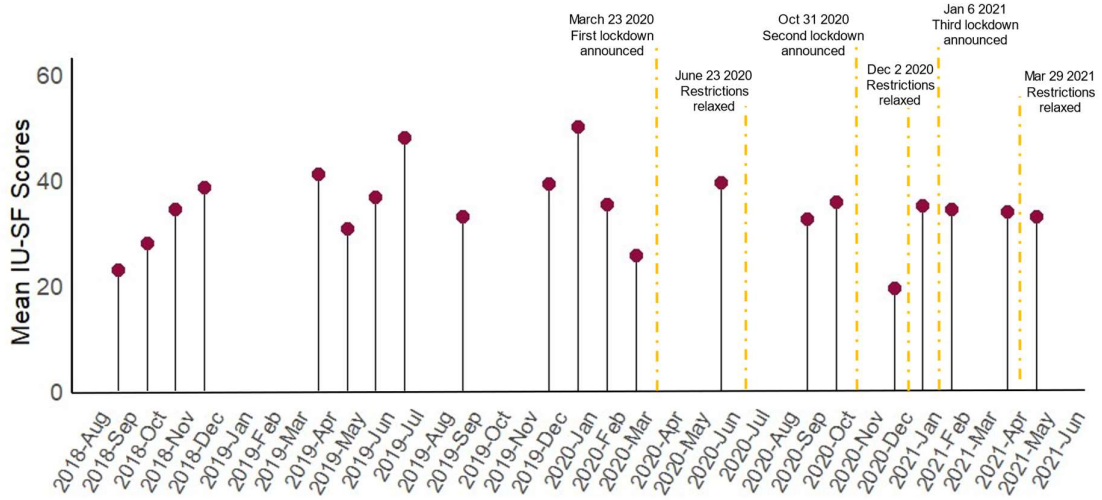
Appendix Table 1. Medical characteristics of participants with COVID.

IU scores were further summarised based on whether participants had received a first or both doses of a vaccine or no vaccine (see Table 9). Generally, IU scores did not seem to differ by vaccine status across time points, however those who had not received their vaccine by Time 3 (August 2021) were elevated relative to those who had received their first or second dose. It is worth noting that three of the four participants without a vaccine at Time 3 had elevated IU-SF scores at Time 1 and Time 2, suggesting scores may be independent of vaccination status.

	No Vaccine	First Dose	Both Doses
Time 1 (March 2021)	33.9 (8.86) *n* = 23	32.5 (10.5) *n* = 22	
Time 2 (April 2021)	32.3 (9.97) *n* = 16	35.3 (9.54) *n* = 25	33 *n = 1*
Time 3 (August 2021)	40.0 (14.6) *n* = 4	29.8 (13.3) *n* = 4	33.3 (10.7) *n* = 40

Appendix Table 2. Mean IU-SF scores with standard deviations based on vaccine status at each data collection time point.

To determine whether IU scores varied as lockdowns and subsequent easing of restrictions, mean IU scores (using Study 1 data, $N = 176$) across all months of data collection were estimated. Results are plotted in Appendix Figure 1. Excluding months where only one participant completed the IU-SF, the month with the highest mean IU-SF scores was May 2020 ($n = 11$, M = 39.45, $SD = 8.25$) and the month with the lowest mean IU-SF scores was November 2020 ($n = 2$, M = 19.50, $SD = 2.12$). For the Inhibitory Anxiety subscale, the month with the highest mean scores was May 2020 ($n = 11$, M = 16.45, $SD = 4.72$) and the lowest August 2018 ($n = 2$, M = 8.50, $SD = 4.94$). For the Prospective Anxiety subscale, the month with the highest mean scores was November 2019 ($n = 28$, M = 23.14, $SD = 4.25$) and the lowest November 2020 ($n = 2$, M = 11, $SD = 1.41$).



Appendix Figure 1. Mean IU scores across all months of data collection for the present chapter ($N = 176$), with dashed lines indicating when restrictions changed for UK residents. Months with no lines indicate that no data was collected for this chapter during those dates.

Chapter 3 Appendices

Appendix items for Chapter 3 include further details on the multiple imputation processes for analyses at Site 1, Site 2, and the combined sample. In order to suitably conduct imputations without increasing risk of bias, type of missingness needed to be determined. Missing data can be either Missing Completely at Random (MCAR; true randomness), Missing at Random (MAR; data is missing *conditionally* at random, for example due to a clinician not including a particular measure in an assessment due to it not being used in the service at that time), and Missing Not at Random (MNAR; missing data is due to systematic tendencies for participants to omit responses, for example participants refusing to answer items that are highly sensitive). MCAR and MAR data are suitable for imputation, thus establishing this was the goal.

Multiple Imputation Processes

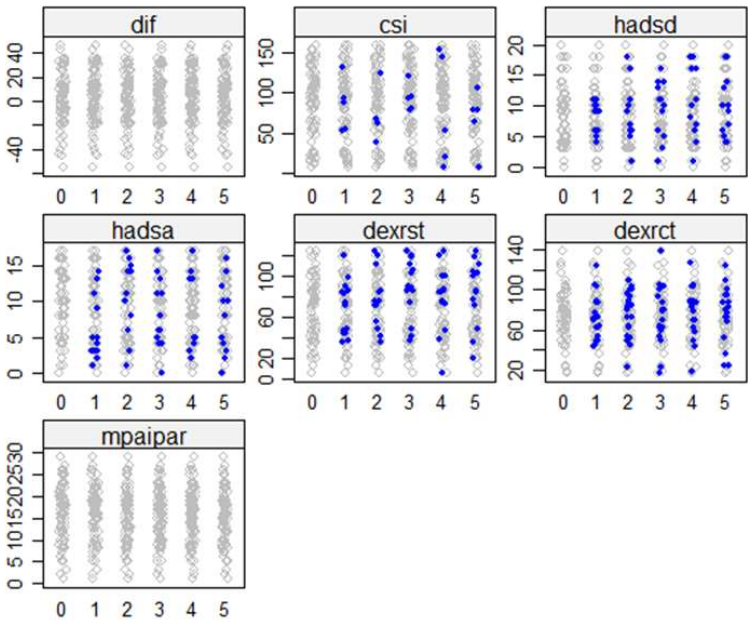
Site 1 Analysis

The dataset at Site 1 had large amount of missing data on the Rosenberg Self-Esteem Scale (RSES; 76.1% missing cases at the observation level) and on Glasgow Coma Scale (GCS) scores (63.6% missing cases). Missing GCS scores were considered to be acceptable, given that non-TBI brain injuries would not have GCS scores available. The RSES was not used for imputation due to the large amount of missing items limited range of imputations in predictive mean matching. This resulted in 60.2% of cases with complete data at Time 1, not including missing data due to GCS scores. For the remainder of the sample, most participants had only two scales with missing variables (e.g., only missing scores on the HADS-A and HADS-D scales) and were considered suitable for imputation.

Hawkins Test of normality and homoscedasticity was only marginally non-significant ($p = 0.05$), indicating data was likely Missing at Random. Considering the context in which data was collected (i.e., a health care setting) and knowledge of the site itself, the amount of

missingness of the remaining study variables (All less than 23% of cases missing at the observation level) was likely to be due to measures being introduced at a later point in services (i.e., DEX-R-S and DEX-R-C), using alternative measures to capture the same construct of interest (i.e., HADS versus other depression/anxiety measures), and non-availability of informants to provide ratings (i.e., CSI). Thus, data was considered to be MAR and suitable for multiple imputation.

Donor variables to conduct predictive mean matching include discrepancy scores, self- and informant-rated DEX-R scores, HADS-D and HADS-A scores, CSI scores, and MPAI-4 Participation scores. A visualisation of the imputed datasets compared to complete cases is shown in Appendix Figure 3.



Appendix Figure 2. Visualisation of imputed datasets compared to complete cases at NHS Site 1. Grey circles are complete cases, blue circles are imputed values for missing observations. The non-imputed dataset is marked as "0" on the x-axes, with x-axis numbers 1 to 5 each representing a separate dataset.
HADSA = Hospital Anxiety and Depression Scale-Anxiety; HADSD = HADS-Depression; CSI = Caregiver Strain Index; MPAIPAR = Mayo Portland Adaptability Inventory; DIF = Discrepancy Scores; DEXRST = Dysexecutive Questionnaire-Self;
DEXRCT = Dysexecutive Questionnaire-Carer.

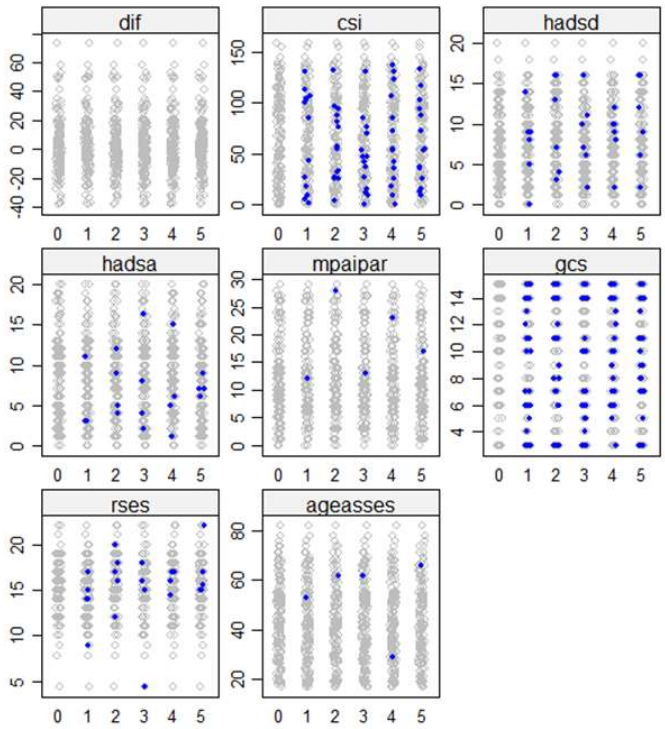
In determining missingness for the longitudinal analysis investigating whether estimation groups differed in clinician-rated participation at follow up, Hawkins Test for normality returned non-significant ($p = 0.76$). Given the above reasons for likely missingness (e.g., missed appointments common at follow-up, assessment not clinically appropriate), the data was considered Missing at Random. As maximum likelihood estimation was used to provide estimates given the missing data, no imputations were conducted on the longitudinal data.

Site 2 Analysis

The Site 2 dataset had less than 10% of cases missing at the observation level for all variables at Time 1 except the GCS. GCS scores were missing for 24.2% of cases. As this measure is rated by an observer and in acute injury settings, its omission is likely due to either it not being assessed or information on GCS not being transferred to the Study 2 site records from acute care (i.e., highly unlikely to be MNAR).

Hawkins Test was significant ($p = 0.03$), indicating that the data is not MCAR. A subsequent non-parametric test of homoscedasticity was non-significant, however ($p = 0.14$), suggesting homogeneity of the covariances. Upon discussion with staff from Site 2, reasons for measures being missing were often due to self-report measures deemed not appropriate for the client (e.g., due to complex injury) or informants being unavailable or unable to complete measures. Data was considered to be MAR and suitable for multiple imputation.

Unlike Site 1, GCS scores were imputed as all clients at Site 2 had a TBI and thus was considered suitable for imputation. To conduct imputations, donor variables included difference scores, GCS scores, RSES scores, HADS-D and HADS-A scores, CSI scores, and MPAI-4 Participation scores. A visualisation is presented in Appendix Figure 3.

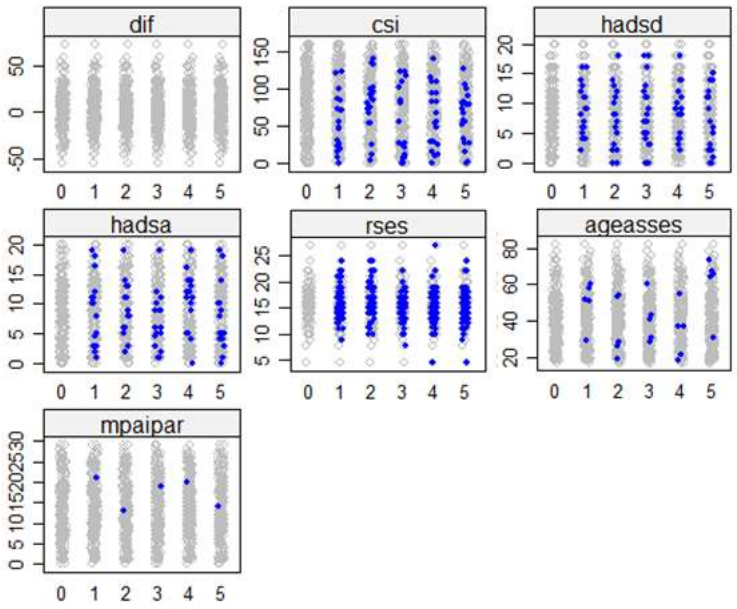


Appendix Figure 3. Visualisation of imputed datasets compared to complete cases at NHS Site 2. Grey circles are complete cases, blue circles are imputed values for missing observations. The non-imputed dataset is marked as "0" on the x-axes, with x-axis numbers 1 to 5 each representing a separate dataset.
HADSA = Hospital Anxiety and Depression Scale-Anxiety; HADSD = HADS-Depression; CSI = Caregiver Strain Index; RSES = Rosenberg Self Esteem Scale; GCS = Glasgow Coma Scale; MPAIPAR = Mayo Portland Adaptability Inventory; DIF = Discrepancy Scores; AGEASSES = Age at assessment.

In determining missingness for the longitudinal analysis, Hawkins Test for normality for Time 2 data was only marginally non-significant (p = 0.05). Visual inspection indicated the CSI had the largest amount of data missing (32%), though the majority of participants had complete cases at Time 1. Roughly 20% to 30% of data was missing at Time 2, though as in Time 1 most had complete cases. The next most common data pattern was to have all variables missing at Time 2, likely suggesting that missingness was due to a participant not completing a follow up assessment, rather than missingness being a result of the study measures themselves. In conjunction with investigations of the missingness patterns at Time 1, data was considered MAR.

Combined Analysis

The variable with the largest amount of missing data was GCS scores (38.5%) followed by RSES scores (29.87%). Otherwise, less than 10% of observations were missing for the remaining Time 1 variables. Hawkins Test returned non-significant ($p = 0.19$) for the combined sample. In consideration of the missingness patterns discussed in Site 1 and 2 above, multiple imputation was conducted under the MAR assumption. Using predictive mean-matching, a total of 5 datasets were imputed for difference scores, RSES scores, HADS-D and HADS-A scores, CSI scores, and MPAI-4 Participation scores. GCS scores were not imputed as participants with Site 1 included non-TBI brain injuries. A visualisation of the imputed data is shown in Appendix Figure 4.



Appendix Figure 4. Visualisation of imputed datasets compared to complete cases at NHS Site 1. Grey circles are complete cases, blue circles are imputed values for missing observations. The non-imputed dataset is marked as "0" on the x-axes, with x-axis numbers 1 to 5 each representing a separate dataset.
HADSA = Hospital Anxiety and Depression Scale-Anxiety; HADSD = HADS-Depression; CSI = Caregiver Strain Index; RSES = Rosenberg Self Esteem Scale; MPAIPAR = Mayo Portland Adaptability Inventory; DIF = Discrepancy Scores; AGEASSES = Age at assessment.

Combined Sample Longitudinal Analysis

In the longitudinal data, the measure with the most amount of missing data was the RSES, with 47.9% of observation-level scores missing, likely due to the large volume of RSES scores missing from Site 1. This was followed by GCS (for TBI participants) and CSI scores, with 38.5% and 33.2% of cases missing, respectively. Hawkins Test for normality for the longitudinal data was significant ($p = 0.003$), though a non-parametric test of homoscedasticity returned non-significant ($p = 0.30$). Considering likely reasons for missingness discussed in Analysis 1 and Analysis 2, analysis of the combined data proceeded under the assumption that the missing data were MAR.

Chapter 4 Appendices

The appended item for this Chapter is the interview script that was used to generate qualitative data. Italicised items are instructions for the interviewer.

Interview Script (Participant Version, Last Iteration – December 12 2018)
Date:

Participant ID#:

The purpose of this interview is to get a better idea of how people with a brain injury solve problems with day to day activities. I will be asking you questions about how you think, feel, and act during everyday activities. There are no right or wrong answers. I would like you to be as honest and open as you can in this interview, although you are always free to not answer questions if you do not want to.

There may be times when I ask you about things that you have already talked about in your earlier answers. So if we have already talked about a certain event that I am asking you questions about, we will just clarify your answer, and then move on.

Also, I will ask you throughout the interview if there is anything else you have to add to your answer. This is not because your answers are wrong, but because I want to make sure that I get all the important information from you.

Please let me know throughout the interview if it is not clear what I am asking.
As you know, the interview will take us about 1 hour. If you are feeling tired or would like to take a break at any time, please let me know. We will break for 5 minutes after 30 minutes into the interview.

Do you have any questions at this point?

Ok, let's get started.

Valued Activities

First, can you tell me how, on a scale of 1 to 100, how important the below categories are to you? 100 would mean very important, and 1 would mean not at all important.

1) Work
2) Self-education/learning
3) Volunteering
4) Intimacy/relationships
5) Family
6) Friendship
7) Religion/Spirituality
8) Entertainment/Recreation
9) Health/Fitness

Is there anything else that I haven't mentioned that you feel is really important to you?

Topic 1: Overall Activity Engagement Experiences

Okay great, now we are going to talk about overall activities. When I say this I mean day-to-day things such as chores, work, appointments, and the like.

First of all, I'd like you to list three things that you complete in a typical week and can generally do since your brain injury.

(Prompt if needed)
This can be anything you like, such as doing the dishes or spending time with a family member.

Okay, great. Can you tell me what helps you get *motivated* on the activities you've mentioned?

(If participant can't think of any, give specific examples such as below)
If you are going out of the house to get groceries, for example, one problem might be that the grocery store is far and you don't think you have the time to get there if you walk. One way to help you get started is to think about other ways to get there, like by public transit. Does thinking about different ways to get there, like in this example, help you get started on what you need to do?

Is there anything else that helps you get motivated for your daily activities?

Great. Have you ever had any problems, related to your brain injury or not, that might stop you from doing what you like *(use specific examples that participants listed)*? What did you do, if anything, to get through these problems?

If these problems ever interrupted your activity all together, how did you feel when you realized you did not complete the activity?

(Prompt)
Do you think that *not* finishing this activity made you feel better/worse?

(if this does not come up organically)
Okay, great. Now, I would like you to tell me how you feel when you've completed an activity.

(Prompts)
Did finishing (participant's specific example) make you feel happy, or good at what you are doing? Did it affect the rest of your day? Do you think that finishing this activity made you feel better/worse?

(if this does not come up organically)
Do you think that finishing this activity helped you in other or future activities?

Topic 2: Engaging in Enjoyable Activities

Now, we are going to talk about enjoyable activities specifically. I will ask a lot about "enjoyable activities" – when I say this, I mean anything that is pleasant or makes you feel good or happy. This can be something simple like calling your best friend or finishing a task at work, or big things like spending a day in London or travelling abroad.

Do you have any questions?

On average, how many enjoyable activities would you say you do in a week since your brain injury?

(Prompt)
Enjoyable activities can be something like reading a book, or watching your favourite show – it doesn't need to be anything fancy, as long as you enjoy it.

Would you say being a part of pleasant or enjoyable activities are important for you? Why or why not?

Now, I'd like you to list three enjoyable activities that you would like to do in the next week.

Can you think of anything that might get in the way of starting these future activities *(input specific examples*), whether related to your brain injury or not?

(For interviewer to note)
Barriers:

Now that what do you think would help you get motivated for these activities (input specific examples)?

(For interviewer to note)
Strategies:

Topic 3: Potential New Strategies

Now, we are going to talk about different ways someone can get through problems that come up when trying to complete an activity. I will ask you for your thoughts about whether you think these will work for you specifically.

I. Mood Monitoring

Some people find that keeping track of how day-to-day activities make them feel helps them feel good about trying out new things. Specifically, people rate how happy they feel after completing an activity in order to get a better sense of what makes them feel good. Do you think keeping track of your mood in everyday activities will help you? Why or why not?

(Example prompt, but ideally make use of specific examples given by participant)
Say you just spent a day with your best friend. You make a note to be aware of how you feel after spending time with your friend, and notice that you are happy. Knowing that spending time with your best friends makes you feel happy, you try to meet with your friends more often. Do you think this would help motivate you to try out new and potentially enjoyable activities?

On a scale of 1 to 100, how useful do you think keeping track of your daily mood would be to you?

(*If strategy is already employed)*

On a scale of 1 to 100, how useful is keeping track of your daily mood to you?

II. Activity Scheduling

Some people like to keep a diary to keep track of what they have to do. Specifically, sometimes someone will plan in pleasant activities to make sure they have activities to look forward to. Do you think keeping an activity diary will help you? Why or why not?

(Example prompt, but ideally make use of specific examples given by participant)
Let's say you make sure to plan in a movie night at home every once in a while no matter what. Do you think this would be helpful for you?

On a scale of 1 to 100, how useful do you think keeping an activity diary would be to you?

(*If strategy is already employed)*
On a scale of 1 to 100, how useful is keeping an activity schedule is to you?

III. Alternative Solutions

Sometimes it's helpful to think ahead of time of different ways to tackle problems when trying out new or different activities. Specifically, it helps some people to think of what they usually do when faced with a problem, and then list other ways to solve it. Do you think this would help you solve any problems you might have starting an activity? Why or why not?

(Example prompt, but ideally make use of specific examples given by participant)
Let's say that every time you want to go shopping, you are worried that your family member will be too busy to drive you, so you decide not to go shopping. The current way that this problem is "solved" is by not going shopping, even though it is something you want to do. Beforehand, you might think of different ways to get you to the store such as calling a taxi, taking public transportation, calling a friend, or even online shopping. Do you think this would be helpful?

One a scale of 1 to 100, how useful do you think listing different solutions to problems would be to you?

(*If strategy is already employed)*
On a scale of 1 to 100, how useful is thinking about back up plans ahead of time to you?

IV. Balancing Types of Activities

Sometimes, people feel that they have too many stressful or important activities on the go, such as various appointments or job requirements. Some people find it helpful to plan pleasant activities to balance out the stressful activities. Do you think this will be helpful for you? Why or why not?

(Example prompt, but ideally make use of specific examples given by participant)
Let's say you have a very busy week and it leaves you feeling frustrated. You decide Tuesdays will be your "relaxation days" where you spend your evening with your family to help you feel better. Do you think this would be helpful?

On a scale of 1 to 100, how useful do you think balancing mandatory and pleasant activities would be to you?

(*If strategy is already employed)*
On a scale of 1 to 100, how useful is balancing enjoyable and mandatory activities to you?

V. Active Engagement

Sometimes, it is easier to let things happen to you rather than make things happen. Some people feel that that playing an active role in their life helps build their confidence and control their lives. Do you think this would be helpful for you? Why or why not?

(Example prompt, but ideally make use of specific examples given by participant)
Let's say that you want to talk to your cousin who lives across the country, but you don't want to bother them so you wait for them to call. An active way of dealing with this situation would be to call them anyway to start the conversation. Do you think learning to do this would be helpful for you?

On a scale of 1 to 100, how useful do you think dealing with situations actively would be for you?

(*If strategy is already employed)*
On a scale of 1 to 100, how useful is taking initiative to plan activities to you?

VI. Mindfulness

Some people like to remind themselves to stay "in the moment" – that is, being aware of what is happening right now rather than looking back to the past or thinking about what will happen in the future. This helps some people get the most out of what they are doing and enjoy each day more. Do you think this would be helpful for you? Why or why not?

(Example prompt, but ideally make use of specific examples given by participant)
Let's say you are having tea with your friends. You keep on worrying about tomorrow, when you have to visit the doctor's, call the hydro company, and get some food for a family dinner. This distracts you from the present moment, which is tea with your friends. In mindfulness, you would learn to keep yourself focused on tea with friends rather than tomorrow's worries. Do you think this would help you?

On a scale of 1 to 100, how useful do you think mindfulness would be for you?

(*If strategy is already employed)*
On a scale of 1 to 100, how useful is mindfulness to you?

VII. Communication and Social Skills

Sometimes, people have a hard time telling others what they want to do, or don't know how to start a conversation about a difficult subject. Other times, we can feel uncertain about speaking with new people. It is helpful for some people to learn how to better communicate with others so they can say what's on their mind or meet new people. Do you think this would be helpful? Why or why not?

(Example prompt, but ideally make use of specific examples given by participant)
Let's say you are trying to tell your partner that you'd like to spend a day at home solving puzzles rather than go to the park, but your partner insists that the park is a good idea. Rather than tell them what you want to do, you go along with it even though you don't want to. Learning how to bring up this information in a respectful way can help avoid hurting any feelings. Do you think this would be helpful?

On a scale of 1 to 100, how useful do you think working on your communication skills would be for you?

(*If strategy is already employed)*
On a scale of 1 to 100, how useful are communicating to others about difficult topics to you?

VIII. Managing Uncertainty

With any health condition or disability, there can be a lot of uncertainty about how you will handle a new situation. For some people, the uncertainty is too worrisome and makes them feel anxious. It can be helpful to learn how to cope with uncertain situations in order to feel more comfortable when starting a new activity. Do you think this will be helpful for you?

(Example prompt, but ideally make use of specific examples given by participant)
Let's say your family wants to take you to shopping in Norwich. You have not yet been to Norwich, and you currently use a walker to help you get around. You are unsure whether the pavement will be uneven, whether all of the shops will have appropriate disabled access, and if you can manage a day in Norwich. These worries make you not want to go to Norwich. Some people find it helpful to manage uncertain situations by taking part in similar uncertain experiences in order to prepare themselves, like going to see a film without knowing anything about it. Do you think this would be useful for you?

On a scale of 1 to 100, how useful do you think working on managing uncertainty would be for you?

(*If strategy is already employed)*
On a scale of 1 to 100, how useful is managing uncertainty to you?

IX. Social Skills (no longer used after October 2018 version of interview)
Every once in while, people can feel uncomfortable or awkward speaking with friends or family, and lose confidence in their social skills. This can either be something people feel generally uncomfortable with, or it could be something that people suddenly are unsure about after their injury. This can lead them to keep to themselves and avoid new activities that involves other people. Some people find it useful to practice their social skills with other people in order to become more confident. Do you think this would be useful for you?

(Example prompt, but ideally make use of specific examples given by participant)
Let's say you are going to visit one of your friends. Your friend is bringing some people that she knows from her neighbourhood. You have not met them yet, and you are unsure if they know that you have had a brain injury. You suddenly feel uncomfortable about meeting new people because you don't know how they will react to you, and you then decide not to go to your friend's home. When learning how to improve social skills, you would practice interacting with new people on a regular basis in order to feel more comfortable. Do you think this would be useful for you?

On a scale of 1 to 100, how useful do you think working on your social skills would be for you?

(*If strategy is already employed)*
On a scale of 1 to 100, how useful are your social skills to you?

Is there anything else that you think would be useful in helping you engage in enjoyable activities?

Chapter 5 Appendices

Appendix items for Chapter 5 includes a detailed account of challenges in trial implementation from my own and the trial steering committee's perspective, a topic discussion guide for the Activity Planning Group, the custom-developed Post-Study Questionnaire and Exit Interview that was used to collect qualitative data, and the fidelity assessment checklists.

Challenges in Trial Implementation – Research Team Perspectives

The main challenges in trial implementation were sufficient recruitment, ensuring inclusion and exclusion criteria was well-specified, practical support when delivering sessions in person compared to online, collecting qualitative and quantitative data while adhering to study protocol, participant preferences of study groups, and adapting the study procedures due to COVID-19.

Recruitment

Though I managed to recruit 60 participants for the study, recruiting a sufficiently representative sample of those with ABI remained a challenge. Recruiting from service user group mailing lists was a particularly useful source of recruitment from NHS sources, though recruiting from active client lists from community ABI services proved difficult. This was mainly due to limited time on behalf of participants, individuals with ABI not perceiving the need to be involved in additional interventions, or clinician concern that an additional intervention would be too much strain on the client in question. Further, sufficient time for NHS staff members to review client lists and make referrals varied across services, suggesting the need for dedicated resources for research recruitment. Conducting recruitment predominantly from the time between acute care and community services, or clients 6 months to 1 year post-community services, may be the most fruitful avenues for eligible participants.

Recruiting through ABI charities and social media self-referrals were promising sources of recruitment. Especially when sessions transitioned online, ABI charities in areas outside of Cambridgeshire could be accessed and participants who may not have services available nearby could participate. ABI charities in locations with a greater population than the Cambridgeshire area such as London benefitted recruitment.

There was a fair balance across gender and age ranges, but not ethnicity. Targeted recruitment, or ensuring that final sample sizes are representative of local or national ethnicity statistics, may enhance transferability of the study results to broader populations. Greater discussion among steering committee members and a Patient and Public Involvement group, alongside further research on methods to enhance representative recruitment, may be necessary before proceeding to a main trial.

Delivering Sessions in Person vs Online

In the transition to online interventions, delivering the Activity Planning Group was comparable to in person, with the exception of limitations in selection of activities complete as homework (see *Impact of COVID-19* below). The Activity Engagement Group, by contrast, was more challenging to deliver online due to excess time and costs posting materials needed to facilitate selected session activities (e.g., craft supplies) and instructions on attempting novel activities (e.g., origami) becoming difficult online. If using online resources to facilitate in session activities, these could become cognitively demanding due to needing to switch between the videoconferencing software and other software needed for the session, or difficulties locating the videoconferencing chatbox to access links. Further, if there were a variety of physical and cognitive difficulties present among group members, selecting activities that all participants could engage in that were also feasible to deliver online became limited, with some activities necessitating repetition or taking more time than expected. Especially in light of the qualitative feedback highlighting the value of group

discussion, potentially making the activities only a partial focus of each session would be beneficial.

From a therapist perspective, creating a "therapeutic milieu" online was more challenging compared to in person. It was easier for myself and participants to become distracted by other events in one's home, and have increased difficulties in smooth conversational transitions between group members or. Noise levels and poor Wi-Fi further affected attention to the group, or it was not possible for some participants to have a dedicated space in their house to join in on calls, affecting a sense of privacy between group members. Further, there was less time for social interaction between group members not focused on session materials, affecting group cohesion. When attempting to incorporate social interaction as part of the scheduled 1.5 hours, often this impacted the amount of time to group components, leading to either groups going over time or less time spent on a particular component. Consciously incorporating time for non-group social discussion when delivering sessions online, especially for the Activity Planning group, should be considered in a main trial.

Mixed-Methods Data Collection

The inclusion of both qualitative and quantitative participant outcomes in trial assessments proved useful, but in practice the methodologies were occasionally at odds with each other. For example, typically purposive sampling is used in qualitative methodology to ensure information-rich data to make the most effective use of limited time and resources. In developing the study, difficulty arose in deciding who should perform purposive sampling; the therapist, for example, may unintentionally select participants for interviews who tend to provide more positive responses, whereas a research assistant being aware of the characteristics of participants and perform purposive sampling prior to assessment may unduly affect blinding procedures needed for quantitative data collection. Though we used

random sampling to decide who participated in the Exit Interview, a longer and more in-depth qualitative assessment, in practice many participants tended to discuss many of the questions asked in the Exit Interview in the PSQ, which all participants received, suggesting that a shorter interview for all participants may overcome challenges in method of sampling.

The timing of the collection of qualitative data is also important to consider for a main trial. In participants with ABI, the 1-month gap may be too much time to recall specific experiences and prevent detailed feedback due to memory impairments. Some participants found it difficult to report on specific use of BA techniques for example, or forgot what specific activities they enjoyed in the Activity Engagement Group. However, collecting the qualitative data at 1-month after the groups end allows for reflection on potential long-term impact of the groups, and information on what experiences tended to "stick." Potentially repeated, short (15 to 20 minute) interviews at the post-group assessment and at 1-month follow up can allow for more detailed investigation of changes at post-group and follow-up. Further, such a design may help enhance trust between the interviewer and participant, leading to richer data. Of course, the pragmatics of separate research assistants for quantitative and qualitative data may not be economically or pragmatically feasible within a research team and the costs associated with such a set up should be carefully considered.

Participant Preference in Groups

Some participants expressed a preference for either the Activity Planning or Activity Engagement group prior to study enrolment. Of note, the Activity Planning group was often perceived to be the "better" group by participants, with some participants stating they would explicitly prefer to be allocated to this group. One participant screened for eligibility stated that they declined participation because they wanted to be guaranteed participation in the Activity Planning group. By contrast, some participants noted an initial preference for the Activity Engagement group, but still found benefit if they ended up in the Activity Planning

Group. However, some who preferred and were randomised to the Activity Engagement Group had less positive experiences than expected, possibly due to its less-clear structure and differing expectations of what an "experiential" BA group would be.

Potentially, there could be more individuals recruited to the trial if the benefits of either approach were more clearly communicated during recruitment. More specification especially for the Activity Engagement Group would benefit its advertisement. Based on the credibility data, the Activity Engagement Group seems to have more variable expectations of how it may contribute to increases in activity level and if the treatment is perceived as logical and useful, suggesting that expectations of therapy may be important to account in estimating outcome in a main trial. Whether outcome is affected by an alignment between allocation and participant preference should be explored, as the current study is underpowered to thoroughly investigate any such effect.

Impact of COVID-19

The impact of COVID-19 on the present trial is separated into short-term difficulties that occurred in the transition of in person to online delivery of the groups and subsequent data collection, and longer-term difficulties that persisted until trial recruitment and data collection had completed.

Short-term difficulties that arose in March 2020 mainly centred on creating appropriate safeguarding regulations for delivery on online interventions, and establishing new relationships with non-NHS recruitment sources outside of Cambridgeshire in order to ensure a steady stream of recruitment. At the time of transition, NHS guidance encouraged use of videoconferencing to continue access to treatments, however data security concerns around protecting personally identifiable information when using videoconferencing software were prevalent. Further, how respond to distress remotely were particular concerns of study sponsors and the steering committee members. As part of the transition, it was necessary to

collect home addresses of participants engaging in sessions remotely so that emergency services could be sent to their homes if needed. Clearly explaining the limits of confidentiality, and regularly reminding participants what these limits were each session, were important in session delivery.

The ongoing difficulties due to COVID-19 that affected trial implementation were mainly due to lack of recruitment from NHS sources, lockdown and social distancing affecting selection of activities as part of the Activity Planning Group, and the ongoing changes due to the pandemic affecting participant wellbeing. At the time of the first lockdown in March 2020, the study was set to recruit participants leaving acute care services from a third NHS site in order to capture participants waiting to begin community-based services. After recruiting predominantly from ABI charities, much of the sample tended to be in the chronic stages of their injury, leaving the question of whether the intervention could be implemented earlier in an ABI care pathway.

In the delivery of the intervention, participants in both groups discussed frustrations of COVID-19 and reduced opportunities to see friends and family members, or reported barriers to executing enjoyable activities as many options were limited. Some expressed fears going for walks outdoors, for example, if they lived in areas with high volumes of people or if they were medically vulnerable due to their ABI or other comorbid health conditions. Others simply found the activities that could be achieved, such as a phone call, to become rote or less reinforcing over time. Potentially, estimations of effect in this study would be different when implementing an online version of the groups pre-COVID.

ACTIVITY PLANNING GROUP
Topic Discussion Guide for the MAPLES Study

Week 1 - Introduction to Group Therapy
Participants are provided with an introduction and rationale for Behavioural Activation, as well as a brief introduction to goal management and executive difficulties after brain injury. Discussion will largely centre on clarification of group expectations and identifying goals for the group itself. Discussion can also be extend to include reflections on past goals (i.e., spending more time with family) and why or why they have not been achieved yet. Along with this, participants may discuss perceived barriers to creating awareness of their own behaviours when using mood-and-mind monitoring techniques (i.e., identifying when they feel happy/sad and when they are distracted).

Week 2 - Identifying Enjoyable Activities
Participants will discuss their homework from the previous week on mood-and-mind monitoring. Participant discussion will largely focus on identifying enjoyable activities based on what has been successful in the past and what core values (i.e., health and fitness) they have. Discussion will centre on how activities align with their goals, and begin discussing barriers and facilitators to engaging in an enjoyable activity. Participants will begin scheduling an activity with task splitting.

Week 3 – Changing Habits and Planning Enjoyable Activities
Participants will discuss their experiences engaging in enjoyable activities. Participants will be provided information on "the automatic pilot" and how it can interfere with completing an activity. Participants will additionally discuss times when they have felt most distracted from what they are doing and identify what may have preceded these periods of distraction. In a similar fashion, participants will discuss antecedents of behaviours that lead to negative feelings. Discussion will be held around ways to prevent feeling distracted and feeling low. Participants end sessions by scheduling another activity.

Week 4 - Goal Review and Balancing Enjoyable and Routine Activities
Participants will discuss homework from last week. Discussion can also be held around the potential positive consequences of engaging in enjoyable activities. Following this, participants will discuss their goal progress to date and what steps need to be taken to reach their goal. Participants will also discuss what types of activities can be done to maintain a balance between routine and enjoyable activities (i.e., if there are a lot of appointments ongoing, schedule in time to relax with a cup of tea). Participants end sessions by scheduling another activity.

Week 5 – Identifying Solutions to Goal Attainment
Participants will discuss homework from last week. Participants will then discuss which avoidance patterns they fall into when attempting to engage in enjoyable activities (e.g., feeling ashamed of self when not productive leads to avoiding responsibilities). Group members will co-develop ways to reduce avoidance patterns and develop strategies to cope with personal triggers (e.g., completing a small task to feel productive such as washing dishes) and are given the option to Stop, Think, Organise, and Plan (STOP) when they fall into an avoidance pattern. Participants end sessions by scheduling another activity.

Week 6 - Increasing Mastery and Managing Fatigue
Participants will discuss homework from last week. Information is provided on the benefits of increasing mastery and avoiding "plateauing." Participants identify personal warning signs of fatigue and how to recognise them when attempting to increase mastery. Participants end sessions by scheduling another activity, and are encourage to schedule in two activities or an activity with a longer duration.

Week 7 - Active Approaches to Engagement
Participants will discuss homework from last week. Participants are provided information on the benefits of social relationships. Participants will review and discuss their attempts to increase activities planned with others and discuss the benefits of actively initiating a task versus passively waiting for them to occur. Brief role play with practice scenarios initiating a social activity is conducted. Participants end sessions by scheduling another activity, challenged to schedule a social activity.

Week 8 - Relapse Prevention
Participants will discuss homework from last week. Participants will discuss group content and their progress throughout the Activity Planning group and identify what take home messages they would like to keep going forward. Participants identify personal triggers for "relapse" or activity level reduction, and what steps can be taken to prevent relapse. Participants end sessions by scheduling another activity, and are encouraged to maintain momentum in activity levels.

MAPLES Post-Study Questionnaire

This questionnaire is just asking you your thoughts on participating in the MAPLES groups. We very much welcome all feedback. Because this is a feasibility study we are trying to figure out what can be done better in the future. So, any feedback, whether positive or negative, is important.

There are no right or wrong answers. I would like you to be as honest and open as you can, although you are always free to not answer questions if you do not want to. Please let me know throughout the interview if it is not clear what I am asking.

To protect the privacy of other group members, I'll ask that you not mention any of the names of the people in your group.

If at any point you are feeling tired or would like to take a break at any time, please let me know.

Do you have any questions?

Randomisation Group (*if participant is not sure, no need to probe to determine if on WL*)

(1) Activity Planning Group
(2) Activity Engagement group
(3) Waitlist to Activity Planning Group
(4) Waitlist to Activity Engagement Group

1. Did you like the idea of a study session focused on <u>activity level</u>? We would like your opinion about the focus on activities, as compared to emotions, brain injury, or any other topic. (Yes or No)
   (*If needed: can you give me your general thoughts on participating in the group?*)

2. Do you see any benefits to being part of group sessions? (Yes or No)

Comments:

3. On a scale of 1 to 10, how ***helpful*** did you find your group?

1 2 3 4 5 6 7 8 9 10

Comments:

(*Prompts – use to facilitate elaboration on rating scale above)*

- Was there one session that you found really helpful?
- Is there something from the group that you found really motivating?
- Was there one session that you didn't think would be helpful for you at all?

4. On a scale of 1 to 10, how ***enjoyable*** did you find your group?

1 2 3 4 5 6 7 8 9 10

Comments:

5. I have here a list of barriers that may have affected participation in the group. Please tell me which barriers you had with a yes or no. After we have gone through them, then I will ask you why they were barriers.

1. Motivation ☐	**4. Time** ☐	**7. Effort** ☐
2. Mood ☐	**5. Technology** ☐	**8. Physical** ☐
3. Organisation ☐	**6. Memory** ☐	**9. Attention** ☐
10. Fatigue ☐		

Please add in any comments/follow up to explain the answers above:

Was there anything else not mentioned above that made it difficult for you to attend the group sessions? For example, health-related difficulties, or other people needing the computer?

(if a participant did not list any barriers, skip this question)

6. Is there anything you can think of that the research team can do to help you overcome these barriers for future group sessions?

7. Do you think that regular contact with the research team by telephone or email was helpful? (Yes or No)

Comments:

8. Did you find having the group conducted online was useful? Do you see any benefits or challenges? (Yes or No)

Comments:

(prompts – use to expand on answer to above question if needed)

- Do you think the groups would be the same in person?
- Do you think that having the groups online was better for your schedule?
- Did it take extra effort to take part in the groups online?

9. Since completing the study, have you noticed any change in the following areas? Please pick the response that you think is the most honest to you. When in doubt, go with your gut

response. Please pick a number or category first, then you will have a chance to explain more if you would like to.

	A lot worse (1)	**A bit worse (2)**	**No change (3)**	**Improved a bit (4)**	**Improved a lot (5)**
Your memory					
Your concentration					
Your ability to plan/ organise yourself					
Your spatial awareness					
Your motivation					
Your mood					
Your number of social interactions					
Or something else					

10. Is there something important to you that you feel wasn't addressed well enough or covered in the group?

11. Do you feel that there are any other improvements not already mentioned that could be made to the group? Please be as detailed as possible.

MAPLES Study Exit Interview

At the start of the audio recording, please state your name and today's date, along with who you are interviewing by participant number.

Participant Number:_____

This Exit Interview covers questions about specific aspects of your group. You will have an opportunity to expand your thoughts in greater detail. Just like in the Post-Study Questionnaire, it is really important to get all sorts of feedback, both positive and negative.

I'll remind you again not to mention any of the names of the people in your group for confidentiality.

Do you have any questions?

Ok, let's begin.

Feedback on Homework in Activity Planning Group

(Ask the below only if participant took part in the Activity Planning Group)

Did you feel that the homework was relevant, manageable, and helpful? Why or why not?

(Homework tasks – use to ask specifically about each task. Interviewer can share screen for specific content if needed as a guidance)

- Planning in meaningful/enjoyable activities/break down activities step by step

- Mood and Mind monitoring – reflecting on what you do on a day-to-day basis and how this makes us feel (mood) and how focused we feel (mind)

- Using the ABCs (Antecedent, Behaviour, Consequence – understanding what triggers negative thoughts or feelings or events)

- TRAP/TRACs (Trigger, Response, Avoidance Pattern/Active Coping)

- Using the STOP acronym (Stop, Think, Organise, Proceed)

- Active vs Passive Approaches to Activities

Was there anything that made it difficult for you to complete the homework?

Now, I will ask about the content within each session, rather than the homework.

Did you find that the content within the group sessions was useful to you?
(if needed, refer to Activity Planning Group discussion guide)

Were there any sessions that were not very useful to you?
(if needed, refer to Activity Planning Group discussion guide)

(*If necessary)*
Can you expand on your answer some more?

All participants are asked the below
Practical Aspects of the MAPLES study

I am going to ask about some practical aspects of being part of the MAPLES study.

Was there someone in your personal life that affected your participation in the study, either for better or for worse? For example, a partner, closer friend, or family member?

Was there something that happened in the group sessions that made you feel like it wasn't helpful? For example, your relationship with other group members? Again, please be careful not to mention anyone's name for confidentiality.

Facilitator Influence

Thank you. Now, we are interested in understanding if the facilitator affects how you respond to the group. Remember that any feedback is welcome, both positive and negative.

Do you think the groups would be the same with someone else running the sessions?

What qualities do you think are necessary for a person running this kind of group? If it's helpful, refer back to other groups you have attended.

Do you think there was something Andrea could have done differently in how she ran the sessions?

(if they have mentioned it PSQ, refer back to answer here)
Okay, now I'd like to ask if you felt 8 sessions was enough, or if it was too much, or not enough.

(prompt)

- How many sessions would be ideal for you?
- What length of session is ideal for you? For example, 1 hour, 2 hours, etc

Did the current pandemic affect your experience in the group? How?

Do you have any other comments or feedback?

MAPLES Pilot Feasibility Trial Fidelity Assessment Checklist
Activity Planning Group

Rating Instructions: Upon listening to each audio recording for each session, rate each aspect on whether they occurred as below:

0: Component not present/not attempted
1: Therapist attempted component partially/questionably
2: Therapist covered component and relevant content

A new checklist should be completed for each cohort of the Activity Planning Group.

Session 1: Introduction to Group Therapy
Cohort Number:
Date:

____ Introduction to the group structure

____ Introduction of group members

____ Introduce link between activity level and mood

____ Discussed examples as relevant to participants

____ Rationale of behavioural activation

____ Education on executive function difficulties in brain injury

____ Introduce concept of absentmindedness

____ Introduce concept of mood and mind monitoring

____ Explained and set homework tasks

Session 2: Identifying Enjoyable Activities
Cohort Number:
Date:

____ Reviewed mood and mind monitoring homework from last week

____ Discuss relationship between mood and attention for each group member

____ Introduce value-based activity planning

____ Discussed examples as relevant to participants

____ Introduce Activity Wheel to identify core values

____ Introduce link between core values and personal goals

____ Participants identify short-term goals within the group and long-term goals

____ Participants begin activity scheduling and learn to break down activity into steps

____ Explained and set homework tasks

Session 3: Changing Habits and Planning Pleasurable Activities
Cohort Number:
Date:

____ Reviewed activity scheduling homework from last week

____ Provide example of how absentminded errors occur in daily life

____ Introduce concept of the automatic pilot

____ Discussed examples as relevant to participants

____ Introduce identifying personal triggers to absentminded errors

____ Participants identify personal triggers to absentminded errors within group

____ Participants schedule another activity and break down activity into steps

____ Explained and set homework tasks

Session 4: Goal Review and Balancing Enjoyable and Routine Activities
Cohort Number:
Date:

____ Reviewed activity scheduling homework from last week

____ Review homework on identifying personal triggers for absentminded errors

____ Education on preventing personal triggers

____ Discussed examples as relevant to participants

____ Participants create personalised strategies to prevent triggers

____ Participants review progress on goals from session 2

____ Group discussion on whether activities in day-to-day life align with values/goals

____ Introduce concept of balancing between routine and enjoyable activities

____ Participants schedule another activity and break down activity into steps

____ Explained and set homework tasks

Session 5: Identifying Solutions to Goal Attainment
Cohort Number:
Date:

____ Reviewed activity scheduling homework from last week

____ Review homework on preventing personal triggers

____ Education on falling into avoidance patterns

____ Discussed examples as relevant to participants

____ Participants create personalised strategies to reverse avoidance patterns

____ Participants review concept of the automatic pilot

____ Participants learn STOP acronym to prevent distraction from goal attainment

____ Participants practice using STOP acronym

____ Participants schedule another activity and break down activity into steps

____ Explained and set homework tasks

Session 6: Increasing Mastery and Managing Fatigue
Cohort Number:
Date:

____ Reviewed activity scheduling homework from last week

____ Review homework on reversing avoidance patterns

____ Education on importance of improving mastery and risks of plateauing

____ Discussed examples as relevant to participants

____ Participants identify “warning signs” of plateauing

____ Education on different types of fatigue post-brain injury

____ Participants identify personalised triggers to fatigue

____ Participants develop personalised strategies to manage fatigue

____ Participants schedule another activity and break down activity into steps

____ Explained and set homework tasks

Session 7: Active Approaches to Engagement
Cohort Number:
Date:

____ Reviewed activity scheduling homework from last week

____ Review homework on attempting strategies to prevent fatigue

____ Education on importance of social relationships in maintaining a good mood

____ Discuss examples as relevant to participants

____ Education on active versus passive approaches to activity scheduling

____ Discussion on personal barriers to taking an active approach

____ Participants practice in session how to initiate a social activity

____ Participants list benefits of the active approach and drawbacks of passive approach

____ Participants schedule another activity and break down activity into steps

____ Explained and set homework tasks

Session 8: Relapse Prevention
Cohort Number:
Date:

____ Reviewed activity scheduling homework from last week

____ Review homework on active and passive approaches

____ Participants identify "take home" message from group

____ Review behavioural activation model from Session 1

____ Review value-based activity planning from Session 2

____ Review concept of automatic pilot from Session 3

____ Review concept of personalised triggers from Session 4

____ Review STOP acronym from Session 5

____ Review importance of increasing mastery from Session 6

____ Review importance of taking an active approach to activities from Session 7

____ Review importance of breaking down activity into manageable steps

____ Education on importance of preventing relapse into lower activity levels

____ Participants identify personal triggers that may cause a relapse

____ Participants create personalised strategies to prevent relapse triggers

____ Participants schedule another activity and break down activity into steps

MAPLES Pilot Feasibility Trial Fidelity Assessment Checklist
Activity Engagement Group

Rating Instructions: Upon listening to each audiorecroding for each session, rate each aspect on whether they occurred as below.

The Activity Engagement Group is flexible by nature, and this should include:

- No mention behavioural activation/activity scheduling
- No encouragement of direct planning beyond the group
- Therapist encouragement of engagement on activities within the group
- Therapist encouragement of participant autonomy of activities chosen
- Non-linear structure of groups

For the first two components, rate as below:

2: Component was not present
1: Therapist attempted component partially/questionably
0: Therapist covered component adequately

For the last three components, rate as below:

0: Component was not present
1: Therapist attempted component partially/questionably
2: Therapist covered component adequately

A new checklist should be completed for each session of each cohort of the Activity Engagement Group.

Cohort Number:
Session Number:
Date:

____ No mention of behavioural activation/activity scheduling

____ No encouragement of direct planning beyond the group

____ Therapist encouragement of engagement on activities within the group

____ Therapist encouragement of participant autonomy of activities chosen

____ Non-linear structure

Due to the broad criteria, examples of the above are below:

No mention of behavioural activation/activity scheduling
2: Component not mentioned at all
1: Therapist casually mentions behavioural activation and the importance of scheduling in activities throughout the week
0: Therapist fully explains what behavioural activation is and how activity scheduling relates to mood

No encouragement of direct planning beyond the group
2: Component not mentioned at all
1: Therapist encourages a participant to plan something beyond the group in session
0: Therapist explains the importance of learning to plan in activities as a concept and encourages planning more than once in session

Therapist encouragement of engagement of activities within the group
2: Therapist encourages participant in completing the activity/encourages socialising in session, and/or provides support for completing an activity, and/or helps explain how to set up an activity to participants
1: Therapist briefly explains an activity or does not explain an activity adequately/little encouragement of socialisation
0: No encouragement present

Therapist encouragement of participant autonomy within the group
2: Therapist asks/encourages participant to choose what they want to do/responds appropriately when a participant requests to do a different activity
1: Therapist responds to participants asking to do something differently within session, but does not follow through with switching
0: No choice/therapist refutes someone wanting to choose to complete a different activity

Non-linear structure
2: If participants want to do something different within session (i.e., an activity that was selected and planned previously), therapist switches the activity/moves on to a different activity or discussion; and/or therapist offers to complete an activity in another session; otherwise if session proceeds as planned rate it a 2
1: Therapist acknowledges request for a new activity in group but does not comply
0: Therapist sets a strict timeline for activities/completion of activities within session or does not allow a switch within session in activities

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