CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

School of Psychology
Ysgol Seicoleg

A Systematic Review of the Effect of Group Based Mindfulness Interventions for Acquired Brain Injury Survivors and an Empirical Study Exploring Stroke Survivors' Views and Experiences of Using '*Rebuilding Your Life After Stroke'* as a Rehabilitation Tool

Thesis submitted in partial fulfilment of the requirement for the degree of:

Doctorate of Clinical Psychology (DClinPsy)

South Wales Doctoral Programme in Clinical Psychology

Cardiff University

Kathleen Williams

Supervised by: Prof Reg Morris

22nd June 2020

Table of contents

Acknowledgements

Firstly, I would like to thank the 13 participants who took part in the study, without whom this research would not have been possible. I will strive to ensure that your words within this project are heard, so that hopefully they will contribute to something that one day will make a difference to the lives of stroke survivors and their families. I would like to extend my gratitude to the professionals in the the NHS, Bristol After Stroke Foundation (BASF) and the Stroke Association for their support in participant recruitment.

When I was diagnosed with a rare, degenerative sight condition at the age of 16, a renowned ophthalmologist discouraged me from pursuing studies in psychology because it would mean ‘too much reading’ and I’d ‘never cope’. There have been times in the past four years where I have fluctuated between feeling that I could cope and indeed times when I really thought I couldn’t. As I look back, I come to realise that with the right support I can cope and my ability can come before my disability. With this in mind, I would like to thank my supervisor Reg Morris for his support and guidance throughout this project and my sincere thanks go to my appraisal tutor Jenny Moses, my professional mentor/placement supervisor Susie Black, and note taker Melanie for all their help and support. It really has been a journey.

I would also like to thank my friends and family, especially my mother and sister Beth for all their support, encouragement and believing that I could do this, even during the times where I was pretty adamant that I couldn’t!

Preface

Advances in acute medical intervention has resulted in an increase of survival rates for those experiencing an acquired brain injury (ABI). ABI such as stroke and traumatic brain injury (TBI) are leading causes of disability and post injury. ABI survivors experience a range of physical, emotional and cognitive difficulties, some of which result in a permanent change in survivors' ability to function. Subsequently, ABI survivors have to adjust to their new way of life, managing with these residual effects and disabilities. Therefore, it is unsurprising that incidence of psychological difficulties such as anxiety or depression are higher in ABI survivors and that they use health services at a higher rate. Additionally, the effective treatment of psychological difficulties by conventional methods such as Cognitive Behavioural Therapy (CBT) is limited. Survivors' cognitive deficits make engaging with approaches such as CBT more challenging and ABI survivors report high levels of unmet needs. Acceptance and Commitment Therapy (ACT) is a relatively new therapy that has shown promise in helping stroke survivors to better manage their difficulties and mindfulness is a method inherent within the ACT approach. With the increase in effective acute intervention and aging population, the number of ABI survivors is set to increase in the coming years. It is anticipated that demand for help will continue to be greater than services will be able to offer, especially as it is likely that healthcare funding will not increase in accordance with the amount of people surviving. Therefore, the quest for the cost-effective dissemination of psychological information and delivery of interventions to reduce the psychological difficulties associated with ABI has burgeoned. The facilitation of group based interventions and development of a condition specific self-help book could be a solution.

Paper 1 presents a systematic review of group-based mindfulness interventions for adults with traumatic brain injury, brain haemorrhage or stroke. PsychInfo, MEDLINE, EMBASE, Web of Science and Scopus databases were electronically searched, the reference lists and author websites of included studies were hand-searched and eleven studies met inclusion criteria. Studies investigated the effect of group based mindfulness on a range of psychological outcomes from anxiety and depression to survivors' abilities to integrate into the community after their ABI. All the outcomes were summarised in the review and studies were quality assessed. As the studies included were of varying quality, it is difficult to draw firm conclusions. However, generally it can be concluded that group based mindfulness can be beneficial across a range of outcomes, particularly in relation to the management of emotional difficulties post injury. The paper concludes with recommendations for future research.

Paper 2 presents a qualitative exploration of stroke survivors' views and experiences of using the *'Rebuilding Your Life After Stroke'* book. Thirteen participants were interviewed and transcripts were analysed using Inductive Thematic Analysis. Three themes emerged 1) Active Process: participants have to actively engage in their rehabilitation, which is improved with professional support. 2) Tailor Made Intervention: the book is flexible and allows survivors to assess and understand their difficulties and gives them choice and control over their rehabilitation. This allows survivors to use strategies to overcome the effects of stroke that would otherwise make rehabilitation difficult. 3) Outcomes: outcomes include an improved understanding, acceptance, the development of new skills and feelings of hope. Participants in this study felt that *'Rebuilding Your Life After Stroke' w*as an accessible, effective and reliable resource, which suggests that the book is suitable for the target audience. Professionals in stroke services or third sector organisations (e.g. charities) can have confidence in the use of the book as a resource. Moreover, the book is also versatile as it can be read independently in its use as a self-help book or can form the basis of interventions such as guided self-help or bibliotherapy.

Paper 1 has been prepared for submission to the Journal of Neuropsychological Rehabilitation in accordance with the author guidelines (Appendix 1).

Paper 1: Group Based Mindfulness Interventions for Acquired Brain Injury Survivors: A Systematic Review

Kathleen Williams and Professor Reg Morris

22nd June 2020

Word count (exc. References/figures/tables): 5684

Abstract

Background: Acquired brain injury (ABI) survivors can experience a range of debilitating physical, emotional, psychological and cognitive difficulties. Mindfulness based interventions (MBI) have received clinical and research attention in recent years and it has been suggested that enthusiasm for the approach has surpassed the evidence base. The delivery of MBI has been modified, moving away from the traditional group based delivery without reviewing its effectiveness in the ABI population.

Method: Peer-reviewed articles were obtained from searching the following electronic databases: PsycINFO, MEDLINE, EMBASE, Scopus and Web of Science, and through the examination of reference lists and author websites, yielding 615 eligible results, which were screened by title and abstract. Eligible articles were quality assessed for methodological rigour.

Results: 11 studies were included and most were of moderate methodological quality. Due to the heterogeneity of ABI severity and group based mindfulness interventions (GBMI) offered, it is difficult to arrive at firm conclusions. However, GBMI can have a positive effect across a range of outcomes post ABI.

Conclusion: GBMI for ABI survivors could lead to positive outcomes particularly in relation to the management of emotions. Future research would benefit from enhanced methodological rigour and the use of outcome measures with psychometric properties applicable to the ABI population.

Key words: Mindfulness, Acquired Brain Injury, Traumatic Brain Injury, brain haemorrhage, stroke.

Introduction

Acquired brain injury (ABI) is defined as ‘cerebral damage that occurs after birth and is not related to congenital disorders, developmental disabilities, or processes that progressively damage the brain’ (Cattelani, Zettin & Zoccolotti, 2010, p.52). In recent years, medical advances have meant that the survival rates for ABI, such as stroke, traumatic brain injury (TBI) and brain haemorrhages, have increased (Welsh Government, 2017). For those who survive, a range of physical, cognitive and emotional difficulties are experienced. Stroke survivors report higher levels of anxiety (Rafsten, Danielsson & Sunnerhagen, 2018) and depression (Hackett & Pickles, 2014), which are also problems for TBI survivors (Scholten et al., 2016) and those who have had a brain haemorrhage (Morris, Wilson & Dunn, 2004). In addition to these mental health difficulties, survivors also report higher levels of chronic pain (Nampiaparampil, 2008) and fatigue (Duncan, Wu & Mead, 2012; Mollayeva *et al.*, 2014; Kutlubaev, Barugh & Mead, 2012). Physical and neuropsychological difficulties, such as memory and attention problems, are also present (Barker-Collo, 2007; Al-Khindi, Macdonald & Schweizer, 2010; Barman, Chatterjee & Bhide, 2016). Therefore, it is not surprising that high levels of disability are associated with ABI (Dikmen, Machamer, Powell & Temkin, 2003) and that post injury a high proportion of ABI survivors require specialist, multidisciplinary rehabilitation (Wright, Zeeman & Biezaitis, 2016). Rehabilitation aims to support the survivor to regain independence in daily function and increase community participation (Hill, 2008), yet effective support for the management of psychological difficulties after ABI is still lacking and post-injury and stroke survivors report high levels of unmet needs (Chen *et al.*, 2019).

In the general population, Cognitive Behavioural Therapy (CBT) is recommended for the management of common mental health problems such as anxiety and depression (NICE, 2011). However, the application of traditional CBT in ABI survivors is challenging due to the presence of cognitive difficulties post injury (Kneebone, 2016). The evidence base for approaches such as Positive Psychology and Acceptance and Commitment Therapy (ACT) in brain injury (Evans, 2011; Cullen *et al.*, 2018) and stroke (Majumdar & Morris, 2019) is developing. Mindfulness is an approach integrated within these therapies. In recent years, mindfulness has received increasing clinical and research interest (Goldin & Gross, 2010).

Mindfulness

Mindfulness has been defined as ‘the awareness that emerges through paying attention on purpose in the present moment, and non-judgementally to the unfolding of experience moment by moment’ (Kabat-Zinn, 2003, p.145). Two common mindfulness-based approaches are Mindfulness-Based Stress Reduction (MBSR, Kabat-Zinn, 2003) and Mindfulness Based Cognitive Therapy (MBCT, Segal, Williams & Teasdale, 2002). MBSR is a structured group programme of mindfulness training that seeks to improve individuals’ awareness of the fleeting and changeable nature of thoughts, emotions and physical sensations. MBSR is composed of hatha yoga, informal and formal meditation practices that set to change the individual focus of attention and shift attention to present moment awareness. Components of MBSR have been integrated with aspects of CBT for major depression (Beck, Rush, Shaw & Emery, 1979) to develop MBCT. MBCT is an eight-week group programme (Segal, Williams & Teasdale, 2002) that seeks to support individuals with major depression to increase their awareness and to relate differently to their thoughts, feelings and bodily sensations. For example, recognising thoughts as momentary and amenable to change.

Evidence base of Mindfulness based interventions (MBI)

The benefits of MBI are documented in the literature, resulting in a reduction of chronic pain, depression and an improvement in quality of life (Hilton *et al.*, 2017). Additionally, MBI result in an amelioration of anxiety and depression symptoms in clinical populations (Hofmann, Sawyer, Witt & Oh, 2010) and can enhance cognitive functions including memory, attention and executive function in healthy individuals (Ziedan, Johnson, Diamond, David & Goolkasian, 2010). Lawrence, Booth, Mercer & Crawford (2013) systematically reviewed the evidence base to evaluate the impact of MBI for stroke survivors and those who had experienced a Transient Ischaemic Attack (TIA). Their review of four papers outlined that no study directly investigated the effect of MBI on perceived stress, but studies did investigate the effect of MBI on psychosocial outcomes such as depression, anxiety and fatigue. Lawrence *et al.* (2013) concluded that MBI are not harmful and the evidence outlines a positive trend in favour of therapeutic benefit. Additionally, it is important to note that this review was conducted at a time when it could be considered that mindfulness was gaining interest as an approach and as such the mindfulness ‘subject heading’ had not been developed. Another systematic review conducted by Kenuk & Porter (2017) investigated the effect of MBI on the lives of TBI survivors. This review included studies of a range of MBI (MBSR, MBCT, Yoga, Tai Chi and Qigong) delivered as part of a group or on an individual basis. Their effect was evaluated across 88 outcomes, including cognitive, physical and psychosocial functioning and concluded that MBI have positive or significant effects on a range of outcomes. The review recommended that MBI are to be delivered as part of a small group or on an individual basis.

Group based interventions

MBSR and MBCT advocate delivery as part of a group setting (Kabat-Zinn, 2003; Segal *et al.*, 2002), but not all mindfulness interventions are delivered in the conventional way and there is a suggestion that the enthusiasm for delivery of MBI has surpassed evidence based recommendations (Dunning *et al.*, 2019). For example, mindfulness has been delivered on an individual basis (Geneme, Perera, Olson & Stutzman, 2019) over the telephone (Bay & Chan, 2018), online (Cikajlo, Staba, Vrhovac, Larkin & Roddy, 2017) or by providing participants with audio recordings (Baylan *et al.*, 2020). Whilst there are advantages in changing the method of delivery, it is unclear whether these modifications can influence the interventions' effectiveness. Moreover, participants may not be able to access the benefits derived from attending a group comprising of others with similar experiences. von Mensenkampff *et al.* (2015) reports that membership of therapeutic groups normalises experiences for individuals with brain injuries and attending groups can circumvent feelings of isolation which are common after stroke (O'Connell *et al.*, 2001). Additionally, from a service perspective, the provision of groups requires minimal resources and is cost effective (Lawrence *et al.*, 2013) and professionals without medical training can deliver MBI (Bedard *et al.*, 2003).

Aims

In light of the commonalities of the difficulties ABI survivors experience after injury, the documented benefits of MBI in the general population, and the delivery of interventions in a group setting, the review sought to provide a review of GBMI for adults with ABI. Although recent reviews independently evaluated MBI in TBI (Kenuk & Porter, 2017) and stroke (Lawrence *et al.*, 2013), these reviews included MBI delivered on an individual and group basis. For the purpose of this review, ABI was a term operationalised to include survivors of stroke, TBI and brain haemorrhage. Furthermore, the term ‘Group Based Mindfulness Intervention’ (GBMI) has been selected for use in this review in order to represent the range of group based mindfulness interventions documented in the literature.

Method

Review method/database searches

The databases EMBASE, Medline, PsychINFO, Scopus and Web of Science were searched during February 2020 to identify relevant studies. Databases were searched from when records began to the 27th February 2020. Reference lists of all relevant full text articles were hand searched and authors' websites were screened to identify any additional relevant studies.

Search terms

The key words and subject headings are outlined in Appendix 2. The Boolean operator 'OR' was used for the 'Mindfulness' terms and 'condition' terms, and the results were then combined with the Boolean operator 'AND'. The development of key words was guided by the literature and discussions with the researcher's academic supervisor.

Inclusion and exclusion criteria

Articles were included in the review if they fulfilled the following inclusion criteria.

Inclusion criteria

Articles must be/have:

- Studied group based mindfulness interventions (GBMI)
- Peer reviewed
- Reported in English
- Participants aged 18 years or over
- Used quantitative methods
- Clinical sample with participants who have a diagnosis of a stroke, ABI or TBI
- Reported only a group based mindfulness intervention

Exclusion criteria

Articles were excluded from the review if they were the following:

- Case study
- Used qualitative methods
- Unpublished or full text was not available

- Not published in English

Systematic review process

1,112 studies were identified as a result of the searches. Duplicates were removed (n = 497). Screening was conducted by two reviewers using the exclusion criteria outlined; studies that did not meet the criteria were discarded. As a result of this process, 25 full text articles were sourced and 11 were eligible for inclusion into the review. Reference lists of retrieved papers and author homepages were reviewed to identify any additional studies that had not been identified by the searches. The process of data extraction is outlined in figure 1.

Process of quality assessment

Quality Assessment Tool for Studies with Diverse Designs (QASTDD, Sirriyeh, Lawton, Gardener & Armitage, 2011) was used to evaluate study quality. The QASTDD was selected as the studies included within this review appeared to have diverse designs. All studies were reviewed for quality by the first author and five out of the 12 papers (41%) of studies obtained were reviewed by another author (AS).

PRISMA diagram

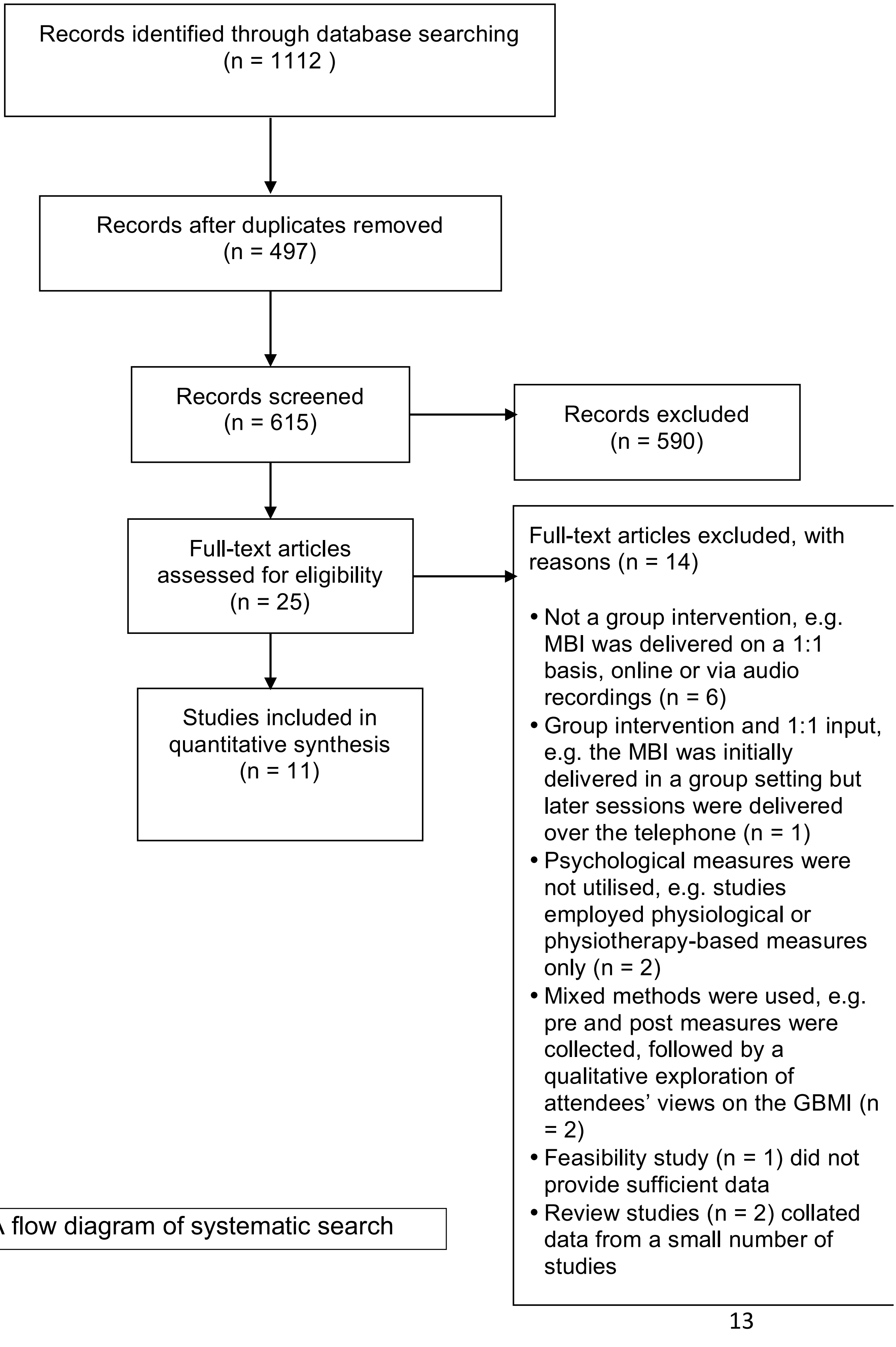


Figure 1: PRISMA flow diagram of systematic search

Results

Quality assessment

The quality of studies assessed was variable and scores ranged from 24/42 to 36/42. Details of the quality assessment process are contained in Appendices 3-6. When scores were calculated and interpreted as percentages, scores ranged from 52% to 86%. Key limitations of the studies included in this review encompassed the lack of statistical assessment of the reliability and validity of the measurement tools used, lack of consideration of sample sizes in relation to analysis and issues relating to the representativeness of the sample of the target group of a reasonable size. Moreover, not a single study documented evidence of service user involvement in its design.

Summary of included studies

The studies looked to investigate the impact of group based mindfulness interventions when delivered to ABI survivors; collectively they investigated a total of 20 outcomes, all of which will be discussed in this review. Group based mindfulness is an approach that has been used to explore the sequelae of brain injury, such as its effect on depression, anxiety, mental fatigue, quality of life (QOL), self-efficacy, pain and comfort, as well as its effect on physical and physiological outcomes. In addition, these studies also investigated whether these approaches improve survivors' ability to be mindful. A summary of each study included in this review is represented in table 1.

Study design and aims

All studies included in this review utilised quantitative methodologies. Data collection for psychological outcomes was obtained by the use of self-report questionnaires. Physical, neuropsychological and physiological outcomes were attained through the completion of healthcare professional derived measures (e.g. neuropsychological testing batteries, physiotherapy assessment tools). The most common study design was pre-post intervention, while other study designs included Randomised Controlled Trials (RCT, Wang, Li, Wang & Lv, 2020; Bedard *et al.*, 2014; Johansson, Bjuhr & Rönnbäck, 2012) and a follow-up study (Bedard *et al.*, 2005).

Author and country	Sample	Method	Outcome measures	Mindfulness intervention details	Key Findings	Quality Score (%)
Azulay, Smart, Mott & Cicerone (2012) US	**Type of brain injury:** Mild TBI post concussion more than 3 months after injury (80% had time post injury of 12 months, none were less than 7 months), receiving concurrent rehabilitation. **Sample size:** 22 **Mean age:** 48.9 years. **Gender:** 50% female. **Participant recruitment:** Convenience sample recruited from clinical referrals in a post-acute brain injury centre. **Attrition:** Not reported, participants who dropped out were used in intent to treat condition.	**Design:** Pre-post intervention. **Control group:** None. **Analysis time points:** 1-2 weeks pre and 1-2 weeks post intervention. **Statistical analysis:** Paired sample *t*-tests.	Perceived Quality of Life Scale (PQOL). Perceived Self-Efficacy Scale (PSE). Neurobehavioural Symptom Inventory (NSI). Social Problem Solving Inventory—Revised Short Form (SPSI-R). Mindful Attention Awareness Scale (MAAS). Neuropsychological battery to investigate central executive aspects of attention and ability to acquire new information. This included: • The Continuous Performance Test of Attention (CPTA). • Paced Auditory Serial Addition Test (PASAT). • California Verbal Learning Test Alternate Form (CVLT).	**Group content:** MBSR based. **Modifications:** • Increased number of sessions (8 to 10). • Reduced group sizes, to allow greater repetition. • Further modelling of more sophisticated techniques. • All assignments provided in written format. **Group size:** Average of 6 TBI survivors. **Frequency:** 10 weekly group sessions (one 2-hour session per week). **Facilitators:** 2 leaders, both of whom were neuropsychologists with training in MBSR. One facilitator is specialied in brain injury rehabilitation and the other had been actively practising and teaching meditation for more than 10 years.	**Self-efficacy:** Significantly higher scores on the PSE post intervention. **QOL:** Significantly higher scores of PQOL post intervention with medium effect sizes. Higher level of improvement on the cognitive and emotional symptoms. **Neurobehavioural symptom severity:** Post intervention, participants obtained lower scores on NSI but these changes were not significant. **Problem solving abilities:** Improved problem solving abilities post intervention but the change was not significant. **Neuropsychological functioning:** • No significant difference on tests of verbal learning or memory with minimal clinical effect. • Significant improvement in measures of attention. • Small effect sizes on CPTA and PASAT. • Participants' ability to learn new information remained unchanged. 1/3 of participants showed clinically significant changes in neuropsychological functioning.	60%

Johannsson, Bjuhr & Rönnbäck (2012) Sweden	**Type of Brain Injury:** Stroke or TBI victims suffering with mental fatigue, 3.5 years after stroke/injury who had recovered from neurological effects. **Sample size:** 29 **Mean age:** Not specified. **Gender:** Not specified. **Recruitment:** Convenience sample – participant opt in. **Attrition:** Not specified.	**Design:** RCT. **Control group:** Waiting list. **Analysis time points:** Intervention group – pre and post intervention. Control group - Baseline, pre and post intervention **Statistical Analysis:** Paired *t*-tests and Mann-Whitney U-test.	Mental Fatigue Scale (MFS). Comprehensive Psycho-phrenological Rating Scale (CPRS) for anxiety and depression. Neuropsychological tests – to measure information processing speed, attention, and working memory. Working Memory and Information Processing tests included digit symbol, digit span, Functional Ambulation Scale (FAS) verbal fluency. Trail making task (TMT) (A and B) Trail making C and D were developed to assess dual task demands. Reading speed based on a dyslexia test.	**Group content:** The intervention was based on Kabat-Zinn's MBSR programme, sessions incorporated aspects of MBSR as well as gentle Hatha yoga, the body scan and sitting meditation. **Modifications:** Unknown**.** **Frequency:** Eight weekly 2.5-hour long group sessions, one day-long silent led retreat between session six and seven. Participants received guided instructions and CDs for home practice. **Group size:** Unknown. **Facilitators:** Unknown.	**Mental fatigue:** Compared to waiting list controls, participants in the MBSR group reported a significant decline in mental fatigue. Controls in this study then completed the MBSR intervention and after the 8-week programme their scores on the mental fatigue schedule decreased significantly. **Anxiety and depression:** Significant change in scores for depression and anxiety post intervention. No such changes were found for the waiting list control group. **Neuropsychological function**: Significant improvements in word fluency post intervention. No significant difference in scores for working memory, trail making A and D, and reading speed. Significant correlation between improvements in scores on MFS and Information Processing Speed scores.	52 %
Wang, Li, Wang & Lv (2020) China	**Type of Brain Injury:** Spontaneous intracranial haemorrhage (SICH) with no cognitive deficits (3-6 months post SICH). **Sample size:** 134 **Mean age:** 59.9 years. **Gender:** 53.7% female. **Recruitment:** Convenience sample – participant opt in. **Attrition:** Rate not provided.	**Design**: RCT with a single blind control. **Control group**: Group based stress management. **Analysis time points**: Pre and post intervention. **Statistical Analysis:** Independent sample *t*-tests were conducted to examine the significant differences of the main variables (e.g. depression, trait mindfulness, QOL and stroke) between control group and intervention group at baseline. Paired sample *t*-tests were used to examine the differences of the outcome variables between pre-test and post-test in control group or intervention group.	Centre for Epidemiologic Studies Depression Scale (CES-D). Mindful Attention Awareness Scale (MAAS). Functional assessment of cancer therapy-brain (FACT-Br, for QOL). NIH Stroke Scale (NIHSS).	**Group content:** MBCT. **Modifications:** Unknown. **Frequency:** 8-week group (one 2-hour session per week). **Group size:** Unknown. **Facilitators:** Training levels unknown.	**Depression**: Post-intervention participants in the mindfulness group were significantly less depressed. **QOL**: Post intervention, QOL scores increased for both the control and intervention groups. But, post-intervention participants in the intervention group had significantly higher levels of social and emotional wellbeing and QOL. **Mindfulness:** Compared to controls, participants in the mindfulness group reported a significant increase in mindfulness, post intervention. **Changes on scores of NIHSS**: There were significant improvements in physical wellbeing and scores on the NIHSS in both the control and intervention group over time. **Correlations**: NIHSS scores were negatively correlated with change in physical wellbeing. Depression was negatively correlated with change in QOL, emotional and functional wellbeing. There was no significant relationship between QOL or depression and mindfulness.	86 %

Wang, Liao & Chen (2019) China	**Type of Brain Injury:** Stroke. **Sample size:** 50 **Mean age:** 61.12 years. **Gender:** 8% female. **Recruitment:** Convenience sample, participants were inpatients. **Attrition:** Not specified**.**	**Design:** 2 group non-randomised non-concurrent design. **Control group:** Observed during routine treatment, provided with mindfulness information after discharge. **Analysis time points:** Measures completed pre and post intervention. Observations throughout intervention time. **Statistical Analysis:** Measurement data was analysed by Independent Sample *t*-test, and numerical data were analysed by Chi-square test or Fisher's exact test. **Baseline and post-test:** Score comparison within each group was conducted by paired sample *t*-test.	Mindful Attention Awareness Scale (MAAS). Short and General Comfort Questionnaire (SGCQ). **Tests of ambulation ability:** Berg balance scale. 10 metre walk test. Functional ambulation classification scale.	**Group content:** Based on Eifert and Forsyth's (2005) 'centering' exercise which can assist in the development of mindfulness skills. **Modifications:** An instruction guide was provided to support participants to understand mindfulness-based practice and record daily practice. **Frequency:** 2 week group (1.5 hour group session per week) individual homework, individual sessions were also offered to participants (frequency and duration not specified). **Group size:** 5-7 participants. **Facilitators:** Groups were facilitated by the first author who had completed a 2-month training programme in mindfulness theory, group practice and individual consultation and four self-practice sessions at the Mental Health Centre of Wuhan.	Participants in the control or intervention group did not differ significantly in measures of mindfulness, comfort or ambulation ability. Significant differences in mindfulness, comfort, ambulation and QOL were observed in the intervention and control groups post intervention. **Mindfulness**: Compared to controls, post-intervention participants in the intervention group scored significantly higher scores on the MAAS. **Comfort**: Significantly higher scores on the SGCQ in the intervention group, greater change in the physical and social cultural subscales. Smaller changes in the spiritual components of the SGCQ but significant differences in the intervention group compared with controls. There was no difference in the environment component between the groups. **Ambulation ability:** No significant difference in ambulation between groups on all measures of ambulation.	79 %

Bedard *et al*. (2012) Canada	**Type of Brain Injury:** TBI < 1 year with depression as diagnosed by the DSM IV. **Sample size:** 20 **Mean age:** 47.1 years. **Gender:** 45% female. **Recruitment:** Convenience sample - eligible participants were identified by a clinical nurse in a brain injury service who approached patients or participants were brain injury association members. **Attrition:** Rate not provided.	**Design:** Pre-post intervention study. **Control group:** No control. **Analysis time points:** Pre and post intervention. **Statistical analysis**: Paired *t*-tests for continuous outcomes, MacNeamar Chi-square test for dichotomous categories.	Beck Depression Inventory, Second Edition (BDI-II). Hospital Anxiety and Depression Scale (HADS). Patient Health Questionnaire 9 (PHQ-9). Mayo-Portland Adaptability Inventory-4 (MPIA-4). Short Form Health Survey-36 (SF-36). Symptoms Checklist 90-Revised (SCL-90-R). Medication usage. Visual analogue scales for pain and energy.	**Group content:** Based on MBSR and MBCT. **Modifications:** - Shortened meditation sessions. - Use of memory aids and repetition. - Frequent reviews. **Frequency:** 8 weekly 90-minute sessions. After each session, the educator encouraged participants to complete some minor written homework and to practice the techniques at home using meditation CDs that the facilitator provided. **Group size:** Unknown. **Facilitators:** Transformative learning educator who has specialised training in MBCT and has extensive experience in teaching mindfulness.	**Anxiety and depression**: Compared to baseline, post-intervention participants in the mindfulness group demonstrated significant reductions in anxiety and depression in the BDI total, including somatic and cognitive domains. Significant reductions in total scores of the PHQ-9 total and HADS total although HADS anxiety didn't change significantly from baseline. For those with a diagnosis of clinical depression according to the Beck threshold, significant reduction in number of participants meeting that threshold. 6/9 participants who scored over 29 on the BDI before reduced afterwards. A score of 10 on the PHQ was considered the threshold for clinical depression; for those who met this threshold, 59% of the sample fell below this threshold post intervention, 7 remained above threshold and another's score increased so that it was above the threshold post intervention. Changes were statistically significant. **Pain**: Post intervention, participants in the mindfulness group demonstrated improvements on pain measures but these weren't significant, although pain intensity significantly decreased. **Energy**: Participants indicated a 40% increase in energy levels post intervention. **Health status**: All subscales of the SF-36 indicated improved health status. Only the general health and mental health subscale scores improved significantly, placing the scores in normal population ranges. **Function**: Changes in scores on the MPIA-4 indicate reduction in obstacles to community integration, but none were statistically significant. **Symptom Severity**: The intervention significantly reduced psychological distress (global severity index). The intervention significantly reduced the intensity of symptoms (positive symptom distress index). The intervention significantly reduced obsessive-compulsive and additional items. **Medication usage**: There was no statistically significant difference in pre- and post-intervention medication use. Medium effect sizes were observed for change in anxiety and pain medications. Small effect sizes were observed for change in depression medications.	74 %

Johansson, Bjuhr & Rönnbäck (2015) Sweden	**Type of Brain Injury:** Stroke and TBI. **Sample size:** 14 **Mean age:** 58.1 years. **Gender:** 64% female. **Recruitment:** Convenience sample – participant opt in. **Attrition:** Not reported.	**Design:** Pre-post intervention study. **Control group:** No control. **Analysis time point:** Before and after the MBSR programme and after the advanced programme. **Statistical analysis:** One-way repeated measure Analysis of Variance (ANOVA) between tests at start, after MBSR, and after the advanced programme.	Mental Fatigue Scale (MFS). **Neurological tests:** Digit Symbol-Coding from the WAIS-III measuring information processing speed (Wechsler, 2003). Trail Making Tests (TMT) A and B (Reitan and Wolfson, 1985) measuring visual scanning, divided attention, and motor speed. A series of new tests were constructed to evaluate higher demands on dual task. (Johansson *et al.*, 2009).	**Group content**: Advanced MBSR programme. Referring to the four boundless mental states of the Brahama Viharas. The mental state of appreciative joy was explored and practiced as 'taking in the good'. Sessions in the advanced programme included interpersonal meditation practice known as Insight Dialogue training. **Modifications:** Techniques were adapted to the patient group. **Frequency:** Eight-month programme with monthly group meetings (2.5 hours) concluding with an all-day retreat. **Group size:** Unknown. **Facilitators:** Clinical psychologist and MBSR teacher trained at UMASS CfM.	**Mental fatigue:** Attendance of the enhanced programme maintained the reduction of metal fatigue that was a result of attending the initial MBSR group. **Neuropsychological function**: Significant differences between scores at start of the initial MBSR intervention and after the advanced programme were found for MFS, Digit Symbol-Coding, TMT B, and TMT C. Similar, significant effects were detected between tests before and after the MBSR programme. No significant effect was detected when comparing the scores after the MBSR and after the advanced programme for the 14 participants. This indicates that the effects of the MBSR were maintained.	58 %
Moustgaard, Bedard & Felteau (2007) Canada	**Type of Brain Injury:** Stroke survivors. **Sample size:** 23 **Mean age:** 63.3 years. **Gender:** 26.1% female. **Recruitment:** Convenience sample – participant opt in. **Attrition:** 9%	**Design:** Pre-post intervention study. **Control group:** No control. **Analysis time points:** Pre and post intervention. **Statistical analysis:** Repeated-measures Analysis of Variance (ANOVA). Because the test of sphericity was not adequate, the conservative Greenhouse-Geisser correction was used. ANOVAs with post hoc analyses between times 1, 2 and 3 with protected t-tests (Fischer's Least Significant Difference (LSD)) with a Bonferroni correction.	Beck Anxiety Index (BAI). Beck Depression Inventory, Second Edition (BDI-II). Hospital Anxiety and Depression Scale (HADS). Short Form Health Survey-36 (SF-36). Stroke Specific Quality of Life Scale (SSQOL)	**Content:** MBCT **Modifications:** • Psychoeducation specific to stroke was included. • Language used was pertinent and sensitive to the needs of the participants. **Frequency:** 9 sessions over 9-week period (1.75 hours per session). **Group size:** Unknown. **Facilitators:** A 3rd year trainee clinical psychologist and a certified and trained Mindfulness Meditation and Yoga Instructor.	**Anxiety**: Reduction in BAI total score between baseline and post-intervention and baseline and follow-up with large effect size. There was no significant difference between post intervention and follow-up. The HADS anxiety scale scores improved from time baseline to post intervention with maintenance of this improvement at follow-up. The difference in scores between post intervention and follow-up with a large effect size. **Depression:** Scores on BDI-II reduced post intervention and at follow-up with a large effect size. The HADS depression scale scores improved from baseline to post intervention with maintenance of this improvement at follow-up with a medium effect size. **Health status:** The mental health subscale of the SF-36 reported an improvement between baseline and post intervention with maintenance at follow-up, with a medium effect size. The physical health subscale of the SF-36 reported an improvement between baseline and post intervention with maintenance at follow-up, with a large effect size. **QOL**: The total SSQOL score showed significant improvement at follow-up with large effect sizes. The mobility scale and upper extremity scale scores revealed improvement between baseline and the three-month follow-up.	68 %

Joo, Lee, Chung & Shin (2010) Korea	**Type of Brain Injury:** Subarachnoid haemorrhage experiencing psychological difficulties. **Sample size:** 11 **Mean age:** 52.6 years. **Gender:** 55% female. **Participant Recruitment:** Convenience sample – participant opt in.	**Design**: Pre-post intervention study. **Control group:** None. **Analysis time points:** Measures completed pre and post intervention. **Statistical Analysis:** Wilcoxon signed rank tests.	Beck Depression Inventory, Second Edition (BDI-II). Trait state anxiety index (STAI). Blood pressure and heart rate variability.	**Group content:** MBSR. **Modifications:** Unknown. **Frequency:** Weekly for 8 weeks, 2.5hrs in duration. **Group size:** Unknown. **Facilitators:** Unknown.	**Blood pressure**: Post intervention, blood pressure scored reduced. The differences were of borderline significance. **Anxiety and depression**: Post intervention there was a significant reduction in symptoms of depression. No significant changes in measures of state or trait anxiety; borderline significant differences were shown. **Changes in heart rate variability:** Post intervention, there were significant increases in standard deviation normal to normal (SDNN), the square root of the mean sum of squared differences between adjacent normal to normal (NN) intervals RMSSD and total power (TP). There was also a significant decrease in the physical stress index (PSI).	62 %
Bedard *et al.* (2003) Canada	**Type of Brain Injury**: TBI survivors who had completed conventional rehabilitation. **Sample size:** 10 **Mean age:** 43 years. **Gender:** 80% female. **Participant recruitment:** Convenience sample – participant opt in. **Attrition:** 23%	**Design**: Non-randomised control group. **Control group:** Drop-outs. **Analysis time points:** Measures completed pre and post intervention. **Statistical Analysis**: *t* -tests, a more conservative approach used a two-way analysis of variance (ANOVA) with drop-outs as controls for all measures. Person *r* coefficients were used to assess correlations.	Beck Depression Inventory, Second Edition (BDI-II). Symptoms Checklist 90-Revised (SCL-90-R). Short Form Health Survey 36 (SF-36). Community Integration Questionnaire (CIQ). Perceived Stress Scale (PSS). Multidimensional Health Locus of Control Scale (MHLC).	**Group content**: MBSR (Kabat-Zinn, 1982) and Kolb's experiential learning cycle (Kolb, 1984). **Modifications:** Intervention aimed to encourage a new way of thinking about disability and how to approach life to bring a sense of acceptance, allowing participants to move beyond limiting beliefs. **Frequency:** 12 weekly group sessions. **Group size:** Unknown. **Facilitators:** Unknown.	**Depression**: Post-intervention scores on the BDI-II decreased significantly with a medium to large effect. There was a significant reduction in scores on the cognitive-affective component of the BDI-II. **QOL:** Improvements on the Mental Health component of SF-36 was observed at follow-up. **SF-36**: Compared to controls, the SF-36 Mental Health score of the intervention group improved significantly post intervention, whereas the SF-36 Physical Health score remained the same post intervention. **Change of scores on SCL-90-R:** Pre and post scores on the global severity index remained unchanged. Reduction in Positive Symptom Distress Index (PSDI) approached significance with moderate effects size. Scores on the global severity index of the SF-36 were unchanged overall but there were improvements on the positive symptom distress index, with moderate to large effect sizes. **Internal locus of control scale**: Internal HLC approached significance but the effect was explained by a shift in external locus of control. **Community integration:** No change in CIQ following intervention. **Perceived stress:** Scores on the PSS were decreased after the intervention, but this was not significant. **Correlations:** Changes in SF-36 were correlated with changes in BDI-II scores but this was not significant.	66 %

Bedard *et al.* (2005) Canada	**Type of Brain Injury:** TBI. **Sample size:** 7 **Mean age:** 45.6 years. **Gender:** 80% female. **Participant recruitment:** Convenience sample – participant opt in. **Attrition:** Not specified.	**Design**: Cohort study where the post measures from the Bedard *et al.* (2003) study are the pre-measures for this study. **Control group:** N/A. **Analysis time points:** 12 months after the completion of the intervention. **Statistical Analysis:** To analyse the data we used repeated-measures one-way analysis of variance (ANOVA) with time as the independent variable (baseline, post-intervention, follow-up). Statistically significant ANOVAs ($p < .05$) were followed by multiple comparisons to evaluate pair-wise comparisons. For these multiple comparisons we relied on Fisher's Least Significant Difference (LSD) protected t-test with a Bonferroni correction (Howell, 1987).	Beck Depression Inventory, Second Edition (BDI-II). Short Form Health Survey 36 (SF-36). Community Integration Questionnaire (CIQ). Multidimensional Health Locus of Control Scale (MHLC). Symptoms Checklist 90-Revised (SCL-90-R). Visual analogue scales (VAS) to assess pain frequency and intensity and energy levels.	**Group content:** Based on Kabat-Zinn's mindfulness-based stress reduction programme (Kabat-Zinn, 1982) and Kolb's experiential learning cycle (Kolb, 1984). The primary techniques included: meditation, breathing exercises, guided visualisation, and group discussions **Modifications:** Unknown by these disabilities. **Frequency:** 12 weekly group sessions. **Group size:** Unknown. **Facilitators:** Unknown.	Improvements that were made after the intervention were maintained at follow-up. The mental health component of the SF-36 increased significantly at the 12-month follow-up. Scores on the cognitive-affective scale of the BDI-II outlined a continued reduction in depressive symptoms. Continued improvement of participant's energy level. **Medication usage**: At follow-up the number of medications that participants were prescribed had decreased, it was lower than at baseline and intervention but the change was not significant.	68 %

Bedard *et al.* (2014) Canada	**Type of Brain Injury:** TBI with clinical depression. **Sample size:** 76 **Mean age:** 46.7 years. **Gender:** 45% female. **Recruitment:** Convenience sample – participant opt in.	**Design:** RCT. **Control group:** Treatment as usual (TAU). **Analysis time points:** Pre-post intervention and 3 month follow-up. **Statistical Analysis:** Repeated design analysis of variance (ANOVA) (2 groups, 3 time points).	Beck Depression Inventory, Second Edition (BDI-II). Patient Health Questionnaire 9 (PHQ-9). Symptoms Checklist 90-Revised (SCL-90-R). Toronto Mindfulness Scale (TMS). Philadelphia Mindfulness Scale (PHLMS).	**Group content included:** Elements of MBCT & MBSR **Modifications:** • Amended to address issues associated with TBI (e.g., problems with attention, concentration, memory, fatigue). • Increased the length of the intervention by 25% (10 weeks). • Further adaptations included simplified language. • Greater repetition and visual aids were used to help reinforce concepts. • Provided with handouts from each session and received the book and CD to encourage meditation. **Frequency:** 10 weekly 90-minute sessions and a recommended daily meditation home practice for 20 to 30 minutes. **Group size:** Unknown. **Facilitators:** Unknown.	**Depression**: Reduction of BDI-II scores was greater in the intervention group than the in controls, with a medium effect. There was no such improvement on the PHQ-9 and SCL-90R depression subscale. At follow-up, all reductions were present across all measures. Scores on the PHQ-9 was reduced at follow-up and this was statistically significant. **Mindfulness**: No overall change on the PHLMS or TMS scales. However, in the PHLMS acceptance and de-centering scales scores increased with a small effect size. These changes were sustained at follow-up.	79 %

Table 1: Summary of each study included in this review.

Measure	**Abbreviation**	**Author(s)**	**Brief Description**
10 Metre Walk Test	10MWT	Nagano, Hori & Muramatsu (2015)	A test to measure walking speed, mobility, gait and vestibular function.
Beck Anxiety Inventory	BAI	Beck & Steer (1993)	A 21-item self-report measure that is used for measuring the severity of anxiety.
Berg Balance Scale	BBS	Berg, Wood-Dauphinee & Williams(1995)	A clinical test of a person's balance ability though the completion of 14 simple balance related tasks.
Beck Depression Inventory, Second Edition	BDI-II	Beck, Steer & Brown (1996)	A 21-item scale which can be divided into a cognitive-affective factor and a somatic factor.
Centre for Epidemiologic Studies Depression Scale	CES-D	Radloff (1977)	A 20-item scale to assess the symptoms of depression.
Community Integration Questionnaire	CIQ	Sander *et al.* (1999)	A 15-item measure of community integration after a traumatic brain injury.
Comprehensive Psychopathological Rating Scale	CPRS	Svanborg & Åsberg (1994)	A 30-item scale used to assess anxiety and depression.
Digit span and symbol coding	N/A	Weshcler (2004)	Measures of working memory and information processing speed.
Functional Ambulation Classification Scale	FAC	Holden, Gill & Magliozzi (1986)	Tool used to categorise an individual's ambulation level.
Functional Assessment of Cancer Therapy-Brain	FACT-Br	Weitzner *et al.* (1995)	A measure of QOL that consists of five dimensions, including physical, social and emotional wellbeing, as well as concerns that are common to individuals with brain tumours.
Hospital Anxiety and Depression Scale	HADS	Zigmond & Snaith (1983)	A 14-item scale used to measure levels of anxiety and depression.
Mayo-Portland Adaptability Inventory 4	MPAI-4	Malec & Lezak (2003)	A 35-item tool that assesses an individual's recovery after an ABI.
Mental Fatigue Scale	MFS	Johansson, Starmark, Berglund, Rödholm & Rönnbäck (2010)	A 15-item assessment of mental fatigue.
Mindful Attention Awareness Scale	MAAS	Brown & Ryan (2003)	A 15-item scale used in the measurement of trait mindfulness.
Multidimensional Health Locus of Control	MHLC	Wallston, Strudler-Wallston &, DeVellis (1978)	An 18-item scale that characterises the individual's beliefs about control over health outcomes.
Neurobehavioural Symptom Inventory	NSI	Cicerone and Kalmar (1995)	A 22-item self-report scale of the symptoms that are characteristic of post-concussion syndrome.
NIH Stroke Scale	NIHSS	Brott *et al.* (1989)	A diagnostic tool to assess the severity of stroke experienced by a survivor, it contains 11 components related to a specific functions, such as consciousness.
Paced Auditory Serial Addition Test	PASAT	Gronwall (1977)	A test that assesses calculation ability, auditory information processing speed and flexibility.
Patient Health Questionnaire 9	PHQ-9	Kroenke, Spitzer & Williams (2001)	A 9-question tool to given to screen for the presence and severity of depression.
Perceived Self-Efficacy Scale	PSE	Lorig, Chastain, Ung, Shoor & Holman (1989)	Measures a survivor's assessment of their self-efficacy in the management of cognitive, emotional and social problems.
Perceived Stress Scale	PSS	Cohen, Kamarck & Mermelstein (1983)	A 14-item questionnaire to measure how much the individual appraises their life to be stressful.
Perceived Quality of Life Scale	PQOL	Patrick, Danis & Southerand & Hong (1988)	Measures individuals' satisfaction with their functioning using a 10 point scale.

Philadelphia Mindfulness Scale	PHLMS	Cardaciotto, Herbert, Forman, Moitra & Farrow (2008)	20-item self-report measure of mindfulness.
Symptom Checklist-90-Revised	SCL-90-R	Derogatis (1994)	A 90-item tool to evaluate a range of psychological problems and symptoms of psychopathology.
Short Form Health Survey (SF-36)	SF-36	Ware & Sherbourne (1992)	A 36-item tool to assess quality of life, it is divided into ‘Mental Health’ and ‘Physical Health’ components.
Social Problem Solving Inventory Revised	SPSI-R	D’Zurilla, Nezu & Maydeu-Olivares (2002)	A 90-item tool that evaluates a range of psychological problems and symptoms of psychopathology.
Stroke Specific Quality of Life Scale	SS-QOL	Williams, Weinberger, Harris, Clark & Biller (1999)	A 49-item questionnaire that assesses health-related quality of life (HRQOL) specific to after stroke.
State Trait anxiety inventory	STAI	Spielberger, Sydeman, Owen & Marsh (1999)	The STAI is a 40-item tool used to measure the anxiety in normal and clinical populations.
Trail Making Test (A and B)	TMT A and B	Reitan & Wolfson (1985)	A test to measure visual scanning, divided attention, and motor speed.
The Shortened General Comfort Questionnaire	SGCQ	Kolcaba, Schirm & Steiner (2006)	A 28-item scale to measure individuals’ perceived levels of comfort.
Toronto Mindfulness Scale	TMS	Lau *et al.* (2006)	A 13-item questionnaire to measure state mindfulness.
Visual Analogue Scale	VAS	Huskisson (1974)	A scale that is used to measure a variable that spans a across a continuum of values which cannot be directly measured. Extremes are presented at either end of the scale.

Table 2: Summary of the measures presented in table 1.

Sample Characteristics

Within the 11 studies, three ABI (traumatic brain injury (TBI), subarachnoid haemorrhage (SAH) and stroke were represented. Studies recruited participants with a TBI (N = 5), stroke (N = 2), SAH (N = 1) and spontaneous intracranial haemorrhage (SICH, N = 1). Three studies (Moustgaard *et al.*, 2007; Johansson *et al.*, 2012; Johansson *et al.*, 2015) had samples comprised of stroke and TBI survivors. Studies totalled 396 participants with sample sizes ranging from seven to 134 (mean = 36.9). Ten out of 11 studies reported on gender and the majority of the participants were male (53.4%). Ten out of 11 studies reported participant's age and the average age was 48.4 years. Study origins were Canada (N = 5), Sweden (N = 2), USA (N = 1), China (N = 2) and South Korea (N = 1).

Participant recruitment

All studies recruited participants using convenience sampling, whereby participants would either opt in by replying to adverts or were referred to the study by healthcare professionals (Azulay *et al.*, 2012) or offered the GBMI when receiving inpatient rehabilitation (Wong *et al.*, 2019).

Mindfulness intervention

Group content

The content of GBMI interventions included in this review were based on a range of approaches, as outlined in table 3.

Group content	**Study**
Based on MBSR	Azulay *et al. (*2012) Bedard *et al. (*2003) Bedard *et al. (*2005) Joo *et al. (*2010) Johansson *et al. (*2012)
Based on MBCT	Moustgaard *et al.* (2007) Wang *et al.* (2020)
Based on the integration of MBCT and MBSR approaches	Bedard *et al.* (2012) Bedard *et al.* (2014)
Based on Eifert and Forsyth's (2005) 'centering' exercise to assist in the development of mindfulness skills	Wang *et al.* (2019)
The four boundless mental states of the Brahama Viharas	Johansson *et al.* (2015)

Table 3: Summary of the content that underpin the GBMI included in this review

Duration, frequency, attendance and adjustments to GBMI sessions

In their enhanced MBSR programme, Johansson *et al.* (2015) delivered an eight session group over eight months concluding with an all-day retreat. These participants had previously attended an eight-week and single one-day retreat MBSR group (Johannson *et al.*, 2012). The remaining mindfulness interventions consisted of a series of weekly sessions, ranging in duration from 1.5 hours to 2.5 hours. The number of group sessions ranged from two to ten, with the most common being eight. The number of group attendees was not reported in the majority of studies. In studies that did report attendance, attendance figures ranged from five to seven. Generally, studies did not provide adequate descriptions of the content of the group interventions. Some studies outlined the modifications made to the group content and structure in order to meet the needs of group attendees. This included shortened duration of sessions (Bedard *et al.*, 2014), an increased number of sessions so the intervention could be paced accordingly, the inclusion of psychoeducation specific to ABI (Moustgaard *et al.*, 2007), increased levels of repetition (Azulay *et al.*, 2012; Bedard *et al.*, 2012; Bedard *et al.*, 2014), greater modelling (Azulay *et al.*, 2012), the creation of resources to facilitate learning, such as written handouts (Azulay *et al.*, 2012; Wang *et al.*, 2019) and one study welcomed the attendance of participants' partners/carers with the premise that they would reinforce mindfulness practice at home (Wang *et al.*, 2019).

Group facilitation

Details of the number, skill or experience of the group facilitators for the studies included in this review are presented in table 3.

Number, skill or experience of the group facilitators	**Study**
No information provided	• Bedard *et al.* (2003) • Bedard *et al. (*2005) • Bedard *et al.* (2012) • Joo *et al. (*2010) • Johansson *et al.* (2012) • Wang *et al.* (2020)
GBMI was delivered by one facilitator	• The facilitator trained according to the research protocol (Bedard *et al.*, 2014). • The primary researcher had attended a two-month training programme in mindfulness theory, practice and consultation as well as completing self-practice (Wang *et al.*, 2020).
GBMI facilitated by two facilitators	• A trainee clinical psychologist and mindfulness and yoga instructor (Moustgaard *et al.*, 2007).

	- A clinical psychologist and MBSR trainer (Johansson *et al.*, 2012; Johansson *et al.*, 2015). - Two clinical neuropsychologists, one who had MBSR training and expertise in brain injury, and the other with experience of MBSR (Azulay *et al.*, 2012).

Table 4: Summary of the number, skill or experience of GBMI facilitators

Control Conditions

Details of the control conditions of the studies included in this review are presented in table 4.

Condition	Study
No control as the studies were pre-post intervention designs	- Azulay *et al. (*2012), Bedard *et al.* (2005), Bedard *et al.* (2012), Johansson *et al. (*2015), Joo *et al. (*2010), Moustgaard *et al.* (2007).
Waiting list/treatment as usual	- Bedard *et al.* (2003), Johansson *et al.* (2012), Wang *et al. (*2019), Bedard *et al.* (2014).
Active treatment comparison	- Wang *et al. (*2020).

Table 5: Summary table of the control groups of the studies included in this review.

Outcomes

In total, 20 outcomes were reported across the studies included in this review. The detailed findings from the studies are presented in table 5. Some studies included did not report statistics fully (e.g. omitted degrees of freedom and value of the test statistc); as a result, only the information provided in the studies can be presented in this review. All studies where reporting was incomplete are denoted with an asterisk (*). Furthermore, six out of the eleven studies included in this review presented effect sizes. Studies that stated the size of the effect (e.g. small, moderate/medium, large) have been deirectly quoted in table 5. However, Moustgaard *et al.* (2007) and Wang *et al*. (2020) did not categorise the effect sizes and these have been interpreted using the following guidance: small < 0.2, medium < 0.5 and large < 0.8.

Outcome	Study	Detailed findings
Depression	Bedard *et al.* (2012)	Post intervention there was a significant reduction in the number of participants meeting the clinical threshold for depression on the PHQ ($t_{(n=20)} = -3.5$; $p = 0.003$). In addition, 59% of participants' depression scores reduced below the threshold for clinical depression. Overall, changes were statistically significant ($t_{(n=20)} = -3.7$; $p = 0.001$) with a large effect size of ($d = 0.71$) for total score, a significant reduction on cognitive subscale scores was reported ($t_{(n=20)} = -2.9$; $p = 0.010$) with a medium effect size of ($d = 0.49$) and large effect size of ($d = 0.74$) for significant improvement ($t_{(n=20)} = -3.3$; $p = 0.004$) on the somatic subscale were reported. Improvements on the HADS depression sub-scale were not significant ($t_{(n=20)} = 2.5$; $p = 0.23$) but a medium effect size was (d = 0.66) and a significant improvement on the PHQ-9 was reported ($t_{(n=20)} = -3.5$; $p = 0.003$) with a large effect ($d = 0.96$).
	Joo *et al.* (2010)	Reported a significant reduction in symptoms of depression as measured by the Korean version of the Beck Depression Inventory ($p = 0.013$)*.
	Moustgaard *et al. (*2007)	Post-intervention declines on the BDI-II were maintained at follow-up with a medium effect size ($F_{(n=23)} = 41.15$; $p = 0.001$, $Eta^2 = 0.62$) and post-intervention declines on the depression subscale of the HADS was also maintained at follow-up, with a small effect size ($F_{(n=23)} = 14.66$; $p = 0.001$, $Eta^2 = 0.42$).
	Johansson *et al.* (2012)	Compared to controls, both GBMI groups in the study had significant reductions in depression post intervention. Group 1 = ($p = 0.004$)*, group 2 = ($p = 0.002$)*.
	Bedard *et al.* (2003)	Compared to waiting list controls, participants' scores in the intervention group on the BDI-II decreased significantly ($t_{(9)} = 3.55$; $p = 0.006$) with a medium to large effect size of ($d = 0.312$).
	Bedard *et al.* (2005)	The improvements reported on the BDI-II in the Bedard *et al.* (2003) study were maintained in this follow-up study ($F_{(n=7)} = 3.698$; $p = 0.056$).
	Bedard *et al.* (2014)	Compared to waiting list controls, participants in the GBMI exhibited non-significant improvements on the BDI-II ($F_{(n=7)} = 3.698$; $p = 0.256$) with a medium effect size ($d = 0.56$). Scales such as the PHQ-9 and SCL-90 were also used to evaluate the effect of GBMI. Compared to controls, scores on the depression subscale of the SCL-90 were reduced but the overall difference was not significant ($F_{(n=46)} = 0.04$; $p = 0.962$). No improvement between groups was documented on these scales post intervention. However, scores on the PHQ-9 increased at follow-up with a significant group by time effect ($F_{(n=46)} = 3.52$; $p = 0.034$).
	Wang *et al.* (2020)	Post intervention, participants in the GBMI group had significantly lower levels of depression with a small effect size ($t_{(n=67)} = 3.58$; $p < 0.001$, $d = 0.31$). Correlations revealed that change in scores of depression was negatively correlated with change of scores in QOL ($r = -.18$, $p < 0.05$), change in scores of emotional wellbeing ($r = -.23$, $p < 0.01$), and change in scores of functional wellbeing ($r = -.18$, $p < 0.05$).
Anxiety	Bedard *et al.* (2012)	There was no significant change in anxiety scores on the HADS from pre to post intervention ($t_{(n=20)} = -1.7$; $p = 0.116$).
	Moustgaard *et al.* (2007)	A significant decrease was observed on the anxiety subscale score of the HADS post intervention and the reduction was maintained at follow-up with a small effect size ($Eta^2 = 0.42$). Statistically significant improvements were observed post intervention and maintained at follow-up with medium effect sizes or the BAI total score ($F_{(n=23)} = 20.42$; $p = 0.001$, $Eta^2 = 0.50$), The BAI neurophysiological subscale ($F_{(n=23)} = 13.45$; $p = 0.001$, $Eta^2 = 0.40$), and BAI subjective subscale ($F_{(n=23)} = 15.89$ $p = 0.001$, $Eta^2 = 0.44$). The BAI panic overall F-value was statistically significant but post hoc analysis did not reveal group differences ($F_{(n=23)} = 5.71$; $p = 0.18$); the autonomic scale showed no significant change over time ($F_{(n=23)} = 3.65$; $p = 0.66$).
	Joo *et al.* (2010)	No significant change in scores of state ($p = 0.091$)* or trait ($p = 0.056$)* anxiety.
	Johansson *et al.* (2012)	Compared to waiting list controls, participants who completed the GBMI group achieved significant reductions in anxiety, group 1 = ($p = 0.04$)* and group 2 ($p = 0.002$)*.

Psychological distress	Bedard *et al.* (2012)	Post intervention, there was a significant reduction from baseline in overall psychological distress, as measured by the global severity index, ($t_{(n=20)} = 2.17$; $p = 0.043$) and the intensity of symptoms as measured by the positive symptom distress index ($t_{(n=20)} = -3.22$; $p = 0.04$), and depression scale scores ($t_{(n=20)} = -2.467$; $p = 0.023$) were observed.
	Bedard *et al.* (2003)	Post intervention, reductions were observed in the obsessive-compulsive scale ($t_{(n=20)} = 3.18$; $p = 0.001$) and additional items scales ($t_{(n=20)} = -2.16$; $p = 0.044$). The global severity index remained unchanged ($F_{(1,11)} = 1.30$; $p = 0.278$). However, the Positive Symptom Distress Index (PSDI) approached statistical significance ($F_{(1,11)} = 4.63$; $p = 0.054$), with a moderate to large effect size ($d = 0.296$).
	Bedard *et al.* (2005)	Participants in the (Bedard *et al.*, 2003) study were followed up 12 months later and it was stated that these changes were sustained at follow-up but were not significantly different ($F_{(2,12)} = 1.649$; $p = 0.233$).
Health Status	Bedard *et al.* (2012)	Post intervention, significant improvements were observed in the general health ($t_{(n=20)} = -2.93$; $p = 0.09$) and mental health ($t_{(n=20)} = 2.63$; $p = 0.007$) subscales of the SF-36. These scores are within normal population ranges.
	Bedard *et al.* (2003)	Compared to controls, the SF-36 Mental Health score of the intervention group improved significantly post intervention ($F_{(1,11)} = 5.70$; $p = 0.036$), whereas the SF-36 Physical Health score remained the same post intervention ($F_{(1,10)} = 1.75$; $p = 0.213$).
	Bedard *et al.* (2005)	Participants from the (Bedard *et al.,* 2003) study were followed up and found that 12 months later, the mental health component of the SF-36 had a sustained improvement than the baseline level ($F_{(2,12)} = 14.197$; $p = 0.001$) and remained comparable to normative data.
	Moustgaard *et al.* (2007)	Scores on the Mental Health and Physical Health subscales of the SF-36 revealed improvement between pre and post intervention and were maintained at follow-up. Mental Health ($F_{(n=23)} = 9.38$; $p = 0.00$, $Eta^2 = 0.32$) and Physical Health ($F_{(n=23)} = 19.95$; $p = 0.001$, $Eta^2 = 0.50$).
QOL	Azulay *et al.* (2012)	QOL significantly improved post intervention with a moderate effect size ($t_{(21)} = 3.37$; $p = 0.003$, $d = 0.43$).
	Moustgaard *et al.* (2007)	The total score of the SSQOL significantly improved after the GBMI and at follow-up with a medium effect size ($F_{(n=23)} = 60.75$; $p = 0.001$, $Eta^2 = 0.75$). All SSQOL subscales improved at follow-up except the mood subscale where post hoc analysis did not reveal any statistical difference between means ($F_{(n=23)} = 6.94$; $p = 0.13$).
	Wang *et al.* (2020)	Reported significantly higher scores in a measure of QOL in the intervention group compared to controls post intervention with a medium effect size ($t_{(n=67)} = -2.80$; $p = 0.01$, $d = 0.51$).
Medication usage	Bedard *et al.* (2003)	No description of medication usage change was provided, despite it being listed as an outcome of interest.
	Bedard *et al.* (2005)	Compared to baseline (Bedard *et al.,*2003), medication usage post intervention decreased and this decrease was observed at follow-up, but the change was not significant ($F_{(2,12)} = 0.15$; $p = 0.861$).
	Bedard et al. (2012)	Post intervention, the use of all pain and anxiety mediation decreased. Although the change was not significant, medium effect sizes were reported ($d = 0.39$, $d = 0.41$ and $d = 0.23$)* and a reduction in medication use for depression with a small effect size ($d = 0.12$)* was reported.
Mindfulness	Bedard *et al.* (2014)	There was no significant change in overall mindfulness scores post intervention, but there were small effect sizes for PLHMS acceptance ($F_{(n=16)} = 0.93$; $p = 0.401$, $d = 0.27$) and TM-Descending scores ($F_{(n=16)} = 3.698$; $p = 0.589$, $d = 0.26$).
	Azulay *et al.* (2012)	The MAAS was used to assess participants' level of mindfulness; although scores post intervention increased, this change was not significant ($t_{(n=17)} = 1.41$; $p = 0.18$).

	Wang *et al.* (2019)	Post intervention, improvements in the MAAS scores was significantly greater in the intervention group compared to controls ($t_{(n=67)} = 5.924$; $p = 0.000$).
	Wang *et al.* (2020)	A significant change on the MAAS was observed post intervention with a small effect size ($t_{(n=67)} = 3.57$; $p < 0.001$, $d = -0.41$). In addition to pre-post changes on mindfulness, the relationship between QOL and mindfulness was explored but the effect was not significant ($r = 0.11$; $p > 0.05$).
Neuropsychological outcomes	Azulay *et al.* (2012)	Although participants seemed to exhibit greater problem solving skills, the change was not significant ($t_{(n=21)} = 11.51$; $p = 0.134$). Additionally, there was no significant effect on verbal learning and memory ($t_{(20)} = 1.66$; $p = 0.11$). However, post intervention, there were significant improvements on scores of attention with a small effect size for scores on continuous performance test of attention ($t_{(20)} = 2.64$; $p = 0.01$, $d = 0.31$) and a small effect size on paced serial auditory addition ($t_{(20)} = 3.69$; $p = 0.001$, $d = 0.32$). Moreover, standard scores were calculated based on participants' age and education. 66% of the sample showed a clinically significant change from the impaired to average category.
	Johansson *et al.* (2012)	Compared to waiting list controls, the GBMI group 1 performed significantly better on a divided attention task ($F_{(n=12)} = 7.39$; $p = 0.013$) and had superior dual task performance ($F_{(n=12)} = 4.84$: p = 0.039) However, the GBMI group scored significantly higher on tests of visual scanning and motor speed at baseline; this was then used as a covariate and the effect disappeared. However, for both GBMI groups, significant improvements on dual task performance post GBMI were reported (group 1: $p = 0.001$, group 2: $p = 0.007$)* as well as significant improvements on measures of processing speed and attention post GBMI (group 1: $p = 0.026$, group 2: $p = 0.028$)*. The difference in improvement between pre- and post-test on the MFS and measures of processing speed were subjected to correlation analysis and a significant correlation of improvement in mental fatigue and information processing speed was detected (*r.* = 0.48; $p = 0.023$). A significant increase in word fluency from pre to post intervention was also reported for the MBSR group 1 ($p = 0.050$)* and group 2 (*p.* = 0.044)*, but not for the control group ($p = 0.081$)*.
	Johansson *et al.* (2015)	Participants in Johansson *et al.* (2012) study were enrolled to this study and completed an eight-month advanced GBMI programme and sustained positive effect at a similar level as after the programme documented by Johansson *et al.* (2012). Significant differences between test at start and after the advanced programme were found on measures of processing speed ($F_{(2,26)} = 5.12$; $p = 0.013$), measures of divided attention ($F_{(2,26)} = 4.70$; $p = 0.018$) and measures of dual task performance ($F_{(2,26)} = 13.30$; $p < 0.0001$), indicating that effects of the initial GBMI were maintained by attending the enhanced GBMI.
Survivors experience of symptoms	Wang *et al.* (2020)	Stroke survivors' experience of stroke severity was assessed using the NIHSS. Participants in both the GBMI group and active treatment control group reported a statistically significant reduction in severity of stroke symptoms post intervention, with a larger effect size in the intervention group ($t_{(n=67)} = 7.62$; $p < 0.01$, $d = 0.77$) compared to a smaller medium effect size ($t_{(n=67)} = 5.89$; $p < 0.01$, $d = 0.64$) in controls. Correlations revealed that change in the NIHSS negatively correlated with change in the scores of physical wellbeing ($r = -0.31$, $p < .001$).
	Azulay *et al.* (2012)	The impact of GBMI on concussion symptomology was evaluated using the Neurobehavioural Symptom Inventory (NSI). Findings from this pre-post intervention study revealed that post intervention, participants reported a significant reduction in symptoms on the NSI, with a small to moderate effect size ($t_{(21)} = 1.90$; $p = 0.07$, $d = 0.32$). Analysis revealed that reductions were most evident for cognitive symptoms ($d = 0.36$), emotional symptoms ($d = 0.38$) and less prominent for somatic/sensory symptoms ($d = 0.22$).
Energy levels	Bedard *et al.* (2005)	Reported that participants' energy levels continued to rise a year post intervention, an increase which was statistically significant ($t_{(2,12)} = 3.3$; $p = 0.004$).
	Bedard *et al.* (2012)	Post intervention, participants reported a significant increase in energy levels ($F_{(n=20)} = 9.590$; $p = 0.003$).

Mental fatigue	Johansson *et al.* (2012)	Compared to waiting list controls, participants in GBMI groups reported significant reductions in mental fatigue, post intervention (*p* = 0.004)*. When participants in the control group participated in the GBMI, their scores post intervention were compared to their scores when they were controls and they also showed similar significant improvements in scores on the MFS (*p* = 0.002)*.
	Johansson *et al.* (2015)	Participants who completed the Johansson *et al.* (2012) study participated in the advanced intervention and there was a significant decrease in scores of mental fatigue at the end of the enhanced programme as compared to the start of the initial GBMI group ($F_{(2,23)}$ = 10.13; *p* = 0.001) but no significant differences were observed between pre and post the enhanced intervention scores. This indicates that effects of GBMI are maintained with the enhanced intervention.
Community Integration	Bedard *et al.* (2003)	Post intervention there were non-significant changes on the home competency ($t_{(1,10)}$ = 0.84; *p* = 0.381), social integration ($t_{(1,10)}$ = 0.20; *p* = 0.666) and productive activity subscales ($t_{(1,10)}$ =0.66; *p* = 0.439) of the community integration questionnaire.
	Bedard *et al.* (2005)	At follow-up, there was no significant change on scores of the home competency ($t_{(2,12)}$ = 0.182; *p* = 0.835), social integration ($t_{(2,12)}$ = 0.770; *p* = 0.485) and productive activity subscales ($t_{(2,12)}$ =0.202; *p* = 0.820) of the community integration questionnaire.
	Bedard *et al.* (2012)	The effect of GBMI on community integration was evaluated via the use of the Meyo-Portland Adaptability Inventory and reported non-significant reductions across the overall scale ($t_{(n=20)}$ = 1.65; *p* = 0.115), abilities ($t_{(n=20)}$ = 1.19; *p* = 0.251), adjustment ($t_{(n=20)}$ = 0.81; *p* = 0.427), participation subscale ($t_{(n=20)}$ =1.89; *p* = 0.77).
Pain	Bedard *et al.* (2005)	Participants were asked to rate their pain frequency and intensity at follow-up. Compared to post-intervention scores, no significant change in pain frequency ($F_{(n=7)}$ = 2.086; *p* = 0.167) or no significant change in pain intensity was reported ($F_{(n=7)}$ = 2.715; *p* = 0.106).
	Bedard *et al.* (2012)	In this pre-post intervention study, post intervention there was no significant reduction in pain frequency ($t_{(n=20)}$ = -1.9; *p* = 0.075) but a significant reduction in pain intensity was observed post intervention ($t_{(n=20)}$ = 2.3; *p* = 0.033).
Health locus of control	Bedard *et al.* (2003)	Post intervention, the internal Health Locus of Control approached statistical significance ($F_{(1,10)}$ = 4.79; *p* = 0.053). The powerful others and chance locus of control subscales were not significantly different between GBMI attendees and controls ($F_{(1,10)}$= 1.16; p = 0.30 and $F_{(1,10)}$ = 2.54; *p* = 0.142).
	Bedard *et al.* (2005)	This follow-up study reported that the Internal HLC score had increased but this change was not significant ($F_{(2,12)}$ = 1.631, *p* = 0.236). The powerful others locus of control subscale decreased but this change was not significant ($F_{(2,12)}$ = 0.549; *p* = 0.591); the chance locus of control subscale decreased but this score was also not significant ($F_{(2,12)}$ =2.663; *p* = 0.110).
Comfort	Wang *et al.* (2019)	Compared to controls, participants who received the mindfulness intervention scored significantly higher on the comfort measure overall, post intervention ($t_{n=67)}$ = 2 .957; *p* = 0.005). The different subscales of the SGCQ were also evaluated and significantly higher scores were achieved on the physical ($t_{n=67)}$ = 3.044; *p* = 0.004) and sociocultural ($t_{n=67)}$ = −2.85; *p* = 0.006) subscales. The score of the psycho-spiritual scale was smaller but the change in the intervention group significantly outweighed that of the control group ($t_{(n=67)}$ = −2.303; *p* = 0.026), and on the psycho-spiritual subscale ($t_{n=67)}$ = −1.705; *p* = 0.026) and there was no significant difference on the environmental subscale ($t_{n=67)}$ = −1.176; *p* = 0.245).
Tests of autonomic nervous system functioning	Joo *et al.* (2010)	Analysis of heart rate variability revealed, post intervention, significant increases in the Standard Deviation of Normal to Normal (SDNN, *p* = 0.013)*, square root of the mean sum of squared differences between adjacent NN intervals (RMSSD, *p* =0.021)* and Total Power (TP, *p* = 0.026)*.
Self-reported problem solving	Azulay *et al.* (2012)	Post GBMI participants demonstrated improved problem solving abilities post intervention but the change was not significant ($t_{(21)}$ = 11.52; *p* = 0.134).

Stress	Bedard *et al.* (2003)	Participating a GBMI led to an increase in PSS scale scores but this was not significant ($F_{(1,10)} = 0.34$, $p = 0.575$;).
Self-Efficacy	Azulay *et al.* (2012)	Reported significant improvements on the Perceived Self-Efficacy Scale (PSE) with moderate effect size ($t_{(21)} = 3.76$; $p = 0.001$, $d = 0.5$)*. Improvements were most evident for the management of cognitive ($d = 0.55$)* and emotional symptoms ($d = 0.56$)*.
Ambulation	Wang *et al.* (2019)	The effect of GBMI on participants' ambulation ability was investigated via the use of the Berg Balance Scale (BBS), Functional Ambulation Scale (FAS) and 10m walk test. Participants in the control and GBMI groups showed significant improvements on these three measures post intervention but there were no significant differences between groups. BBS ($t_{(n=25)} = 0.285$; $p = 0.709$) FAS ($t_{(n=25)} = -0.251$; $p = 0.803$) 10m walk test ($t_{(n=25)} = -1.504$; $p = 0.139$).

Table 6: Detailed outcomes of the studies included in this review.

Discussion

Brief overview of the design and methodology

The purpose of this review was to investigate the outcomes of GBMI in ABI survivors. Eleven studies were eligible for this review. As mindfulness is not a goal-orientated approach (Kabat-Zinn, 2003) its application provides researchers with the opportunity to evaluate its effect on many outcomes of interest. Therefore, it is unsurprising that the studies included in this review evaluated the effect of GBMI on a range of difficulties experienced and rehabilitation goals for ABI survivors. GBMI was offered to ABI survivors at varying times in the rehabilitation trajectory and some outcomes were investigated more than others. The QASSD (Sirriyeh *et al*., 2011) was selected to assess the quality of studies in this review; there was variance in the quality of the studies included, with the majority of studies being of reasonable quality. Notably no studies included service users in their development.

How do the findings fit in with the previous research?

The findings of this review support the evidence base for the application of GBMI for ABI survivors. As there are aspects of the evidence base that are lacking, results have been contextualised, where possible, in relation to other chronic or neurological conditions.

Depression and anxiety

Depression was the most extensively researched outcome and findings from higher quality studies (Wang *et al.,* 2020; Bedard *et al*., 2014; Moustgaard *et al*., 2007) indicate that GBMI significantly reduces symptoms of depression. These reductions were observed in studies that recruited TBI survivors who were experiencing clinical depression, utilising pre-post intervention designs or non-clinically depressed ABI survivors compared to waiting list or active controls. Anxiety was a further investigated outcome and, based on higher quality studies that employed the use of established measurement tools (Bedard *et al*., 2012; Moustgaard *et al*., 2007), it appeared that GBMI significantly reduced anxiety symptoms in ABI survivors. The depression and anxiety reductions reported in this review support the evidence base which documents that MBI improve anxious and depressive symptomology in patients with other chronic conditions such as cancer (Zhang *et al*., 2015). However, caution must be exercised when comparing reductions in anxiety or depression in ABI to the general and to other clinical populations. A systematic review completed by Burton & Tyson (2015) evaluated the use of outcome measures to assess mood, and suggested that these measures assume that psychological difficulties (e.g. anxiety and depression) experienced by ABI survivors are experienced in the same way as they are in the general population, when this might not be true. For example somatic symptoms of ABI can overlap with symptoms of depression.

Mindfulness

Findings from higher quality studies (Bedard *et al*., 2014; Wang *et al*., 2019) suggest that GBMI improves one's ability to be mindful, but the effects are small. This supports previous research (Carmody & Baer, 2008). Visted, Vøllestad, Nielsen & Nielsen (2015) states that MBI has a positive effect on mindfulness but this finding is tentative as methodological limitations of the studies reviewed in the meta-analysis and the psychometric properties of the tools used to measure mindfulness make it difficult to draw definite conclusions. Moreover, the measurement of mindfulness is a contentious issue as a consensus of the definition has not yet been reached (Garland & Gaylord, 2009) and some researchers argue that mindfulness cannot be assessed via the use of self-report measures (Grossman & Van Dam, 2011). As mindfulness has a multidimensional definition, it could be wondered whether members of the population may not have enough of an understanding of its definition and meaning which in turn affects their ability to rate their level of mindfulness (Wang *et al*., 2020).

Mental Fatigue

Studies in this review (Johansson *et al*., 2012; Johansson *et al*., 2015) suggest that GBMI have a significant effect on mental fatigue compared to waiting list controls and the effect was maintained after participants attended a second GBMI. Mental fatigue was measured by the Mental Fatigue Scale (MFS, Johansson *et al*., 2010). As a result, the evidence base for the effect of MBI on this specific component of fatigue is limited and developing. However, the evidence base for the effect of GBMI on fatigue in other neurological conditions such as Multiple Sclerosis (MS) indicates favourable outcomes (Nejati, Esfahani, Rahmani, Afrookhteh & Hoveida, 2016) and traditional measures of fatigue include items to assess mental fatigue. Moreover, having energy can be considered as the antithesis of fatigue and Bedard *et al.* (2003) reported that GBMI led to increased levels of energy in TBI survivors which was maintained at follow-up.

Community Integration

Two studies (Bedard *et al*., 2003; Bedard *et al*., 2005) that evaluated the effect of GBMI on community integration reported no significant differences post-intervention. A possible explanation for this finding is that community integration is a goal of a rehabilitation plan that often requires multidisciplinary intervention (McCabe *et al*., 2007), as it is a complex process requiring a plethora of practical solutions to circumvent the challenges which are a result of the ABI. This is in contrast to the process-driven ethos of mindfulness (Kabat-Zinn, 2003) which can be delivered by a facilitator who does not need to be a clinician (Bedard *et al*., 2003). Moreover, anxiety and depression can also be a barrier to successful community reintegration and whilst GBMI do reduce these difficulties, it can be postulated that this alone is insufficient.

Medication usage

Medication usage had become an outcome of interest in three studies (Bedard *et al.*, 2003; Bedard *et al.*, 2005; Bedard *et al.*, 2012). Overall, findings suggest that GBMI reduces medication usage. However, these findings need to be viewed with caution. Generally, pain, anxiety and depression medication usage decreased post intervention, but these changes were not significant. It is difficult to reach consensus of these results as the type of medication was not specified (i.e. if the medication was part of an ongoing medication regimen or used as and when required). The researcher’s rationale for evaluating medication change was based on the hypothesis that if mindfulness was effective in reducing pain, depression or anxiety then a decrease in medication usage would be documented. However, it can be wondered whether the relationship between medication usage and reduction in pain, anxiety and depression is as linear as Bedard *et al.* (2003) proposes, especially when considering that, post injury, survivors are routinely placed on medication to manage their mood which is sometimes without their knowledge (Turner-Stokes &

MacWalter, 2005). Moreover, it is also a risk for participants to discontinue with their medication because they feel their symptoms have improved after participating in a brief research trial and the implications this might hold if the improvements in their symptoms are not sustained. Conversely, given the range of cognitive difficulties post ABI, adherence to medication can be problematic and MBI has been found to be effective in improving medication adherence in individuals with cognitive difficulties as a result of conditions such as Alzheimer's disease (Lima, Gago, Garrett & Pereira, 2016). This outlines that mindfulness is a mediator as increased awareness of the disease results in improved medication adherence.

Pain

The effect of GBMI on pain experience was evaluated by two studies. Findings were mixed and the findings from a higher quality study (Bedard *et al*., 2012) postulate that post intervention, GBMI does not significantly reduce pain frequency but does does significantly reduce pain intensity. This was assessed using a visual analogue scale (VAS, Huskisson, 1974). Findings from this study support the evidence base for the effect of GBMI on pain in participants with other neurological conditions such as MS, which outlined that post-intervention participants reported reduced intensity in bodily pain (Tavee, Rensel, Planchon, Butler & Stone, 2011), indicating that although mindfulness may not reduce pain frequency it is a strategy that individuals can employ to manage the experience of pain, which is consistent with previous qualitative research (Morone, Lynch, Greco, Tindle & Weiner, 2008). However, the evidence base would benefit from future research evaluating the effect of GBMI on pain frequency and whether the reduction in pain intensity is mainlined over time.

QOL

Higher quality studies state that GBMI improves QOL (Wang *et al.* 2020; Moustgaard *et al.* 2007); these findings are congruent with the literature exploring the benefits of GBMI for individuals experiencing chronic fatigue syndrome (CFS, Surawy, Roberts & Silver, 2005) and MS (Grossman *et al*., 2010). The findings reported by Grossman *et al.* (2010) outline that GBMI has a significant effect on QOL in MS patients post intervention but these effects declined at follow-up, advocating a booster session to be offered at two months. Although the effect of GBMI was sustained at a three month follow-up for participants in the study completed by Moustgaard *et al.* (2007), future research with follow-up could explore whether a booster session would be advantageous for ABI survivors.

Psychological distress

Findings from the higher quality study (Bedard *et al.*, 2014) indicate that GBMI does reduce psychological distress but this study did not investigate whether the reduction was maintained. Lower quality studies (Bedard *et al*., 2003; Bedard *et al.,* 2005) reported improvements in some aspects of psychological distress post intervention, but these were not maintained at follow-up. A recent meta-analysis completed by Virgili (2015) reported that, for working age adults experiencing higher levels of distress than the general population, GBMI was effective in reducing psychological distress and its effect was maintained at follow-up. This is contrary to the findings in ABI populations as it is unclear whether GBMI does reduce psychological distress in the ABI population as it could be could be a result of the factors (e.g. disability, loss of role etc.) that are unique to the population and there is a lack of research evaluating whether the effects of GBMI on psychological distress are maintained at follow-up.

Neuropsychological function and symptom severity

Neuropsychological function was assessed in three studies (Azulay *et al.* 2012; Johansson *et al.* 2012; Johannson *et al.* 2015) and findings postulate that GBMI can lead to improvements in attention, processing speed and word fluency; this is encouraging when considering that cognitive difficulties are common post ABI (Barker-Collo, 2007; Al-Khindi, Macdonald & Schweizer, 2010; Barman, Chatterjee & Bhide, 2016) and this is consistent with the findings of recent qualitative research that outlined that participants felt their memory and attention improved after a MBI (Niraj, Wright & Powell, 2020). Azualy *et al.* (2012) and Wang *et al.* (2020) evaluated the effect of GBMI on survivors' experience of post-injury symptoms using psychometric measures and reported that attending a GBMI led to the reduction in severity of symptoms experienced post ABI. These findings can also be supported by Niraj *et al*. (2020), as MBI has a positive effect on survivors' emotional wellbeing, sleep and pain experience, therefore reducing the severity of some symptoms experienced as a result of ABI.

Self-efficacy and control

One study investigated the effect of GBMI on self-efficacy (Azulay *et al*., 2012) and reported that the GBMI improved self-efficacy in the management of emotional and cognitive symptoms of brain injury. Backhaus, Ibarra, Klyce, Trexler & Malec (2010) reported that a coping skills group led to a significant improvement in brain injury survivors' perceived levels of self-efficacy with very large effect sizes. Although the magnitude of the effect size was greater in the CBT approach, this could be due to the enhanced methodological rigour of the study and as such the results reported in the pilot study by Azulay *et al.* (2012) are promising. Despite the positive effect of GBMI on self-efficacy, survivors' perceived level of control over their health was measured in two studies (Bedard *et al.* 2003; Bedard *et al.* 2005) but no significant change was observed after participants attended GBMI. Post intervention, participants felt that, to a degree, their health was still under the control of chance and powerful others. This is unsurprising as rehabilitation requires support from others such as caregivers and professional teams and the period of recovery is considered as an uncertain time for ABI survivors and their carers (Hunt & Smith, 2004).

Health Status

The effect of GBMI on health status as measured by the SF-36 was evaluated in three studies (Bedard *et al.* 2003; Bedard *et al.* 2005; Bedard *et al*., 2012). Findings from the higher quality study (Bedard *et al.* 2012) suggest that GBMI leads to significant improvements in survivors' general and mental health, as measured by the SF-36. This finding is consistent with previous research, illustrating the effects of MBI on SF-36 performance in a heterogeneous sample, composed of participants experiencing a range of health conditions such as chronic pain and hypertension (Reibel, Greenson, Brainard & Rosenzweig, 2001). However, participants in the Reibel *et al.* (2001) study exhibited improvement across a wealth of SF-36 subscales, whereas the improvements for ABI survivors was observed in a smaller number of subscales and it could be postulated that this is a reflection of the debilitating nature of ABI.

Stress

Bedard *et al.* (2003) investigated the effect of GBMI on perceived stress and reported that GBMI did have a positive effect but this was not significant. This finding is contrary to the previous research for the effect of MBSR on perceived stress in clinical samples (those experiencing pain, chronic illness and challenging life circumstances) which concluded that MBSR leads to significant reductions in participants' levels of perceived stress**.** In addition, Joo *et al.* (2010) also investigated the role of GBMI on stress but measured it objectively using heart rate variability. Joo *et al.* (2010) reported that, post intervention, HRV increased which suggests that participants were able to better manage their stress post intervention. Therefore, more research evaluating the effect of GBMI on stress is welcomed in order to draw firm conclusions.

Ambulation ability

A single study (Wang *et al.*, 2020) investigated the effect of GBMI on stroke survivors' ambulation ability but did not find significant improvements compared to active controls. Previous systematic reviews completed by Lawrence *et al.* (2013) and Lazaridou, Philbrook & Tzika (2013) suggest that MBI result in improved ambulation and mobility and had a positive effect on balance self-efficacy in stroke survivors. This finding was not supported by the single study included in this review (Wong *et al.,* 2020), outlining that GBMI did not significantly improve stroke survivors' ambulatory ability. This may be a result of the timing of the GBMI in the survivors' rehabilitation trajectory as the participants were inpatients, typically two weeks after their stroke.

Comfort

Kiston, Dow, Calabrese, Locock & Athlin (2013) reported that being on an inpatient ward after stroke was a negative experience which resulted in decreased feelings of comfort and had a negative effect on rehabilitation. Therefore, Wang *et al.* (2019) hypothesised that a GBMI would improve stroke survivors' level of comfort, as proposed by Kolcaba's Theory of Comfort (Kolcaba, 2010). However, compared to controls, there was no significant change post intervention on the subscales except the environmental subscale, which is understandable as the hospital environment is less amenable to change.

Self-reported problem-solving

One study (Azulay *et al.*, 2012) investigated the effect of GBMI on problem-solving and, although participants exhibited more positive problem-solving orientation after the intervention, there was no significant improvement in self-reported problem-solving skills. A systematic review completed by Kennedy *et al.* (2008) suggested that problem solving interventions are based on the goal to improve functional impairments in everyday living. This goal-orientated approach is not congruent with the process-driven approach of mindfulness and Kennedy *et al.* (2008) advocate the use of meta-cognitive strategy interventions. Another consideration for the evaluation of GBMI on problem-solving ability can be the measures used to capture change, as Visser *et al.* (2016) questions that psychometric properties of problem solving measures which are utilised by researchers such Azulay *et al.* (2012).

Strengths and limitations of the studies included in this review

A large proportion of the studies included in this review were pre-post intervention designs with no control group. Therefore, it is difficult to isolate the effect of GBMI on the outcomes under investigation and benefits could have been derived as a result of other variables (e.g. group membership and social identification). For the few studies that employed the use of a control group, randomised allocation did not fully occur. Additionally, for the majority of the studies, sample sizes were small and subsequently results lacked statistical power. Moreover, outcome measures were typically collected at the end of the intervention, follow-up was inconsistent and so it is difficult to establish the permanence of the effect of GBMI. Limitations within the samples recruited are also present. All studies employed the use of convenience sampling, which in turn encumbers the generalisability of findings. The majority of participants recruited were volunteers who may have been motivated to take part in a novel intervention and research or were individuals who may have exhausted all other treatment options. Therefore, it can be questioned whether the participants recruited in the studies are representative of the ABI population. Studies included in this review investigated the role of GBMI on a range of difficulties experienced post ABI; some difficulties were evaluated more than others (e.g. depression, anxiety) and a range of outcome measures with varying psychometric properties were used. Some of these were more sensitive and specific to the ABI population than others, thus making it difficult to draw firm conclusions. Self-report measures were used as the primary method of data collection. This can be especially problematic in this population as insight after a brain injury can be limited (Bedard *et al*., 2003) and participants' insight was not routinely assessed in the studies included in this review. Additionally, ABI survivors may lack understanding of the constructs being measured (e.g. mindfulness). Therefore, it is difficult to fully establish the effectiveness of GBMI as an intervention to support survivors of an ABI.

Strengths and limitations of the review process

As far as the author is aware, this is the first review to investigate the effect of GBMI in the ABI population. Consequently, the findings contribute to the evidence base for GBMI and ABI. Although recent research efforts have sought to adapt the delivery of MBI using technology, this review advocates that GBMI needs to be more rigorously evaluated to assess whether it meets the needs of the ABI population and is effective in reducing the difficulties associated with ABI, before altering the delivery of the intervention.

A strength of this review was that it adhered to PRISMA (Sirriyeh *et al*., 2011) guidance, utilised clear inclusion criteria and assessed studies for quality using an established quality assessment tool. Inter-rater reliability was achieved at multiple times throughout the process, including paper selection and quality assessment, reducing the amount of bias inherent in the review process. Despite these strengths, limitations are also present. Firstly, ABI is an umbrella term used for a range of brain injuries and, as a result, participants recruited across the studies are heterogeneous. Moreover, ABI severity ranged from post-concussion syndrome with no evidence of a brain injury on a brain scan (Azulay *et al.,* 2012) to those who had more severe brain injuries (Moustgaard *et al*., 2007). GBMI was offered to participants at varying stages of their rehabilitation trajectory, from inpatient (Wong *et al*., 2019) to a number of years post ABI (Bedard *et al*., 2003). It is likely that ABI survivors' needs vary as a result of brain injury severity and differ throughout the rehabilitation trajectory, thus impacting the potential effectiveness of GBMI. Also, mindfulness interventions were heterogeneous and there is variability between the skills of the facilitator, number of sessions and the time scale in which the GBMI was offered. Additionally, session attendance and adherence to exercises (e.g. homework) was not recorded. Moreover, the QASSD quality tool (Sirriyeh *et al.*, 2011) did not evaluate facilitator's competence or whether the intervention was manualised.

Although interventions were not assessed formally for quality using a quality assessment tool, the first author considered this during synthesis, in addition to the adjustments made to the GBMI in order to suit the needs of ABI survivors (e.g. increased repetition, practices to circumvent memory problems etc.). Also, mindfulness is an approach that is not as firmly rooted in the evidence base (when compared to approaches such as ACT or CBT) and variations of the approach are present. Therefore, it is unlikely that GBMI across the studies were fully comparable. Additionally, this review only included studies from peer-reviewed journals published in English and included studies which utilised a quantitative methodology, so participants' views or experiences of the process of mindfulness were not captured.

Implications of the review

There is an abundance of opportunities to develop the evidence base for GBMI in the ABI population, which is congruent with the recommendations outlined by Lawrence *et al.* (2013) and Kenuk & Porter (2017). Therefore, future research would benefit from a higher degree of experimental rigour such as the introduction of randomised control groups and the recruitment of larger sample sizes sufficient for statistical power. What this current review recommends is the application of outcome measures that have psychometric properties that are sensitive and specific to the ABI population. Importantly, this review used the term 'acquired brain injury' to encompass stroke, TBI and brain haemorrhage, when separate condition specific systematic reviews have previously been conducted. The nature of ABI means that there is variability in the severity of individual ABI and consequently survivors' difficulties and needs vary, but these difficulties and needs are common across ABI. It is hoped that health care provision is based on need and therefore when needs across ABI are similar, the literature for other ABI can be drawn upon to benefit survivors. Concurrent with the recommendations of previous reviews it is suggested that GBMI is robustly evaluated for ABI survivors before the method of delivery is altered. However, the author is aware that with ABI survival rates increasing there is pressure on services to provide interventions in a cost effective manner, which may include amending the method of delivery to reach more ABI survivors, which could be via the use of technology. This review has highlighted that adherence to GBMI homework tasks is unknown and it is wondered whether there is an opportunity to embrace technology as an adjunct to GBMI in order to remind participants to complete homework tasks or facilitate mindfulness-based practices in between formal sessions.

Conclusion

This review highlighted the potential benefit of the use of GBMI in ABI; however, the evidence base would benefit from studies of higher methodological rigour and utilisation of psychometric measures suitable for the ABI population. It is hoped that this review will stimulate thinking into the need to evaluate the benefit of mindfulness approaches delivered by traditional methods and the need to tailor the GBMI to the ABI population, taking into account ABI severity, and to identify the optimum time of delivery in the rehabilitation trajectory.

References

Al-Khindi, T., Macdonald, R. L., & Schweizer, T. A. (2010). Cognitive and functional outcome after aneurysmal subarachnoid hemorrhage. *Stroke*, *41*(8), e519-e536. https://doi.org/10.1161/STROKEAHA.110.581975

Azulay, J., Smart, C., Mott, T., & Cicerone, K. D. (2012). A pilot study examining the effect of mindfulness-based stress reduction on symptoms of chronic mild traumatic brain injury/postconcussive syndrome. *Journal of Head Trauma Rehabilitation, 28*(4), 323–331. *DOI: 10.1097/HTR.0b013e318250ebda*

Backhaus, S. L., Ibarra, S. L., Klyce, D., Trexler, L. E., & Malec, J. F. (2010). Brain injury coping skills group: a preventative intervention for patients with brain injury and their caregivers. *Archives of Physical Medicine and Rehabilitation*, *91*(6), 840-848. DOI:https://doi.org/10.1016/j.apmr.2010.03.015

Barker-Collo, S. L. (2007). Depression and anxiety 3 months post stroke: prevalence and correlates. *Archives of Clinical Neuropsychology*, *22*(4), 519-531. doi:10.1016/j.acn.2007.03.002

Barman, A., Chatterjee, A., & Bhide, R. (2016). Cognitive impairment and rehabilitation strategies after traumatic brain injury. *Indian Journal of Psychological Medicine*, *38*(3), 172. 10.4103/0253-7176.183086

Bay, E., & Chan, R. R. (2018). Mindfulness-based versus health promotion group therapy after traumatic brain injury. *Journal of Psychosocial Nursing and Mental Health Services*, *57*(1), 26-33. https://doi.org/10.3928/02793695-20180924-03

Baylan, S., Haig, C., MacDonald, M., Stiles, C., Easto, J., Thomson, M., ... & Broomfield, N. M. (2020). Measuring the effects of listening for leisure on outcome after stroke (MELLO): A pilot randomized controlled trial of mindful music listening. *International Journal of Stroke*, *15*(2), 149-158. https://doi.org/10.1177/1747493019841250

Beck, A. T., Rush, J., Shaw, B., & Emery, G. (1979). Cognitive Therapy of Depression. New York: Guildford Press

Beck, A. & Steer, R. (1993). Beck Anxiety Inventory Manual. San Antonio: The Psychological Corporation, Harcourt Brace.

Beck, A. T., Steer, R. A., & Brown, G. K. (1996). Beck Depression Inventory-II (BDI-II). Toronto: The Psychological Harcourt Brace

Bedard, M., Felteau, M., Marshall, S., Cullen, N., Gibbons, C., Dubois, S., ... & Gainer, R. (2014). Mindfulness-based cognitive therapy reduces symptoms of depression in people with a traumatic brain injury: results from a randomized controlled trial. *The Journal of Head Trauma Rehabilitation*, *29*(4), E13-E22. *DOI: 10.1097/HTR.0b013e3182a615a0*

Bedard, M., Felteau, M., Marshall, S., Dubois, S., Gibbons, C., Klein, R., & Weaver, B. (2012). Mindfulness-based cognitive therapy: benefits in reducing depression following a traumatic brain injury. *Advances in Mind-Body Medicine*, *26*(1), 14-20. PMID: 22875545

Bedard, M., Felteau, M., Mazmanian, D., Fedyk, K., Klein, R., Richardson, J., et al. (2003). Pilot evaluation of a mindfulness-based intervention to improve quality of life among individuals who sustained traumatic brain injuries. *Disability and Rehabilitation, 25*(13), 722–731. DOI: 10.1080/0963828031000090489

Bedard, M., Mazmanian, D., Felteau, M., Fedyk, K., Gibbons, C., Mack, G., & Klein, R. (2005). A mindfulness-based intervention to improve quality of life among individuals who sustained traumatic brain injuries: one-year follow-Up. *The Journal of Cognitive Rehabilitation*, spring, 8–13

Berg, K., Wood-Dauphinee, S., & Williams, J. I. (1995). The Balance Scale: reliability assessment with elderly residents and patients with an acute stroke. *Scandinavian Journal of Rehabilitation Medicine*, *27*(1), 27-36.

Brott, T., Adams Jr, H. P., Olinger, C. P., Marler, J. R., Barsan, W. G., Biller, J., ... & Hertzberg, V. (1989). Measurements of acute cerebral infarction: a clinical examination scale. *Stroke*, *20*(7), 864-870.

Brown, K. W., & Ryan, R. M. (2003). The benefits of being present: mindfulness and its role in psychological well-being. *Journal of Personality and Social Psychology*, *84*(4), 822. DOI: 10.1037/0022-3514.84.4.822

Burton, L. J., & Tyson, S. (2015). Screening for mood disorders after stroke: a systematic review of psychometric properties and clinical utility. *Psychological Medicine*, *45*(1), 29-49. doi:10.1017/S0033291714000336

Cardaciotto, L., Herbert, J. D., Forman, E. M., Moitra, E., & Farrow, V. (2008). The assessment of present-moment awareness and acceptance: The Philadelphia Mindfulness Scale. *Assessment*, *15*(2), 204-223. DOI: 10.1177/1073191107311467

Carmody, J., & Baer, R. A. (2008). Relationships between mindfulness practice and levels of mindfulness, medical and psychological symptoms and well-being in a mindfulness-based stress reduction program. *Journal of Behavioral Medicine*, *31*(1), 23-33. OI 10.1007/s10865-007-9130-7

Cattelani, R., Zettin, M., & Zoccolotti, P. (2010). Rehabilitation treatments for adults with behavioral and psychosocial disorders following acquired brain injury: A systematic review. *Neuropsychology review*, *20*(1), 52-85. DOI 10.1007/s11065-009-9125-y

Chen, T., Zhang, B., Deng, Y., Fan, J. C., Zhang, L., & Song, F. (2019). Long-term unmet needs after stroke: systematic review of evidence from survey studies. *BMJ Open*, *9*(5), e028137. doi:10.1136/bmjopen-2018-028137

Cikajlo, I., Staba, U. C., Vrhovac, S., Larkin, F., & Roddy, M. (2017). A cloud-based virtual reality app for a novel telemindfulness service: rationale, design and feasibility evaluation. *JMIR Research Protocols*, *6*(6), e108. DOI: 10.2196/resprot.6849

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 385-396.

Cullen, B., Pownall, J., Cummings, J., Baylan, S., Broomfield, N., Haig, C., ... & Evans, J. J. (2018). Positive PsychoTherapy in ABI Rehab (PoPsTAR): A pilot randomised controlled trial. *Neuropsychological Rehabilitation*, *28*(1), 17-33. 10.1080/09602011.2015.1131722

D'Zurilla, T. J., Nezu, A. M., & Maydeu-Olivares, A. (2002). SPSI-R Social Problem Solving Inventory- Revised, TechnicalManual. Multi Health Systems Corporation https://doi.org/10.1037/t05068-000

Derogatis, L. R. (1994). SCL-90-R: Administration, scoring and procedures manual. Minneapolis, MN: National Computer Systems.

Dikmen, S. S., Machamer, J. E., Powell, J. M., & Temkin, N. R. (2003). Outcome 3 to 5 years after moderate to severe traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, *84*(10), 1449-1457. DOI:https://doi.org/10.1016/S0003-9993(03)00287-9

Duncan, F., Wu, S., & Mead, G. E. (2012). Frequency and natural history of fatigue after stroke: a systematic review of longitudinal studies. *Journal of Psychosomatic Research*, *73*(1), 18-27. https://doi.org/10.1016/j.jpsychores.2012.04.001

Dunning, D. L., Griffiths, K., Kuyken, W., Crane, C., Foulkes, L., Parker, J., & Dalgleish, T. (2019). Research Review: The effects of mindfulness-based interventions on cognition and mental health in children and adolescents–a meta-analysis of randomized controlled trials. *Journal of Child Psychology and Psychiatry*, *60*(3), 244-258. **https://doi.org/10.1111/jcpp.12980**

Evans, J. J. (2011). Positive psychology and brain injury rehabilitation. *Brain Impairment*, *12*(2), 117.

Garland, E., & Gaylord, S. (2009). Envisioning a future contemplative science of mindfulness: fruitful methods and new content for the next wave of research. *Complementary Health Practice Review*, 14(1), 3–9. doi:10.1177/1533210109333718.

Geneme, Z., Perera, A., Olson, D. M., & Stutzman, S. E. (2019) Piloting Test of a Mindfulness Meditation Intervention to Reduce Stress in Younger Stroke Patients *Journal of Neurological & Neurosurgical Nursing 8(2)*, 48-53.

Goldin, P. R., & Gross, J. J. (2010). Effects of mindfulness-based stress reduction (MBSR) on emotion regulation in social anxiety disorder. *Emotion*, *10*(1), 83. doi: 10.1037/a0018441

Gronwall, D. M. A. (1977). Paced auditory serial-addition task: a measure of recovery from concussion. *Perceptual and Motor Skills*, *44*(2), 367-373. https://doi.org/10.2466/pms.1977.44.2.367

Grossman, P., Kappos, L., Gensicke, H., D'Souza, M., Mohr, D. C., Penner, I. K., & Steiner, C. (2010). MS quality of life, depression, and fatigue improve after mindfulness training: a randomized trial. *Neurology*, *75*(13), 1141-1149. doi: 10.1212/WNL.0b013e3181f4d80d

Grossman, P., & Van Dam, N. T. (2011). Mindfulness, by any other name…: trials and tribulations of sati in western psychology and science. *Contemporary Buddhism*, *12*(1), 219-239. OI: 10.1080/14639947.2011.564841

Hackett, M.L., Pickles, K. (2014). Part 1: Frequency of Depression after stroke: an updated systematic review and meta-analysis of observational studies.*International Journal of Stroke* . 9,8. 1017-25. https://doi.org/10.1111/ijs.12357

Hill, K. (2008). Australian Clinical Guidelines for Acute Stroke Management 2007: Acute Stroke Guidelines Writing Subgroup on behalf of the National Stroke Foundation Clinical Guidelines for Acute Stroke Management Expert Working Group. *International Journal of Stroke*, *3*(2), 120-129.

Hilton, L., Hempel, S., Ewing, B. A., Apaydin, E., Xenakis, L., Newberry, S., ... & Maglione, M. A. (2017). Mindfulness meditation for chronic pain: systematic review and meta-analysis. *Annals of Behavioral Medicine*, *51*(2), 199-213. https://doi.org/10.1007/s12160-016-9844-2

Hofmann, S. G., Sawyer, A. T., Witt, A. A., & Oh, D. (2010). The effect of mindfulness-based therapy on anxiety and depression: A meta-analytic review. *Journal of Consulting and Clinical Psychology*, *78*(2), 169. https://doi.org/10.1037/a0018555

Holden, M. K., Gill, K. M., & Magliozzi, M. R. (1986). Gait assessment for neurologically impaired patients: standards for outcome assessment. *Physical Therapy*, *66*(10), 1530-1539. https://doi.org/10.1093/ptj/66.10.1530

Hunt, D., & Smith, J. A. (2004). The personal experience of carers of stroke survivors: an interpretative phenomenological analysis. *Disability and Rehabilitation*, *26*(16), 1000-1011. https://doi.org/10.1080/09638280410001702423

Huskisson, E. C. (1974). Measurement of pain. *The Lancet*, *304*(7889), 1127-1131.

Johansson, B., Bjuhr, H., & Rönnbäck, L. (2012). Mindfulness-based stress reduction (MBSR) improves long-term mental fatigue after stroke or traumatic brain injury. *Brain injury*, *26*(13-14), 1621-1628. https://doi.org/10.3109/02699052.2012.700082

Johansson, B., Bjuhr, H., & Rönnbäck, L. (2015). Evaluation of an advanced mindfulness program following a mindfulness-based stress reduction program for participants suffering from mental fatigue after acquired brain injury. *Mindfulness*, *6*(2), 227-233. DOI: 10.1007/s12671-013-0249-z

Johansson, B., Starmark, A., Berglund, P., Rödholm, M., & Rönnbäck, L. (2010). A self-assessment questionnaire for mental fatigue and related symptoms after neurological disorders and injuries. *Brain Injury*, *24*(1), 2-12. https://doi.org/10.3109/02699050903452961

Joo, H. M., Lee, S. J., Chung, Y. G., & Shin, I. Y. (2010). Effects of mindfulness based stress reduction program on depression, anxiety and stress in patients with aneurysmal subarachnoid hemorrhage. *Journal of Korean Neurosurgical Society*, *47*(5), 345. 10.3340/jkns.2010.47.5.345

Kabat-Zinn, J. (2003). Mindfulness-based interventions in context: Past, present and future. Clinical Psychology: *Science and Practice*, 10, 144-156. **https://doi.org/10.1093/clipsy.bpg016**

Kennedy, M. R., Coelho, C., Turkstra, L., Ylvisaker, M., Moore Sohlberg, M., Yorkston, K., Choo, H.H., & Kan, P. F. (2008). Intervention for executive functions after traumatic brain injury: A systematic review, meta-analysis and clinical recommendations. *Neuropsychological Rehabilitation*, *18*(3), 257-299. DOI:10.1080/09602010701748644

Kenuk, S., & Porter, H. R. (2017). The outcomes of mindfulness-based interventions for adults who have experienced a traumatic brain injury: A systematic review of the literature. *American Journal of Recreation Therapy*, *16*(2), 9-19. https://doi.org/10.5055/ajrt.2017.0129

Kitson, A. L., Dow, C., Calabrese, J. D., Locock, L., & Athlin, Å. M. (2013). Stroke survivors' experiences of the fundamentals of care: A qualitative analysis. *International Journal of Nursing Studies*, *50*(3), 392-403. https://doi.org/10.1016/j.ijnurstu.2012.09.017

Kneebone, I. I. (2016). A framework to support cognitive behavior therapy for emotional disorder after stroke. *Cognitive and Behavioral Practice*, *23*(1), 99-109. https://doi.org/10.1016/j.cbpra.2015.02.001

Kolcaba, K. (2010). The comfort line. Retrieved from http://www. thecomfortline.com/ on 21 June 2020

Kolcaba, K., Schirm, V., & Steiner, R. (2006). Effects of hand massage on comfort of nursing home residents. *Geriatric Nursing*, *27*(2), 85-91. https://doi.org/10.1016/j.gerinurse.2006.02.006

Kroenke, K., Spitzer, R., & Williams, J. (2001) The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16 (9), 606-613.

Kutlubaev, M. A., Barugh, A. J., & Mead, G. E. (2012). Fatigue after subarachnoid haemorrhage: a systematic review. *Journal of Psychosomatic Research*, *72*(4), 305-310. https://doi.org/10.1016/j.jpsychores.2011.12.008

Lau, M. A., Bishop, S. R., Segal, Z. V., Buis, T., Anderson, N. D., Carlson, L., ... & Devins, G. (2006). The Toronto mindfulness scale: Development and validation. *Journal of Clinical Psychology*, *62*(12), 1445-1467. DOI: 10.1002/jclp.20326

Lawrence, M., Booth, J., Mercer, S., & Crawford, E. (2013). A systematic review of the benefits of mindfulness-based interventions following transient ischemic attack and stroke. *International Journal of Stroke*, *8*(6), 465-474. https://doi.org/10.1111/ijs.12135

Lazaridou, A., Philbrook, P., & Tzika, A. A. (2013). Yoga and mindfulness as therapeutic interventions for stroke rehabilitation: a systematic review. *Evidence-Based Complementary and Alternative Medicine, 2013.* Doi:http://dx.doi.org/10.1155/2013/357108

Lima, S., Gago, M., Garrett, C., & Pereira, M. G. (2016). Medication adherence in Alzheimer's disease: The mediator role of mindfulness. *Archives of Gerontology and Geriatrics*, *67*, 92-97. http://dx.doi.org/10.1016/j.archger.2016.06.021

Lorig, K., Chastain, R. L., Ung, E., Shoor, S., & Holman, H. R. (1989). Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. *Arthritis & Rheumatism: Official Journal of the American College of Rheumatology*, *32*(1), 37-44.

Majumdar, S., & Morris, R. (2019). Brief group-based acceptance and commitment therapy for stroke survivors. *British Journal of Clinical Psychology*, *58*(1), 70-90. **https://doi.org/10.1111/bjc.12198**

Malec, J. F., & Lezak, M. D. (2003). *Manual for the Mayo-Portland Adaptability Inventory (MPAI-4)* (1st ed.).

McCabe, P., Lippert, C., Weiser, M., Hilditch, M., Hartridge, C., & Villamere, J. (2007). Community reintegration following acquired brain injury. *Brain Injury*, *21*(2), 231-257 https://doi.org/10.1080/02699050701201631

Mollayeva, T., Kendzerska, T., Mollayeva, S., Shapiro, C. M., Colantonio, A., & Cassidy, J. D. (2014). A systematic review of fatigue in patients with traumatic brain injury: the course, predictors and consequences. *Neuroscience & Biobehavioral Reviews*, *47*, 684-716. https://doi.org/10.1016/j.neubiorev.2014.10.024

Morone, N. E., Lynch, C. S., Greco, C. M., Tindle, H. A., & Weiner, D. K. (2008). “I felt like a new person.” The effects of mindfulness meditation on older adults with chronic pain: qualitative narrative analysis of diary entries. *The Journal of Pain*, *9*(9), 841-848.

Moustgaard, A., Bedard, M., & Felteau, M. (2007). Mindfulness-based cognitive therapy (MBCT) for individuals who had a stroke: results from a pilot study. *Journal of Cognitive Rehabilitation*, *25*, 1-10.

Nagano, K., Hori, H., & Muramatsu, K. (2015). A comparison of at-home walking and 10-meter walking test parameters of individuals with post-stroke hemiparesis. *Journal of Physical Therapy Science*, *27*(2), 357-359. https://doi.org/10.1589/jpts.27.35

Nampiaparampil, D. E. (2008). Prevalence of chronic pain after traumatic brain injury: a systematic review. *Jama*, *300*(6), 711-719. doi:10.1001/jama.300.6.71

National Institute Clinical Excellence (2011) Common mental health problems: ident cation and pathways to care. Clinical Guidance London https://www.nice.org.uk/guidance/cg123/resources/common-mental-health-problems-identification-and-pathways-to-care-pdf-35109448223173

Nejati, S., Esfahani, S. R., Rahmani, S., Afrookhteh, G., & Hoveida, S. (2016). The effect of group mindfulness-based stress reduction and consciousness yoga program on quality of life and fatigue severity in patients with MS. *Journal of Caring Sciences*, *5*(4), 325 doi: 10.15171/jcs.2016.034

Niraj, S., Wright, S., & Powell, T. (2020). A qualitative study exploring the experiences of mindfulness training in people with acquired brain injury. *Neuropsychological Rehabilitation*, *30*(4), 731-752. https://doi.org/10.1080/09602011.2018.1515086

O'Connell, B., Hanna, B., Penney, W., Pearce, J., Owen, M., & Warelow, P. (2001). Recovery after stroke: a qualitative perspective. *Journal of Quality in Clinical Practice*, *21*(4), 120-125. **https://doi.org/10.1046/j.1440-1762.2001.00426.x**

Patrick, D. L., Danis, M., Southerland, L. I., & Hong, G. (1988). Quality of life following intensive care. *Journal of General Internal Medicine*, *3*(3), 218-223.

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, *1*(3), 385-401.

Rafsten, L., Danielsson, A., & Sunnerhagen, K. S. (2018). Anxiety after stroke: a systematic review and meta-analysis. *Journal of Rehabilitation Medicine*, *50*(9), 769-778. doi: 10.2340/16501977-2384

Reibel, D. K., Greeson, J. M., Brainard, G. C., & Rosenzweig, S. (2001). Mindfulness-based stress reduction and health-related quality of life in a heterogeneous patient population. *General Hospital Psychiatry*, *23*(4), 183-192.

Reitan, R. M., & Wolfson, D. (1985). *The Halstead-Reitan neuropsychological test battery: Theory and clinical interpretation* (Vol. 4). Reitan Neuropsychology.

Sander, A. M., Fuchs, K. L., High Jr, W. M., Hall, K. M., Kreutzer, J. S., & Rosenthal, M. (1999). The Community Integration Questionnaire revisited: an assessment of factor structure and validity. *Archives of Physical Medicine and Rehabilitation*, *80*(10), 1303-1308.

Scholten, A. C., Haagsma, J. A., Cnossen, M. C., Olff, M., Van Beeck, E. F., & Polinder, S. (2016). Prevalence of and risk factors for anxiety and depressive disorders after traumatic brain injury: a systematic review. *Journal of Neurotrauma*, *33*(22), 1969-1994. https://doi.org/10.1089/neu.2015.4252

Segal, Z. V., Williams, J. M. G., & Teasdale, J. D. (2002). Mindfulness-based cognitive therapy for depression. A new approach to preventing relapse. New York: The Guilford Press.

Sirreyeh, R., Lawton, R., Gardner, P., Armitage, G. (2011) Reviewing studies with diverse designs: The development and evaluation of a new tool. *Journal of Evaluation in Clinical Practice*, 18(4):746-52. doi: 10.1111/j.1365-2753.2011.01662.x

Spielberger, C. D., Sydeman, S. J., Owen, A. E., & Marsh, B. J. (1999). *Measuring anxiety and anger with the State-Trait Anxiety Inventory (STAI) and the State-Trait Anger Expression Inventory (STAXI)*. Lawrence Erlbaum Associates Publishers.

Surawy, C., Roberts, J., & Silver, A. (2005). The effect of mindfulness training on mood and measures of fatigue, activity, and quality of life in patients with chronic fatigue syndrome on a hospital waiting list: a series of exploratory studies. *Behavioural and Cognitive Psychotherapy*, *33*(1), 103-109. DOI: https://doi-org.abc.cardiff.ac.uk/10.1017/S135246580400181X

Svanborg, P., & Åsberg, M. (1994). A new self-rating scale for depression and anxiety states based on the Comprehensive Psychopathological Rating Scale. *Acta*

Psychiatrica Scandinavica, *89*(1), 21-28. **https://doi.org/10.1111/j.1600-0447.1994.tb01480.x**

Tavee, J., Rensel, M., Planchon, S. M., Butler, R. S., & Stone, L. (2011). Effects of meditation on pain and quality of life in multiple sclerosis and peripheral neuropathy: a pilot study. *International Journal of MS Care*, *13*(4), 163-168.

Turner-Stokes, L., & MacWalter, R. (2005). Use of antidepressant medication following acquired brain injury: concise guidance. *Clinical Medicine*, *5*(3), 268 doi: 10.2340/16501977-0383

Virgili, M. (2015). Mindfulness-based interventions reduce psychological distress in working adults: a meta-analysis of intervention studies. *Mindfulness*, *6*(2), 326-337.

Visser, M. M., Heijenbrok-Kal, M. H., van 't Spijker, A., Lannoo, E., Busschbach, J. J., & Ribbers, G. M. (2016). Problem-solving therapy during outpatient stroke rehabilitation improves coping and health-related quality of life: randomized controlled trial. *Stroke*, *47*(1), 135-142. ttps://doi.org/10.1161/STROKEAHA.115.010961

Visted, E., Vøllestad, J., Nielsen, M. B., & Nielsen, G. H. (2015). The impact of group-based mindfulness training on self-reported mindfulness: a systematic review and meta-analysis. *Mindfulness*, *6*(3), 501-522. DOI 10.1007/s12671-014-0283-5

von Mensenkampff, B., Ward, M., Kelly, G., Cadogan, S., Fawsit, F., & Lowe, N. (2015). The value of normalization: Group therapy for individuals with brain injury. *Brain Injury*, *29*(11), 1292-1299. https://doi.org/10.3109/02699052.2015.1042407

Wallston, K. A., Strudler Wallston, B., & DeVellis, R. (1978). Development of the multidimensional health locus of control (MHLC) scales. *Health Education Monographs*, *6*(1), 160-170. https://doi.org/10.1177/109019817800600107

Wang, M., Liao, W., & Chen, X. (2019). Effects of a Short-term Mindfulness-Based Intervention on Comfort of Stroke Survivors Undergoing Inpatient

Rehabilitation. *Rehabilitation Nursing Journal*, *44*(2), 78-86. doi: 10.1097/rnj.0000000000000098

Wang, X., Li, J., Wang, C., & Lv, J. (2020). The effects of mindfulness-based intervention on quality of life and poststroke depression in patients with spontaneous intracerebral hemorrhage in China. *International Journal of Geriatric Psychiatry*, *35*(5), 572-580. **https://doi.org/10.1002/gps.5273**

Ware Jr, J. E., & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical Care*, 473-483. https://www.jstor.org/stable/3765916

Wechsler, D. (2004). Wechsler Adult Intelligence Scale–third edition, WAIS-III NI, Swedish version.

Weitzner, M. A., Meyers, C. A., Gelke, C. K., Byrne, K. S., Levin, V. A., & Cella, D. F. (1995). The Functional Assessment of Cancer Therapy (FACT) scale. Development of a brain subscale and revalidation of the general version (FACT-G) in patients with primary brain tumors. *Cancer*, *75*(5), 1151-1161. **https://doi.org/10.1002/1097-0142(19950301)75:5<1151::AID-CNCR2820750515>3.0.CO;2-Q**

Welsh Government (2017) 2017-2020 Stroke Delivery Plan: A Refreshed Delivery Plan for NHS Wales and its Partners: Cardiff

Williams, L. S., Weinberger, M., Harris, L. E., Clark, D. O., & Biller, J. (1999). Development of a stroke-specific quality of life scale. *Stroke*, *30*(7), 1362-1369. https://doi.org/10.1161/01.STR.30.7.1362

Wright, C. J., Zeeman, H., & Biezaitis, V. (2016). Holistic practice in traumatic brain injury rehabilitation: Perspectives of health practitioners. *PloS one*, *11*(6), e0156826. https://doi.org/10.1371/journal.pone.0156826

Zeidan, F., Johnson, S. K., Diamond, B. J., David, Z., & Goolkasian, P. (2010). Mindfulness meditation improves cognition: Evidence of brief mental training. *Consciousness and Cognition*, *19*(2), 597-605. https://doi.org/10.1016/j.concog.2010.03.014

Zhang, M. F., Wen, Y. S., Liu, W. Y., Peng, L. F., Wu, X. D., & Liu, Q. W. (2015). Effectiveness of mindfulness-based therapy for reducing anxiety and depression in patients with cancer: a meta-analysis. *Medicine*, *94*(45)

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Ppsychiatrica Scandinavica*, *67*(6), 361-370. . **https://doi.org/10.1111/j.1600-0447.1983.tb09716.x**

Paper 2 has been prepared for submission to the Journal of Neuropsychological Rehabilitation in accordance with the author guidelines (Appendix 1).

"It's made me think that I can continue and that I can move forward whereas before I was stuck": A Qualitative Exploration of Stroke Survivors Views and Experiences of Using '*Rebuilding Your Life After Stroke*' as a Rehabilitation Tool

Kathleen Williams and Professor Reg Morris
22nd June 2020

Word count (exc. References/figures/tables): 7425

Abstract

Introduction: The '*Rebuilding Your Life After Stroke'* book was developed by stroke clinicians, survivors and the Stroke Association to provide cost-effective guidance and therapy to promote adjustment after stroke. The aim of this research was to explore stroke survivors' views and experiences of the book.

Method: Data was collected using semi-structured interviews. Transcripts were analysed using Inductive Thematic Analysis (Braun & Clarke, 2012).

Findings: Three themes emerged: 1) Active Process: participants must actively engage in their rehabilitation, a process which is enhanced with professional support. 2) Tailor Made Intervention: The book allows survivors to assess and formulate their difficulties and provides choice and control over their rehabilitation, allowing the adoption of strategies to overcome the effects of stroke that would influence their ability to engage in rehabilitation. 3) Outcomes: Outcomes include an improved understanding, acceptance, the development of new skills and feelings of hope.

Discussion: Participants perceived *'Rebuilding Your Life After Stroke'* as an accessible, effective and reliable resource that can form the basis of an idiosyncratic intervention. The benefits of using the book include an increased awareness of the effect of stroke and greater levels of acceptance. The utility of the book as a rehabilitation tool can be enhanced with professional support.

Keywords: Stroke, Acceptance and Commitment Therapy, self-help book

Introduction

The annual prevalence of stroke in the United Kingdom (UK) is 100,000 (Stroke Association, 2018). Given the catastrophic consequences of stroke, national initiatives have focused on its early detection and intervention. This has been successful and survival rates have increased (Welsh Government, 2017). Current estimates state that there are 1.2 million stroke survivors in the UK, a figure that is expected to continue to rise over the next two decades (Stroke Association, 2018). Stroke has long term effects on survivors and is the the third highest cause of disability worldwide (World Health Organisation, 2012). Stroke is associated with significant healthcare costs (Jennum, Iversen, Ibsen,& Kjellberg, 2015).

Post stroke, survivors can experience a plethora of physical, cognitive and emotional difficulties including fatigue (Duncan, Wu & Mead, 2012), anxiety (Rafsten, Danielsson & Sunnerhagen, 2018), depression (Hackett & Pickles, 2014), and post-traumatic stress disorder (Edmondson, Richardson & Fausett, 2014). These psychological difficulties can exacerbate the residual memory and attention difficulties survivors experience as a consequence of stroke (Barker-Collo, 2007).

Evidence base

The National Institute for Clinical Excellence (NICE, 2011) recommend cognitive behavioural therapy (CBT) for the management of anxiety and depression in the general population. Stroke survivors' abilities to engage in psychological therapy delivered by traditional means can be impeded by their cognitive and communication problems (Kneebone, 2016). This poses a challenge for service delivery and subsequently many stroke survivors' needs are not met (Chen *et al.,* 2019).

Condition specific self-help books have increased the accessibility of psychological approaches so that they can be disseminated to wide audiences (Bergsma, 2008). As such, self-help books can be an early stage in the stepped-care model for the management of psychological difficulties (Bower & Gilbody, 2005) and book prescription schemes to disseminate these approaches have been developed across the UK.

Benefits of self help

The use of self-help books has been positively accepted by service users (Frude, 2011) and a recent meta-analysis outlined that when compared to face to face interventions, the effect of self-help was comparable in reducing symptoms of anxiety and depression (Cuijpers, Donker, Van Straten & Andersson, 2010). Moreover, from a service provider perspective, the development and dissemination of a condition-specific book has multiple advantages. Self-help interventions are inexpensive, can reach wide audiences and allow readers to engage in rehabilitation at their own pace, in their own environment and at any point of their rehabilitation trajectory, even when professional support has ceased (Jacobs & Mosco, 2008). Additionally, it is a flexible resource that can form the basis of bibliotherapy (Campbell & Smith, 2003) and guided self-help interventions (Cuijupers *et al*., 2010). Furthermore, a book is a permanent resource that can be accessed as and when required. This is advantageous in the context of common post stroke memory and attention difficulties.

At present there is no recommended self-help book for the management of psychological difficulties post stroke. As a result, stroke clinicians in Wales collaborated with stroke survivors and the Stroke Association to develop *'Rebuilding Your Life After Stroke'* to address the psychological difficulties experienced after stroke. The book is based on Acceptance and Commitment Therapy (ACT).

ACT

ACT is a trans-diagnostic approach (Hayes, 2004). The main focus of ACT is not to directly reduce distress but to facilitate acceptance of difficult situations and increase psychological flexibility. A recent study outlined that four, two-hour ACT-based didactic group sessions resulted in increased self-rated health status and enhanced levels of hopefulness for stroke survivors. Moreover, compared to controls, significantly more participants in the ACT group reached clinically significant change of depression (Majumdar & Morris, 2019). The group was also perceived to support stroke survivors' adjustment to their residual stroke symptoms or disability (Large, Samuel & Morris, 2019).

Usability

Concerns have been expressed in relation to the usability of self-help resources. Martinez, Whitfield, Dafters & Williams (2008) assessed the readability of commonly recommended self-help books for the management of depression in the general population, reporting that a significant proportion of the books were written to a level that was above users’ reading abilities. As a result, a substantial amount of the population would be unable to use the book for its intended purpose. Moreover, additional adjustments may be required for specific populations, including stroke survivors. A systematic review completed by Matcham, Rayner, Hutton, Monk, Steel & Hotopf (2014) outlined that as a result of their cognitive deficits, stroke survivors respond poorly to generically written information as they have difficulty interpreting and retaining information. From this it can be postulated that stroke survivors may require concrete stroke-specific examples, shorter sentences, simple language, larger print etc. All these adjustments were taken into consideration by the professional-service user collaboration when developing the book.

The aim of this study was to explore stroke survivors’ views and experiences of using a book called ‘*Rebuilding Your Life After Stroke*’. To explore if the book was perceived to achieve its aims and whether it was experienced as accessible and therapeutic by stroke survivors.

Methodology

Design and theoretical background

The methods employed Inductive Thematic Analysis of semi-structured interviews completed with stroke survivors. The purpose of the interviews was to explore their views and experiences of using the *‘Rebuilding Your Life After Stroke’* book. Inductive Thematic Analysis is an accessible and flexible form of analysis (Braun & Clarke, 2012) and the inductive approach of the method allows the researcher to systematically identify patterns of meaning derived from participants’ responses and was considered an appropriate approach as it would provide an in-depth understanding of participants’ views and experiences of using the book.

Several other qualitative methodologies were considered for this study. Interpretative Phenomenological Analysis (IPA, Smith & Osborn, 2003) is concerned with the meaning that participants attribute to a given phenomenon. Although this was part of the aim of the current study, adopting IPA as an approach may have overlooked any external (social, cultural) influences that might affect participants’ engagement with the book or their experience of using it. As a result, IPA was not deemed appropriate for this study. Grounded Theory (Glaser & Strauss, 1967) was also rejected as an approach as it seeks to develop a theory based on theoretical sampling. However, the aim of the current study was to explore participants’ views and experiences of a new book and it did not seek to develop a theory at this stage.

Sample and sampling

Participants were recruited by one of four methods:

1. By clinicians working in NHS University Health Boards (UHB) in South Wales.
2. By professionals employed by a charitable organisation in Wales.
3. By a trainee clinical psychologist who had completed a supported bibliotherapy intervention with participants using the book.
4. The Welsh branch of the Stroke Association holds an annual conference in which copies of the book are made available to stroke survivors. At the conference, brief information was given about this research and individuals who collected a copy of the book were informed that if they would like to

receive more information about the research then they could leave their contact details for the researcher to contact them.

In all the aforementioned methods of recruitment, the researcher distributed participant information packs to each prospective participant that contained; a consent to be contacted by the researcher form, a study consent form, a participant information sheet, a participant panel invitation (Appendices 6-9) and a self-addressed envelope (for participants to return completed consent forms and participant panel invitation).

For methods 1-3, participants were selected by professionals who were guided by the inclusion/exclusion criteria outlined in Table 1. For condition 4, participant eligibility was assessed when they were contacted by the researcher to determine whether they wanted more information about the study.

Inclusion criteria	**Exclusion Criteria**
• A stroke survivor who has experience of using the *'Rebuilding Your Life After stroke'* book for at least one month. • They are 18 years or over. • They have no significant cognitive impairment or communication difficulty that would make engaging in the study difficult or stop them from giving informed consent.	Individuals will be excluded from the study if they have one of the following: • Any other form of acquired brain injury (e.g. brain tumours, traumatic brain injury etc.). • A cognitive or language impairment that would prevent them from answering the questions asked. • Those experiencing severe psychotic symptoms.

Table 1: Summary of exclusion and inclusion criteria

Ethical considerations

Ethical approval

This study was approved by Health and Care Research Wales (HCRW, Appendix 10) and was also given Research and Development approval by three NHS UHB in

Wales, in accordance with their Research and Development policy. The study was sponsored by Cardiff University (Appendix 11).

Informed consent

Written informed consent was gained from all participants. A participant information sheet was developed to include information about the study (aims and objectives, process, etc.) and was issued to participants. Participants were invited to read the information and were given the opportunity to discuss their queries and ask for clarification, if needed. Following this, if they wanted to participate in the study, they were asked to complete the written consent form. Once the researcher received the completed consent form, participants were contacted to arrange a convenient time for the interviews to be conducted. At the end of the study participants were provided with a debrief letter (Appendix 12).

Confidentiality

In accordance with General Data Protection Regulation Law (2018) and Health Care Professionals Council (HCPC) code of conduct (2012), pseudonyms were allocated to participants to safeguard their identity. Interviews were recorded and stored on an encrypted USB device, interviews were transcribed by the researcher or an individual employed by an external agency, with sufficient confidentiality provisions. Audio recordings will be destroyed one year after study completion and interview transcripts will be securely stored in a locked cabinet and destroyed five years after study completion.

Materials

'Rebuilding Your Life after Stroke' is a comprehensive resource that can aid survivors' recovery from the psychological aspects of stroke. The book is accessible to readers as it has clear print, illustrations to support meaning making and quotes from stroke survivors. It is 232 pages in length and is Canadian bound so that it can be used with one hand for readers with physical difficulties after their stroke. There are four key sections to the book. Section one is an introduction which provides a rational for its development (i.e. that there are high levels of unmet needs in stroke survivors) and the use of ACT as an approach. Section two outlines the psychological and cognitive changes that can occur as a result of a stroke. Section

three describes strategies to reduce these difficulties using neuropsychological approaches for common problems and ACT for irreversible problems. Also contained within this section are written and audio-visual exercises to acquire skills in techniques such as mindfulness. Section four seeks to integrate the aforementioned sections to support survivors to continue and maintain their progress.

Data collection and analysis

Data collection and analysis occurred concurrently. Two interviews were completed in participants' homes upon request and the remaining 11 were completed over the telephone. Duration of interviews ranged from 21 to 86 minutes, with an average length of 38 minutes. A demographic questionnaire and semi-structured interview schedule (Appendices 13 and 14) were developed between the researcher and her academic supervisor. The semi-structured interview schedule was used to act as a flexible guide in conducting the interviews which allowed participants to discuss issues that were important but not included in the schedule. Interviews were audio-recorded and transcribed. The researcher made notes and discussed the process of data collection and analysis with her supervisor, which also provided an opportunity for feedback and reflection. The researcher adhered to the six stages of Inductive Thematic Analysis as prescribed by Braun & Clarke (2012), (see Appendix 15).

Ensuring rigour in qualitative research

The quality of qualitative research is often criticised due to its perceived lack of rigour. Therefore, the researcher adhered to the systematic approach prescribed by Braun & Clarke (2012) and O'Brien & Harris (2014) to ensure quality, especially in relation to reflexivity. Smith (2007) outlines that the researcher has an active role in qualitative research and is part of the construction of meaning. For this study the researcher engaged with their subjectivity by keeping a research diary, reading qualitative texts and discussing her position as a researcher in supervision. In addition, upon recruitment, participants were invited to be part of a panel which would review and comment on the findings of the research once complete. The results from the Thematic Analysis were emailed to these participants and feedback was invited, modifications would be made to the results based upon this feedback. Three out of five participants replied to the researcher's request for feedback. Participants were content with the findings and no amendments were required.

Results

Data saturation was reached after the completion of 13 interviews. Data saturation is a point of analysis whereby no new information is gleaned from the data (Guest, Bunce & Johnson, 2006). Therefore, 13 participants were recruited to this study, eight of whom were male and five females. A summary of participant demographic information is provided in Table 2. Two participants were recruited from NHS Wales, five participants were recruited from a Welsh stroke charity, (three from a stroke conference, two were recommended by professionals employed by the charity) and the remaining five participants had participated in supported bilbliotherapy research (see appendix 16 for details), one participant was recruited to the study on an opportunistic basis. A summary of sources of participant recruitment is provided in Table 3.

Gender	Female: 5 Male 8	**Age (Years)**	32-73 Mean: 54.08
Duration after stroke	>1 year: 2 > 2 years: 3 >3 years: 0 >4 years: 5 < 4 years: 2 Unknown: 1	**Living Arrangements**	Alone: 2 With others: 8 Carer: 3
Employment status:	Employed: 6 Unemployed: 5 Retired: 2	Psychological difficulties after stroke:	Yes: 12 No: 1

Table 2: Summary of demographic information

Welsh stroke charity	Bibliotherapy research	NHS	Other
Daniel	Elizabeth	Luke	Alex
Darren	Rachel	Heather	
Helen	Peter		
Natasha	Liam		
James	Joshua		

Table 3: Sources of participant recruitment

12 out of 13 participants reported post stroke psychological difficulties (e.g. anxiety, depression) and all participants reported experiencing a range of comorbid residual difficulties (e.g. limb weakness, fatigue, difficulty managing emotions and cognitive impairment). All participants were asked to name the location and type of stroke that they had sustained, this knowledge was limited. For many, knowing the site or type of stroke was not necessary for their rehabilitation. However, for participants who experienced a less common type or location of stroke they endeavoured to acquire information about the function of the different parts of the brain.

Results of Thematic Analysis

Analysis yielded three overarching themes. Table 4 outlines these themes and their associated sub-themes.

Active Process	Tailor Made Intervention	Outcomes
Requires motivation Demanding Requires support from others Effective and reliable	Choice and control Adoption of strategies to overcome difficulties	Improved understanding Acceptance Hope Development of new skills Feelings of coincidence

Table 4: The three overarching themes and associated subthemes

Theme one: Active Process

Participants are key stakeholders in their own rehabilitation and for this to occur they need to be motivated, resilient to cope with its demands and able to persevere with the challenges it engenders. This process is enhanced with professional support.

Requires motivation

Participants' motivation to adjust to life after their stroke was apparent before they procured a copy of the book. Many participants were autonomous in finding opportunities to receive support and gain information about stroke that they could apply to their experience. This included attending public events, such as conferences:

> *"I was at the seminar…I always try to pick up anything that can benefit me. The lady was there and basically offered me the book to read." (*Darren)

Searching the internet:

> *"Looking on the Web about things, but nothing as in-depth as in this book."* (Rachel)

Or participating in research:

> "*I said 'yes, yes, I'll do anything' as I was that low at the time."* (Joshua)

Demanding

Once participants secured a copy of the book they discovered that the process of reading the book was demanding, both physically and emotionally. Which they felt halted their progress. Participants outlined that initially having the book was overwhelming and they were anxious that they would not be able to use it appropriately:

> *"Well, it looks like a text book, it looks like something you give an 'A' level student and when I first saw it I thought "Oh my God, really" – it is going to be a serious commitment isn't it, if you have got all this to read."* (Liam)

And some sections were more challenging to go through than others:

> (section 1) *"I remember reading that and thinking this is difficult to wade through."* (Luke)

The process of reading the book was difficult and was affected by the effects of their stroke, such as fatigue:

> *"You know that you have to do something about it and you want to do something about it, but you just haven't got the energy."* (Joshua)

Other participants outlined that when they did have the energy and engaged with the content of the book, they felt frustrated because they couldn't absorb the information due to the residual effects of their stroke, such as limited attention:

> *"It would take time to go in."* (Helen)

Or they would have difficulty remembering what they had read:

> *"I cannot always remember what I had for breakfast."'* (Darren)

Another participant described his stroke as being sudden and wanted his rehabilitation to follow the same trajectory, but this was not the case. Moreover, when he completed the exercises the oscillating nature of adjustment engendered feelings of hopelessness:

> (the exercises) *"were ok to a certain extent but sometimes I didn't feel like I could do them if you know what I mean [sic] and can I say, you just give up. You didn't feel like it was working and (when it did) it didn't work quick enough for me."* (Joshua)

For others, working through the book was emotionally challenging as it facilitated reflection of their difficulties, limitations and aspects of their post-stroke life which they avoided thinking about. This influenced their engagement with the material contained in the book:

> *"The difficulty was that it brought up a lot of stuff that you hadn't thought about. It sort of makes you shy away from it again because it is not a nice feeling so you don't keep doing it."* (Elizabeth)

Furthermore, participants outlined that when the content of the book emotionally resonated, this made the process more difficult:

> *"Some that touched the nerves were more tricky…I had to force myself to do these things. I didn't want to do them but I knew that if I didn't do anything I would just be stuck around at home not doing anything and not helping myself."* (Peter)

This was echoed by another participant and he recommended that further editions of the book should outline these challenges and encourage survivors to read the book and to complete the exercises. Viewing these challenges are short-lived and a necessary part of achieving their goals:

> *"Say something in big and large that says 'Look, this will be difficult for you to work through but if you do you will get this sort of benefit' – something that makes it very clear that there is a definite quid pro quo for doing it."* (Liam)

Requires support from others

Participants spoke about the benefit of having a professional available to support and guide them in the process, this was either as part of the bibliotherapy trial:

> *"We talked about various things and then (staff name) would point me to the various sections of the book that would be helpful." (*Elizabeth)

Or as part of inpatient psychological rehabilitation:

> *"Yes I did a few (exercises) because (staff name) did a few with me…* one of *them that I found the most useful was thought challenging…because I was dealing with like [sic] lots of negative thoughts and health anxiety."* (Heather)

Professional involvement also motivated participants to complete agreed activities:

> *"I didn't want to get into trouble with (staff name) for not doing them."* (Peter)
>
> *"I suppose it didn't matter really whether I did it or not, but it does make you, well, [sic] do things."* (Rachel)

Participants also valued the collaborative approach as it had additional benefits, this enhanced the intervention:

> *"They will motivate you to do the difficult things, get you to elaborate and are able to explain in more depth than the book goes."* (Peter)

> *"The sessions with (staff name) helped as they kind of cemented it."* (Elizabeth)

Heather had brief support from an assistant psychologist when she was an inpatient, since professional input was limited, Heather chose what exercises she did or did not complete, potentially missing out on what could have been beneficial:

> *"I think there were lots of them in there and I kind of only did the ones that (staff name) guided me towards. Because I think I was kind of in a little bit of denial even then about wanting to approach this subject altogether, I just wanted to block out that it had happened."* (Heather)

It also supported participants in making the process manageable and less anxiety provoking:

> *"It wasn't that bad actually, once it was broken into healthy chunks by (staff name)."* (Liam)

Effective and reliable

Participants described the book as being an effective and reliable resource. As a result, they were confident that if they needed support or techniques in the future then they could be easily accessed:

> *"If I am feeling a bit on the downside I can pick it up. That's what happens – you get a bit down and depressed and just pull yourself out of it." (*Daniel)

> *"I always know they (exercises) are there to go back to."* (Rachel)

This in turn allows them to be autonomous in the future:

> *"Instead of asking somebody you can just refer to the book. It is a good reference guide if you like."* (Luke)

In addition, participants are confident that the book is effective and reliable and subsequently have recommend it to others, such as family, as this would help relatives understand what the survivor was experiencing:

> *"I occasionally am frustrated and tired and fatigued. Getting my wife to read that bit of the book was hugely helpful because it helped her to understand that that is why I am sometimes a real prat, and that was a great, great help."* (Darren)

> *"I folded down pages for my husband to read, pages like the fatigue section because he wanted to try and understand what was going on."* (Heather)

Participants have also recommended the book to other stroke survivors as part of their volunteer roles within a charity:

> *"We are giving the book out to stroke survivors, it is that good*." (James)

Participants outlined the process of obtaining a copy of the book, and this was attributed to chance. Given its effectiveness and reliability, survivors advocate that copies of the book should be made more freely available.

> *"One thing I would say is… this book to be put on a shelf unit, on a wall somewhere stroke survivors could read it."* (Joshua)

Theme two: Tailor made intervention

The book is a therapeutic tool which facilitates the development of an idiosyncratic intervention which is specific to participants' interests and perceived difficulties. The book also provides the opportunity for participants to adopt strategies to circumvent difficulties which may have limited their engagement.

Choice and control

Participants outlined that the book offered them choice and control in relation to their rehabilitation. For some, it gave them the opportunity to be thorough in their approach and gain an overall knowledge of stroke and its effects:

> *"I've used every part of the book. I read it from front to back several times to be honest." (*Daniel)

Others incorporated reading the book into their lifestyle alongside completing activities of daily living:

> *"It started off pretty much a page to page thing and it simply got broken up by other things needing doing like taking the dogs out, but it was kept by the side of me for a long time until I had worked through it."* (Darren)

Participants could choose the sections to read, based on their assessment of their difficulties and what interested them. Consequently, information that wasn't applicable was discarded:

> *"The other stuff you will either dust over a bit or perhaps even leave to one side."* (Darren)

For participants with an awareness of their difficulties, understanding and using the relevant sections of the book can be a successful therapeutic tool. However, confusion about the purpose and function of the exercises in the book and participants being unable to distinguish the difference from other exercises they had completed, could have provided a rationale for participants' non-completion:

> *"I didn't do the exercises 'cos I was doing things with the clinical neuropsychologist in the hospital."* (James)
>
> *"I did lots of exercises with the MDT in the hospital, I did lots there… But out of the book, no I didn't."* (Liam)

Moreover, when participants had little awareness of the theoretical underpinning of the exercises contained within the book, this would be a justification for non-completion:

> *"noting, noticing…I didn't, I thought that was b***cks" (Alex)*

Adopting strategies to overcome difficulties

The book also gave participants the opportunity to make adjustments to their approach to reading in order to overcome the difficulties they experienced as a result of their stroke:

> *"I tend to read things two or three times…two or three paragraphs and then go back and forth and make sure that…I've got it" (*Alex)

> *"Actually I went right through the book and I done every section. I tried to do one section a week. I took it all nice and slow, like* [*sic*]. *I would read a page and if it didn't sink in I would re-read it and go back to it the next day until it got through that way."* (Joshua)

Theme three: Outcomes

Participants reported positive outcomes such as an improved understanding of stroke, growth, acceptance, the facilitation of new skills and hope.

Improved understanding

Prior to their stroke, participants outlined that they had little knowledge of stroke and conceptualised it as something that affected people later in life and that its consequences are fatal:

> *"Something that old people had and most of them did not survive it."* (Luke)

After reading the book, attending groups and conferences, participants conceptualised the effects of stroke as part of a spectrum that affects people in different ways:

> *“Each stroke survivor is different.”* (James)

Whilst reading the book participants identified their difficulties as they were akin to the examples presented in the book:

> *“I’ve never suffered with it (anxiety and depression) and I just didn’t know what I was experiencing, and then when I read about these things I thought ‘Well, that’s me, all over’ so, yes, it was an eye opener.”* (Joshua)

This was beneficial as it normalised participants’ experiences and reassured them that they were not alone in the process of adjusting after stroke:

> *“(it) explained to me what I was going through and that what I was feeling was normal.”* (Luke)

Which in turn helped participants feel less isolated:

> “*It makes you feel like you are not alone.”* (Heather)

Acceptance

Participants described how the book had helped to facilitate the acceptance of their post stroke self and abilities:

> *“It has helped me find the new me…and a life with It, rather than being stressful’*.” (Peter)

> *“I might never be 100% again so it is getting to accept it, which I never thought I would.”* (Rachel)

In addition to accepting what had changed, working through the book and completing exercises led participants to reflect on the aspects of themselves that had remained the same:

> *"I found it quite cathartic actually to sit down and think about what your values are and those are still the same."* (Peter)

Giving hope

One participant outlined the difference the book has made to his life and it has given him hope for the future:

> *"It's made me think that I can continue and that I can move forward whereas before I was stuck… I was stuck in a world of my own, whereas I read different people's stories and I realise that it is a big world out there and you are not on your own."* (Joshua)

Development of new skills

Reading the book and completing the exercises allowed participants to adopt strategies and develop skills to help manage their difficulties when needed:

> "*It is almost as if you have been given a different set of skills that you can call on when you need them."* (Elizabeth)
>
> *"It's easy enough to put into practice, five minutes or so to put you back on track."* (Rachel)

Feelings of coincidence

Participants discussed the wealth of positive outcomes associated with reading the book and attributed sourcing a copy to chance, as without it their experience would have been different. Therefore, they advocated that the book should be widely available:

> *"One thing I would say is, if this book was to be put on a shelf unit, on a wall somewhere stroke survivors could read it."* (Joshua)

Another participant outlined that the book should be readily available on the inpatient ward, so that the stroke survivor or their relatives have the information available and can decide whether they want to learn more:

“So maybe having a copy, in the room, or being offered it would have perhaps been one way that it might have been useful.” (Heather)

Discussion

As a result of the methodology used in this research, the findings presented the perspectives and experiences of the participants interviewed in this study and therefore may not generalise to those outside the sample. The sample was diverse in relation to age, amount of time since their stroke and whether they read the book with or without support. 39% of the sample read the book with support as part of a bobliotherapy study, 8% of the sample had brief support from an assistant psychologist when they were an inpatient on a rehabilitation ward and the remaining 53% of the sample read the book alone. Consequently, the findings of this research are indicative of how the book was experienced and used and may inform further editions of the book and its use within a clinical setting.

Theme one: Active Process

Participants were motivated to engage in their rehabilitation. Eng, Brauer, Kuys, Lord & Hayward (2014) describe how motivation is a result of internal or external factors. Participants in this study outlined their endeavours to facilitate adjustment to their post-stroke presentation, this was gained through any means available to them, which was often at the point of desperation, before crisis occurred. Whilst this could be an internal factor, there could be an interaction between internal and external factors, more specifically, the lack of an external mechanism to obtain support which then stimulated internal factors to source the book and engage in recovery. This motivation did not cease when participants had procured a copy of the book. Dixon, Thornton & Young (2007) report that inpatients (including stroke survivors) on a neurological ward found the rehabilitation process difficult and valued support from staff. The findings in this study echo those of Dixon *et al.* (2007) as participants outlined that their engagement with the content of the book was integral to rehabilitation. Moreover, participants articulated the times where their motivation would subside and they would require support and guidance from healthcare professionals. Support was considered especially advantageous when the content was emotive or the residual effects of stroke (depression, fatigue) had an adverse effect on their motivation and ability to read the book. This is congruent with the previous research completed by Flinn & Stube (2010), which described the effect of fatigue on stroke survivor's ability to complete activities such as reading. Participants also valued the support of a healthcare professional to identify appropriate exercises and describe the book's content.

The book was well received by participants which is consistent with previous research (Frude, 2011). Moreover, participants in this study also stated that the book was an effective and reliable source and they had confidence that it would be helpful in the future, if needed. Participants also outlined that they often used the book to explain their difficulties to their family members. From this it can be deduced that there is lack information available to carers which is congruent with previous research (Eames, Hoffmann, Worrall & Read, 2010).

Theme two: Tailor made intervention

The book acknowledges the heterogeneous effects of stroke and the subsequent needs of survivors. Participants seized any opportunity to gain information about stroke, as reflected in their attendance at conferences and participation in research, thus highlighting their need for information, which has been previously documented (Peoples, Satink Steultjens, 2011). Making information about stroke available to survivors allowed them to make an informed choice about the content of their rehabilitation, which can be understood as being 'tailor made' (formulation driven). This is consistent with the recommendations provided in the NICE guidance (DOH, 2013) and is in accordance with stroke survivors wishes and needs so that interventions are individualised (Clark, Bennett, Ward & Jones, 2018). Matcham *et al.* (2014) reported that stroke survivors' cognitive deficits limit their ability to interpret and retain written information. This was outlined by participants in this study but what this research adds is an insight into the strategies that participants adopt to overcome their difficulties in assimilating information as a result of their stroke. For example, they could re-read sections if they had forgotten or alter the pace of working through the book if they became fatigued. This is a strength of using a book as a therapeutic approach which is not inherent in face to face methods e.g. group therapy.

A wealth of benefits can be derived from stroke survivors having choice and control in their rehabilitation, these include improved satisfaction (Wain, Kneebone & Billings, 2008). Additionally, feelings of choice and control are integral to the concept of self-efficacy (Bandura, 1982) which in turn results in improvements in quality of life and perceived health status (Jones & Riazi, 2011). The book gave participants choice and control which then allowed them to assess and formulate their own difficulties and choose the strategies that they felt would seek to ameliorate these challenges. However, if used independently, the utility of the book as an intervention is dependent on participants' assessment and formulation of their difficulties. Smeets, Vink, Ponds, Winkens & van Heugten (2017) state that after an acquired brain injury (including stroke) survivors' self-awareness can be limited. Therefore, if stroke survivors do not identify their needs appropriately, they will remain unmet. Additionally, unless specified, participants may not have a full awareness of the theoretical underpinning and therefore the function of the exercises contained within the book. Participants viewed some exercises and more formal assessments such as neuropsychological tests to have the same function, which is incorrect. This was a reason for non-completion. Therefore, without adequate self-awareness or knowledge of the purpose or function of the exercises contained in the book, the full benefit of the book might not have been achieved. This supports previous research by Maclean, Pound, Wolfe & Rudd (2000) who outline that stroke survivors had higher motivation and were more likely to engage in their inpatient rehabilitation when they understood the process.

Theme three: Outcomes

Overall, the book as a therapeutic tool was received well by participants. Reading the book resulted in several positive effects. A key outcome for participants was an improved understanding of stroke and its effects, as prior to reading the book participants felt that their knowledge was limited. Martinez *et al*. (2008) state that the readability of a book is a result of the interaction between the individuals' prior knowledge and the features of the book that would allow them to access the information in the text. Prior to reading the book, participants stated that they had very little knowledge of stroke which was greatly improved afterwards. Therefore, the features of the book must have been sufficient for participants to understand and therefore it can be postulated that the participants in this study found the book to be readable. This could be a result of the book being co-produced with stroke survivors and would support existing research as Crawford *et al.* (2002) report that the inclusion of service users leads to improved sources of information for those who need them.

In this study, participants outlined that they identified with the examples of other stroke survivors' experiences contained within the quotes in the book, which in turn normalised their own experiences. Cameron (2018) stated that through meeting others, social identification leads to improved self-efficacy and improved mental and physical health outcomes. von Mensenkampff *et al*. (2015) reports that membership of therapeutic groups normalises experiences for individuals with brain injuries and Peoples *et al. (*2011) state that comparing oneself to others facilitates empowerment. Therefore, it can be suggested that the book is a mechanism that engenders the benefits of social identification and comparison that occurs virtually without physically meeting others. This can be particularly advantageous when considering 'hard to reach' individuals who may not be able to identify with others by conventional methods. Participants reflected on the process of acceptance of their difficulties and acquired new skills as a result of reading the book and discussed the advantages of using these skills (e.g. mindfulness, acceptance, thought challenges). This is consistent with previous research outlining that ACT can lead to acceptance of residual difficulties after stroke (Large, Samuel & Morris, 2019; Graham, Gouick, Krahe & Gillanders, 2016).

Participants who read the book with support spoke more in depth about the psychological concepts and exercises than those who used it alone. There could be several reasons why this was the case. Firstly, participants who read the book as part of the bibliotherapy trial did so as they were experiencing psychological distress as a result of their stroke, and therefore would have found the therapeutic techniques helpful to ameliorate these difficulties, which is congruent with the findings of Majumdar & Morris 2019). However, the difference may be a result of the need for support for more abstract constructs and the benefit of reading the book with a healthcare professional. This finding is similar to previous research completed by Fledderus, Bohlmeijer, Pieterse & Schreurs (2012). In this Randomised Controlled Trial (RCT) participants were given an ACT book and allocated to one of three groups, guided self-help (GSH) with enhanced support, GSH with minimal support and the control group read the book alone. Compared to controls, participants in both the enhanced and minimal support GSH condition groups had reduced rates of depression, anxiety and fatigue and experienced higher levels of positive mental health and mindfulness. There was no significant difference between the GSH groups. This supports the results of this study which found that even minimal support (e.g. support on an inpatient ward) has greater benefits than reading the book alone.

Throughout the interviews participants spoke about their journey of recovery. They discussed the shock they experienced when finding out that they had a stroke, their motivation to gain information about stroke, their feelings of hopelessness and the process of rehabilitation and adjustment engendered by the book. This created feelings of hope for the future which is consistent with previous research (Majumdar & Morris, 2019).

Strengths and limitations of the research

As the *'Rebuilding Your Life After Stroke'* book was the first self-help text of its kind, this research adds to the evidence base in relation to the usability and feasibility of this type of therapeutic tool for stroke survivors. This in turn will inform the development of resources and service provision in the future. This study also fulfils criteria for good quality research, data saturation was reached and analysis was rigorous and informed by well established, robust guidance (Braun & Clarke, 2012). The themes were also authenticated by participants.

Despite these strengths, some limitations are present. Firstly, this project was based on participants' recollections of using the book. As a result, some participants gave limited detail about the approaches used in the book and the majority of the interviewees who used the book alone did not attempt the exercises and therefore could not give feedback on them. Moreover, individuals with speech and communication difficulties were excluded so the views and experiences of participants with aphasia were not captured. Moreover, participants were all community dwelling who lived independently or with family members and most were returning to a form of paid employment or participating in meaningful activities, such as volunteering or membership of social/leisure groups. All of which are components of the 'formula for happiness' (Selligman, 2004) and have a positive effect on wellbeing and therefore psychological adjustment after stroke. Future research would benefit from the recruitment of participants whose access to these components may be limited (e.g. from residential homes) to establish the wider effect of the book on wellbeing and adjustment.

In addition, participants were volunteers and most were offered the book and given information about the study by professionals in the NHS or third sector who may have contributed to the book's development. As result, social desirability bias may have occurred and only participants with positive experiences may have consented to take part in the research. Furthermore, this study was completed at a time of austerity, when resources were limited. The majority of participants interviewed were aware of the scarcity of support available and this could have resulted in the inflation of the positive effect of the book as a therapeutic tool, since the alternative was no intervention at all. Also, an additional challenge of completing research with stroke survivors is the residual effects of stroke (memory difficulties, executive dysfunction, poor concentration, deterioration in mood and fatigue). Although the researcher did all that was possible to safeguard against these residual effects, they may have affected the quality of data collected during interviews.

Clinical Implications

'Rebuilding Your Life After Stroke' as a self-help resource

In this study, participants perceived '*Rebuilding Your Life After Stroke'* book as an effective and reliable resource. Findings from this research suggest that the book is pitched at the right level and is usable. Additionally, the book gave participants choice and control over their rehabilitation and resulted in the development of a tailor made intervention. Therefore, it could be used as a clinical resource for stroke survivors in NHS services.

'Rebuilding Your Life After Stroke' as the basis for guided self-help/ bibliotherapy

'*Rebuilding Your Life After Stroke'* is a flexible resource, it has utility as a self-help book and can form the basis of guided self-help or bibliotherapy. Which is also in line with previous research (Campbell & Smith, 2003). Participants who were supported by a professional outline the advantages of the support which in turn further enhanced their experience the book and benefits derived from reading it. The provision of brief professional support to introduce the content of the book and orientate survivors to relevant sections would further improve its utility as a rehabilitation tool.

The use of ‘*Rebuilding Your Life After Stroke’* in the NHS and third sector Organisations

Participants in this study reported that the book was an effective and reliable resource and findings suggest that the book has usability. As a result, professionals in the third sector organisations and NHS can confidently and readily disseminate the book to individuals who they feel would benefit. Clinicians can use the book as a rehabilitation tool for stroke survivors accessing stroke services in the NHS. However, it would be recommended for staff to exercise their clinical judgment in relation to the amount of support the stroke survivor may need obtain maximum benefit from the book.

ACT

Stroke survivors feel that ACT facilitates acceptance of their difficulties and adjustment to their post-stroke life (Large, Samuel & Morris, 2019). ‘*Rebuilding Your Life After Stroke’* is a resource that can disseminate ACT theory and exercises in an accessible, effective and reliable manner.

Conclusion

Participants in this study spoke positively about the *‘Rebuilding Your Life After Stroke’ book.* The book is an accessible resource that can be used with or without professional support. Participants had an active role in their rehabilitation and as a rehabilitation tool, the book can form the basis of an idiosyncratic intervention. Participants had to adopt strategies to overcome some residual effects of stroke (e.g. poor concentration, memory problems) which would otherwise have limited their engagement with the book. Participants articulated the benefits of using the book such as an increased awareness about the effects of stroke, the development of new skills and greater levels of acceptance.

References

Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, *37*(2), 122. https://doi.org/10.1037/0003-066X.37.2.122

Barker-Collo, S. L. (2007). Depression and anxiety 3 months post stroke: prevalence and correlates. *Archives of Clinical Neuropsychology*, *22*(4), 519-531. doi:10.1016/j.acn.2007.03.002

Bergsma, A. (2008). Do self-help books help? *Journal of Happiness Studies*, *9*(3), 341-360. DOI 10.1007/s10902-006-9041-2

Bower, P., & Gilbody, S. (2005). Stepped care in psychological therapies: access, effectiveness and efficiency: narrative literature review. *The British Journal of Psychiatry*, *186*(1), 11-17. DOI: 10.1192/bjp.186.1.11

Braun, V., & Clarke, V. (2012). *Thematic analysis.* In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbooks in psychology®. APA handbook of research methods in psychology, Vol. 2. Research designs: Quantitative, qualitative, neuropsychological, and biological* (p. 57–71). American Psychological Association. https://doi.org/10.1037/13620-004

Campbell, L. F., & Smith, T. P. (2003). Integrating self-help books into sychotherapy. *Journal of Clinical Psychology*, *59*(2), 177-186. https://doi.org/10.1002/jclp.10140

Chen, T., Zhang, B., Deng, Y., Fan, J. C., Zhang, L., & Song, F. (2019). Long-term unmet needs after stroke: systematic review of evidence from survey studies. *BMJ Open*, *9*(5), e028137. doi:10.1136/bmjopen-2018-028137

Clark, E., Bennett, K., Ward, N., & Jones, F. (2018). One size does not fit all–stroke survivor’s views on group self-management interventions. *Disability and Rehabilitation*, *40*(5), 569-576. https://doi.org/10.1080/09638288.2016.1268653

Crawford, M. J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., & Tyrer, P. (2002). Systematic review of involving patients in the planning and development of health care. *BMJ*, *325*(7375), 1263.

Cuijpers, P, Donker, T., Van Straten, A., Li, J., Andersson, G. (2010). Is guided self-help as effective as face-to-face psychotherapy for depression and anxiety disorders? A systematic review and meta-analysis of comparative outcome studies. *Psychological Medicine*, 40, 12. 1943-57. doi: 10.1017/S0033291710000772

Dixon, G., Thornton, E. W., & Young, C. A. (2007). Perceptions of self-efficacy and rehabilitation among neurologically disabled adults. *Clinical Rehabilitation*, *21*(3), 230-240. https://doi.org/10.1016/j.jpsychores.2012.04.001

Duncan, F., Wu, S., & Mead, G. E. (2012). Frequency and natural history of fatigue after stroke: a systematic review of longitudinal studies. *Journal of Psychosomatic Research*, *73*(1), 18-27. https://doi.org/10.1016/j.jpsychores.2012.04.001

Eames, S., Hoffmann, T., Worrall, L., & Read, S. (2010). Stroke patients' and carers' perception of barriers to accessing stroke information. *Topics in Stroke Rehabilitation*, *17*(2), 69-7 https://doi.org/10.1310/tsr1702-69

Edmondson, D., Richardson, S., Fausett, J. K., Falzon, L., Howard, V. J., & Kronish, I. M. (2013). Prevalence of PTSD in survivors of stroke and transient ischemic attack: a meta-analytic review. *PloS One*, *8*(6). 10.1371/journal.pone.0066435

Eng, X. W., Brauer, S. G., Kuys, S. S., Lord, M., & Hayward, K. S. (2014). Factors affecting the ability of the stroke survivor to drive their own recovery outside of therapy during inpatient stroke rehabilitation. *Stroke Research and Treatment*, *2014*. https://doi.org/10.1155/2014/626538

Fledderus, M., Bohlmeijer, E. T., Pieterse, M. E., & Schreurs, K. M. G. (2012). Acceptance and commitment therapy as guided self-help for psychological distress and positive mental health: a randomized controlled trial. *Psychological Medicine*, *42*(3), 485-495. https://doi.org/10.1017/S0033291711001206

Flinn, N. A., & Stube, J. E. (2010). Post-stroke fatigue: qualitative study of three focus groups. *Occupational Therapy International*, *17*(2), 81-91. DOI: 10.1002/oti.286

Frude, N. (2011). Book prescription Wales: A strategy for enhancing treatment choice for mental health. Prescriber information booklet. http://www.wales.nhs.uk.abc.cardiff.ac.uk/sitesplus/documents/829/BPW%20Prescriber%20Information%20booklet%20.pdf

Glaser, B. G. & Strauss, A. L. (1967). The discovery of grounded theory: Strategies for qualitative research. New York: Aldine de Gruyter.

Global Health Estimates. Geneva: World Health Organization; 2012. Available from: http://www.who.int/healthinfo/global_burden_disease/en/ [retrieved 25th April 2020].

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, *18*(1), 59-82. DOI: 10.1177/1525822X05279903

Hackett, M.L., Pickles, K. (2014). Part 1: Frequency of Depression after stroke: an updated systematic review and meta-analysis of observational studies. *International Journal of Stroke*. 9,8. 1017-25. https://doi.org/10.1111/ijs.12357

Hayes, S.C. (2004). Acceptance and commitment therapy, relational frame theory and the third waves of behavioural and cognitive therapies. *Behaviour Therapy*, 35. 639- 665. *doi: 10.1016/S0005-7894(04)80013-3.*

Health and Care Professions Council [HCPC] (2012). Standards of conduct, performance and ethics. London: Health and Care Professions Council.

Jacobs, N.N., Mosco, E. (2008). In O’Donohue, W., Cummings, N.A. (2008). Evidence-based adjunctive treatments. Academic Press: 1st edn. DOI: 10.1016/B978-012088520-6.50003-2

Jones, F., & Riazi, A. (2011). Self-efficacy and self-management after stroke: a systematic review. *Disability and Rehabilitation*, *33*(10), 797-810. https://doi.org/10.3109/09638288.2010.511415

Kneebone, I. I. (2016). A framework to support cognitive behavior therapy for emotional disorder after stroke. *Cognitive and Behavioral Practice*, *23*(1), 99-109. https://doi.org/10.1016/j.cbpra.2015.02.001

Large, R., Samuel, V., & Morris, R. (2019). A changed reality: Experience of an acceptance and commitment therapy (ACT) group after stroke. *Neuropsychological Rehabilitation*, 1-20. https://doi.org/10.1080/09602011.2019.1589531

Maclean, N., Pound, P., Wolfe, C., & Rudd, A. (2000). Qualitative analysis of stroke patients' motivation for rehabilitation. *BMJ*, *321*(7268), 1051 1054. https://doi.org/10.1136/bmj.321.7268.1051

Majumdar, S., & Morris, R. (2019). Brief group-based acceptance and commitment therapy for stroke survivors. *British Journal of Clinical Psychology*, *58*(1), 70-90. **https://doi.org/10.1111/bjc.12198**

Martinez, R., Whitfield, G., Dafters, R., & Williams, C. (2008). Can people read self-help manuals for depression? A challenge for the stepped care model and book prescription schemes. *Behavioural and Cognitive Psychotherapy*, *36*(1), 89-97. https://doi.org/10.1017/S1352465807004067

Matcham, F., Rayner, L., Hutton, J., Monk, A., Steel, C., & Hotopf, M. (2014). Self-help interventions for symptoms of depression, anxiety and psychological distress in patients with physical illnesses: a systematic review and meta-analysis. *Clinical Psychology Review*, *34*(2), 141-157. https://doi.org/10.1016/j.cpr.2014.01.005

National Institute Clinical Excellence (2011) Common mental health problems: identication and pathways to care. Clinical Guidance London https://www.nice.org.uk/guidance/cg123/resources/common-mental-health-problems-identification-and-pathways-to-care-pdf-35109448223173

National Institute for Health & Clinical Excellence (2013). Stroke rehabilitation in adults;Clinical Guideline 162, London: NICE. www.nice.org.uk/guidance/cg162

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine*, *89*(9), 1245-1251. doi: 10.1097/ACM.0000000000000388

Peoples, H., Satink, T., & Steultjens, E. (2011). Stroke survivors' experiences of rehabilitation: A systematic review of qualitative studies. *Scandinavian Journal of Occupational Therapy*, *18*(3), 163-171.

Rafsten, L., Danielsson, A., & Sunnerhagen, K. S. (2018). Anxiety after stroke: a systematic review and meta-analysis. *Journal of Rehabilitation Medicine*, *50*(9), 769-778. doi: 10.2340/16501977-2384

Seligman, M. E. (2004). *Authentic happiness: Using the new positive psychology to realize your potential for lasting fulfillment*. Simon and Schuster.

Smeets, S. M., Vink, M., Ponds, R. W., Winkens, I., & van Heugten, C. M. (2017). Changes in impaired self-awareness after acquired brain injury in patients following intensive neuropsychological rehabilitation. *Neuropsychological Rehabilitation*, *27*(1), 116-132. https://doi.org/10.1080/09602011.2015.1077144

Smith, J. A. (Ed.). (2007). *Qualitative psychology: A practical guide to research methods*. Sage.

Smith, J. & Osborn, M. (2003). Interpretive phenomenological analysis. In J.A. Smith (Eds) Qualitative psychology: A practical guide to research methods (pp.51-80). London:Sage.

The Stroke Association (2018) State of the Nation, Stroke Statistics von Mensenkampff, B., Ward, M., Kelly, G., Cadogan, S., Fawsit, F., & Lowe, N. (2015). The value of normalization: Group therapy for individuals with brain injury. *Brain Injury*, *29*(11), 1292-1299. https://doi.org/10.3109/02699052.2015.1042407

Wain, H. R., Kneebone, I. I., & Billings, J. (2008). Patient experience of neurologic rehabilitation: a qualitative investigation. *Archives of Physical Medicine and Rehabilitation*, *89*(7), 1366-1371. https://doi.org/10.1016/j.apmr.2007.11.050

Welsh Government (2017) 2017-2020 Stroke Delivery Plan: A Refreshed Delivery Plan for NHS Wales and its Partners: Cardiff

Appendix I : Submission for the Journal of Neuropscyhological Rehabilitation

Instructions for authors

COVID-19 impact on peer review
As a result of the significant disruption that is being caused by the COVID-19 pandemic we understand that many authors and peer reviewers will be making adjustments to their professional and personal lives. As a result they may have difficulty in meeting the timelines associated with our peer review process. Please let the journal editorial office know if you need additional time. Our systems will continue to remind you of the original timelines but we intend to be flexible.
Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements.

This title utilises format-free submission. Authors may submit their paper in any scholarly format or layout. References can be in any style or format, so long as a consistent scholarly citation format is applied. For more detail see the format-free submission section below.

Contents

About the Journal
Neuropsychological Rehabilitation is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.
Please note that this journal only publishes manuscripts in English.
Neuropsychological Rehabilitation accepts the following types of article: original articles, scholarly reviews, book reviews.

Open Access
You have the option to publish open access in this journal via our Open Select publishing program. Publishing open access means that your article will be free to access online immediately on publication, increasing the visibility, readership and impact of your research. Articles published Open Select with Taylor & Francis typically receive 32% more citations* and over 6 times as many downloads** compared to those that are not published Open Select.
Your research funder or your institution may require you to publish your article open access. Visit our Author Services website to find out more about open access policies and how you can comply with these.
You will be asked to pay an article publishing charge (APC) to make your article open access and this cost can often be covered by your institution or funder. Use our APC finder to view the APC for this journal.
Please visit our Author Services website or contact openaccess@tandf.co.uk if you would like more information about our Open Select Program.
*Citations received up to Jan 31st 2020 for articles published in 2015-2019 in journals listed in Web of Science®.
**Usage in 2017-2019 for articles published in 2015-2019.

Peer Review and Ethics
Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be single blind peer reviewed by independent, anonymous expert referees. Find out more about what to expect during peer review and read our guidance on publishing ethics.

Preparing Your Paper
All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, prepared by the International Committee of Medical Journal Editors (ICMJE).
Clinical trials: must conform to the Consort guidelines http://www.consort-statement.org. Submitted papers should include a checklist confirming that all of the Consort requirements have been met, together with the corresponding page number of the manuscript where the information is located. In addition, trials must be pre-registered on a site such as clinicaltrials.gov or equivalent, and the manuscript should include the reference number to the relevant pre-registration.
Systematic reviews: submitted papers should follow PRISMA http://www.prisma-statement.org/ guidelines and submission should also be accompanied by a completed PRISMA checklist, together with the corresponding page number of the manuscript where the information is located.
Single-case studies: submitted papers should follow SCRIBE guidelines (http://psycnet.apa.org/fulltext/2016-17384-001.html

) and include a completed SCRIBE checklist together with the corresponding page number of the manuscript where the information is located.

Observational studies: submitted papers should follow the STROBE guidelines (https://www.strobe-statement.org/index.php?id=strobe-home) and also include a completed checklist of compliance, together with the corresponding page number of the manuscript where the information is located.

Qualitative studies: should follow the COREQ guidelines (http://www.equator-network.org/reporting-guidelines/coreq/) and be accompanied by a completed COREQ checklist of compliance, together with the corresponding page number of the manuscript where the information is located.

The EQUATOR Network (Enhancing the Quality and Transparency of Health Research) website provides further information on available guidelines.

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

Word Limits

Please include a word count for your paper. There are no word limits for papers in this journal.

Format-Free Submission

Authors may submit their paper in any scholarly format or layout. Manuscripts may be supplied as single or multiple files. These can be Word, rich text format (rtf), open document format (odt), or PDF files. Figures and tables can be placed within the text or submitted as separate documents. Figures should be of sufficient resolution to enable refereeing.

- There are no strict formatting requirements, but all manuscripts must contain the essential elements needed to evaluate a manuscript: abstract, author affiliation, figures, tables, funder information, and references. Further details may be requested upon acceptance.
- References can be in any style or format, so long as a consistent scholarly citation format is applied. Author name(s), journal or book title, article or chapter title, year of publication, volume and issue (where appropriate) and page numbers are essential. All bibliographic entries must contain a corresponding in-text citation. The addition of DOI (Digital Object Identifier) numbers is recommended but not essential.
- The journal reference style will be applied to the paper post-acceptance by Taylor & Francis.
- Spelling can be US or UK English so long as usage is consistent.

Note that, regardless of the file format of the original submission, an editable version of the article must be supplied at the revision stage.

Taylor & Francis Editing Services

To help you improve your manuscript and prepare it for submission, Taylor & Francis provides a range of editing services. Choose from options such as English Language Editing, which will ensure that your article is free of spelling and grammar errors, Translation, and Artwork Preparation. For more information, including pricing, visit this website.

Checklist: What to Include

1 **Author details.** Please ensure everyone meeting the International Committee of Medical Journal Editors (ICMJE) requirements for authorship is included as an author of your paper. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.

2 Should contain an unstructured abstract of 200 words.

3 You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.

4 Between 5 and 5 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

5 **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:

6 For single agency grants

7 This work was supported by the [Funding Agency] under Grant [number xxxx].

8 For multiple agency grants

9 This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].

10 **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a conflict of interest and how to disclose it.

11 **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.

12 **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.

13 **Geolocation information.** Submitting a geolocation information section, as a separate paragraph before your acknowledgements, means we can index your paper's study area accurately in JournalMap's geographic literature database and make your article more discoverable to others. More information.

14 **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.

15 **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, TIFF, or Microsoft Word (DOC or DOCX) files are acceptable for figures that have been drawn in Word. For information relating to other file types, please consult our Submission of electronic artwork document.

16 **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to

interpret the table without reference to the text. Please supply editable files.

17 **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.

18 **Units.** Please use SI units (non-italicized).

Using Third-Party Material in your Paper

You must obtain the necessary permission to reuse third-party material in your article. The use of short extracts of text and some other types of material is usually permitted, on a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this informal agreement, you will need to obtain written permission from the copyright owner prior to submission. More information on requesting permission to reproduce work(s) under copyright.

Disclosure Statement

Please include a disclosure statement, using the subheading “Disclosure of interest.” If you have no interests to declare, please state this (suggested wording: The authors report no conflict of interest). For all NIH/Wellcome-funded papers, the grant number(s) must be included in the declaration of interest statement. Read more on declaring conflicts of interest.

Clinical Trials Registry

In order to be published in a Taylor & Francis journal, all clinical trials must have been registered in a public repository at the beginning of the research process (prior to patient enrolment). Trial registration numbers should be included in the abstract, with full details in the methods section. The registry should be publicly accessible (at no charge), open to all prospective registrants, and managed by a not-for-profit organization. For a list of registries that meet these requirements, please visit the WHO International Clinical Trials Registry Platform (ICTRP). The registration of all clinical trials facilitates the sharing of information among clinicians, researchers, and patients, enhances public confidence in research, and is in accordance with the ICMJE guidelines.

Complying With Ethics of Experimentation

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All papers which report in vivo experiments or clinical trials on humans or animals must include a written statement in the Methods section. This should explain that all work was conducted with the formal approval of the local human subject or animal care committees (institutional and national), and that clinical trials have been registered as legislation requires. Authors who do not have formal ethics review committees should include a statement that their study follows the principles of the Declaration of Helsinki.

Consent

All authors are required to follow the ICMJE requirements on privacy and informed consent from patients and study participants. Please confirm that any patient, service user, or participant (or that person’s parent or legal guardian) in any research, experiment, or clinical trial described in your paper has given written consent to the inclusion of material pertaining to themselves, that they acknowledge that they cannot be identified via the paper; and that you have fully anonymized them. Where someone is deceased, please ensure you have written consent from the family or estate. Authors may use this Patient Consent Form, which should be completed, saved, and sent to the journal if requested.

Health and Safety

Please confirm that all mandatory laboratory health and safety procedures have been complied with in the course of conducting any experimental work reported in your paper. Please ensure your paper contains all appropriate warnings on any hazards that may be involved in carrying out the experiments or procedures you have described, or that may be involved in instructions, materials, or formulae.

Please include all relevant safety precautions; and cite any accepted standard or code of practice. Authors working in animal science may find it useful to consult the International Association of Veterinary Editors’ Consensus Author Guidelines on Animal Ethics and Welfare and Guidelines for the Treatment of Animals in Behavioural Research and Teaching. When a product has not yet been approved by an appropriate regulatory body for the use described in your paper, please specify this, or that the product is still investigational.

Submitting Your Paper

This journal uses ScholarOne Manuscripts to manage the peer-review process. If you haven't submitted a paper to this journal before, you will need to create an account in ScholarOne. Please read the guidelines above and then submit your paper in the relevant Author Centre, where you will find user guides and a helpdesk.

Please note that Neuropsychological Rehabilitation uses Crossref™ to screen papers for unoriginal material. By submitting your paper to Neuropsychological Rehabilitation you are agreeing to originality checks during the peer-review and production processes.

On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about sharing your work.

Data Sharing Policy

This journal applies the Taylor & Francis Basic Data Sharing Policy. Authors are encouraged to share or make open the data supporting the results or analyses presented in their paper where this does not violate the protection of human subjects or other valid privacy or security concerns.

Authors are encouraged to deposit the dataset(s) in a recognized data repository that can mint a persistent digital identifier, preferably a digital object identifier (DOI) and recognizes a long-term preservation plan. If you are uncertain about where to deposit your data, please see this information regarding repositories.

Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer reviewed as a part of the journal submission process. It is the author’s responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

Publication Charges

There are no submission fees, publication fees or page charges for this journal.

Colour figures will be reproduced in colour in your online article free of charge. If it is necessary for the figures to be reproduced in colour in the print version, a charge will apply.

Charges for colour figures in print are £300 per figure ($400 US Dollars; $500 Australian Dollars; €350). For more than 4 colour figures, figures 5 and above will be charged at £50 per figure ($75 US Dollars; $100 Australian Dollars; €65). Depending on your location, these charges may be subject to local taxes.

Copyright Options

Copyright allows you to protect your original material, and stop others from using your work without your permission. Taylor & Francis offers a number of different license and reuse options, including Creative Commons licenses when publishing open access. Read more on publishing agreements.

Complying with Funding Agencies

We will deposit all National Institutes of Health or Wellcome Trust-funded papers into PubMedCentral on behalf of authors, meeting the requirements of their respective open access policies. If this applies to you, please tell our production team when you receive your article proofs, so we can do this for you. Check funders' open access policy mandates here. Find out more about sharing your work.

My Authored Works

On publication, you will be able to view, download and check your article's metrics (downloads, citations and Altmetric data) via My Authored Works on Taylor & Francis Online. This is where you can access every article you have published with us, as well as your free eprints link, so you can quickly and easily share your work with friends and colleagues.

We are committed to promoting and increasing the visibility of your article. Here are some tips and ideas on how you can work with us to promote your research.

Article Reprints

You will be sent a link to order article reprints via your account in our production system. For enquiries about reprints, please contact the Taylor & Francis Author Services team at reprints@tandf.co.uk. You can also order print copies of the journal issue in which your article appears.

Queries

Should you have any queries, please visit our Author Services website or contact us here.

Appendix 2: Systematic Review Terms

Mindfulness terms

- Mindfulness
- Mindfulness Based Stress Reduction
- Mindfulness based cognitive therapy
- Mindfulness Meditation
- Meditat*

Condition

- Acquired Brain Injury
- Traumatic Brain Injury
- Head injury
- Cerebral Ischemia
- Stroke
- Brain haemorrhage

Appendix 3: Quality Assessment Tool

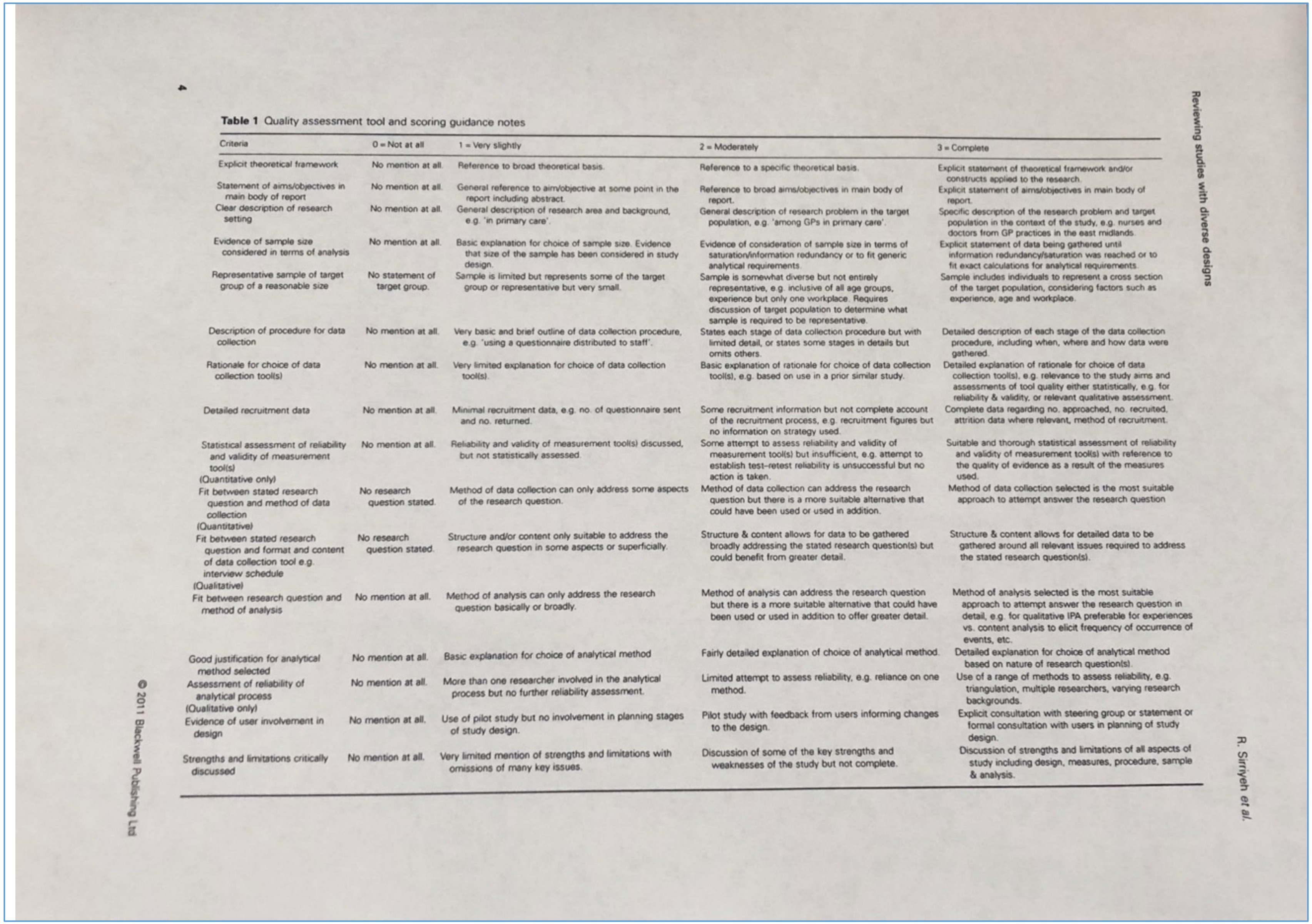


Table 1 Quality assessment tool and scoring guidance notes

Criteria	0 = Not at all	1 = Very slightly	2 = Moderately	3 = Complete
Explicit theoretical framework	No mention at all.	Reference to broad theoretical basis.	Reference to a specific theoretical basis.	Explicit statement of theoretical framework and/or constructs applied to the research.
Statement of aims/objectives in main body of report	No mention at all.	General reference to aim/objective at some point in the report including abstract.	Reference to broad aims/objectives in main body of report.	Explicit statement of aims/objectives in main body of report.
Clear description of research setting	No mention at all.	General description of research area and background, e.g. 'in primary care'.	General description of research problem in the target population, e.g. 'among GPs in primary care'.	Specific description of the research problem and target population in the context of the study, e.g. nurses and doctors from GP practices in the east midlands.
Evidence of sample size considered in terms of analysis	No mention at all.	Basic explanation for choice of sample size. Evidence that size of the sample has been considered in study design.	Evidence of consideration of sample size in terms of saturation/information redundancy or to fit generic analytical requirements.	Explicit statement of data being gathered until information redundancy/saturation was reached or to fit exact calculations for analytical requirements.
Representative sample of target group of a reasonable size	No statement of target group.	Sample is limited but represents some of the target group or representative but very small.	Sample is somewhat diverse but not entirely representative, e.g. inclusive of all age groups, experience but only one workplace. Requires discussion of target population to determine what sample is required to be representative.	Sample includes individuals to represent a cross section of the target population, considering factors such as experience, age and workplace.
Description of procedure for data collection	No mention at all.	Very basic and brief outline of data collection procedure, e.g. 'using a questionnaire distributed to staff'.	States each stage of data collection procedure but with limited detail, or states some stages in details but omits others.	Detailed description of each stage of the data collection procedure, including when, where and how data were gathered.
Rationale for choice of data collection tool(s)	No mention at all.	Very limited explanation for choice of data collection tool(s).	Basic explanation of rationale for choice of data collection tool(s), e.g. based on use in a prior similar study.	Detailed explanation of rationale for choice of data collection tool(s), e.g. relevance to the study aims and assessments of tool quality either statistically, e.g. for reliability & validity, or relevant qualitative assessment.
Detailed recruitment data	No mention at all.	Minimal recruitment data, e.g. no. of questionnaire sent and no. returned.	Some recruitment information but not complete account of the recruitment process, e.g. recruitment figures but no information on strategy used.	Complete data regarding no. approached, no. recruited, attrition data where relevant, method of recruitment.
Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only)	No mention at all.	Reliability and validity of measurement tool(s) discussed, but not statistically assessed.	Some attempt to assess reliability and validity of measurement tool(s) but insufficient, e.g. attempt to establish test–retest reliability is unsuccessful but no action is taken.	Suitable and thorough statistical assessment of reliability and validity of measurement tool(s) with reference to the quality of evidence as a result of the measures used.
Fit between stated research question and method of data collection (Quantitative)	No research question stated.	Method of data collection can only address some aspects of the research question.	Method of data collection can address the research question but there is a more suitable alternative that could have been used or used in addition.	Method of data collection selected is the most suitable approach to attempt answer the research question
Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative)	No research question stated.	Structure and/or content only suitable to address the research question in some aspects or superficially.	Structure & content allows for data to be gathered broadly addressing the stated research question(s) but could benefit from greater detail.	Structure & content allows for detailed data to be gathered around all relevant issues required to address the stated research question(s).
Fit between research question and method of analysis	No mention at all.	Method of analysis can only address the research question basically or broadly.	Method of analysis can address the research question but there is a more suitable alternative that could have been used or used in addition to offer greater detail.	Method of analysis selected is the most suitable approach to attempt answer the research question in detail, e.g. for qualitative IPA preferable for experiences vs. content analysis to elicit frequency of occurrence of events, etc.
Good justification for analytical method selected	No mention at all.	Basic explanation for choice of analytical method	Fairly detailed explanation of choice of analytical method.	Detailed explanation for choice of analytical method based on nature of research question(s).
Assessment of reliability of analytical process (Qualitative only)	No mention at all.	More than one researcher involved in the analytical process but no further reliability assessment.	Limited attempt to assess reliability, e.g. reliance on one method.	Use of a range of methods to assess reliability, e.g. triangulation, multiple researchers, varying research backgrounds.
Evidence of user involvement in design	No mention at all.	Use of pilot study but no involvement in planning stages of study design.	Pilot study with feedback from users informing changes to the design.	Explicit consultation with steering group or statement or formal consultation with users in planning of study design.
Strengths and limitations critically discussed	No mention at all.	Very limited mention of strengths and limitations with omissions of many key issues.	Discussion of some of the key strengths and weaknesses of the study but not complete.	Discussion of strengths and limitations of all aspects of study including design, measures, procedure, sample & analysis.

R. Sirriyeh *et al.*

Appendix 4: QATSDD Criteria

	QATSDD criteria
A	Explicit theoretical framework
B	Statement of aims/objectives in main body of report
C	Clear description of research setting
D	Evidence of sample size considered in terms of analysis
E	Representative sample of target group of a reasonable size
F	Description of procedure for data collection
G	Rationale for choice of data collection tool(s)
H	Detailed recruitment data
I	Statistical assessment of reliability and validity of measurement tool(s) Quantitative only)
J	Fit between stated research question and method of data collection (Quantitative)
K	Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative)
L	Fit between research question and method of analysis
M	Good justification for analytical method selected
N	Assessment of reliability of analytical process (Qualitative only)
O	Evidence of user involvement in design
P	Strengths and limitations critically discussed

Table 1: QATSDD criteria have been assigned a letter as and presented in appendix 5

Appendix 5: Table 2, QATSDD scores for studies included in this systematic review

	QATSDD criteria 0=Not at all, 1= Very slightly, 2= Moderately, 3=Completely																	
		A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	TOTAL
Study	Azulay *et al.* (2012)	3	3	3	0	2	2	2	2	0	3		3	0		0	2	25
	Beddard *et al.* (2014)	3	3	3	3	2	3	2	3	0	3		3	3		0	2	33
	Wang *et al.* (2019)	3	3	2	3	2	2	3	3	2	3		3	3		0	2	33
	Mousgaart *et al.* (2007)	3	3	2	0	1	2	2	2	0	2		3	3		0	3	28
	Beddard *et al.* (2003)	3	3	3	0	1	2	2	2	1	3		3	3		0	3	28
	Beddard *et al.* (2005)	3	3	2	0	1	2	0	2	1	3		3	1		0	3	25
	Wang *et al.* (2020)	3	3	3	3	2	3	3	2	3	3		3	3		0	2	36
	Johansson *et al.* (2012)	3	3	0	0	1	2	0	3	0	3		3	3		0	1	32
	Jo *et al.* (2010)	2	3	2	0	2	2	3	3	0	3		3	2		0	1	26
	Beddard *et al.* (2012)	3	3	3	0	2	3	3	3	0	3		3	3		0	2	31
	Johansson *et al.* (2015)	3	3	1	0	1	1	2	1	0	3		3	3		0	3	24

Appendix 6: Participant Contact Information Form

Participant Contact Information Form

Study Title: *'Rebuilding Your Life After Stroke'*: A Qualitative Exploration of Stroke Survivor and Staff Experiences

If you are happy to be contacted by myself to take part in the study, please fill out your details below and return in the enclosed envelope. I will aim to contact you by telephone within 7 days of receiving your details.

Many thanks

Kathleen Williams

Name:	
Address:	
Telephone (home):	
Telephone (mobile):	

Appendix 7 - Participant Information Sheet (Survivor)

Participant Information Sheet (Survivor)

Study Title: *'Rebuilding Your Life After Stroke':* A Qualitative Exploration of Stroke Survivor and Staff Experiences

We would like to invite you to take part in a research study. Before you decide whether or not to take part, we want to tell you more about the study.

Please read this Participant Information Sheet carefully as it is important that you fully understand why we are running the study and what it would involve if you decide to take part. You do not have to decide now whether you would like to take part. Please take your time to think about this information sheet and talk about it to your friends and family if you wish.

If you would like to take part in the study, please complete the enclosed Participant Contact Information Form and return it in the envelope provided. The researcher will then contact you to arrange an interview and to provide further information about the study.

Title of the study:

***'Rebuilding Your Life After Stroke'*: A Qualitative Exploration of Stroke Survivor and Staff Experiences**

Why have I been asked to take part?

You have used the '*Rebuilding Your Life After Stroke'* self-help book. This book has been developed by Stroke survivors, carers and staff working in Stroke Services. This study is being carried out throughout South Wales and Bristol and professionals in your area are part of the research team. They have identified you as a potential participant and have given you information about this study.

What is the purpose of the study?

As the book is new, we would like to know your views about the book and your experiences of using it. In doing this, we want to find out what the most helpful parts of the book were and the parts that could be improved to help other Stroke survivors and their carers in the future.

Do I have to take part?

Your involvement in the study is completely voluntary and you will only be involved in the research after reading this information sheet, agreeing to be contacted by the researcher and signing a consent form to confirm your participation in the study. If you decide to take part, but later change your mind, you can withdraw from the study at any time, without giving any reason. All information you give will be anonymised, so if you decide that you want to withdraw from the study after being interviewed, the researcher will not be able to remove any information you have given and your data will be analysed with other participants' data.

Choosing not to take part in the study will not affect your current or future care and treatment or any involvement with the [redacted].

What will taking part in the study involve?

You will be asked to commit to an interview session with the researcher, which should last about an hour. You will be asked to complete a consent form before participating in the interview session. The interview can be at an NHS location near you, your home, or over the telephone/Skype. The interview will be audio-recorded to support the researcher in understanding and analysing what you have said.

To ensure that the researcher has accurately captured everyone's responses, the researcher will be inviting participants to be part of a participant panel. Being part of this panel will mean that the researcher will send you the initial findings of the research and you will be invited to comment/ suggest changes if you wish. If you want to be part of this panel, please tick the box on the Participant Panel Invitation. When the research findings have been finalised, the final results of the study will be sent to all participants who have opted to see them. This is for your own personal reference at can be read at your leisure, you will not be asked to provide any feedback on the finalised results.

How will the information obtained during the study be used?

The information gathered might be used in a number of ways:

- The results of the research will be written up as a thesis and submitted as part of a Doctorate in Clinical Psychology at Cardiff University.
- It is also hoped that the results will be published in a scientific journal and presented at Conferences.
- All research participants will be offered the opportunity to receive a summary of the research when the results of the study are finalised.

Whilst it is possible that the researcher may use direct quotes obtained from the interview sessions, please be assured that names of participants and/or other identifiable information will not be included in any reports so you will not be identified in any report/publication related to this research.

What are the benefits of taking part?
We hope that by taking part in the research it will give you an opportunity to think about your experience of using the book, to consolidate what you've learnt and encourage you to practice the things that you found helpful.

We also hope that participation may benefit you and others in the future. As this is a new stroke book, we hope that your direct feedback and views can help contribute to the development of new psychological and support services for stroke survivors and their carers.

Are there any disadvantages of taking part?
Talking about stroke and the events after it can be distressing and you may feel upset. The researcher will minimise this risk by having focused questions about the book. If you do become distressed, the researcher will stop the interview, discuss any issues that arise and provide you with information of local support groups, if appropriate.

Will my taking part in the study be confidential?
All information collected from you during the study will be kept strictly confidential and any personal data you provide will be held in accordance with data protection law (please see 'What will happen to my Personal Data' below for further information).

The audio-recordings will only be heard by the named researcher, members of the research team and transcribers (from an external agency who will be subject to appropriate confidentiality provisions) whilst transcribing the material, and all data within the transcript will be anonymised to protect your identity. The audio-recordings will be stored at Cardiff University as a locked and encrypted file and destroyed within 1 year of completion of the study. The anonymised research data, and all other paper records (including your consent form) will be retained securely at Cardiff University for a period of 15 years, in accordance with Cardiff University's Records Management Policy.

As an exception, if the researcher or a member of the research team has concerns about your safety, or the safety of others, they may be legally required to override confidentiality and report this to appropriate persons.

The researcher would try and discuss this with you in the first instance if appropriate to do so.

What will happen to my Personal Data?
Cardiff University is the sponsor for this study based in the United Kingdom. Cardiff University will be using information from you in order to undertake this study and will act as the data controller for this study. This means that the University is responsible for looking after your information and using it properly. Cardiff University will keep identifiable information about you for 15 years after the study has finished (namely your consent form). As noted above, transcripts from the audio-recorded interviews will be anonymised to remove identifiable information and the audio-recordings destroyed within 1 year of study completion.

Under data protection law, the University has to specify the legal basis that we are relying on to process your personal data. In providing your personal data for this research we will process it on the basis that doing so is necessary for our public task for scientific and historical research purposes in accordance with the necessary safeguards, and is in the public interest. The University is a public research institution established by royal charter to advance knowledge and education through its teaching and research activities. The charter can be found on the Cardiff University website.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Cardiff University has a Data Protection Officer who can be contacted at [redacted]. Further information about Data Protection, including your rights and details about how to contact the Information Commissioner's Office should you wish to complain about how your personal data has been handled, can be found at *https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection.*

Who has reviewed this study?

This research has been reviewed by an NHS Research Ethics Committee [insert reference number] who have given it a favourable ethical opinion for conduct.

Contact for further information

If you wish to obtain further information about this study, or if you have any queries, please contact the named researcher, using the contact details below. Alternatively, you are invited to contact the Academic Supervisor using the contact details below.

Raising a concern and complaints

If you wish to raise a concern, or complain about the study, please contact the named researcher or the Academic Supervisor of the study, using the contact details below.

Alternatively, if you would like to raise a concern or complaint with someone who is independent of this study, please contact [redacted]

Thank you for taking the time to read this information sheet.

The Research Team

The Research Team

<table>
<tr><td>[redacted]</td><td>[redacted]</td></tr>
<tr><td colspan="2">[redacted]</td></tr>
</table>

Appendix 8: Consent Form

Consent Form

Study Title: '*Rebuilding Your Life After Stroke*': A Qualitative Exploration of Stroke Survivor and Staff Experiences

Name of Researcher: Kathleen Williams

Please initial the boxes if you agree with the following statements and **sign and date** at the bottom of the form:

1. I confirm that I have read and understood the Participant Information Sheet dated 7/1/19, version 4, for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand my participation is voluntary and that I am free to withdraw from the study at any time without giving a reason and without it affecting my care or rights in any way. ☐

3. I understand that all of the information I provide during the study will be held securely and in confidence by the research team, unless they are legally required to disclose information as a result of concerns about my safety, or the safety of others. ☐

4. I agree to the interview being audio-recorded and for this to be transcribed in full by an external party subject to a strict duty of confidence. ☐

5. I understand that the audio recording will be stored securely at Cardiff University in locked and protected files and destroyed within1 year of study completion. I understand that the transcripts of the audio-recordings will be anonymised by the researcher and retained securely at Cardiff University for 15 years. ☐

6. I am aware that excerpts from my interview, or descriptions of them, may be used by the researcher within their thesis or other papers published in scientific journals or presented at Stroke, for the purpose of research. I give permission for the information to be used with the understanding that I will remain anonymous. ☐

7. I understand that the anonymised research data, and all other paper records (including this consent form), will be retained securely at Cardiff University for a period of 15 years. ☐

8. I agree to take part in the study. ☐

9. I have been informed about the opportunity to become a member of the Participant Panel and am aware that there is no obligation to be part of this panel. I understand that if I would like to be part of this panel then I will need to complete the invitation and give it to the researcher. ☐

10. I **<u>would</u>** like to receive a summary of the findings of this study once finalised by the research team. I agree that the summary may be sent to my email or postal address below. ☐

Email Address:

Postal Address (including postcode):

Participant Signature ………………………………………………………………….. Date…………………….

Name (please print) ………………………………………………........................

Researcher Signature ………………………………………………………………….. Date……………………..

Appendix 9: Participant Panel Invitation

Participant Panel Invitation

***'Rebuilding Your Life After Stroke'*: A Qualitative Exploration of Stroke Survivor and Staff Experiences**

Thank you for agreeing to take part in our study. After we have completed the interview, your responses will be collated with other participants' answers and written up as a piece of research. It is important to us that the research accurately captures what participants have said. To ensure this, we need a small panel of participants to read a draft of the research and suggest any modifications if required. This can be done via email or post and further information about this activity is outlined in the Participant Information Sheet.

We would like to invite you to be part of this panel. This is completely voluntary and you do not have to be part of this panel. Deciding not to be part of this panel will not affect your responses or opportunity to participate in any future research.

You do not have to decide now whether you would like to be part of the panel, you can think about it, take this information sheet away with you and talk about it to friends and family before you make up your mind. If you would like to know more, or like to be part of this panel, please write your details below and return it in the envelope provided. The researcher will then call you to establish the best way to do this.

Please tick one of the boxes below, complete your contact details and return the reply slip to the research team in the enclosed envelope.

No, I would not like to be part of the panel ☐

Yes, I agree to being part of the panel and agree for the researcher to contact me about it. ☐

Name: ____

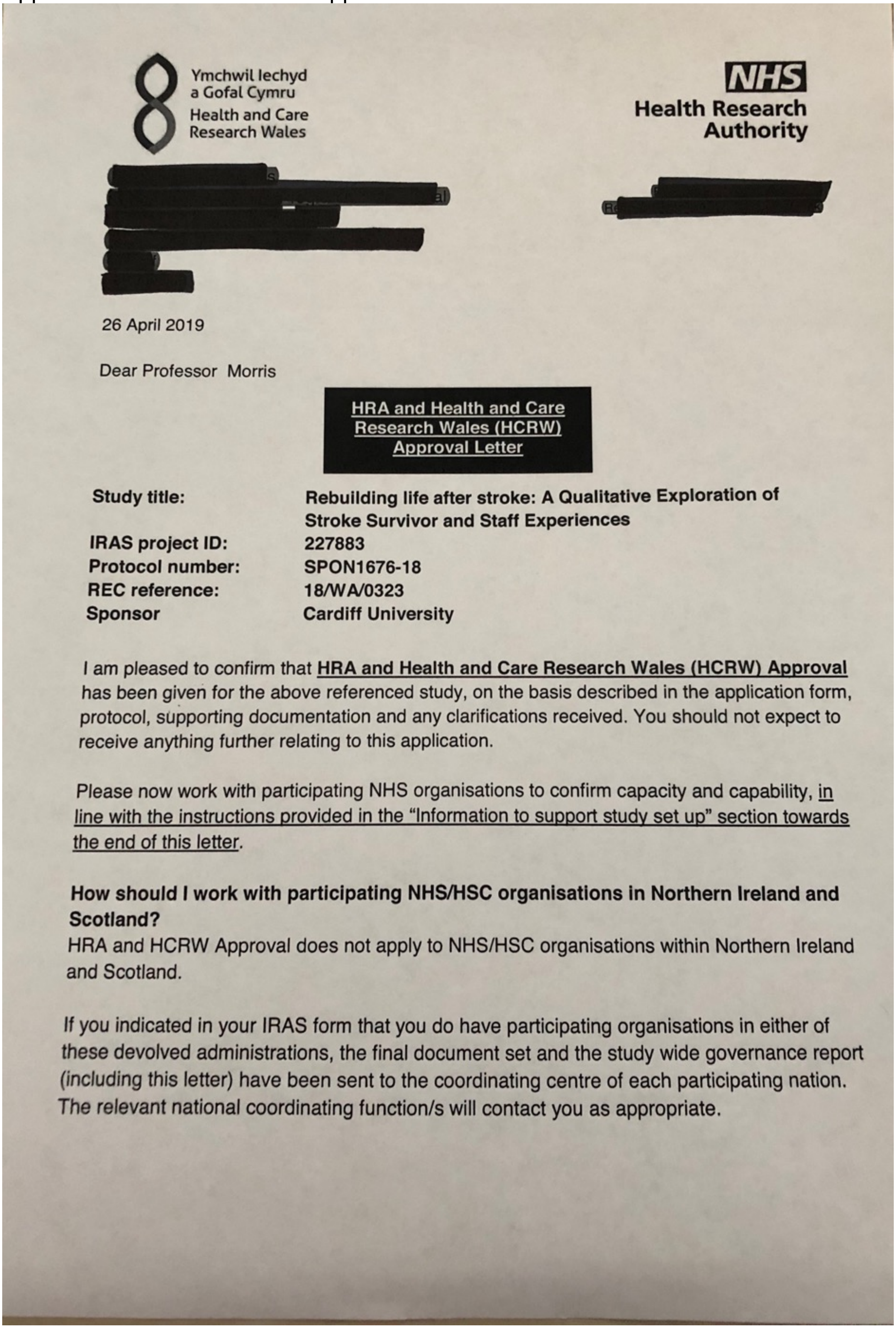
Telephone Number:

____

The best time to contact me is:

____

Appendix 10: Letter of ethical approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

[redacted]

[redacted]

26 April 2019

Dear Professor Morris

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Rebuilding life after stroke: A Qualitative Exploration of Stroke Survivor and Staff Experiences**
IRAS project ID:	**227883**
Protocol number:	**SPON1676-18**
REC reference:	**18/WA/0323**
Sponsor	**Cardiff University**

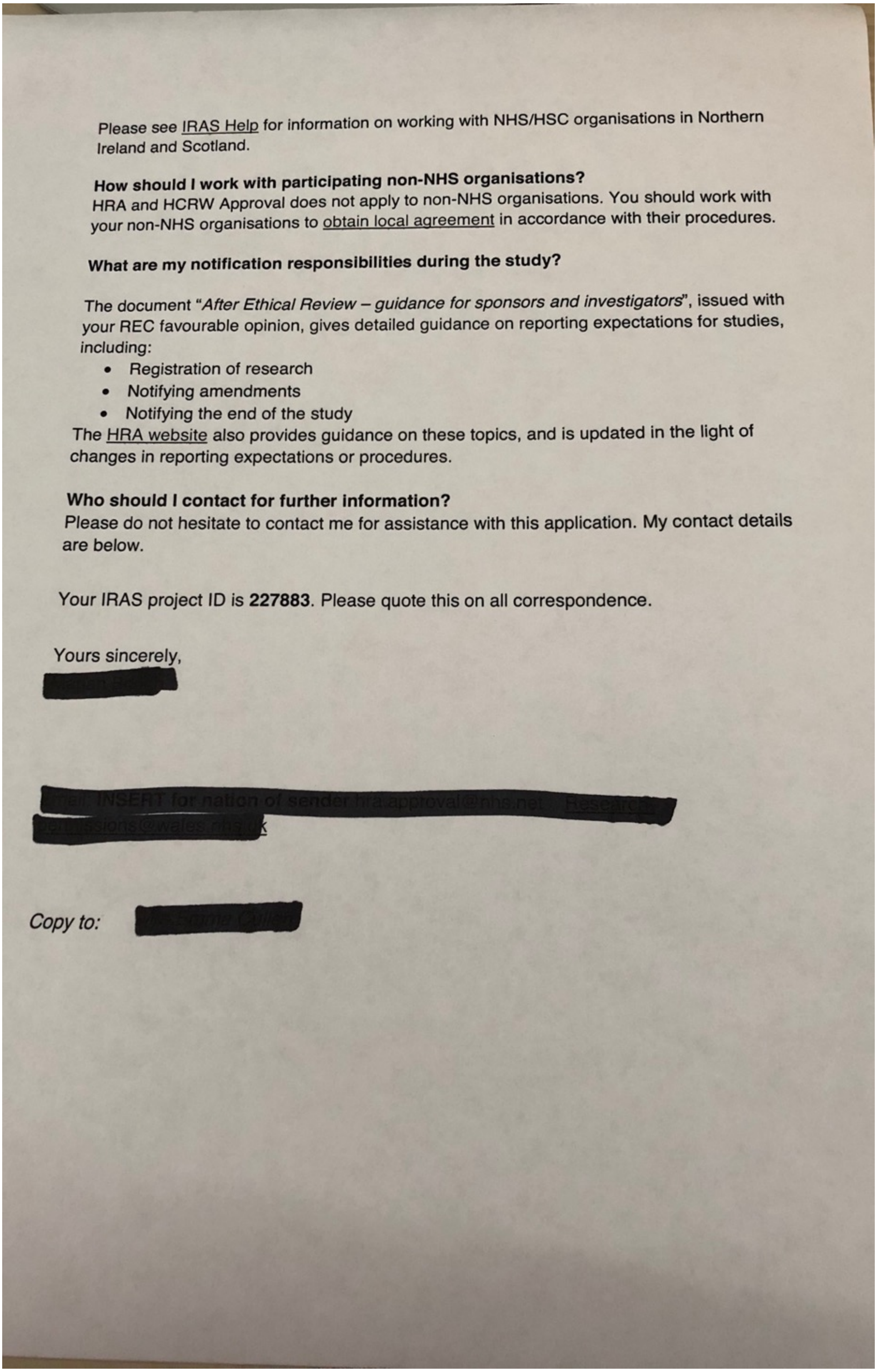
I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further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

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

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

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

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



Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

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

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

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

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

Who should I contact for further information?

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

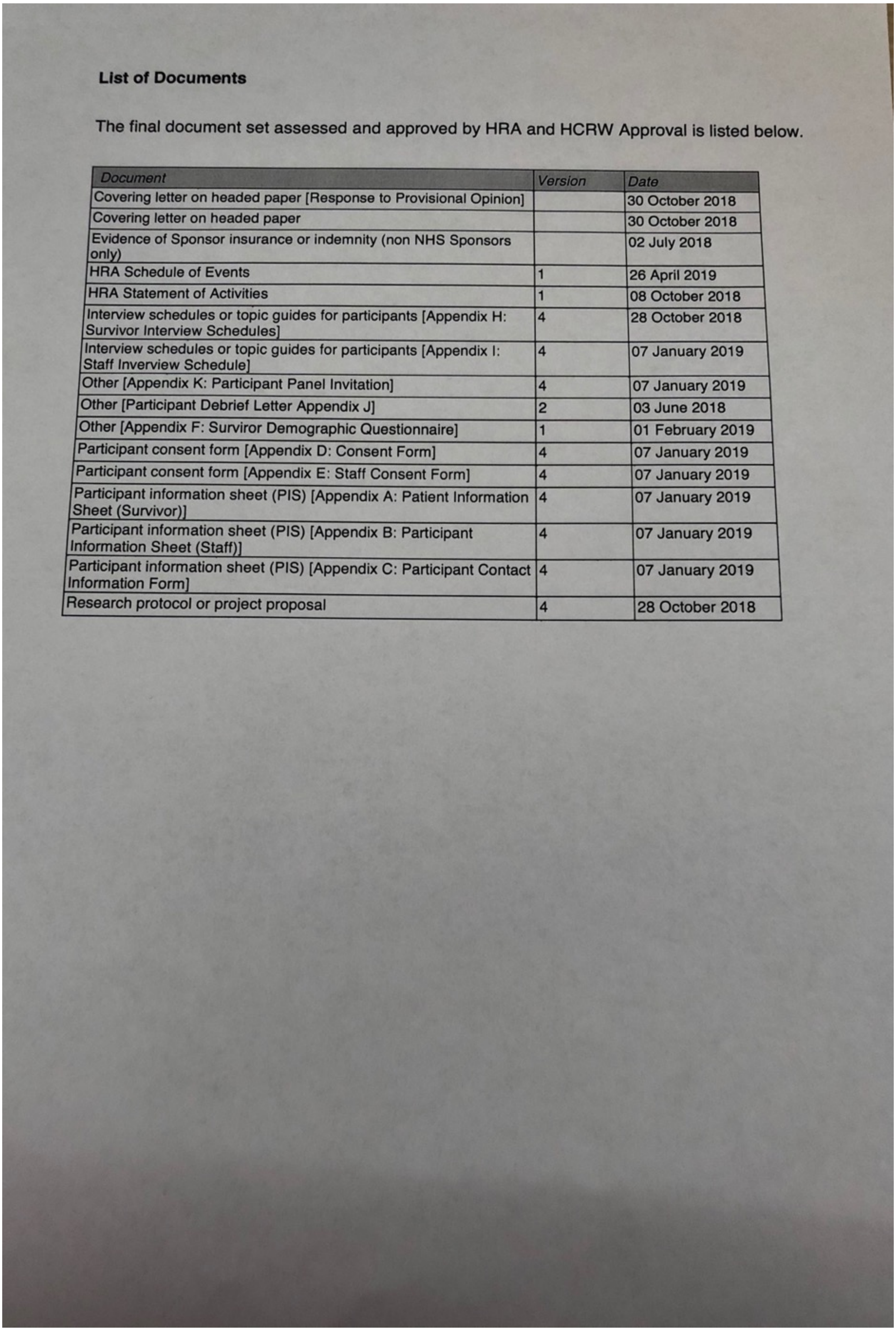
Your IRAS project ID is **227883**. Please quote this on all correspondence.

Yours sincerely,

[redacted]

[redacted]

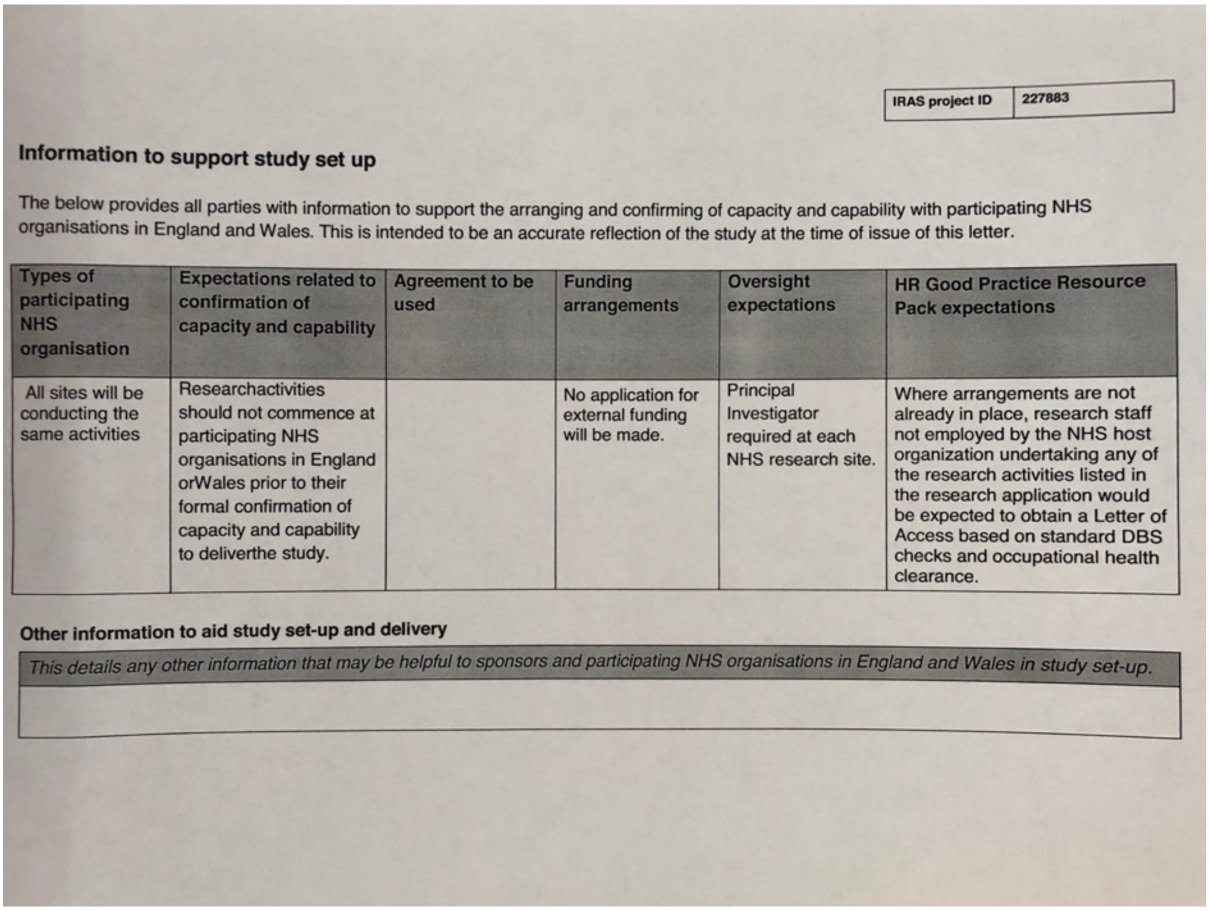
Copy to: [redacted]



List of Documents

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

Document	*Version*	*Date*
Covering letter on headed paper [Response to Provisional Opinion]		30 October 2018
Covering letter on headed paper		30 October 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		02 July 2018
HRA Schedule of Events	1	26 April 2019
HRA Statement of Activities	1	08 October 2018
Interview schedules or topic guides for participants [Appendix H: Survivor Interview Schedules]	4	28 October 2018
Interview schedules or topic guides for participants [Appendix I: Staff Inverview Schedule]	4	07 January 2019
Other [Appendix K: Participant Panel Invitation]	4	07 January 2019
Other [Participant Debrief Letter Appendix J]	2	03 June 2018
Other [Appendix F: Surviror Demographic Questionnaire]	1	01 February 2019
Participant consent form [Appendix D: Consent Form]	4	07 January 2019
Participant consent form [Appendix E: Staff Consent Form]	4	07 January 2019
Participant information sheet (PIS) [Appendix A: Patient Information Sheet (Survivor)]	4	07 January 2019
Participant information sheet (PIS) [Appendix B: Participant Information Sheet (Staff)]	4	07 January 2019
Participant information sheet (PIS) [Appendix C: Participant Contact Information Form]	4	07 January 2019
Research protocol or project proposal	4	28 October 2018



IRAS project ID	227883

Information to support study set up

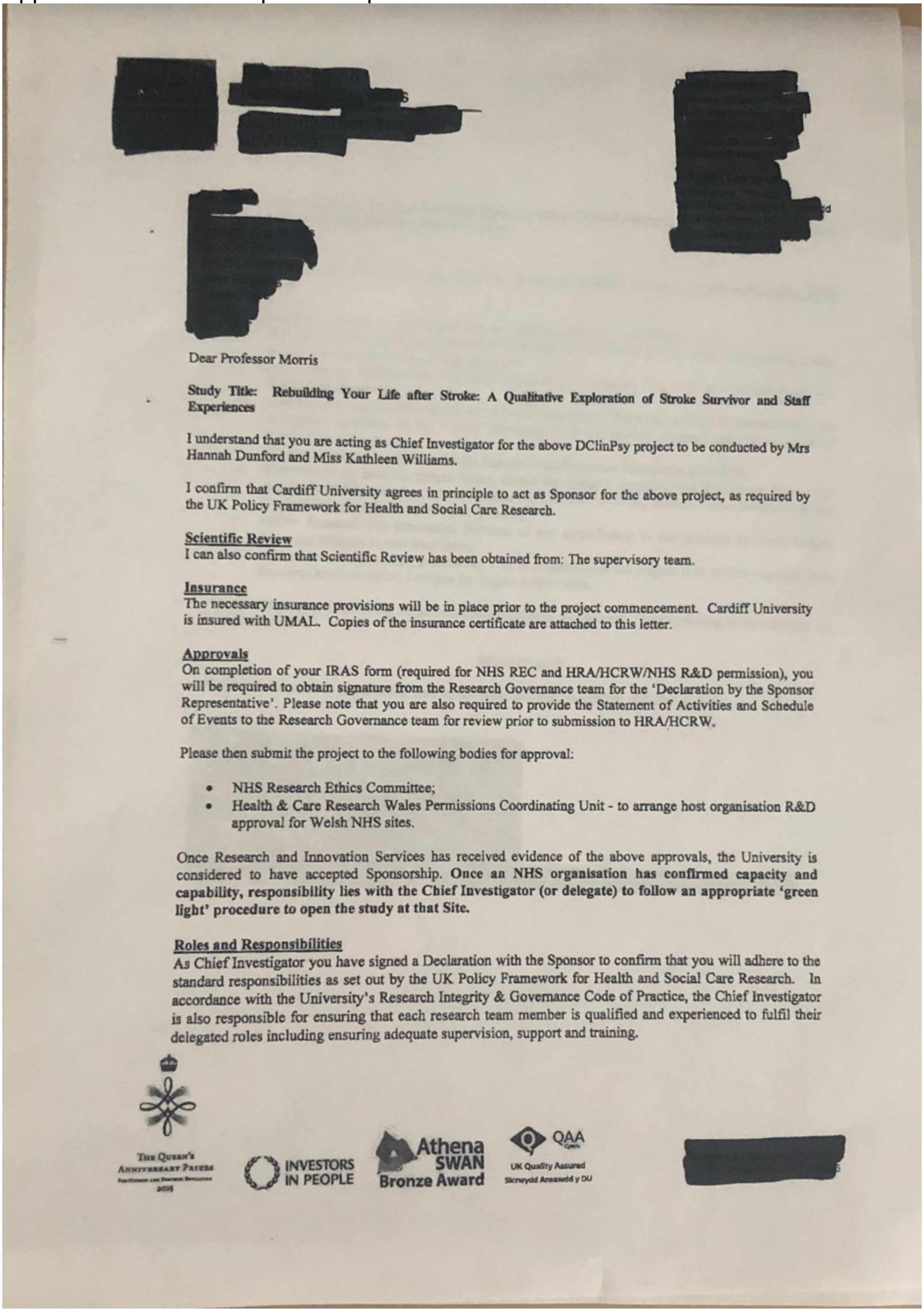
The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
All sites will be conducting the same activities	Researchactivities should not commence at participating NHS organisations in England orWales prior to their formal confirmation of capacity and capability to deliverthe study.		No application for external funding will be made.	Principal Investigator required at each NHS research site.	Where arrangements are not already in place, research staff not employed by the NHS host organization undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other information to aid study set-up and delivery

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

Appendix 11: Letter of sponsorship



[redacted]

[redacted]

[redacted]

[redacted]

Dear Professor Morris

Study Title: Rebuilding Your Life after Stroke: A Qualitative Exploration of Stroke Survivor and Staff Experiences

I understand that you are acting as Chief Investigator for the above DClinPsy project to be conducted by Mrs Hannah Dunford and Miss Kathleen Williams.

I confirm that Cardiff University agrees in principle to act as Sponsor for the above project, as required by the UK Policy Framework for Health and Social Care Research.

Scientific Review
I can also confirm that Scientific Review has been obtained from: The supervisory team.

Insurance
The necessary insurance provisions will be in place prior to the project commencement. Cardiff University is insured with UMAL. Copies of the insurance certificate are attached to this letter.

Approvals
On completion of your IRAS form (required for NHS REC and HRA/HCRW/NHS R&D permission), you will be required to obtain signature from the Research Governance team for the 'Declaration by the Sponsor Representative'. Please note that you are also required to provide the Statement of Activities and Schedule of Events to the Research Governance team for review prior to submission to HRA/HCRW.

Please then submit the project to the following bodies for approval:

- NHS Research Ethics Committee;
- Health & Care Research Wales Permissions Coordinating Unit - to arrange host organisation R&D approval for Welsh NHS sites.

Once Research and Innovation Services has received evidence of the above approvals, the University is considered to have accepted Sponsorship. **Once an NHS organisation has confirmed capacity and capability, responsibility lies with the Chief Investigator (or delegate) to follow an appropriate 'green light' procedure to open the study at that Site.**

Roles and Responsibilities
As Chief Investigator you have signed a Declaration with the Sponsor to confirm that you will adhere to the standard responsibilities as set out by the UK Policy Framework for Health and Social Care Research. In accordance with the University's Research Integrity & Governance Code of Practice, the Chief Investigator is also responsible for ensuring that each research team member is qualified and experienced to fulfil their delegated roles including ensuring adequate supervision, support and training.

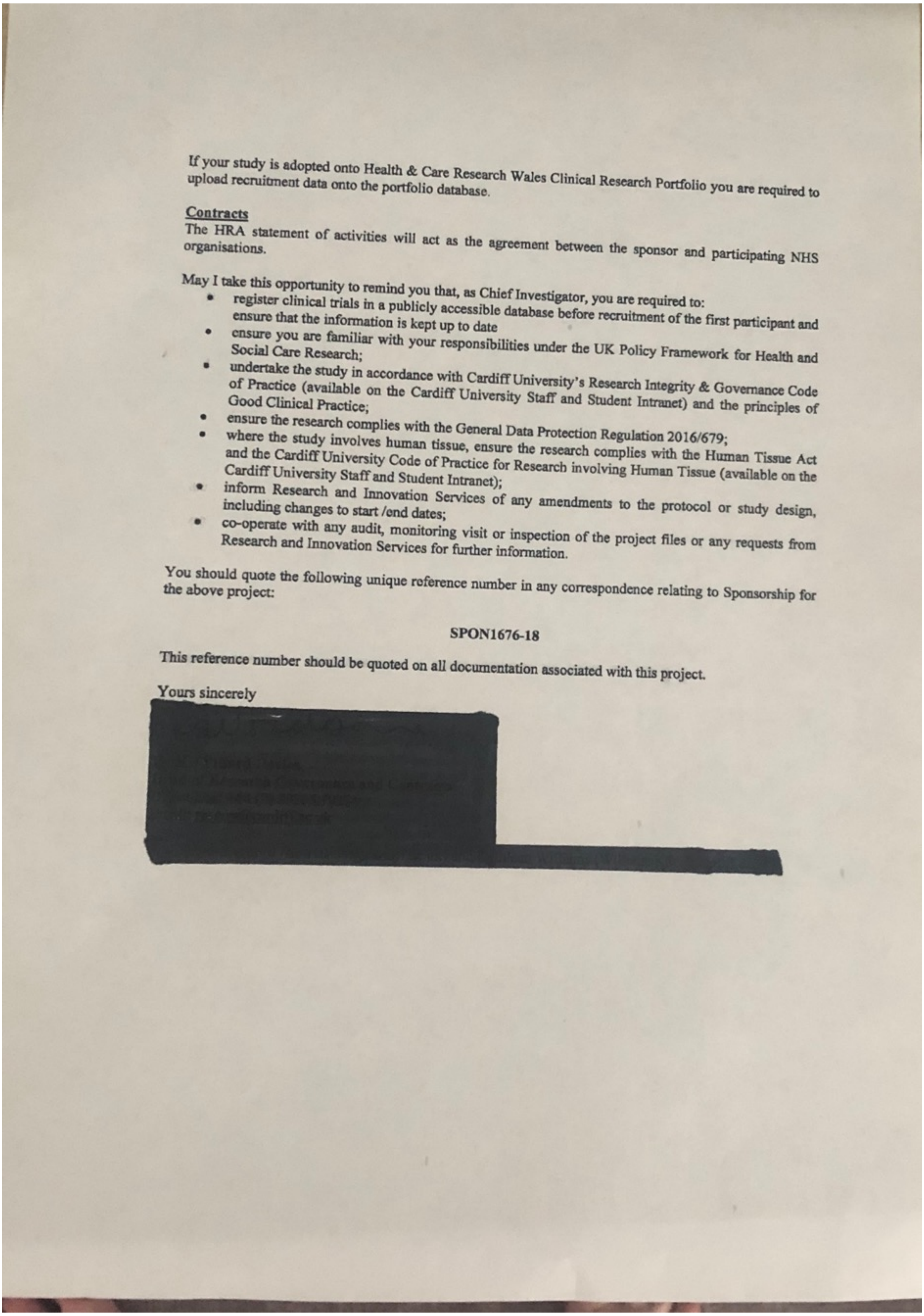
The Queen's Anniversary Prizes
2015

Investors in People

Athena SWAN Bronze Award

QAA Cymru
UK Quality Assured
Sicrwydd Ansawdd y DU

[redacted]



If your study is adopted onto Health & Care Research Wales Clinical Research Portfolio you are required to upload recruitment data onto the portfolio database.

Contracts

The HRA statement of activities will act as the agreement between the sponsor and participating NHS organisations.

May I take this opportunity to remind you that, as Chief Investigator, you are required to:

- register clinical trials in a publicly accessible database before recruitment of the first participant and ensure that the information is kept up to date
- ensure you are familiar with your responsibilities under the UK Policy Framework for Health and Social Care Research;
- undertake the study in accordance with Cardiff University's Research Integrity & Governance Code of Practice (available on the Cardiff University Staff and Student Intranet) and the principles of Good Clinical Practice;
- ensure the research complies with the General Data Protection Regulation 2016/679;
- where the study involves human tissue, ensure the research complies with the Human Tissue Act and the Cardiff University Code of Practice for Research involving Human Tissue (available on the Cardiff University Staff and Student Intranet);
- inform Research and Innovation Services of any amendments to the protocol or study design, including changes to start /end dates;
- co-operate with any audit, monitoring visit or inspection of the project files or any requests from Research and Innovation Services for further information.

You should quote the following unique reference number in any correspondence relating to Sponsorship for the above project:

SPON1676-18

This reference number should be quoted on all documentation associated with this project.

Yours sincerely

[redacted]

Appendix 12: Participant Debrief Letter

Participant Debrief Letter

Study Title: *'Rebuilding Your Life After Stroke'*: A Qualitative Exploration of Stroke survivors, carers and staff views.

Dear Participant,

Thank you for participating in the research study. From your interview your anonymised responses have been recorded and will be combined with other participants' responses.

As the book is new, we wanted to know what you found helpful about the book, as well as the parts that were less useful. Your feedback will guide us in the future, to make sure that the best possible book is printed, so that it is helpful for those who need to use it. After all the interviews have been completed, we will send the draft findings to participants who have opted to be part of the Participant Panel. The Participant Panel Invitation should have been given to you at the time you consented to participate in the study. The panel will review the draft findings and suggest amendments to the research team. If you would like to be part of the Participant Panel but have not completed the invitation, you can still become a member of the panel, please ask the researcher for another copy.

We also want others to know about, and learn from this research. Therefore, we are hoping to present these findings at conferences and publish it in scientific journals.

As well as this, your anonymised responses have been used as part of a project that will contribute to the researcher gaining a Doctorate in Clinical Psychology. We will learn from your experience and apply it to our practice when we qualify as Clinical Psychologists in the future.

We hope that you have found the experience positive and we will send you the findings of the research when it is completed.

Thank you once again.
Yours sincerely,

Trainee Clinical Psychologist

Appendix 13 - Demographic Questionnaire for stroke survivor

Demographic Questionnaire for stroke survivor

Title of the study: '*Rebuilding Your Life After Stroke*': A Qualitative Exploration of Stroke Survivor and Staff Experiences

As noted on the ethics form we need some more information here, please add in below:

Tell us how the stroke has affected you:

Choose one:
My speech has not been affected
My speech has been affected a bit
My speech has been affected quite a lot

Choose one:
I can walk without any aids.
I can walk with a stick/frame.
I use a wheel chair some of the time
I use a wheel chair all/most of the time

Choose one:
I have full use of both arms
I have partial use of one arm
I have little or no use of one arm

Tell us if the stroke has affected you in other ways:

………………………………………………………………………
………………………………………………………………………

==

The following information will be used anonymously in the study. Please answer as many questions as possible. However, you do not have to answer anything that you don't want to. Thank you.

Today's Date: ____________ **Participant #: [office use]**____________

Age: ________ **Gender (please tick):**

☐ **Male**
☐ **Female**
☐ **Transgender**

☐ **Yes**______

Have you had more than 1 stroke? ☐ **No**

Date of first stroke _ /_ / _

Date of most recent stroke (if applicable) _ / _ / _

Type of Stroke (if known): ____________________________

Location of the Stroke (if known): ____________________________

What is your dominant hand? ______________________________

How old were you when you left education? ____________________________

Highest qualifications obtained: __________________________

Are you currently in employment? ☐ **Yes** ☐ **No** **Are you retired?** ☐ **Yes** ☐ **No**

Current / previous work:

____

____

____

Living circumstances:

☐ **Living with a carer**
☐ **Living with someone who is not a carer**
☐ **Living alone**

Have you been affected by psychological problems like anxiety, depression or fatigue since your stroke: Yes/No:

If 'Yes' please tell us how you were affected:…………………………..
……………………………………………………………………………………

Have you received any treatment/help for this? Yes/No

If 'Yes' please tell us about the treatment/help provided:…………………
…………………………………………………………………………………………

About *'Rebuilding Your Life After Stroke'* book

When were you give a copy of the book? DATE__________________

Who gave you a copy of the book? NAME________________

Which parts of the book have you read/used?

	Please tell us about what you used in each part
In Part 1 • About this book • What you will find in the book • Psychological effects of stroke	
In Part 2 • **Chapter 1:** Difficult feelings • **Chapter 2:** Feeling different • **Chapter 3:** Changing relationships • **Chapter 4:** Thinking differently	
In Part 3 • **Chapter 5**: Becoming mindful • **Chapter 6**: Watching your thoughts • **Chapter 7**: Building acceptance • **Chapter 8**: Making the most of life after stroke	
In Part 4 • **Resources –** More information Websites • **Helplines** • **Books** • **List of videos and audio exercises available via web links**	

Did you attempt the written exercises?

	Please tick	
YES		**Which ones?**
NO		

Did you attempt the audio visual exercises?

	Please tick	
YES		**Which ones?**
NO		

Thank you for completing this questionnaire.

Appendix 14: Interview Schedule

Accessibility

1. How did you find out about the book?
2. Was it easy to obtain? YES/NO
    a. What made obtaining the book easy or difficult?

Content

1. What parts of the book applied to you the most?
2. What parts of the book weren't relevant to you?
3. Did you use any of the exercises in the book?
    Prompt: i. Which ones? What are the reasons for completing these exercises?

Experience

4. How did you use the book?
    Prompt: i. Alone or with others (e.g. staff, carers, other survivors)?
    ii. In parts over a period of time?
5. What sections of the book did you use?
6. How did you find the written exercises?
    Prompts: i. Were they easy or difficult?
    ii. Were useful or not useful?
7. How did you find the audio-visual exercises?
    Prompts: i. Were they easy or difficult?
    ii. Were useful or not useful?
8. What was the most helpful part of the book?
9. What was the most unhelpful part of the book?
10. In what ways (if any) has the book changed your life?

Usability

11. How easy was the book to use?
    Prompts: i. How easy was the book to navigate?
    ii. How easy was the text to read?
    iii. How easy were the exercises to read?
    iv. How easy were the Audio-visual exercises to complete?
    v. What changes would make the book easier to use
12. How understandable was the language used?
13. How do you think the book could be used to be most helpful?
    a. Reading by yourself (stroke survivor alone)
    b. Reading with a friend/partner/carer
    c. Reading with another stroke survivor
    d. Reading with a group of stroke survivors
    e. Reading with a member of staff

Appendix 15: Stages of Thematic Analysis

Stage 1: Data familiarisation

During this phase the researcher familiarises themselves with the data by reading and re-reading participants' transcripts. During this phase the researcher is curious about the data and attempts to find meaning and identify anything that is related to the research question.

Stage 2: Gathering initial codes

Initial codes are generated and are used to summarise or interpret portions of the data. The underlined portions of text in the interview excerpt column correspond to the initial codes in the left hand column.

Initial codes	Interview excerpt
	Researcher: What was the most helpful part of the book for you? Participant: Umm, I would say the anxiety and depression. **R: So, ok. Things around your mood.**
• Effect of stroke was unknown • Identified with content of the book	P: I've never suffered with it and I just didn't know what I was experiencing, and then when I read about these things I thought "Well, that's me, all over". So, yes, it was an eye opener.
	R: Yes and then you know the book has got quotes from people who have had a stroke before…people sharing their experience of anxiety or depression or fatigue, was that helpful? P: It was, yes. **R: In what way do you think?**
• Not alone, support • Improves awareness	P: Well it made me feel that I wasn't going through this on my own. There were other people before me and no doubt other people after me. But until you read about it…I mean I was totally oblivious to anything to do at all with strokes.
• Stroke causes an instant change	You know I was having a normal life, everything was hunky dory and then all of a sudden…BANG. And it is such a shock.
	R: And has the book helped with that shock?
• Motivation to continue	P: Yes it has definitely made me realise I am not on my own and that I have to carry on.
	R: Were there any parts of the book that were unhelpful?
• Stoke effects people in different ways • Focus on what's applicable	P: No, I think different people have got different things in different ways. Like I say the anxiety and depression really interested me whereas that stuff

• Positive experience • Able to move forward • Gives hope • Not alone	may not have interested a person who hadn’t suffered with it. P: On the whole it is a very good book. **R: That is really lovely, really good to hear. One of my questions here is, and I know you said the book helped you with your anxiety and low mood, but in what ways, if any, has the book changed your life?** P: It’s made me think that I can continue and that I can move forward whereas before I was stuck… I was stuck in a world of my own, whereas I read different people’s stories and I realise that it is a big world out there and you are not on your own.

Table 1: Example of stage 2 of Thematic Analysis - gathering initial codes

Stage 3: Searching for themes

During this phase, the researcher has an active role in searching for codes that capture something interesting and relevant to the research question. Codes are then clustered around pertinent issues that are relevant to the research question. During this phase, the researcher aims to identify themes that are distinct yet link together. A theme map is often used to diagrammatically present this.

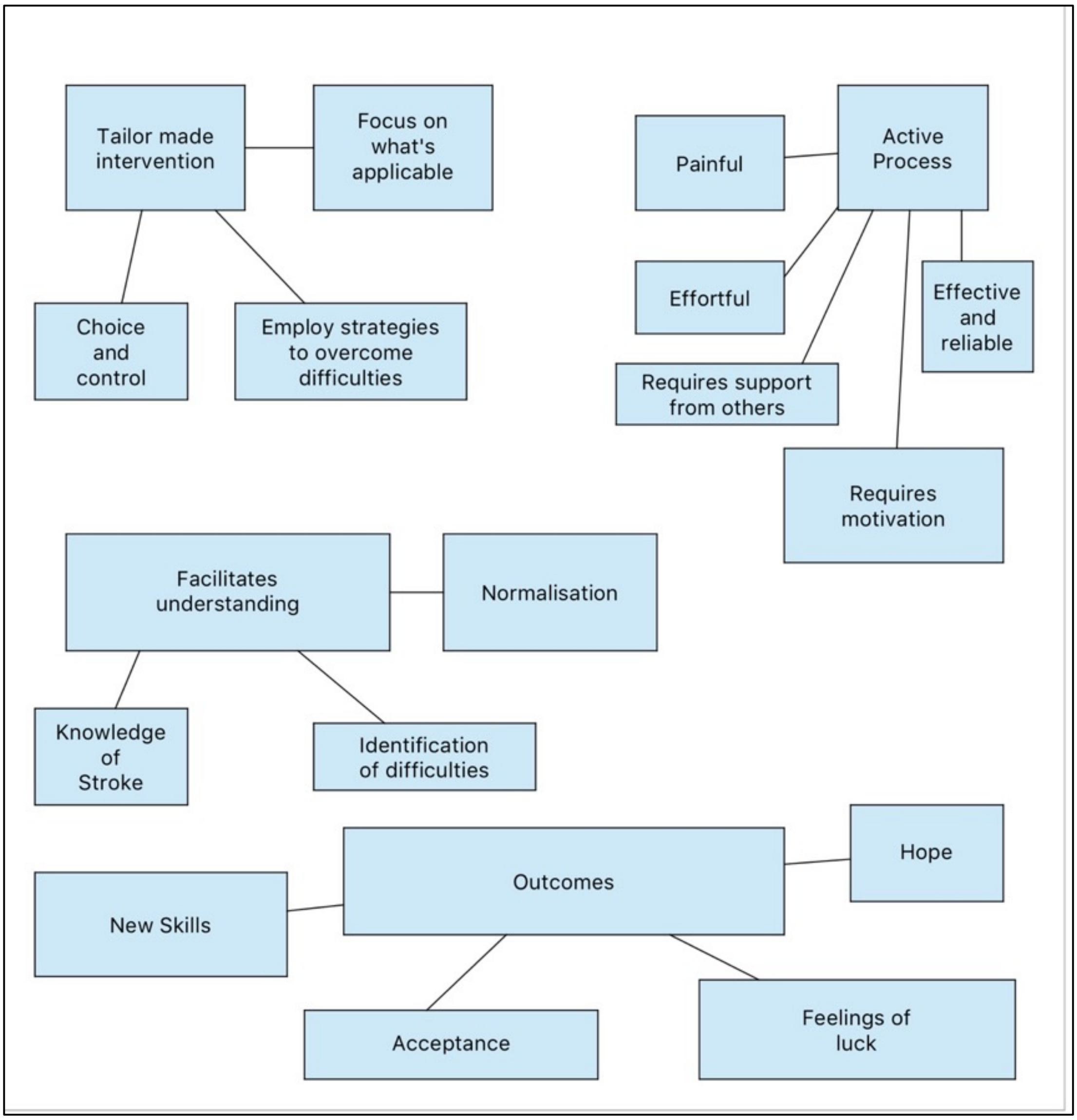


Figure 1: Visual representation of stage 3 of Thematic Analysis

Stage 4: Reviewing potential themes

During this phase, the researcher reviews the themes in relation to the data set in an attempt to ensure quality. During this phase, the theme can be changed or the boundaries can be reviewed in order to ensure that the theme is reflective of the data set and sets out to answer the research question. In this phase, the researcher reviewed the themes and the initial four themes were condensed into three.

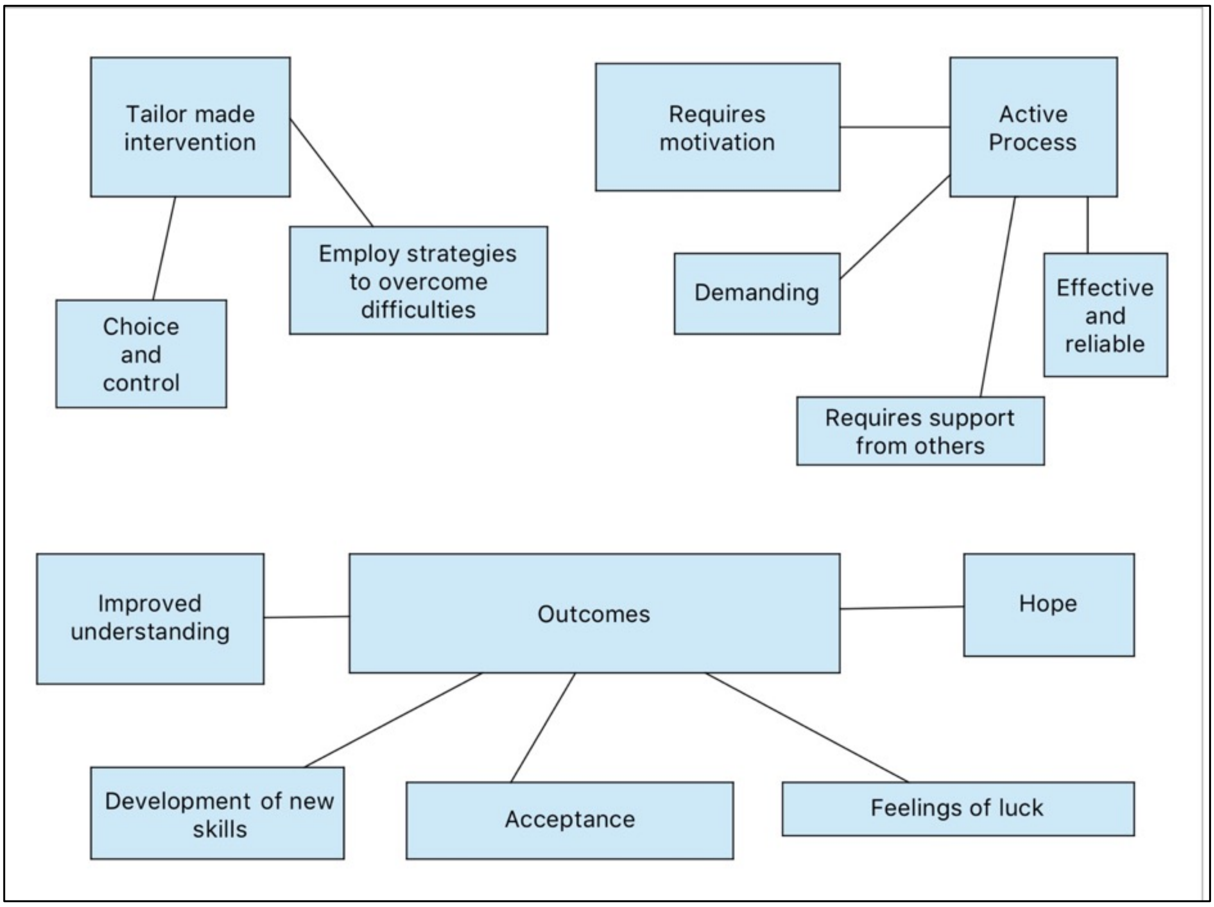


Figure 2: Visual representation of stage 4 of Thematic Analysis

Stage 5: Defining and naming themes

During this stage, the researcher provides an overview of the theme and ensures that they have a single focus and do not overlap.

Theme one: Active Process	Participants are key stakeholders in their own rehabilitation and for this to occur they need to be motivated, resilient to cope with its demands and to persevere with the challenges it engenders. This process is enhanced with professional support.
Theme two: Tailor made intervention	The book is a therapeutic tool which facilitates the development of an idiosyncratic intervention which is specific to participants' interests and perceived difficulties. The book also provides the opportunity for participants to adopt strategies to circumvent difficulties which may have limited their engagement.
Theme three: Outcomes	Participants reported positive outcomes such as an improved understanding of stroke, growth, acceptance, the facilitation of new skills and hope.

Table 2: Summary table of stage 5.

Stage 6: Report writing

Writing up the themes in a way so that they tell a coherent story.

Appendix 16 – Description of the bibliotherapy study

Five participants in this current study read *'Rebuilding Your Life After Stroke'* as part of a bibliotherapy study. All participants in the bibliotherapy study were recruited from the same Health Boards and charities that the current study had sought approval for. The inclusion criteria for the bibliotherapy study was the same as the inclusion criteria for the current study, but an additional inclusion criteria for the bibliotherapy study was that participants reported psychological distress (e.g. anxiety depression).

The aim of the bibliotherapy study was to investigate the efficacy of bibliotherapy in stroke survivors using the *'Rebuilding Your Life After Stroke'* book. Participants read the book with a clinician (trainee clinical psychologist) on a fortnightly basis. The amount of bibliotherapy sessions offered was dependent on need and the number of sessions ranged from 8-16. Each session was 40-50 minutes in duration and during this time the clinician provided support on how to use the book and apply its principles.