



“The mind is an absolute **”: adjustment to residual disability following an Acceptance and Commitment Therapy (ACT) group for Stroke Survivors***

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THESIS ABSTRACT

This portfolio comprises of three papers: a systematic review, an empirical study and a critical evaluation of the research process.

Systematic Review:

The systematic review explored the influence of psychological flexibility on physical and psychosocial functioning in adults living with chronic pain. Four electronic bibliographic databases were searched from 1980 onwards. From 2,521 citations 23 studies met the inclusion criteria. All studies revealed psychological flexibility or individual facets of the flexibility model improved daily functioning; including change in pain-related distress; depression-related interference; psychosocial functioning and in two cases improved physical health. There is some evidence that these effects are sustained over time. Proposals for further investigations into psychological flexibility are offered, in light of the methodological limitations associated with included articles.

Empirical Study:

This study aimed to explore stroke survivor's experiences of an Acceptance and Commitment Therapy (ACT) group and the elements that supported them in adjusting to stroke limitations. Thirteen participants with varying residual stroke disabilities were interviewed; responses were analysed using Grounded Theory. Central to participant's experiences was a concern of needing to accept a changed reality following stroke. Six core categories emerged from the data around processes that help facilitate movement towards improved acceptance. This intervention was found to support most stroke survivors with adjustment; although further replication and extension of this study is warranted due to certain methodological limitations. Implications for clinical practice and service development are considered.

Critical Evaluation:

Critical appraisal and reflections are offered on the research process.

TABLE OF CONTENTS

Paper 1: Systematic Review

Abstract	10
1.0 Introduction	11-12
2.0 Rationale for review	12 -13
3.0 Materials and Methods	13 - 18
3.1 Review method/database searches	
3.2 Search terms	
3.3 Inclusion and exclusion criteria	
3.4 Systematic Review Process	
3.5 Quality Assessment	
4.0 Results	19 - 43
4.1 Summary of included studies	
4.1.1 Study designs and aims	
4.1.2 Study location	
4.1.3 Sample characteristics	
4.1.4 Process measures	
4.1.5 Treatment outcome measures	
4.2 Summary of Psychological Flexibility process	
4.2.1 Acceptance and catastrophizing	
4.2.2 Decentering	
4.2.3 Values	
4.2.4 Mindfulness	
5.0 Discussion	44 - 49
6.0 References	50 - 64

Paper 2: Empirical Study

Abstract	66
1.0 Introduction	67 - 70
1.1 Stroke impact and adjustment	
1.2 Status of current stroke provisions	
1.3 Potential utility of third-wave interventions	
1.4 Study Aims	
2.0 Methodology	71 - 76
2.1 Design and theoretical background	
2.2 Sample and sampling	
2.3 Intervention	
2.4 Ethical considerations	
2.4.1 Ethical Approval	
2.4.2 Informed consent	

	2.4.3 Confidentiality and anonymity	
	2.5 Data collection and analysis	
	2.6 Ensuring rigour in qualitative research	
3.0	Results	77 - 92
3.1	Participants	
3.2	Grounded theory findings	
	3.2.1 Core Category 1: Negotiating challenges of stroke	
	3.2.2 Core Category 2: Contextual factors	
	3.2.2.1 Practicalities	
	3.2.2.2 Teaching methods and translatability	
	3.2.3 Core Category 3: Translating knowledge into practice	
	3.2.4 Core Category 4: Becoming Freer	
	3.2.5 Core Category 5: Valuing other stroke survivors	
	3.2.6 Core Category 6: Accepting a changed reality	
3.3	Conceptual framework/theory	
4.0	Discussion	93 - 99
4.1	Findings in relation to existing literature	
	4.1.1 Negotiating Challenges of Stroke	
	4.1.2 Conceptual Framework	
4.2	Strengths and limitations	
4.3	Clinical and service implications	
5.0	Conclusion	100
6.0	References	101 - 110

Paper 3: Critical Evaluation

1.0	Appraisal of Systematic Literature review	111 - 117
1.1	Inclusion Criteria	
	1.1.1 Articles must be peer reviewed	
	1.1.2 Adult population (> 18 years+)	
	1.1.3 Patients experiencing non-specific pain	
	1.1.4 Articles must be reported in English	
	1.1.5 Outcome measures relating to psychological wellbeing, disability and/or functioning	
	1.1.6 Psychological flexibility must be evaluated in some form	
1.2	Quality Appraisal Tool	
2.0	Research process of empirical paper	118 - 151
2.1	Reasons for undertaking this research project	
2.2	Experience of working with stroke survivors	
2.3	Reflections of ACT group	
	2.3.1 Design	
	2.3.2 Group format	
2.4	Experience of qualitative research	
2.5	Process of qualitative research	

2.5.1	Ethics	
2.5.2	Recruitment and Sampling	
2.5.2.1	Sample diversity	
2.5.2.2	Decreasing interrogation, Increasing abstraction	
2.5.2.3	Reliability/Validity	
2.6	Grounded theory methodology	
2.7	Data Collection	
2.7.1	Interviews	
2.7.2	Interview schedule	
2.8	Data Analysis	
2.8.1	Data management	
2.8.2	Coding	
2.8.3	Conceptual framework	
2.9	Quality Assurance	
2.9.1	Validity of Theory	
2.9.1.1	Fit	
2.9.1.2	Workability	
2.9.1.3	Relevance	
2.9.1.4	Modifiability	
2.9.2	Reliability of Theory	
2.9.2.1	Owning one's perspective	
2.9.2.2	Situating the sample	
2.9.2.3	Grounding in examples	
2.9.2.4	Providing credibility checks	
2.9.2.5	Coherence	
2.9.2.6	Accomplishing general vs specific research tasks	
2.9.2.7	Resonating with the member	
2.10	Supervision	
3.0	Research and Clinical Implications.....	152 - 157
3.1	Research	
3.2	Clinical	
4.0	Personal and Professional Development.....	158 - 161
5.0	References.....	162 - 166
Appendices		167 - 251

LIST OF APPENDICES

Appendix A	Search terms for systematic review
Appendix B	QATSDD Quality Assessment Results
Appendix C	Participant Demographic Questionnaire
Appendix D	Activate Your Life After Stroke (AYLAS) Course Leaflet
Appendix E	Activate Your Life After Stroke (AYLAS) Course Outline
Appendix F	Activate Your Life After Stroke (AYLAS) Example Presentation Slides
Appendix G	Activate Your Life After Stroke (AYLAS) Example of supplementary material and home activities
Appendix H	Ethics Process (1) REC Ethics Form (2) Letter of Favourable Opinion (3) Sponsorship Letter
Appendix I	Consent Form
Appendix J	Participant Information Sheet
Appendix K	Draft Interview Schedule
Appendix L	Memo Writing Excerpt
Appendix M	Data Analysis – Full Category Structure A.1 Core Category: Negotiating Challenges of Stroke A.2 Core Category: Contextual Factors A.3 Core Category: Translating Knowledge into Practice A.4 Core Category: Being Freer A.5 Core Category: Valuing Other Stroke Survivors A.6 Core Category: Accepting a Changed Reality
Appendix N	E-mail response from Dr. Stephen Hayes
Appendix O	Examples of coded transcripts B.1 Example Extract 1 (Mark) B.2 Example Extract 2 (Abigail) B.3 Example Extract 3 (Charles) B.4 Example Extract 4 (Liam)
Appendix P	Reflective Journal extract
Appendix Q	Criteria for Research Journal
Appendix R	Debrief Form

LIST OF TABLES

- Table 1.0** Description of Psychological Flexibility Processes
- Table 1.1** Tabulated Summaries of Systemic Review Results
- Table 1.2** Inclusion / Exclusion Criteria for Empirical Study
- Table 1.3** Participant Demographic Data

LIST OF FIGURES

- Figure 1.0** Acceptance and Commitment Therapy (ACT) model of Psychological Flexibility.
- Figure 1.1** Data Extraction Process for Systematic Review
- Figure 1.2** Conceptual Framework of Grounded Theory Model
- Figure 1.3** A visual representation of Grounded Theory
- Figure 1.4** Diagram of interviewing process in Grounded Theory
- Box 1.0** Recommendations for adapting ACT groups for Stroke



Paper 1

Investigating the role of psychological flexibility in physical and psychosocial functioning in chronic pain populations: a systematic review.

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ABSTRACT

Objective: There is mounting support for the relationship between psychological flexibility and functioning in chronic pain, however as yet there is no systematic review detailing this evidence. The aim of this paper is to review literature on psychological flexibility amongst chronic pain individuals' to determine effects on functioning, disability and life satisfaction.

Methods: A systematic search of the literature was conducted. Included studies were screened and quality assessed by independent raters. **Results:** Searches yielded 2,521

studies, of which 23 were included. Psychological flexibility significantly correlated, predicted or mediated change in pain-related distress and daily functioning. Investigations into individual facets of flexibility evidenced strong relationships between acceptance and functioning, whilst recent studies into other facets (e.g. values, defusion etc.) are producing promising findings.

Conclusions: Results suggest interventions to enhance psychological flexibility yield clinically worthwhile outcomes for individuals with chronic pain. These results have future implications for the management of chronic pain and the delivery of ACT interventions. Future research may benefit from more rigorous study designs to infer causality, improvements in selection and recruitment methods to enhance representation of the target population, and benefit from the inclusion of adjustment-specific measures.

1.0 INTRODUCTION

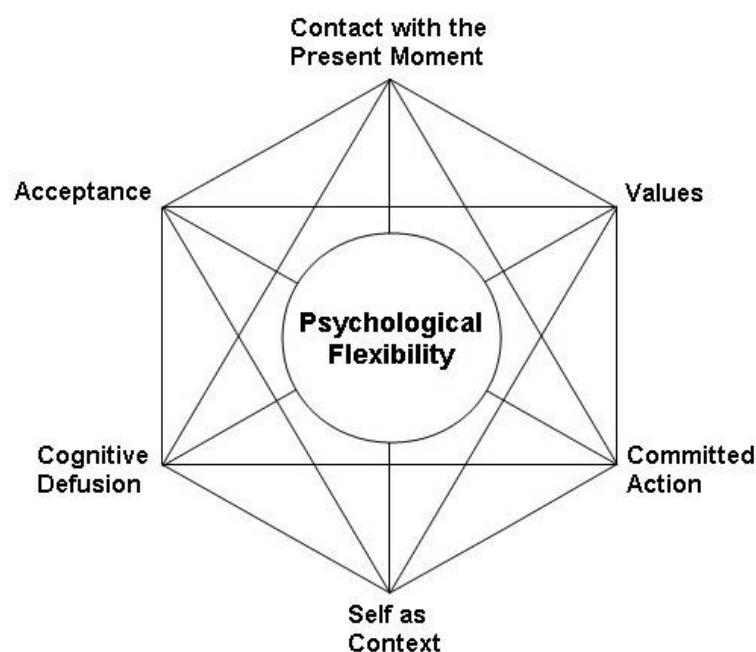
Despite chronic pain being one of the most prominent causes of disability worldwide (Fayaz *et al.*, 2016; Vos *et al.*, 2010), it continues to be one of the greatest underestimated challenges in healthcare systems (Breivik *et al.*, 2013). Chronic pain, both nociceptive and neuropathic subtypes, are characterised by pain which exceeds normal healing periods (typically > 3 months; Turk & Okifuji, 2001), and can be viewed as a multi-faceted condition with wide-ranging effects (Gatchel & Okifuji, 2006; Turk & Theodore, 2011). The complex interplay of affective, cognitive, behavioural and physical factors means individuals with chronic pain can experience a myriad of symptoms which markedly affect health-related quality of life (Breivik *et al.*, 2006), impair daily functioning (Tenhunen & Elander, 2005) and increase prevalence of psychological comorbidity, particularly anxiety and depression (Breivik *et al.*, 2006; Miller & Cano, 2009).

The impact of living with chronic pain has led to copious research into the efficacy of interventions; where difficulties managing persistent pain by purely pharmacological methods suggests psychological input also plays a central role in individuals care (Turk *et al.*, 2011). Robust evidence attests to the efficacy of cognitive-behavioural approaches, although considerable variations have been noted in outcomes which raise issues around replicability and generalisability of the data (Vlayen & Morley, 2005; Williams *et al.*, 2012). More recently, third-wave psychological interventions have been adopted within pain settings, with Acceptance and Commitment Therapy (ACT) evidenced as a useful alternative (Powers *et al.*, 2009; Hayes *et al.*, 2011). This approach has garnered considerable evidence for its efficacy in both mental (A-Tjak *et al.*, 2015) and physical health settings (Thewes *et al.*, 2014; Veehof *et al.*, 2011; Hann & McCracken, 2014; Hughes *et al.*, 2016), and more

recently, a growing body of empirical support has been published into the models constituent parts (Levin *et al.*, 2012).

ACT maintains distress and suffering are normal human reactions elicited in response to challenging events, which should not be pathologised or perceived as experiences that need eradicating (Hayes & Smith, 2005). Rather than attempting to control or ameliorate pain and suffering, ACT advocates that individuals remain open to private experiences (both positive and negative) and should focus on committing to a life which is congruent with their core values (McCracken & Morley, 2014). Its fundamental premise is to cultivate *psychological flexibility*, a tenet reflecting a number of interrelated psychological qualities (figure 1.0) which help to promote healthy functioning and wellbeing (Hayes *et al.*, 1999; Bonanno *et al.*, 2004). This contrasts to the absence of flexibility which often portends to heightened distress and psychopathology (Hayes *et al.*, 2006; Nolen-Hoeksema *et al.*, 2008; Bond *et al.*, 2011).

Figure 1.0: The ACT 'Hexaflex Model' of Psychological Flexibility (Hayes *et al.*, 2006).



Despite its popularity as a desired treatment outcome, the construct of psychological flexibility has been difficult to operationalise. Questions around whether flexibility is a multiple entity or single concept, if it's dynamic or static (Kashdan & Rottenberg, 2010), and whether it is a psychological skill to acquire (Hayes *et al.*, 2006) or an innate phenomenon, have been raised. "Psychological flexibility" is largely derived from the ACT movement, however other research into flexibility outside of the current "hexaflex" model have been reported on. As such, call for refinement and a more thorough understanding of the term is warranted (Gloster *et al.*, 2011). In its broadest sense, flexibility depicts a wide spectrum of behaviour and comprises behavioural, cognitive, physiological and emotional channels (Ben-Itzhak *et al.*, 2014). Lack of a unified definition across these domains has led to narrower conceptualisations of flexibility meaning different terminology is often used across settings depending on the reporting specialism or the date of research publication. To date, it has been investigated under the umbrella of emotion regulation or literacy, neuropsychology (known as cognitive or mental flexibility), personality and mindfulness and acceptance (known as psychological flexibility). Although literature reports subtle differences in how flexibility is defined across these contexts, there is some evidence, particularly within cognitive flexibility research, that suggests a closer alignment with psychological flexibility than initially considered (Ionescu, 2012). This may suggest an overarching construct of flexibility, with overlaps when respective fields are fully expanded. Specifically, "psychological flexibility" in ACT is credited as an inter-related, multi-process construct (Hayes *et al.*, 2006; table 1.0). Research surrounding different therapies has emphasised the importance of delineating mechanisms of therapeutic action to identify components responsible for eliciting change and supporting treatment effectiveness (Kazdin, 2007). There are studies emerging that have targeted ACT processes in attempts to understand how they affect study outcomes, which has

been conducted in a range of contexts (Hayes *et al.*, 2011; McCracken, 2013; Wright *et al.*, 2011).

Table 1.0: Description of Psychological Flexibility processes.

ACT SUB- PROCESSES	DEFINITION
Acceptance	Framed as an alternative to experiential avoidance; Acceptance relates to opening up and making room for painful experiences (thoughts, feelings, sensations etc.).
Cognitive Defusion	Ability to separate or detach from thoughts; rather than fusing with cognitions and perceiving them as ‘fact’.
Self-as- context	Ability to adopt different perspectives on one’s thoughts, feelings and behaviour, without investing too much in them.
Committed Action	Taking effective action that is guided by personal values, to build a life that is full and meaningful. It encourages people to move forward in life whilst incorporating painful or difficult experiences.
Values	Desired qualities that give life meaning and purpose.
Contact with present moment	Being psychologically present i.e. consciously connecting with and engaging in whatever is happening in the moment, and doing this non-judgementally.

2.0 RATIONALE FOR REVIEW

The aforementioned literature advocates ACT as an alternative and effective treatment in supporting individuals with persistent and chronic pain. It is clear extensive research has been conducted into the efficacy of ACT for this population, although it is only in the past two decades that interest in understanding the relative contribution of psychological flexibility and its sub-processes has proliferated. Emerging evidence has started to identify which facets contribute to change and functioning when individuals are learning to live with intractable pain.

This review was undertaken to explore and critically appraise existing research in this field, with the intention of providing comprehensive up-to-date knowledge of which ACT treatment processes may influence individuals' functioning and have the potential to support adjustment to chronic pain. To the researcher's knowledge there is currently no published review conducted in this field.

3.0 MATERIALS AND METHODS

3.1 Review Method/Database Searches

A systematic review of the literature was conducted to examine the influence of psychological flexibility (and its facets) on functioning and living with chronic pain. It was hoped that exploring the relationships between psychological flexibility and functioning would help elicit insight into what is needed to support adjustment processes for chronic pain individuals.

The main review question was as follows:

“How does psychological flexibility influence functioning when living with chronic pain?”

To identify relevant studies, the following four electronic bibliographic databases were searched on 21st and 22nd December 2016: PsycInfo; Ovid Medline; Embase; and AMED. Databases were searched from 1980 (the introduction/conceptualisation of ACT) to present date. Reference lists of full-text articles retrieved using the search strategy below were further hand-searched to identify additional research studies.

3.2 Search Terms

Subject heading and keyword searches using relevant words for each key area were identified (see appendix 1), this included the use of synonyms and antonyms (e.g. psychological inflexibility). Antonyms were included as flexibility features on a continuum, and this review wanted to be inclusive of all relevant papers.

These search terms were developed through both discussion with the academic supervisor and initial ‘first-run’ searches of various databases. Boolean operators were used to combine different search terms using the words ‘AND’ or ‘OR’.

3.3 Inclusion and Exclusion Criteria

All articles were screened against the following criteria.

Inclusion criteria:

Articles must be/include:

- Peer-reviewed
- Adult populations (> 18 years)
- Clinical samples with patients experiencing non-specific chronic pain
- Reported in English
- Treatment outcome measures relating to psychological wellbeing, disability and/or functioning.
- Psychological Flexibility was evaluated in some form, either collectively or via individual facets.

Exclusion Criteria:

- Case Studies

- The majority of individuals in the study must present with primary/non-specific chronic pain, and not pain secondary to other medical conditions e.g. HIV, Cancer, Multiple Sclerosis, etc.
- Paediatric populations (due to differences in physiology and pain assessment measures)
- Unpublished studies/abstract only.
- Articles not published in English

3.4 Systematic Review Process

Searches yielded 2,521 studies, which following the removal of duplicates (n=880), were reviewed by title and abstract for relevance to psychological flexibility and its underlying processes. Screening was conducted by two reviewers independently using the above criteria. Articles were eliminated at this stage if they met any of the exclusion criteria (n=1,602). From this process, 39 full-text articles were retrieved; 22 were eligible for inclusion in this systematic review. Reference lists of retrieved papers and homepages of authors were screened for references not identified by the original search; yielding one further study. The data extraction process is illustrated in Figure 1.1. Study quality via use of the Quality Assessment Tool for Studies with Diverse Designs (QASTDD; Sirriyeh *et al.*, 2011) was assessed by one reviewer, and checked by a second. Use of quality assessment measures is recommended for the rigorous implementation of a systematic review (Schlosser, 2007). Tabulation of results of all included studies is depicted in Table 1.1. Any disagreement around the inclusion of certain articles was discussed between reviewers until a consensus was achieved.

3.5 Quality Assessment

Overall, quality appraisal of included texts should be interpreted with caution, as study quality was variable (see appendix B for QASTDD). Of the 23 studies, quality assessment

revealed scores ranging between 18/42 and 32/42; indicating some papers were of a higher quality than others. Interpreted as an average percentage, scores ranged from 40% - 76%. The main limitations comprised of: the lack of statistical assessments of the reliability and validity of outcome tools; issues regarding the reliability of the analysis process and failure to consider sample size in terms of analysis.

Figure 1.1: Systematic Data Extraction Process

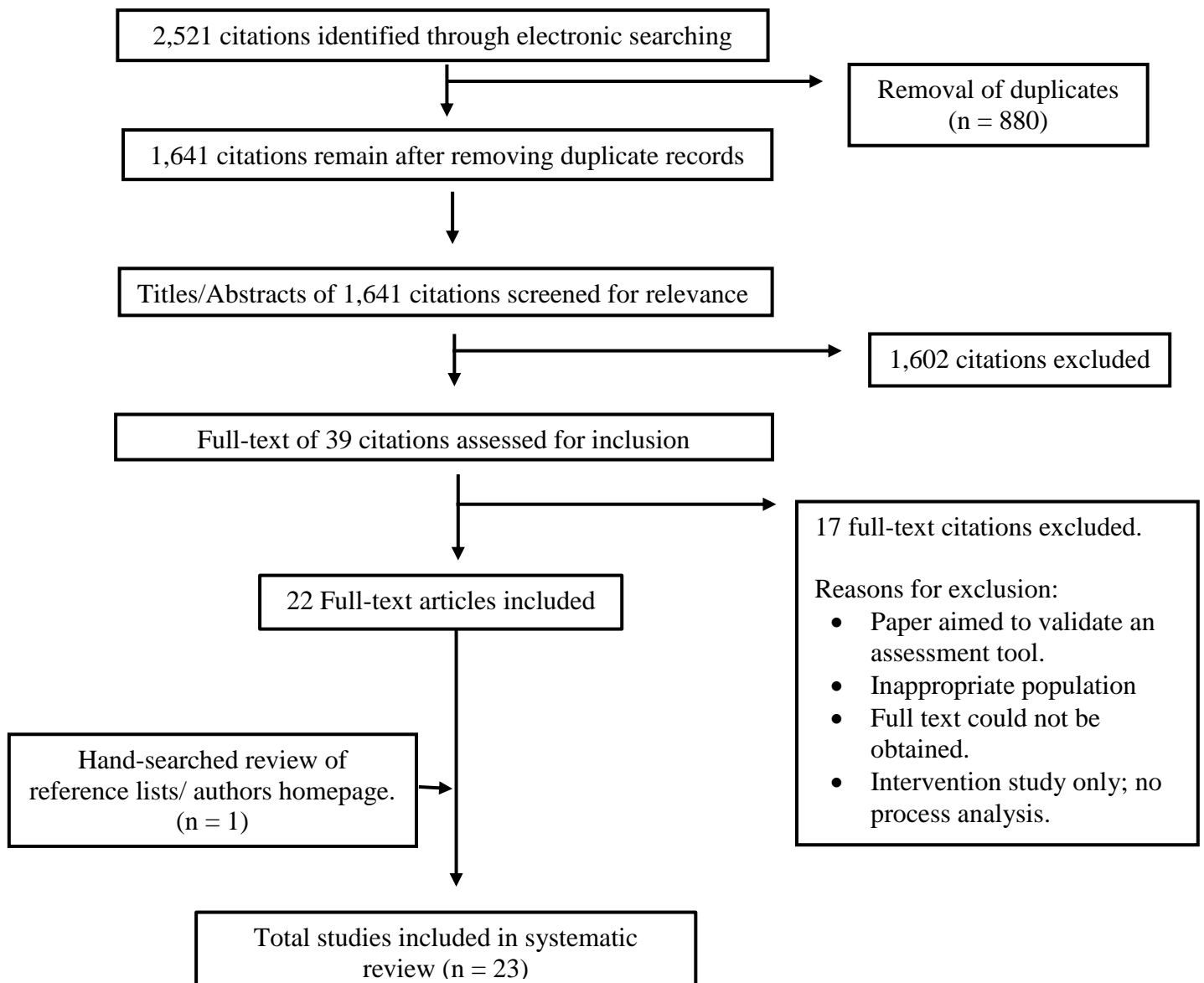


Table 1.1: *Tabulation of summaries from systematic review papers*

Paper	Country	Aim	Sample	Method	Measures/ Variables	Key Findings	Key Limitations	Quality Score (+ %)
(1) McCracken, Barker & Chilcot (2014)	UK	To verify the validity of the Experiences Questionnaire (EQ) and to investigate the relationship between decentering and rumination.	N = 352 Age (Years) M = 47.3; SD = 11.69 Gender Female = 235 Male = 117 Median pain duration (months) = 97.0.	Participant Recruitment Consecutive admission Design Cross-Sectional Data Collection Baseline measures Data Analyses 1. Correlations 2. Mediation Analyses: SEM	Process EQ AAQ-II CPAQ Outcome PHQ-9 SF-36	<ul style="list-style-type: none"> Decentering neg. correlated with dep, and pos. correlated with social and mental health functioning. Decentering and rumination indirectly and directly related to mental health, social functioning and dep. Neither rumination nor decentering correlated with physical functioning. 	<ul style="list-style-type: none"> Cross-sectional design Bias in use of self-report measures. Issues with wider extrapolation of data (reliability/generalisability). 	32 (76%)
(2) McCracken & Zhao- O'Brien (2010)	UK	To assess general psychological acceptance and its relations with patient functioning.	N = 144 Age (Years) M = 42.4; SD = 11.5 Gender Female = 92 Male = 52 Median pain duration (months) = 139.0	Participant Recruitment Consecutive admission Design Cross-Sectional Data Collection Baseline measures Data Analyses 1. Pearsons Correlation	Process AAQ-II CPAQ MAAS PASS-20 Outcome BC-MDI SIP	<u>AAQ + Functioning</u> <ul style="list-style-type: none"> Psych. acceptance neg. correlated with pain-related distress, dep, pain-related anx, and disability. <u>Pain Acceptance + functioning</u> <ul style="list-style-type: none"> Strong neg. correlation between pain acceptance and dep ($r = -.69$) + psychosocial disability ($r = -.65$). Strong correlation between pain acceptance + pain-related anx. ($r = -.74$). 	<ul style="list-style-type: none"> Cross-sectional design Bias in use of self-report measures. Bias introduced by recruiting from tertiary care; issues of generalisability. 	29 (69%)

				2. Multiple Regression		<u>Regression Analyses</u> <ul style="list-style-type: none"> Across all outcome measures, general psychological acceptance and pain acceptance accounted for greater variance (average 29%) than that explained by pain intensity (average 11%). 		
(3) McCracken, Gutiérrez-Martínez & Smyth (2013)	UK	To investigate the contribution of 'decentering', (alone and with other facets of psychological flexibility), in patient functioning.	N = 150 Age (Years) M = 43.0; SD = 11.7 Gender Female = 104 Male = 46 Median pain duration (months) = 94.0	Participant Recruitment Consecutive admission Design Cross-Sectional Data Collection Baseline measures Data Analyses 1. Pearsons Correlation 2. Multiple Regression	Process EQ CPAQ MAAS AAQ-II CPVI Outcome BCMDI SIP PASS-20	<ul style="list-style-type: none"> Decentering significantly correlated with patient's emotional and psychosocial functioning. Decentering did not correlate with physical disability or medical visits. 	<ul style="list-style-type: none"> Use of retrospective and correlational data; cross-sectional design. Bias introduced by recruiting from tertiary care; issues of generalisability. 	27 (64%)
(4) McCracken & Velleman (2010)	UK	Investigating specific psychological flexibility processes within a primary care setting.	N = 239 Age (Years) M = 61.5; SD = 13.7 Gender Female = 139 Male = 100	Participant Recruitment Convenience; Patient Opt-in. Design Cross-Sectional Data Collection Baseline measures	Process CPAQ MAAS AAQ CPVI Outcome SF-36	<ul style="list-style-type: none"> Blocked model of process variables contributed to overall variance in outcome, in 9 regression equations. Mean variance = 24%. Pain intensity significantly predicted physical functioning, role functioning physical, role functioning emotional and social functioning. 	<ul style="list-style-type: none"> Cross-sectional design Selective sampling bias. Limits with assessment measures. 	29 (69%)

			Median pain duration (months) = 120.0	Data Analyses 1. Pearsons Correlation 2. Multiple Regression				
(5) Kwok, Chan, Chen & Lo (2016)	Hong Kong	Investigating psychological (in)flexibility and regulatory processes (i.e. self-discrepancy and pain adjustment)	N = 100 Age (Years) R = 21 - 80 Gender Female = 67 Male = 33 Median pain duration (months) = 70.94	Participant Recruitment Convenience; Patient Opt-in. Design Cross-Sectional Data Collection Baseline measures Data Analyses 1. Correlations 2. Mediation analysis (Sobel Test and Bootstrapping)	Process AAQ-II CPAQ Outcome BPI HADS HSQ	<ul style="list-style-type: none"> • PiF pos. correlated with pain interference ($r=.38$; $p<.001$) and emotional distress ($r=.69$; $p<.001$). • Self-discrepancy pos. correlated with pain interference ($r=.62$; $p<.001$) and emotional distress ($r=.39$; $p<.001$). • PiF inversely correlated with pain acceptance ($r=-.61$; $p<.001$); whilst self discrepancy neg. correlated with acceptance ($r=-.42$; $p<.001$) • PiF explained significant relationship between self-discrepancy and pain outcomes. 	<ul style="list-style-type: none"> • Cross-sectional design • Convenience Sampling • Small Sample Size • Bias in use of self-report measures. 	26 (62%)
(6) De Boer, Steinhagen, Versteegen, Struys & Sanderman (2014)	Netherla nds	Investigating the relationship between mindfulness, acceptance and pain-related catastrophizing.	N = 89 Age (Years) M = 51.33 SD = 15.54 Gender Female = 55 Male = 34	Participant Recruitment Consecutive Admission Design Cross-Sectional Data Collection Baseline measures Data Analyses 1. Pearsons Correlation	Process AAQ-II MAAS Outcome PCS NRS	<ul style="list-style-type: none"> • Strong correlations between: <ul style="list-style-type: none"> - Mindfulness + acceptance ($r(85)=.52$; $p<.001$) - Acceptance + catastrophizing ($r(82)=-.42$; $p<.001$) • Controlling for age, gender, & pain intensity, general psychological acceptance was a strong predictor of pain-related catastrophizing (explained additional 12% variance). 	<ul style="list-style-type: none"> • Validity of using MAAS tool • Cross-sectional design • Bias in use of self-report measures. • Issues of generalisability; sample included severe pain patients only. • Bias from sampling method. 	27 (64%)

				2. Multiple Linear Regression		<ul style="list-style-type: none"> Mindfulness was not a strong predictor of pain-related catastrophizing (incl. when acceptance is a moderator). 		
(7) Cederberg, Cernvall, Dahl, von Essen, Ljungman (2016)	Sweden	Exploring mediating effects of acceptance on life satisfaction and physical functioning.	N = 115 Age (Years) M = 46.0 SD = 12.3 Gender Female = 74 Male = 41 Median pain duration (months) = >12.0	Participant Recruitment Convenience; Patient Opt-In. Design RCT (ACT vs. AR) Data Collection Pretreatment, posttreatment, FU (6 [FU1]/12 mths [FU2]) Data Analyses 1. Mediation Analysis (Product of Coefficients).	Process CPAQ Outcome SWLS ÖMPQ HADS NRS	<u>ACT Group</u> <ul style="list-style-type: none"> Indirect effect of treatment via acceptance in physical functioning, between preassessment & FU1. <ul style="list-style-type: none"> Indirect trend found between preassessment and FU2. No indirect effects of treatment on change in life satisfaction, via any mediator. 26% variance in change in physical functioning accounted for by acceptance, after adjusting for pain intensity. 	<ul style="list-style-type: none"> Attrition Low power 	31 (74%)
(8) Wicksell, Olsson & Hayes (2010a)	Sweden	To explore mechanisms of change in patients with chronic pain following whiplash injuries.	N = 21 Age (Years) Unknown Gender Unknown Median pain duration (months) = 83.0	Participant Recruitment Convenience; Patient Opt-In. Design Data taken from original RCT study. Data Collection Pretreatment, posttreatment, FU	Process PIPS Outcome PDI SWLS VAS HADS SES TSK	<ul style="list-style-type: none"> No mediation effects for all outcome measures pre-post change in pain-related disability and life satisfaction. Treatment effects significantly mediated by psychological flexibility on pain-related disability and life satisfaction (Pre>Post; Pre >FU) 	<ul style="list-style-type: none"> Small sample size Risk of confounding bias in their mediation analyses. Issues with generalisability to other contexts/pain conditions. 	22 (52%)

				Data Analyses 1. Mediation Analysis (Product of Coefficients)				
(9) Vowles, McCracken & Zhao-O'Brien (2011)	UK	Investigating longitudinal treatment processes of ACT.	N = 108 Age (Years) M = 47.1 SD = 10.7 Gender Female = 67 Male = 41 Median pain duration (months) = 96.0	Participant Recruitment Convenience; Patient Opt-In. Design Longitudinal Data Collection Pretreatment, FU (3months/ 3 years). Data Analyses 1. ANOVA 2. Correlations 3. Multiple Regression	Process CPAQ CPVI Outcome BCMDI PASS-20 SIP	<ul style="list-style-type: none"> Reliable improvements reported across dep, pain-related anx. and disability both at 3-month (av. 46.2%) and 3-year FU (av. 35.8%). Individually, at 3mths FU 84.1% had reliably improved (n=66) since treatment on 1+ measures; 64.8% at 3yr FU (n=70). Change in pain acceptance and values-based action over 3-years accounted for significant variance in changes in overall functioning: dep (53%); pain-related anx. (61%); psychosocial disability (37%); physical disability (22%) and healthcare use (11%). 	<ul style="list-style-type: none"> Attrition No control group Bias in use of self-report measures. 	26 (62%)
(10) McCracken, Davies, Scott, Paroli, Harris & Sanderson (2015)	UK	Examining ACT process variables following attendance to a brief interdisciplinary treatment for chronic pain.	N = 86 Age (Years) M = 49.2 SD = 12.8 Gender Female = 48 Male = 38	Participant Recruitment Consecutive Admission Design Non-Randomised Data Collection	Process CPAQ CAQ Outcome PHQ-9 SF-36	<ul style="list-style-type: none"> Significant improvements pre>posttreatment on all outcome and process measures. Pain acceptance significantly correlated with change in all outcome measures, except pain intensity. Committed action significantly correlated with change in dep, 	<ul style="list-style-type: none"> No control group Lack of investigation into maintained gains. Bias introduced by recruiting from one treatment centre; generalisability difficulties. 	25 (60%)

			Median pain duration (months) = 123.6	Pretreatment, posttreatment Data Analyses 1. ANOVA 2. Pearson Correlations 3. Multiple Regression		mental health and physical functioning. • Only change in pain acceptance contributed unique variance to change in all outcome variables (dep; mental health; physical functioning).		
(11) Scott, Hann & McCracken (2016)	UK	Investigating change in 4 psychological flexibility facets following an ACT-based intervention.	N = 384 Age (Years) M = 46.4 SD = 11.6 Gender Female = 255 Male = 129 Median pain duration (months) = 99.0	Participant Recruitment Consecutive Admission Design Longitudinal Data Collection Pretreatment, posttreatment; 9- month FU. Data Analyses 1. ANOVA 2. Pearson Correlations 3. Multiple Regression	Process CPAQ CFQ EQ CAQ Outcome PHQ-9 SF-36	<ul style="list-style-type: none"> Significant improvements reported on all study variables between pre>post and pre>9-month FU. Combined changes in process variables accounted for 6-27% variance in clinical outcomes between pre>post. <ul style="list-style-type: none"> CPAQ predicted change on all outcome variables. CFQ predicted change in social functioning/dep. CAQ predicted change in dep. Pre>FU combined changes in process variables accounted for 7-27% variance in clinical outcomes. <ul style="list-style-type: none"> CPAQ predicted change in only pain intensity/social functioning CFQ predicted change in social functioning/dep. CAQ predicted change in physical functioning/dep. 	<ul style="list-style-type: none"> No control group Possibility of spontaneous remission on some variables e.g. dep. Difficult to infer causal relationship from correlational design. Attrition at FU Bias in use of self-report measures 	29 (69%)

(12)	UK	Exploring psychological flexibility processes in ACT for chronic pain.	N = 168 Age (Years) M = 43.5 SD = 13.0 Gender Female = 112 Male = 56 Median pain duration (months) = 97.5	Participant Recruitment Consecutive Admission Design Non-randomised Data Collection Pretreatment, posttreatment; 3-month FU. Data Analyses 1. Pearson Correlations 2. Multiple Regression	Process CPAQ AAQ-II MAAS CPVI Outcome BCMDI PASS-20 SIP Medical Visits	<ul style="list-style-type: none"> • Change in PF measures significantly correlated with changes in dep, pain-related anx. and disability. • Change in pain acceptance correlated with changes in pain intensity ($r = -.31$; $p < .001$). • Controlling for pain intensity, all process variables explained an av. 18% variance in outcome variables; except medical visits. • Psychological acceptance uniquely contributed to dep, physical disability, psychosocial disability. • Pain acceptance uniquely predicted pain-related anx. 	<ul style="list-style-type: none"> • No control • Psychological Flexibility is a difficult concept to assess; first generation of instrument development. • Bias in use of self-report measures 	31 (74%)
(13)	UK	Exploring mediating effects of pain acceptance, between patient functioning and catastrophizing.	N = 334 Age (Years) M = 42.6 SD = 11.4 Gender Female = 208 Male = 126 Median pain duration (months) = 96.0	Participant Recruitment Consecutive Admission Design Cross-sectional Data Collection Baseline measures. Data Analyses 1. Pearson Correlation 2. Mediation Analyses (Causal Steps Method)	Process CPAQ PCS Outcome BDI PASS-20 SIP Physical functioning tests (timed walk + sit-to-stand exercises)	<ul style="list-style-type: none"> • Catastrophizing and acceptance of pain significantly correlated with functioning. • Catastrophizing significantly accounted for variance across all outcome measures (except physical functioning tests). • Controlling for catastrophizing, acceptance of pain significantly predicted scores on all outcomes measures (except pain intensity + timed walk); indicating partial mediation effects. • Indirect effects of pain acceptance were significant for each outcome measure. 	<ul style="list-style-type: none"> • Cross-sectional study; cannot infer causation. • Bias in use of self-report measures • Use of single measures to depict each domain; measuring a complex construct. 	21 (50%)

(14)	Netherlands	Exploring whether change in psychological flexibility and catastrophizing influenced change in pain interference and patient functioning, via online ACT.	<p>N = 238</p> <p>Age (Years) *ACT, EW and WL respectively</p> <p>M = 52.9; 52.3; 53.2 SD = 13.3; 11.8; 12.0</p> <p>Gender *ACT, EW and WL respectively</p> <p>Female = 63; 60; 58 Male = 19; 19; 19</p> <p>Pain duration (months) = >6 months for inclusion; high % of participants had pain >5 years.</p>	<p>Participant Recruitment Convenience; Patient Opt-In</p> <p>Design Data used from* previous RCT (ACT vs. Expressive Writing, EW Vs. Waiting List, WL)</p> <p>Data Collection Data collected at 5 time-points for ACT group and 3 for other trial arms.</p> <p>Data Analyses 1. T-tests 2. Pearson Correlation 3. Mediation Analyses (Product of Coefficients)</p>	<p>Process PIPS PCS</p> <p>Outcome MPI HADS NRS</p>	<p><u>ACT</u></p> <ul style="list-style-type: none"> Increased PF mediated change in pain interference and intensity, and psychological distress. Catastrophizing uniquely affected pain-related outcomes. Evidence of reciprocal relationships between psychological flexibility and catastrophizing. 	<ul style="list-style-type: none"> Selective sampling; issues with generalisability High Attrition Multiple t-tests increases likelihood of Type 1 error Causality only investigated using ACT data; difficult to decipher if this is a result of ACT or if change presented would be observed in other trial arms. 	<p>25 (60%)</p>
(15)	UK	To prospectively investigate the role of pain acceptance and values-based	<p>N = 115</p> <p>Age (Years) M = 48.1 SD = 11.0</p>	<p>Participant Recruitment Consecutive Admission</p>	<p>Process CPAQ CPVI</p>	<ul style="list-style-type: none"> Significant increases observed on activity engagement, pain willingness, overall pain acceptance and values-based action between time 1 and time 2. 	<ul style="list-style-type: none"> Bias in use of self-report measures Arbitrary interval period between times 1 and 2; and variance between 	<p>24 (57%)</p>

		action on patient functioning.	Gender Female = 65 Male = 50 Median pain duration (months) = 77.0	Design Longitudinal Data Collection Baseline measures (time 1) and pre-treatment (time 2). Data Analyses 1. T-tests 2. Pearsons Correlation 3. Multiple Regression	Outcome PASS-20 BC-MDI SIP	<ul style="list-style-type: none"> Acceptance neg. correlated with pain intensity. Acceptance and valued-action neg. correlated with pain-related distress, anx. and dep; functioning and disability. All regression equations were significant. Total of acceptance and values accounted for 8.3% - 47.0% variance. 	participants - > increases bias of confounding factors. <ul style="list-style-type: none"> Generalisability issues. 	
(16) McCracken & Eccleston (2005)	UK	To prospectively investigate relations between pain acceptance and patient functioning.	N = 118 Age (Years) M = 44.2 SD = 10.7 Gender Female = 76 Male = 42 Median pain duration (months) = 87.5	Participant Recruitment Consecutive Admission Design Cohort Study Data Collection Baseline measures (time 1) and pre-treatment (time 2). Data Analyses 1. Pearsons Correlation 2. Multiple Regression	Process CPAQ Outcome BDI PASS SIP	<ul style="list-style-type: none"> Neg. correlations found between acceptance and dep; pain-related anx.; disability and daily rest due to pain. Pain acceptance accounted for significant variance across emotional, social and physical functioning; ranging from 6.3% - 29.0% 	<ul style="list-style-type: none"> Generalisability issues Difficulty inferring causality One process measure used; suggests a need for more sensitive measures to fully assess acceptance experiences and behaviour. 	23 (55%)
(17)	UK	To investigate relations between	N = 105 Age (Years)	Participant Recruitment	Process MAAS CPAQ	<ul style="list-style-type: none"> Mindfulness significantly correlated with all outcomes variables. 	<ul style="list-style-type: none"> Cross-sectional design Issues with generalisability 	21 (50%)

McCracken, Gauntlett-Gilbert & Vowles (2007)		mindfulness and patient functioning.	M = 46.9 SD = 12.5 Gender Female = 63 Male = 42 Median pain duration (months) = 96.0	Consecutive Admission Design Cross-sectional Data Collection Baseline measures Data Analyses 1. Pearsons Correlation 2. Multiple Regression	Outcome BC-MDI PASS-20 SIP	<ul style="list-style-type: none"> • Mindfulness significantly predicted all domains of functioning in chronic pain patients, and medication use. • Average variance increment across all equations for process variables = Mindfulness - 60%; Combined mindfulness and acceptance - 28% 		
(18) Vowles, McCracken & Eccleston (2007)	UK	To explore the contribution of pain, acceptance and catastrophizing processes in relation to changes in treatment outcomes.	N = 252 Age (Years) M = 44.2 SD = 11.4 Gender Female = 157 Male = 95 Median pain duration (months) = 96.0	Participant Recruitment Consecutive Admission Design Non-randomised. Data Collection Pre-treatment, Posttreatment, FU – 3months. Data Analyses 1. ANOVAs 2. Pearson Correlation 3. Linear Regression	Process PCS CPAQ Outcome BDI PASS SIP Physical performance measures – walk; sit-to-stand.	<ul style="list-style-type: none"> • Acceptance and catastrophizing changed over treatment (pre>post; pre > FU); both processes contributed to change in outcome variables. 	<ul style="list-style-type: none"> • Bias in use of self-report measures • Issues with generalisability • Query: selection bias with using data from treatment completers only. 	26 (62%)
(19)	UK	Comparing traditional	N = 114	Participant Recruitment	Process BCPI-2	<ul style="list-style-type: none"> • Traditional pain management strategies (i.e. activity pacing, 	<ul style="list-style-type: none"> • Attrition at FU 	18

Vowles & McCracken (2010)		coping methods to change in psychological flexibility, with regards to patients functioning.	Age (Years) M = 46.1 SD = 10.0 Gender Female = 73 Male = 41 Median pain duration (months) = 96.0	Design Non-randomised. Data Collection Pre-treatment, Posttreatment, FU – 3months. Data Analyses 1. ANOVA 2. Pearson Correlation 3. Linear Regression	Outcome BC-MDI PASS-20 SIP No. of medical visits. Physical functioning measures x2	relaxation, exercise etc.) were not related to improvements in functioning Pre > FU. <ul style="list-style-type: none"> PF (incl. mindfulness, defusion, valued-based activity etc.) significantly related to improvements in functioning. Change in traditional pain management methods accounted for an average of 0.34% of changes in outcomes variables. PF accounted for an average 9.1% variance. 	<ul style="list-style-type: none"> Bias in use of self-report measures 	(43%)
(20) McCracken & Yang (2006)	UK	To investigate the relationship between values-based action and patient functioning.	N = 140 Age (Years) M = 47.6 SD = 11.7 Gender Female = 95 Male = 45 Median pain duration (months) = 87.0	Participant Recruitment Consecutive admission Design Cross-Sectional Data Collection Baseline Measures Data Analyses 1. Pearson Correlation 2. Multiple Regression	Process CPVI CPAQ Outcome BC-MDI PASS-20 SIP NRS	<ul style="list-style-type: none"> Success scores (i.e. people living according to their values) neg. correlated with disability, dep, dep-related interference and pain-related anx. Discrepancy scores (i.e. not living in line with values) pos. correlated with each of the above variables. Patients successfully living according to values was related to acceptance of pain (CPAQ; variance increments ranged from 13%-35%); but also uniquely contributed to overall patient functioning (statistically significant variance ranging from 3% - 12%). 	<ul style="list-style-type: none"> Limitations with CPVI; measures may exist which explore different value domains, and have improved importance ratings. Issues with generalisability: re: pain severity and culturally non-diverse (important especially for assessing values which are typically culturally derived). Cross-sectional design. 	27 (64%)

(21)	UK	Investigating patterns of change between psychological flexibility and treatment outcomes.	N = 117 Age (Years) M = 45.5 SD = 11.0 Gender Female = 84 Male = 33 Median pain duration (months) = 52.0	Participant Recruitment Consecutive admission Design Non-randomised, open trial. Data Collection Pre-treatment, Posttreatment, 3-month FU. Data Analyses 1. Mediation Analyses (SEM)	Process CPAQ CPVI BPCI-2 SCS Outcome NRS No. of medical visits SIP BC-MDI PASS-20 Physical functioning tasks – walking and sit-to-stand.	<ul style="list-style-type: none"> Individual change in pain acceptance, PF, self-compassion and the difference between values importance and success significantly mediated change in disability, dep, pain-related anxiety, and no. of medical visits + prescribed analgesics. Pain acceptance and self-compassion were significant mediators of change in psychosocial disability, dep, and pain-related anxiety. Pain acceptance, self-compassion and values were all significant mediators of change in no. of medical visits and prescribed analgesics. Pain acceptance was a significant mediator of changes in physical disability. Self-compassion was a significant mediator in changes of other disability. Reliable and clinically significant change reported on at least 1 of 3 functioning measures at FU (dep, pain-related anxiety or disability). 	<ul style="list-style-type: none"> Lack of control group Homogenous sample -> issues with generalisability Bias in use of self-report measures. Issues of study feasibility/replicability in other treatment contexts. Attrition 	30 (71%)
(22)	UK	To examine the concept of pain acceptance.	N = 160 Age (Years) M = 46.9 SD = 14.8 Gender	Participant Recruitment Consecutive admission Design Cross-Sectional	Process CPAQ Outcome BDI PASS SIP	<ul style="list-style-type: none"> Correlation found between improved pain acceptance and reductions in pain intensity, pain-related anx., avoidance, dep and disability. Low correlation between acceptance and pain intensity. 	<ul style="list-style-type: none"> Bias in use of self-report measures Cross-sectional design Sample comprised of patients seeking treatment; introduce bias. 	20 (40%)

			Female = 106 Male = 54 Median pain duration (months) = 36.0	Data Collection Baseline Measures Data Analyses 1. Pearson Correlation 2. Multiple Regression		<ul style="list-style-type: none"> After controlling for gender, age, and pain intensity, acceptance of pain significantly predicted change on measures of: dep, anxiety, avoidance, disability, daily uptime and work status. 		
(23) Esteve, Ramirez-Maestre, & Lopez-Martinez (2007)	Spain	To compare pain acceptance, pain-related cognitions and chronic pain in predicting patient adjustment.	N = 117 Age (Years) M = 54.0 SD = 11.34 Gender Female = 83 Male = 34 Median pain duration (months) = 137.0	Participant Recruitment Consecutive admission Design Cross-Sectional Data Collection Baseline Measures Data Analyses 1. Structural Equation Modelling (SEM)	Process CPAQ PRSS PRCS Outcome VPMI HADS IFI NRS	<ul style="list-style-type: none"> Acceptance had a strong pos. correlation with active coping ($r=.54$) and pos. correlation with resourcefulness beliefs ($r=.32$); it neg. correlated with passive coping ($r=-.38$) and catastrophizing self-statements ($r=-.38$). All path coefficients were statistically significant in the final equation model. <ul style="list-style-type: none"> Higher levels of passive coping, linked to higher levels of anx. and dep. Higher levels of active coping, associated with decrease in depressive symptoms Higher occurrence of catastrophizing statements, related to greater anxiety and pain intensity Greater acceptance linked to better functional status and decrease in functional impairment. 	<ul style="list-style-type: none"> Bias in use of self-report measures Cross-sectional design Possibility of coping and cognitive measures not being as clearly demarcated as expected; query overlap of construct measures. 	22 (52%)

M = Mean; **SD** = Standard Deviation; **FU** = Follow Up; **R** = Range; **RCT** = Randomised Controlled Trial; **ACT** = Acceptance and Commitment Therapy; **AR** = Applied Relaxation; **PF** = Psychological Flexibility; **PiF** = Psychological Inflexibility; **neg.** = negative; **pos.** = positive; **av.** = average; **dep** = depression; **anx** = anxiety

PROCESS MEASURES:

AAQ-I/II Acceptance and Action Questionnaire (Hayes *et al.*, 2004; Bond *et al.*, 2011); **BPCI-2**= Brief Pain Coping Inventory -2 (McCracken & Vowles, 2007); **CFQ**= Cognitive Fusion Questionnaire (Gillanders *et al.*, 2014); **CPAQ**= Chronic Pain Acceptance Questionnaire (McCracken *et al.*, 2004); **CPVI**= Chronic Pain Values Inventory (McCracken & Yang, 2006); **EQ**= Experiences Questionnaire (Fresco *et al.*, 2007); **MAAS**= Mindful Attention Awareness Scale (Brown & Ryan, 2003); **PCS**= Pain Catastrophizing Scale (Sullivan *et al.*, 1995); **PASS-20**= Pain Anxiety Symptoms Scale – 20 (McCracken & Dhingra, 2002); **PIPS**= Psychological Inflexibility in Pain Scale (Wicksell *et al.*, 2010b); **PRSS**= Pain-Related Self-Statement Scale (Flor *et al.*, 1993); **PRCS**= Pain-Related Control Scale (Flor *et al.*, 1993) **SCS**= Self-compassion scale (Neff, 2003).

OUTCOME MEASURES:

BDI= Beck Depression Inventory (Beck *et al.*, 1996); **BPI**= Brief Pain Inventory (Cleeland & Ryan, 1994); **BC-MDI**= British Columbia-major depression inventory (Iverson & Remick, 2004); **CAQ**= Committed Action Questionnaire (McCracken, 2013); **HADS**= Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983); **HSQ**= Hardin's Selves Questionnaires (Hardin & Leong, 2005); **IFI**= Impairment and Functioning Inventory (Ramirez-Maestre & Valdivia, 2003); **MPI**= Multidimensional Pain Inventory, subscale pain interference in daily life (Kerns *et al.*, 1985); **NRS**= Numeric Rating Scale (of pain intensity); **ÖMPQ**= Örebro Musculoskeletal Pain Questionnaire (Linton, 1999); **PDI**= Pain Disability Index (Tait *et al.*, 1987); **PHQ-9**= Patient Health Questionnaire (Kroenke *et al.*, 2001); **SWLS**= Satisfaction with Life Scale (Diener *et al.*, 1985); **SES**= Self-Efficacy Scale (Altmaier *et al.*, 1992); **SF-36**= Short Form Health Survey (Ware *et al.*, 1993); **SIP**= Sickness Impact Profile (Bergner *et al.*, 1981); **TSK**= Tampa Scale of Kinesiophobia (Swinkels-Meewisse *et al.*, 2003); **VAS**= Visual Analogue Scale; **VPMI**= Vanderbilt Pain Management Inventory (Brown & Nicassio, 1987).

4.0 RESULTS

4.1 Summary of Included Studies

These studies looked to investigate the role and contribution of psychological flexibility, as defined by ACT, in relation to patient functioning. In addition, it was hoped that this review would also indicate what processes may influence adjustment to living with chronic pain, via its impact on daily functioning and wellbeing. Table 1.1 shows summary data for each study included in this review.

4.1.1. Study Design and Aims

All included studies used quantitative methodologies, with self-report questionnaires as the main form of data collection. Of the 23 studies, 11 consisted of a cross-sectional design; five were pre-post trials without a control group; 3 were RCTs (two of which used data from previous RCTs not documented in this review); 3 were longitudinal and 1 was a cohort study.

All studies aimed to explore the relationship between the processes of psychological flexibility and patient functioning, via correlation or regression analysis. Eight studies also investigated either psychological flexibility or specifically, pain acceptance as a mediator; mediating between decentering, rumination and functioning (McCracken *et al.*, 2014); psychological flexibility and pain adjustment (Kwok *et al.*, 2016); life satisfaction and physical functioning (Cederberg *et al.*, 2016) or pain-related disability (Wicksell *et al.*, 2010a); functioning and catastrophizing (Vowles *et al.*, 2007), pain interference and functioning (Trompetter *et al.*, 2015); functioning and wellbeing (Vowles *et al.*, 2014) and between pain-related cognitions and pain adjustment (Esteve *et al.*, 2007). The longitudinal study included in this review examined whether pain acceptance and values-based action

predicted change in pain-related functioning (Vowles *et al.*, 2011), and one cross-sectional study examined whether traditional coping methods differed from psychological flexibility in improving patient disability and functioning (Vowles & McCracken, 2010). All treatment and process instruments had good psychometric properties.

4.1.2 Study Location

The majority of included studies were conducted in the UK ($n = 17$); two in the Netherlands (De Boer *et al.*, 2014; Trompetter *et al.*, 2015), two in Sweden (Wicksell *et al.*, 2010a; Cederberg *et al.*, 2016); one in Spain (Esteve *et al.*, 2007) and one in Hong Kong (Kwok *et al.*, 2016). The locations of these studies illustrate that most are European-based, suggesting data is heavily representative of western culture and healthcare systems, potentially limiting the extent to which results can be generalised across other cultures or contexts.

4.1.3 Sample Characteristics

In most studies, there was a notable difference in female to male ratio. Participants consisted of adults with a mean age between 40-64 years; although age ranged across studies from 21 – 92 years suggesting a representative sample with regards to age. Study size ranged from a small-scale RCT of 21 subjects (Wicksell *et al.*, 2010a) to a large cohort study involving 384 subjects (Scott *et al.*, 2016). The majority of participants comprised of a white, European population. Median pain duration across studies was reported at 96.0 months, with the majority of papers frequently identifying chronic lower back pain as the main presenting problem ($n = 18$).

All studies (except one where recruitment process was unreported) used either consecutive or convenience sampling, either recruiting samples from pain clinics, a GP database or via

public advertisements. Nineteen studies were conducted within an interdisciplinary or specialty pain management centre (2 of which included a residential program and 1 longitudinal study which followed-up on an initial intervention in specialty care); the remainder were conducted within primary care (n = 1), via an online intervention (n = 1) or through a university pain centre (n = 1). One study failed to report the context in which participants were recruited. Exclusion criteria and response rates were not made clear in a number of studies.

4.1.4 Process Measures

Psychological flexibility is typically measured by the Acceptance and Action Questionnaire, AAQ (version I [Hayes *et al.*, 2004] or version II [Bond *et al.*, 2011]). It examines flexibility along a continuum, looking at both acceptance and experiential avoidance, depending on the scoring system used. Both the 7-item and 10-item AAQ-II were used across 8 out of the 24 studies included in this review; 6 used this measure to reflect general psychological acceptance, whilst 1 study used this measure to determine levels of non-acceptance, experiential avoidance and psychological inflexibility. Other measures included the Psychological Inflexibility in Pain Scale (PIPS) and the Brief Pain Coping Inventory -2, flexibility subscale (BPCI-2).

Nineteen out of 23 studies used the CPAQ, a measure of pain acceptance, which records activity engagement and participants' willingness to experience pain without intent to control or avoid. Other measures explored values-based action (CPVI; n = 7); mindfulness (MAAS; n = 6); decentering (EQ; n = 3); pain catastrophizing (PCS; n = 4), pain inflexibility (PIPS; n = 2), committed action (CAQ; n = 2) and cognition fusion (CFQ; n = 1).

4.1.5 Treatment Outcome Measures

Pain-related fear (n=14), depression and/or anxiety (n=18) and disability (physical/psychosocial; n=15) outcomes were the most commonly assessed outcomes across studies. Other outcomes included life satisfaction (n=2), pain-related factors and interference (n=3) and self-efficacy (n=1).

4.2 Summary of psychological flexibility processes

Across the 23 studies, psychological flexibility (assessed either as one entity or via individual facets) was found to significantly correlate, predict or mediate improvements in pain-related distress, disability and functioning. A narrative synthesis of this evidence is detailed below, with studies investigating specific components of the model (e.g. values, mindfulness) detailed under separate subheadings for ease of reading.

Overall, positive correlations were reported between psychological flexibility processes, pain-related affect and functioning; whilst specifically, psychological acceptance negatively correlated with pain-related anxiety, depression, psychosocial and physical disability, and in some instances pain intensity (McCracken & Gutierrez-Martinez, 2011; McCracken & Vowles, 2008). Similar results were achieved when exploring the opposite end of the flexibility spectrum, whereby those who were less willing to accept their pain (i.e. psychologically inflexible), reported greater pain interference and emotional distress (Kwok *et al.*, 2016). Psychological flexibility was accountable for improvements in daily functioning over time, both short-term (months) and long-term (years) (Cederberg *et al.*, 2016; Scott *et al.*, 2016; Vowles *et al.*, 2007; Vowles *et al.*, 2011; Wicksell *et al.*, 2010a), and was found to reliably and significantly contribute to change in patient functioning compared

to more traditional pain management strategies such as pacing or relaxation (Vowles & McCracken, 2010). Although literature corroborates this research (Hann & McCracken, 2014; Veehof *et al.*, 2011), the quality reviews of these aforementioned articles suggest results should be interpreted with some caution. These moderate quality studies are open to bias from attrition, narrow participant demographics and reliance on self-report measures.

These findings largely support the theoretical premise of ACT, in that attempts to control, avoid or suppress unwanted internal experiences (i.e. pain and pain-related events) paradoxically increase individuals' pain and suffering; whilst remaining open to these events and acting in a way that aligns with personal values is associated with more successful health-related outcomes. This is also strengthened by studies which found pain did not mediate change in disability or life satisfaction, implying symptom remission was not solely the cause of reduced functional impairment but that increased flexibility was a main contributor (Cederberg *et al.*, 2016; Wicksell *et al.*, 2010a). The methodological rigour of Cederberg *et al.*'s (2016) study offers support to the dependability and quality of this data, however Wicksell *et al.*'s (2010a) findings should be interpreted more tentatively given the extremely small sample size and selective population.

These findings emphasise the influence and benefit of psychological flexibility on outcomes for chronic pain sufferers and suggest this construct should be considered for inclusion in future pain treatment programmes. It should be acknowledged however that the majority of studies in this review consisted predominantly of cross-sectional methodology, and those which explored maintenance effects were largely of pre-post design without a necessary control group. This limits the extent to which results can infer causation, and opens up the research to both bias and confounding influences which restrict the generalisability of the

data to different contexts. Moreover, most research to date has been conducted within specialty pain clinics thus giving rise to sampling and recruitment bias, and limiting the general applicability of the data to other treatment contexts or to individuals with less complex and disabling pain. Of promise, is that one study in primary care replicated patterns observed in tertiary services (McCracken & Velleman, 2010); similar effects were seen in individuals with less pain complexity who are not seeking specialty care, and who demographically are slightly older than individuals accessing pain clinics. A large sample size, broad age range and good representation from both male and female participants strengthens the quality of this study, and the validity of the data. More research, particularly with control groups, in both primary and tertiary care services are warranted to determine the broader applications of psychological flexibility and its components.

Regression analyses highlighted that psychological flexibility predicts change in depression and functioning in biopsychosocial domains (McCracken, 1998; McCracken & Velleman, 2010; McCracken & Gutierrez-Martinez, 2011; McCracken & Zhao-O'Brien, 2010; Scott *et al.*, 2016). After controlling for pain intensity, change in psychological flexibility processes in one study was found to account for 6-27% combined variance in depression, mental health and daily functioning between pre- and post- treatment, and that a similar variance (7-27%) was documented at 9-month follow up (Scott *et al.*, 2016). Scott *et al.* (2016) used various assessment instruments to represent psychological flexibility and further found unique contributions for cognitive fusion on depression and social functioning, and committed action on depression; these remained stable over time. Effect size for cognitive fusion interestingly was larger at follow-up, possibly suggesting defusion is a skill requiring more practice before it is effectively implemented (Scott *et al.*, 2016). Pain acceptance in contrast was seen to predict change on all outcome measures between pre- and post- assessments, compared to 9-

month follow-up where it was only predictive of pain intensity and social functioning (Scott *et al.*, 2016). This is consistent with work conducted by Vowles & McCracken (2008) where acceptance dominated change in outcomes at post-treatment, compared to values-based action which had more leverage in predicting follow-up outcomes. Other studies have similarly reported the unique contributions made to functional status by the individual components of the flexibility model (McCracken & Gutierrez-Martinez, 2011; McCracken & Zhao-O'Brien, 2010; Trompetter *et al.*, 2015; Wicksell *et al.*, 2010a). Compared to pain intensity, general psychological acceptance and pain acceptance accounted for greater average variance (11% vs. 29% respectively) in predicting patient outcomes (McCracken & Zhao-O'Brien, 2010). However, in McCracken *et al.* (2015) study only pain acceptance uniquely predicted change in mental health and physical functioning. Acceptance remained a predictor of functioning, even when it was compared against other strong predictors, suggesting it plays a distinctive role in living with chronic pain (McCracken *et al.*, 2010). These findings suggest different flexibility processes are responsible for changes in functioning and emotional wellbeing, and that each component sustains different benefits across time. The temporal differences seen in these specific processes warrant further investigation. It also raises questions around what assessment measures should be promoted to measure psychological flexibility, and whether this construct should be examined as a whole unit or via its individual facets. Arguably, the AAQ has received criticism as a measure of psychological flexibility given it predominantly looks to assess general psychological acceptance or experiential avoidance, but no other underlying processes. Revisions to the AAQ may be needed to refine the tool to ensure it encapsulates the whole psychological flexibility model and to ensure construct validity.

One prospective study, of moderately-high quality, adds to the literature above. Researchers found individuals who were willing to tolerate their pain and pursue activities regardless, were likely to engage better in daily activity, have improved work status' and reduced dependency on pain medication (McCracken & Eccleston, 2005). The quality of this study was aided by its prospective nature, minimising the risk of confounding factors which may unintentionally affect the findings, and through the use of varied assessment measures (i.e. numerical ratings, reports of work status etc.). Given the majority of studies included in this review rely upon cross-sectional methods, it appears there is a need to conduct more scientifically rigorous and prospective investigations into ACT processes.

Eight studies found mediational effects between psychological flexibility and health-related outcomes. Increased psychological flexibility was found to mediate change in pain interference, psychological distress and pain intensity (Trompetter *et al.*, 2015), and in life satisfaction, physical functioning, and the relationship between catastrophizing and pain-related outcomes (Cederberg *et al.*, 2016; Trompetter *et al.*, 2015; Wicksell *et al.*, 2010a). Two studies found change in pain acceptance mediated change in disability (Esteve *et al.*, 2007; Vowles *et al.*, 2014). Use of mediation analysis and structural equation modelling allowed the complex and dynamic relationship between variables to be captured, and offer more confidence in the direction of relationship between measures. Nonetheless, these studies had a number of limitations which influence their overall quality and generalisability, including small sample size, attrition rates and use of selective samples. Mediational analyses may also be exposed to risks of confounding biases, as they provide no control measures against extraneous variables which may impact on the process, relationship and treatment outcome. Future studies should look to enforce more control over parallel processes which may bias the data.

4.2.1 Acceptance and Catastrophizing

In this context, catastrophizing represents times when individuals negatively appraise or exaggerate their pain experiences. Three studies, of low-to-moderate quality, found psychological acceptance either strongly correlated or predicted pain-related catastrophizing (De Boer *et al.*, 2014; Vowles *et al.*, 2007, 2008). Individual differences in pain acceptance and catastrophizing were also identified to uniquely predict emotional functioning and disability, with variances accounted for by these two processes remaining relatively stable across time (Vowles *et al.*, 2007). This data implies generally that greater rates of acceptance and lower rates of catastrophizing are associated with improved functional abilities. The use of cross-sectional design and self-report measures however limits the reliability of these findings and causation cannot be inferred; controlled, experimental designs are necessary to determine the directional relationship between these variables. Consideration of other assessment measures may also be beneficial, given the complexity of the construct these studies are attempting to explore.

4.2.2 Decentering

Two studies investigated whether increased decentering was associated with or predicted functional improvement in chronic pain patients (McCracken *et al.*, 2013, 2014). Decentering reflects the dimension of cognitive defusion within the psychological flexibility model and is conceptualised as the metacognitive capacity of observing thoughts and feelings as transient, objective events, rather than perceiving them as true descriptions of reality (Teasdale *et al.*, 2002). It was measured by the EQ in each study, which has both a decentering and rumination subscale. A series of correlations and mediational analyses found decentering contributed to differences in emotional and psychosocial functioning (McCracken *et al.*, 2013, 2014), yet contrary to expectation did not correlate with physical

health. Decentering and rumination was also found to have mediational effects on mental health, social functioning and depression (McCracken *et al.*, 2014). Past literature substantiates these findings; decentering is seen to improve emotional functioning (Orzech *et al.*, 2009), and negatively correlate with avoidance and depression (Fresco *et al.*, 2007; Gayner *et al.*, 2012), whilst rumination has been linked to worse mental health and greater psychological inflexibility in both clinical (Kasdan & Rotterberg, 2010) and non-clinical populations (Tillfors *et al.*, 2015). It should be noted however that rumination has more than one meaning; in other literature (e.g. bereavement and stroke) ruminative coping instils hope, aids adjustment and post-traumatic growth (Hallam & Morris, 2013).

4.2.3 Values

The CPVI was used to assess values (covering 6 life domains) and to score the discrepancy between importance and success ratings of values-guided behaviour. When values were investigated within a chronic pain setting, findings revealed that despite holding important values across each life domain, individuals felt they were not successfully living according to them (McCracken & Yang, 2006). Smaller discrepancies between importance ratings and success at values-guided action were seen to reduce levels of pain-related disability, depression and anxiety (McCracken & Yang, 2006). Regression analysis supports this notion, as individuals living according to their values was predictive of patient functioning and wellbeing, although was not directly related to physical disability or pain-related anxiety. The sample population and cross-sectional nature of this study fails to determine causation and limits generalisability of the data, however it offers preliminary insight into how being guided by personal values may aid patient functioning.

Other studies report similar findings when considered in conjunction with measures of acceptance. When values-based action and pain acceptance were investigated together, both predicted functioning over time (>3years), including change in pain severity, pain-related distress, interference with functioning and disability (McCracken & Vowles, 2008; Vowles *et al.*, 2011). Living in line with one's values and making a commitment to act on those values was also seen to predict medication use in individuals (McCracken & Vowles, 2008) and significantly correlated with change in mental health and functioning (McCracken *et al.*, 2015).

4.2.4 Mindfulness

Seven studies used a mindfulness measures (i.e. MASS) within a wider psychological flexibility context to assess its contribution to patient functioning and pain-related distress. However, one empirical study directly investigated mindfulness' contribution to living with chronic pain in tertiary care patients (McCracken *et al.*, 2007). Individuals reporting greater present-focused awareness and non-reactivity to internal events (implied by mindfulness), were found to experience significantly less pain-related difficulties (e.g. with affect, disability, life interference etc.) and reported lower utilisation of pain-related analgesics. Mindfulness continued to predict patient functioning, after controlling variances in background characteristics, pain intensity and acceptance of pain. Such findings are consistent with pain literature (Veehof *et al.*, 2011) and other physical health complaints (Crowe *et al.*, 2016). This provides some support for the inclusion of mindfulness in treatment packages for chronic pain.

5.0 DISCUSSION

Interest in applying the psychological flexibility model to the field of chronic pain has proliferated over the past two decades. The model has been examined in relation to its contribution to disability and functioning, and has gained increased attention into what processes mediate treatment outcomes for chronic pain individuals. The purpose of this review was to empirically investigate how psychological flexibility impacted on patients' functional ability and to consider this relationship in regards to a wider adjustment process to living with long-term pain. It was expected that individuals who embraced an ACT philosophy (i.e. increased acceptance, living congruently to values, present-focused etc.) would function better across all life domains. This expectation was largely supported by the evidence documented in this review.

All studies reviewed demonstrate evidence of a strong relationship between the assessed components of psychological flexibility and improved daily functioning. This included change in pain-related distress, depression-related interference, psychosocial functioning and in two cases a notable improvement in physical health status (Cederberg *et al.*, 2016; Wicksell *et al.*, 2010a). Findings were sustained over time, emphasising the durability of these psychological qualities. The role of psychological flexibility in patient functioning is further enhanced by studies revealing pain was not a mediator of disability (Cederberg *et al.*, 2016; Wicksell *et al.*, 2010a); this indicates change in health status was not merely attributable to reductions in pain but rather confirms psychological flexibility heavily influenced patient outcomes. These findings compare favourably to past literature which investigate therapeutic change in health-related outcomes as a result of ACT, including research in diabetes self-management (Greg *et al.*, 2007), cancer (Feros *et al.*, 2013), and

epilepsy (Lundgren *et al.*, 2006). Moreover, some of these studies are enhanced by more robust data analysis via the use of mediation or structural equation modelling, which offers better insight into the relationship dynamics that exist between process and treatment variables. Although these methods cannot establish causality (Kazdin, 2007), they are able to highlight potential mechanisms or pathways of change and indicate to what extent clinical outcomes are accounted for by psychological flexibility (i.e. total variance). The results presented in this review stress the importance of developing a sound understanding of the ingredients that facilitate change and not just researching intervention effectiveness. To accommodate this, more rigorous study designs are required which incorporate measures of temporal precedence (Kazdin, 2007). Employing such measures allows mediating and treatment variables to be assessed simultaneously over several time intervals, to explore whether mediating factors change prior to change in treatment outcomes (Kazdin, 2007). Further research into psychological flexibility as a treatment mechanism will assist the development and delivery of future ACT programmes for chronic pain populations.

A large focus of the research reviewed was centred on the role of acceptance, both general psychological acceptance and more specifically, acceptance of pain. There appears to be a general consensus that when attempting to live with chronic pain, the ability to accept unwanted experiences can significantly influence change in life satisfaction and functioning, regardless of pain intensity, duration or chronicity (McCracken & Gutierrez-Martinez, 2011; McCracken & Vowles, 2008). As such, individuals appear to report better quality of life and less restrictions imposed by their condition. From individuals being more open and willing to sit with undesirable psychological experiences (e.g. thoughts, emotions, images or urges) we could hypothesise that acceptance may therefore assist in adjustment to managing persistent pain, in a way that empowers sufferers to live a rich, full and meaningful life without their

pain experiences monopolising day-to-day events. This notion is substantiated by similar research around the role of acceptance in other physical conditions and within mental health contexts (Bendayan *et al.*, 2012; Rodero *et al.*, 2011). Despite copious research into acceptance, there is also upcoming evidence supporting the role of other psychological flexibility facets which need to be addressed more thoroughly. For example, research also reveals that individuals who are less reactive or fused with internal events and who live in accordance with their values are seen to function better in emotional and psychosocial domains (McCracken *et al.*, 2007; McCracken *et al.*, 2013; McCracken & Yang, 2006). Although preliminary studies indicate strong relationships between these facets and patient functioning, the literature remains in its infancy and reliance on cross-sectional designs prevents researchers from establishing causality. Better understandings of these relationships could be gained from employing randomised controlled, prospective or longitudinal designs in future investigations.

Recognising the role psychological flexibility has on the physical and psychological aspects of chronic pain, affords some insight into the factors that support adjustment to living with this condition. To explicate the contribution of flexibility processes further, future research would benefit from employing extended temporal precedence measures. Kazdin (2007) reports these measures can be utilised to assess whether the mediating factor changes prior to the studied outcome variables. Simultaneously testing changes in outcome measures and the hypothesised mediator at different points can improve causal specificity, enabling researcher to state with a greater degree of certainty whether or not the mediator initiated change in outcome (Kazdin, 2007). Improved understanding of psychological flexibility as a mediating factor in adjustment to chronic pain may offer important insights that could call for the revision of current treatment packages and enhance the efficacy of interventions. Arguably,

the validity and reliability of psychological flexibility measures should also be reviewed. Criticisms around the AAQ and BPCI as measures of psychological flexibility suggest they capture at least two processes out of six, meaning many dimensions of the model are omitted. Evidently, further instrument development is warranted, or researchers should consider using multiple instruments and approaches to reflect each facet. This itself may have limitations but would ensure all areas of the model are assessed adequately.

This review has several strengths. Most importantly, to the best of the authors' knowledge this is the first systematic review specifically exploring psychological flexibility and its components, in relation to disability and functioning in chronic pain sufferers. It supplements the growing literature base into ACT and chronic pain, and supports efficacy studies which have previously been the focus of many reviews. It has also amalgamated research into the components of psychological flexibility, to consider its potential role in pain adjustment and the future implications for treatment. Use of a clear inclusion criteria, a quality appraisal tool and inter-rater reliability of selected articles, are further strengths which limit the degree of bias entering this review.

Despite findings offering promising insight into the role of psychological flexibility, naturally this review has a number of limitations. The primary limitation is the heavy use of cross-sectional studies and their reliance on self-report measures. The reliance on measures taken at a single-time point, without manipulation, means causal relationships between variables cannot be inferred without further research using more scientifically rigorous designs. Likewise, self-report measures are susceptible to influences which may prevent accurate and representative data of individuals' behaviour. Consideration of other, more stringent, assessment tools are warranted. Secondly, aside from three studies, the remainder of the

research sampled highly selective chronic pain populations who were referred to specialist pain management units. The clientele here represent people who experience complex and highly disabling pain, who have been unsuccessfully treated within primary and secondary care services. Caution should be taken when attempting to extrapolate these findings to different contexts i.e. non-treatment seekers or primary care patients. Interestingly, one study conducted in primary care reported similar outcomes around psychological flexibility to that seen in tertiary services; however this appears to be the only research to date in this setting. Follow-up investigations are needed to determine the replicability and generality of the data. Thirdly, issues regarding sampling method and diversity of the target population (with respect to culture, ethnicity, and gender) may restrict the generalisability of the data. Similarly of note, is that a large proportion of the articles included in this review are conducted by the same authors. Since articles were based on independent studies it was felt their inclusion in the review was of paramount importance to understanding flexibility processes and their role in functional wellbeing, however the research appears to be conducted in areas where the authors work which limits the geographical diversity of the sample.

In conclusion, psychological flexibility is found to be associated with, predict or mediate improvements in chronic pain individuals' quality of functioning, and thus could be a key contributory factor in supporting individuals' in adjusting to life with an intractable illness. Inclusion of adjustment measures in upcoming studies are therefore required to determine this association. Research into acceptance has dominated past literature, whilst the role of other flexibility facets remain in its infancy. Further experiments or intervention trials are needed to ascertain the role and relationship of these other processes in patient outcomes, and need to consist of more rigorous designs that can assess a greater level of causal specificity of how

these processes bring about therapeutic change. A strategy assessing the multiple aspects of psychological flexibility simultaneously, both over time and during treatment, is further recommended to determine the models position as a mechanism of change.

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Paper 2: Empirical Paper

*“The mind is an absolute *****”*: adjustment to residual disability following an Acceptance and Commitment Therapy (ACT) group for Stroke Survivors

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ABSTRACT

Objective: Copious research on the utility of Acceptance and Commitment Therapy (ACT) in long-term conditions (including those with neurological origins) has been conducted, with promising effect. However, little research to date has been conducted on ACT within stroke contexts, particularly studies that are qualitative in nature. The aim of this paper was therefore to gain insight into stroke survivors' experiences of ACT and to explore what processes facilitate adjustment in living with residual disability. **Method:** Interviews with thirteen stroke survivors following their attendance to an adapted ACT group were conducted and analysed using a grounded theory approach. Stroke survivors varied in age, severity of stroke limitations and duration since stroke. **Results:** Interviews revealed a main difficulty of '*accepting a changed reality*' following stroke. Survivors' narratives regarding their experiences of ACT revealed insight into what processes helped facilitate movement towards accepting symptoms and a changed reality. **Conclusion:** Findings illustrate the use of ACT in stroke contexts is a valuable resource to support survivors in adjusting to stroke limitations. Knowledge of processes that support adjustment and the long-term psychosocial needs of this population should be integrated into current policies, guidelines and services to enhance the quality and delivery of stroke care. Further replication and extension of this study is proposed.

Key Words: Acceptance and Commitment Therapy • Psychoeducation • Stroke • Acceptance • Adjustment • Disability.

1.0 INTRODUCTION

Stroke is medically defined as an acute neurological deficit, of cerebrovascular origin, which can be divided into ischemic (vascular occlusion) or haemorrhagic (vascular rupture) subtypes (Montagu *et al.*, 2012; Sacco *et al.*, 2013). In the UK alone 152,000 adults are hospitalised each year following stroke (Townsend *et al.*, 2012). It is arguably one of the most disabling conditions, causing huge upheaval, destabilisation and life-long consequences for stroke survivors and their families (Maaijwee *et al.*, 2014; Newton *et al.*, 2015; Rutten-Jacobs *et al.*, 2013).

1.1 Stroke impact and adjustment

As a result of neurological damage, individuals may report deficits in motor, perceptual, emotional and/or cognitive functioning (Lezak *et al.*, 2004; Toole *et al.*, 2004), alongside secondary consequences of social isolation, reduced psychological wellbeing, increased distress and a generalised sense of loss, with regards to autonomy, participation in normal activities and pre-existent roles (Ayerbe *et al.* 2013; Campbell-Burton *et al.* 2013; Lincoln *et al.*, 2012; The Stroke Association [TSA], 2015). The heterogeneous effects of stroke pose multiple challenges for survivors and can significantly interfere with quality of life (QoL); with uncertainty about the future and recovery leaving many survivors confronting a new and threatening reality (Falvo, 1999). It is unsurprising therefore that a number of individuals report difficulty adjusting to their situation (TSA, 2015) and particularly struggle with the difference between their pre- and post-stroke identity (Dowswell *et al.*, 2000).

It has been suggested that individuals move from a stage of overwhelming fear, hope and loss during the initial stroke crisis, to a place of negotiation, acceptance and re-engagement later on (Kirkevold, 2002); however insight into what processes facilitate change are somewhat lacking. Interest in understanding how individuals appraise and make meaning of their stroke, and what strategies they employ to support successful adjustment has therefore proliferated over the past decade (Gillies & Neimeyer, 2006; Hayes *et al.*, 2006; White, 2004). Review of the literature illustrates adjustment to living with stroke is complex and multi-faceted, influenced by the severity and visibility of functional impairment (Robison *et al.*, 2009; Stone, 2005); degree of emotional disturbance (Taylor *et al.*, 2011); the meaning attached to stroke, disability and rehabilitation (Hjelmblink *et al.*, 2009); level of disruption to sense of self, roles and relationships (Lawrence, 2010) and perceived amount of social or peer support (Kessler *et al.*, 2014; Venna *et al.*, 2014). Adjustment is also influenced by other stroke survivors, where drawing negative or positive comparisons with others can affect an individual's self-evaluation, mood and motivation for an improved future (Festinger, 1954).

Given the aforementioned literature, it is imperative that services focus on the long-term needs of stroke survivors and adjustment to residual disability. Following the ending of the National Stroke Strategy in 2017, it is unsurprising that revisions to stroke provisions are being called for nationally.

1.2 Status of current stroke provisions

To date, interventions have largely focused on the early management of stroke in attempts to alleviate acute symptoms and minimise the risk of further cerebral damage (Bruins *et al.*, 2008). However, this has often been at the expense of recognising and supporting the longer-

term ramifications of stroke, such as psychological, cognitive or social needs (O'Neill *et al.*, 2008). A community-based study corroborates this notion, where almost half of the survivors' reported one or more unmet long-term needs during the first five years post-stroke (McKevitt *et al.*, 2011). National health strategies (Department of Health, 2007; Welsh Government, 2012) and clinical guidelines (National Institute for Health and Clinical Excellence [NICE], 2013) have therefore emphasised the need to extend support beyond active rehabilitation and physical care, to facilitate healthy adjustment in other life domains. Psychological services have attracted considerable attention for their role in supporting the wider-reaching needs of stroke survivors (British Psychological Society [BPS], 2012; TSA, 2013). Although in its infancy, there is emerging evidence supporting the use of psychotherapeutic interventions in stroke (NICE, 2013); with its involvement being linked to a five-fold improvement in quality of life (Gillham *et al.*, 2012). There is a dearth of high quality studies for the efficacy of specific psychological interventions in stroke, however, and methodological flaws associated with the research limit the extent findings can be generalised (Kneebone & Lincoln, 2012).

1.3 Potential Utility of Third-Wave Interventions

Third-wave interventions within physical health contexts are becoming increasingly popular. Acceptance and Commitment Therapy (ACT), in particular, has proven effective in supporting people with a range of chronic illnesses, including cancer (Feros *et al.*, 2013), pain (Hann & McCracken, 2014), and neurological conditions such as multiple sclerosis (Carrigan & Dysch, 2015) or acquired brain injury (Kangas & McDonald, 2011). Compared to other psychotherapies which may look to eliminate distress, ACT functions to modify relationships with undesirable (yet inevitable) human experiences rather than using

counterproductive attempts to suppress, minimise or avoid them (Hayes & Smith, 2005). By engendering psychological flexibility, ACT provides a repertoire of skills which enables individuals to become more adept at remaining present-focused, acting with more conscious awareness, and connecting more to values in pursuit of meaningful activity (Hayes & Smith, 2005). Given ACT's guiding principles, it's plausible the model will have additional applicability with stroke populations, especially given the possibility that full recovery (i.e. of neurological or physical deficits) may be unrealistic. Encouraging individuals to be more open and accepting of internal events, whilst living congruously with their values, may help orient survivors towards a fuller and more meaningful life despite stroke limitations.

1.4 Study Aims

The purpose of this study was to understand survivors' experiences of an adapted ACT group and to explore what processes enabled survivor's to make improvements in living with residual stroke symptoms. This study adds depth and nuance to a new area of stroke inquiry, and contributes to the growing ACT research base. Implications of the research, along with directions for future study, will be discussed.

2.0 METHODOLOGY

2.1 Design and theoretical background

This paper presents a Grounded Theory (GT) analysis (Charmaz, 2014) of in-depth semi-structured interviews conducted with stroke survivors. It explores their understanding and experiences of attending an ACT course and its role in supporting change in living with residual stroke effects. A qualitative methodology was adopted in this study due to the paucity of literature in this field. The application of qualitative methods have been advocated when limited research or theory exists (Fossey *et al.*, 2002), and it was therefore deemed most appropriate for exploring the relationship between ACT and adjustment to stroke.

In this study, a constructivist GT was employed (Charmaz, 2014). The interpretivist nature of this variation of GT was felt to suit the intended research goals, whereby meaning is co-constructed with stroke survivors around their group experience and in understanding what processes may facilitate adjustment to life after stroke. It was hoped this approach would inform future research as well as assist in shaping future service and rehabilitation provisions for stroke survivors.

2.2 Sample and Sampling

Stroke survivors (and carers) reporting difficulty adjusting to residual stroke symptoms were invited to attend an ACT group intervention. All individuals accessed the group via a third sector organisation or the NHS across South-West England and South Wales. . Members were screened against an inclusion/exclusion criteria (table 1.2) and could attend the group at

any stage across the stroke care pathway after discharge from hospital. In total, across all groups approximately 123 members attended; wider demographic data for the sample is not available however as not all members were involved in this specific research.

Table 1.2 Inclusion/Exclusion Criteria for ACT group.

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • 18 Years or older • Clinical diagnosis of stroke (or be carers of someone who has experienced stroke) • Must be able to understand English and communicate responses 	<ul style="list-style-type: none"> • Patients with any other acquired brain injuries, such as traumatic brain injury, encephalitis, tumours etc. • Patients with a diagnosed degenerative condition e.g. dementia. • Significant cognitive/language impairment that would prevent them from engaging with the group • Those experiencing severe psychotic symptoms • Those who are receiving other therapies, as part of a multi-component intervention that would prevent any changes specific to group psychotherapy to be estimated (with the exception of drugs for depression and anxiety).

For this particular study, only stroke survivors attending the course were invited to participate in interviews. Participants were recruited from the third sector in south-west England or from three NHS University Health Boards (UHBs) in south Wales; between March 2016 – September 2016. The researcher attended the first session of each ACT course to share details of the research project with group members; those interested in participating were

given further written information and asked to provide contact details to the group facilitators. Thirteen survivors in total (with various residual disabilities) were interviewed; two additional survivors expressed interest in participating but withdrew prior to interview. Demographic data was collected (appendix C); results are reported in section 3.1.

A theoretical sampling method, where interviews are driven by the emerging theory, was utilised to direct the researcher to participants who could contribute to the evolving dataset by either challenging or elaborating on tentative categories. This continued until data saturation was achieved i.e. no new concepts or properties to categories emerged (Charmaz, 2014).

2.3 Intervention

'Activate Your Life After Stroke' (AYLAS) is a four-week, psychoeducation ACT intervention, adapted specifically for stroke survivors and their carers. Groups ranged in size from 10 – 30 people depending on the research site, and ran for a duration of two hours. The intervention was delivered didactically via PowerPoint presentation and comprised of theory, skills training and experiential exercises (see appendices D, E & F for examples of group material). Content focused on all ACT processes: acceptance; defusion; contact with the present moment; values; committed action; and self-as-context. The intervention was delivered by two or three group facilitators; these were either clinical psychologists, assistant psychologists, charity workers or stroke peers. All facilitators attended a 3-day training course with the creator of AYLAS to ensure competence in delivery of the intervention.

The intervention itself was developed by a Consultant Clinical Psychologist with an expertise in ACT, and adapted jointly with stroke survivors. Survivors involved in adapting course

content and supplementary materials (see examples, appendix G) had wide-ranging residual disabilities (including paralysis, visual/cognitive impairments and aphasia), and were consulted to ensure material was user-friendly and stroke-relevant.

2.4 Ethical Considerations

2.4.1 Ethical Approval

This study was granted approval by a National Research Ethics Committee (NREC) and was similarly granted independent ethics approval across three NHS UHBs in Wales, in line with their local Research and Development (R&D) department policy (appendix H). Overall, the research was sponsored by Cardiff University as per local agreement protocol for trainees on the Doctoral Programme in Clinical Psychology.

2.4.2 Informed Consent

Participants provided written consent prior to each interview taking place (appendix I). To ensure consent was informed, all participants were provided with an information sheet regarding the study (appendix J).

2.4.3 Confidentiality and Anonymity

In accordance with the Data Protection Act (1998) and the Healthcare Professionals Council (HCPC) Code of Conduct (2012), pseudonyms were assigned to participants to protect their

identity. Participants were aware confidentiality would only be breached if they disclosed information that pertained to risk to either themselves or others (British Psychological Society, BPS, 2009). Interviews were recorded and stored on an encrypted USB device, were only transcribed by the researcher herself, and were deleted immediately after use.

2.5 Data Collection and Analysis

Data collection and analysis occurred simultaneously, in an evolving process (Charmaz, 2014). Interviews were conducted in participants' own home as this was the most convenient location; duration ranged between 30 – 70 minutes. An interview schedule (appendix K) comprising 7 stem questions was constructed between the researcher and her academic supervisors. This was used as a guide and revised regularly to progressively focus on new lines of enquiry and emerging theory. Interviews were audio-recorded and transcribed verbatim by the researcher. Concurrent memo-writing and discussions with supervisors provided space for the researcher to reflect on feedback, make comparisons in the data and identify areas that required greater elaboration. This assisted in enriching data analysis and guided data collection. Where possible, analysis was conducted after each interview; this progressed from initial line-by-line coding into more focused codes and concepts. A continued process of comparing and contrasting codes across the dataset, and use of memos, helped facilitate the development of more abstract concepts. The final analytic stage involved generating a theory to explain the main concern or dilemma reported by survivors.

2.6 *Ensuring rigour in qualitative research*

Qualitative research is frequently subjected to scrutiny due to its perceived lack of scientific rigour (Rolfe, 2016). To overcome this criticism, a quality assurance framework was adopted to minimise bias (Elliot *et al.*, 1999; refer to paper 3 (2.9)). This included remaining reflexive throughout the research process (e.g. use of a reflective journal; appendix P), and repeated discussions with academic supervisors to help organise, manage and define emerging categories.

3.0 RESULTS

3.1 Participants

This study comprised of thirteen stroke survivors, the majority of whom were male and had suffered an ischaemic stroke (for full demographics see table 1.3). Participants from each research site consented to this study; 4 were interviewed from the first UHB; 3 from second UHB; 3 from third UHB and 3 from Bristol. Stroke survivors reported wide-ranging, comorbid residual disabilities. These included: paralysis, limb weakness, mild aphasia, hemianopia/visual deficits, emotionality, fatigue and mild cognitive impairment. Psychological difficulties post-stroke (i.e. anxiety/depression) were also reported by some survivors.

Table 1.3 Participant Demographic Data

Gender	Male: 11 Female: 2	Age (Years)	39-69 [Mean: 58.8]
Duration Post-Stroke (Months)	3 – 24 [Mean: 10.9]	Type of Stroke	Ischaemic: 8 Haemorrhagic: 4 Stroke-Related Event: 1
Ethnicity	Welsh: 9 British: 4	Living Arrangements	Cohabiting: 6 Living with Carer: 6 Alone: 1
Employment Status	Retired: 8 Employed: 5	Psychological Difficulties Post-Stroke	Yes: 8 No: 5

3.2 Grounded Theory Findings

The adversity faced by stroke survivors when learning to adjust and manage the physical and psychological sequelae of stroke was voiced by each participant; with accounts indicating a

prevalent issue of needing to accept a changed reality. Analysis of the data assisted in the development of a conceptual framework explaining how stroke survivors work towards accepting change following stroke, following attendance at an ACT group. Interviews revealed individuals fluctuate throughout this acceptance process, and that narratives were largely influenced by: age; duration since stroke, stroke severity and the perceived permanency of disability.

GT analysis yielded six core categories. These will be discussed in turn with reference to their underlying conceptual categories; see figures A.1-A.6 in appendix M for full category structure. Although the research aimed to explore what processes support participants in accepting an altered reality, there was a striking need for survivors to first situate their experiences by describing the initial impact of stroke (see core category 1). Quotations, in *bold italics* and inverted commas, are used to represent verbatim statements to illustrate these core categories; pseudonyms have been added to highlight the quoting participant. Information in square brackets [] has been added by the researcher, whilst three dots (...) indicate quotes which have been shortened.

3.2.1 CORE CATEGORY 1: NEGOTIATING THE CHALLENGES OF STROKE

The inescapable limitations of stroke and their potential threat to one's self-identity, functional capabilities, aspired futures and psychological wellbeing, meant all survivors were faced with negotiating the challenges of stroke and a changed reality.

The emotional trauma of having experienced a stroke was universal amongst survivors, with many ruminating on the losses incurred by stroke and reflecting on the differences between

their past (pre-stroke) and present self. All participants acknowledged heightened feelings of guilt and self-worthlessness associated with diminished functional abilities and increased dependency on others, whilst some also described intense fears of re-stroking. Negative self-appraisals of being *“a failure in asking for help”*, *“useless”* or *“inadequate”*, and concerns of being evaluated unfavourably by others, were further seen to exacerbate negative affect and detrimentally impact on individuals functioning and QoL. In attempts to alleviate distress, survivors described avoiding situations, battling with thoughts or ploughing on regardless; however this was found to have a paradoxical effect and imposed further restrictions in addition to those caused by existing stroke impairments.

“I was suffering a lot of anxiety...it was almost a desperation, something has got to help me get over the pain that I was causing myself. It was like I had lost everything really. I hadn’t, but it had blown out of proportion...it just kept coming back that I was useless”
(Connor).

Reports of feeling far removed from the life survivors previously ascribed to and disruptions to planned futures punctuated participants’ narratives. As such, survivors described experiencing considerable loss; acknowledging a profound shift in roles, responsibilities, identity, sense of self and changes to their known reality. The disparity identified between pre and post-stroke identities, and the associated loss of activities which symbolised independence and competence, were found to increase distress and diminish individuals’ sense of self, worth and purpose. For two wheelchair users, distress and difficulty accepting a changed reality were compounded further by denying the severity of their disabilities and continued efforts to return to full mobility.

“I woke up [from my stroke] and found my situation totally removed from where I had been before. When I’m asleep I think about myself walking about, doing things and having the mobility that I used to have. When I open my eyes and become conscious, all those things peel away...if I accept that I am in a wheelchair then there is no point me making any effort whatsoever to walk... whereas the reality I think in my head, is that it’s an uphill battle.” (Ron)

Managing the aftermath of stroke was complicated further by the perception that care ceased following hospital discharge. Survivors voiced concerns of *“being set adrift”* (Mark) by services during a time that felt overwhelming, uncertain and frightening, whilst also acknowledging *“once the support stops that’s when the problems start”* (Mark).

Participants alluded to a vulnerability in being left unsupported, which was seen to increase feelings of isolation and amplify negative affect.

3.2.2 CORE CATEGORY 2: CONTEXTUAL FACTORS

Given limited provisions exist to address the wider needs of stroke survivors, many participants described attending the ACT group as a highly positive experience, recognising different factors supported them in making meaning of their stroke and progressing in their recovery. Initially, various foundational factors were central to participants feeling able to assimilate course information; including group practicalities, teaching methods used to deliver ACT ideas and the translatability of material.

3.2.2.1 Practicalities

Venue appropriateness, consideration of survivors' disability needs (e.g. sensory or perceptual adjustments) and group layout were deemed important factors to facilitate learning and enjoyment of the ACT group; this was perhaps more pronounced given its didactic format. These factors were mentioned by all participants as being important regardless of stroke severity, and helped create an environment that minimised chances of distraction or discomfort. Optimising the learning environment was viewed essential in improving concentration on group content, which in turn could aid how successfully participants translate knowledge into practice.

“The venue is very important when you are running groups...thinking about the venue and hard chairs, if you’re just being lectured at, your mind starts to wander, you lose concentration and might start thinking about the discomfort you’re in” (Paul)

Transparency around group agendas and scheduled breaks further aided learning potential by structuring the course in a way that felt containing to participants. For example, one survivor valued knowing when breaks would be taken given the cognitive demands of sustaining attention for prolonged periods of time. This enabled him to attend to the course fully without anxiety or apprehension. The didactic format of the group also offered security for some participants, as five individuals mentioned disclosing personal information would have acted as a deterrent to them attending.

“The biggest thing I was worried about was whether we’d be sat in a round circle and we’d be talking about our feelings. I didn’t want to talk to anybody about my feelings. If that

would have happened, I would have just walked straight out the door. It was really good in that as soon as we got there [the facilitator] said...you just have to sit and listen...whilst that might be a bit tedious at times...that actually put me at ease really quickly, as you suddenly think ok I'm not going to be laid bare in front of all these people" (Connor)

Despite the aforementioned preference for a non-discursive group from some survivors, others in contrast expressed a desire for increased interaction. These individuals felt the didactic or paternalistic approach minimised the value of shared learning experiences, and suggested without contact the material could have been taught via self-practice: *"we were just being talked at...I felt I could have just been given a handout to read"* (Josh). A cluster of survivors indicated discussion could have aided outcomes further by contributing to their understanding of stroke, and by providing a chance to learn vicariously from others about ways to manage certain difficulties or frustrations. *"There wasn't much opportunity to interact with others, it would have been nice to have heard other people's experiences as well because until I had this stroke unfortunately I hadn't realised what a stroke was or what effect it can have on your life"* (George). Interestingly, although the group was psycho-educational and therefore did not encourage interaction, evidence from the emergent framework suggests the value of meeting other stroke survivors played an important role in their acceptance of a change reality (see section 3.2.5).

3.2.2.2 Teaching Methods and Translatability

Educating survivors via different teaching modalities (e.g. psychoeducation; metaphors or key phrases such as *'face the fear and do it anyway'*; and experiential exercises) were found to support the learning process by offering a variety of methods that could accommodate

different learning styles and needs. As such, survivors had choice in how they took on information; this was particularly useful given the vast spectrum of stroke disability. ***“I think some of the descriptions and analogies relating to your brain is working, how you feel, memories coming in and drifting our...I found those really helpful. They were quite intuitive to me and they were things I could remember” (Mark).*** This learning process was strengthened further when material was personally salient to survivors, with some describing an ‘epiphany moment’ from gaining better clarity or insight into causes of their distress and problems; helping them make more meaning out of their stroke experience: ***“you know when someone says something and you think ‘that’s what I’ve been missing’, it was like that hurrah moment” (Mark).***

Translatability of material was also aided by the authenticity of group facilitators in their delivery of ACT. Survivors suggested new concepts were easier to comprehend when facilitators embodied ACT and were able to elaborate with personal examples: ***“breaking things down with personal examples was easier to understand and get ideas across because I struggled with abstract concepts” (Charles).*** This not only normalised survivors’ experiences (i.e. unwanted events are universal), but helped individuals understand how the model relates and can be applied to daily life. In contrast, facilitators believed to possess superficial knowledge of ACT were criticised by participants. Two survivors acknowledged ***“I don’t think they [facilitators] were that experienced themselves...It felt like someone else had written it but they were just the front person” (Ivy)*** and ***“it was like they were just reading it and didn’t really know it...they didn’t have that inner thing to get across the points” (Paul).*** This was reported to act as a barrier to taking on group ideas, particularly abstract concepts, and potentially undermined belief in the model.

3.2.3 CORE CATEGORY 3: TRANSLATING KNOWLEDGE INTO PRACTICE

Alongside contextual factors, survivors' narratives indicated how knowledge was translated into practice to support movement towards accepting a changed reality. Firstly, all participants equated knowledge with power; variations in accounts suggest some survivors felt ACT offered new insight whilst others believed it reinforced pre-existing knowledge. Regardless, knowledge afforded participants more freedom, choice and control over how to proceed with their recovery, consequently enabling them to make informed decisions about whether their responses would be effective or ineffective, and likely to exacerbate pain or suffering. Application of knowledge was supported by a number of facilitating factors, including group tasks, homework sheets and repetition of experiential exercises. These helped to consolidate group material, monitor progress, and provided a referencing tool (especially for individuals with cognitive deficits to aid recall). These components socialised survivors to ACT, enhanced self-awareness and enabled participants to reflect on areas that needed further practice. The excerpts below best illustrate this:

“I’d do the homework and try to use the tips they were giving through those daily, it meant you had a bit of reference material if I perhaps forgot something, and also noticing the changes in my thinking, my feeling, my personality since the group” (Mark)

“The paperwork - that was really useful, because you know [the group] is only once a week and you need to go through it a couple of times in the week to remind you of what you’ve heard. It’s useful to have because you can highlight what you’ve taken on, the messages that you’ve taken on and you can keep going back and looking at it” (Connor)

Engagement with these activities and experimenting with different processes appeared dependant on survivors' motivation and understanding of ACT, with varying accounts of successful implementation. Difficulty understanding abstract concepts meant some participants struggled to generalise ideas outside of the group context, subsequently acting as a deterrent to practicing independently: ***"I could see what they were saying when they were doing it, but after the session I got a bit confused"*** (Phil).

In addition, filtering information based on its personal relevance and applicability to survivors' situations was found to help translate knowledge into practice for a small minority of individuals: ***"If it wasn't helpful I would tend to blank it from my mind...I took what was relevant for me"*** (George). It appears extracting salient information managed demands on survivors' cognitive reserves, enabling them to implement key concepts they deemed most helpful in supporting their current needs, opposed to expelling energy in practicing all skills. Likewise, discussing and sharing knowledge with wider social networks (e.g. partners, family or friends) supported skill acquisition: ***"I had [my wife] with me...we'd talk about it after the group, what we got from it"*** (Chris). This strengthened individuals' connection to the material, aided recall ability and provided a forum for rehearsal or revision of topics, which in turn opened up more opportunities to implement strategies.

3.2.4 CORE CATEGORY 4: BECOMING FREER

From attending the ACT group, almost all participants reported broadening their psychological repertoires to manage painful stroke experiences more effectively. Extrapolating knowledge to internal events was seen to help survivors improve their capacity for self-awareness, to feel more confident in confronting their fears, and provide greater

flexibility or choice over their behaviour: ***“Your mind sort of bullies you into a certain direction and you can decide to take a different direction if you want to” (Josh)***. Modifying responses to stroke meant participants felt less isolated and restricted by their actions, and had more freedom in how they approached their recovery; thus supporting movement towards acceptance of a changed reality. By comparison, two participants acknowledged the value of ACT but were unwilling to nurture these skills, instead showing continued inflexibility in their thoughts and actions, and pursuit of unattainable goals regardless of the emotional struggles that ensued. This was witnessed to increase the intensity and frequency of painful experiences, and worsen negative affect.

“I go to bed every night thinking I’m going to wake up and it’s all going to disappear. I’m going to be the person I was before... but it hasn’t happened yet. Since the stroke I’m a different person....I’m still stuck with it and I still want answers” (John).

Importantly, ACT skills provided a basis for many participants to experiment in changing habitual patterns of behaviour that previously governed their recovery. Becoming more attuned to subjective experiences and learning to accept their presence (despite negative or critical content), enabled stroke survivors to react more mindfully in a way that was conducive to improving recovery, psychological wellbeing and resilience: ***“rather than listening to those things [critical thoughts]...you need to not struggle with them, let them go over you” (Charles)***. Altering relationships with difficult internal events was further witnessed to cultivate distance e.g. supporting participants in letting go, stepping back and living in the moment, and helped participants disentangle from the content of these events e.g. reappraising the power of thoughts. ***“This thing of ‘you are not your mind’, that had never connected with me, I always thought even before I had the stroke this thing***

constantly pushing me, criticising me, I thought you just had to put with it, it was part of life...so you're disconnecting yourself from your mind and thinking about what is it that I am actually doing now, what's important now, that was really helpful" (Connor). As a consequence of reducing internal struggles, more than half of stroke survivors' narratives highlighted a shift in perspective; descriptions of richer, more fulfilling and values-driven lives were reported despite the existence of residual disability. Participants further reflected on feeling more empowered and re-establishing control from reacting differently towards stroke limitations: *"I take things a bit at a time now... or look at things in a different way... so I'm feeling more relaxed and in control of myself"* (Phil).

Interestingly, although a few participants reported fighting against their limitations (e.g. not being able to complete tasks as quickly or to the same standard as before), they recognised making even small adaptations could allow them to continue participating in activities they enjoyed, providing them with a sense of fulfilment and a renewed sense of purpose. This is illustrated in the following excerpt: *"I've done my best to apply myself...I can't do the shopping in the same sort of way, but I go shopping on a Sunday with my wife, I go in this [wheel]chair...I like to think I'm taking an active role... I find it really important. I like the interface with doing something I used to do".* (Ron)

3.2.5 CORE CATEGORY 5: VALUING OTHER STROKE SURVIVORS

In conjunction with the aforesaid categories, all participants' emphasised being amongst other stroke survivors was in itself unique, highly valuable and helpful in facilitating adjustment to stroke limitations; *"[it's] a little community where everyone understands what it's like"* (Paul). The group context enabled stroke survivors to share experiences without

judgement, develop a sense of belongingness, and created a platform where participants felt valued and equal. This unity allowed emotions and stroke experiences to be normalised and validated, whilst simultaneously assisting in reducing feelings of isolation. As such, the majority of participants alluded to an improved acceptance of their current situation, which could further facilitate acceptance of a changed reality.

“To be able to go [to the group] and understand that you are not alone, you know there are other people out there who have gone through the same thing, the feelings are the same, their feelings of despair are exactly like yours, you know and just to have those other people to relate to is a benefit” (Abigail)

Within this category, participants also recounted making comparisons against other survivors, leading many to situate themselves along a continuum in terms of their health, stroke experiences, and stage of recovery. In most instances, this was deemed a helpful strategy which instilled hope and optimism about the future, and enabled participants to positively re-define their sense of self in light of stroke disability. The following quote encapsulate this: ***“I was expecting to be the youngest person there and I wasn’t. Some people had far worse experiences than what I had...it made me quite thankful, dare I say it, that my experience for having had to have an experience of that type, was quite positive” (Josh)***

Nonetheless in contrast some participants reflected on drawing either negative or derogatory comparisons against others (***“I was in a wheelchair... [but] they were nearly all walking, they weren’t in wheelchairs or anything”: Ivy***), or acknowledged feeling fraudulent compared to those whose residual disabilities were more chronic and enduring (***“The difference physically was immense. I think maybe I felt a bit of a fraud, in that I wasn’t as***

bashed up as they were”: Liam). The latter was compounded further for one young survivor who described being wrongly identified by group participants as a carer. Those participants making upward comparisons seemed to struggle more with unpleasant internal events, alluded to increased feelings of inferiority or described a resigned hopelessness about the future, and were less flexible in their approach to accepting a changed reality.

3.2.6 CORE CATEGORY 6: ACCEPTING A CHANGED REALITY

From strong narratives about the challenges of living with stroke limitations (both physical and psychological), the main dilemma confronting stroke survivors was around accepting a changed reality. Moving towards acceptance was considered to be a process dictated by time and one which fluctuated depending on participants’ willingness or readiness to change.

Nevertheless, many participants recognised the value of attending the ACT group in developing new coping skills, insight and a realisation that they were not alone in the difficulties they faced: *“I could have walked round with blinkers on if I wanted but I had to accept that I’d had a stroke and I needed to learn to deal with the aftermath of it”* (Mark).

These aspects of the group appeared to support most participants in their recovery by encouraging greater flexibility and choice in how survivors respond to the effects of stroke. For some individuals who were able to connect to ACT ideas and implement skills, they reported regaining a sense of control, and working more towards things they valued regardless of the impact of stroke. Re-engaging with a life that survivors thought was previously lost or unattainable, meant participants reported holding a more optimistic outlook on the future: *“I’m not glad I’ve had the stroke by a long shot, but positives have come out of it.”* (Liam). One young lady highlights her move towards accepting a changed reality by stating:

“People don’t like change but change is good...if you can embrace that and accept that, then you can get over your stroke a lot better..... You can give yourself a life that you didn’t think you could have in the beginning. You’ve got to come to accept the fact that you aren’t the same person you were before, doesn’t mean to say you are a lesser person, but just understand where your limits are, and what you can or can’t do now” (Abigail)

3.3 Conceptual Framework/Theory

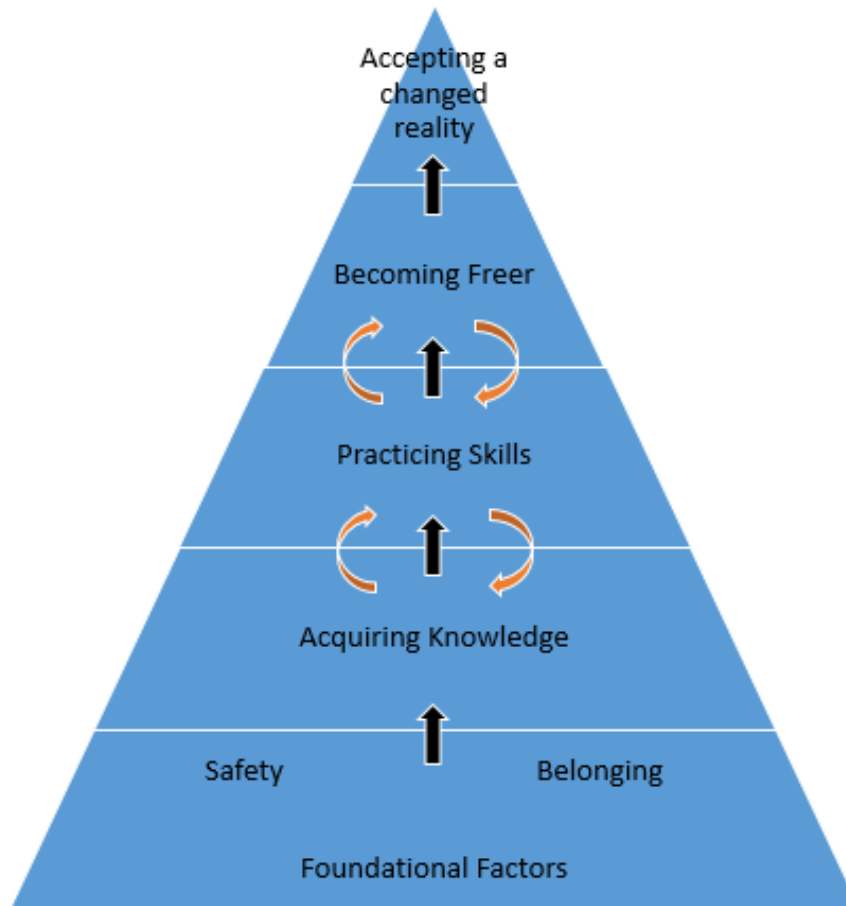
A sense of safety and belonging for survivors appear to be necessary prerequisites before any movement towards improved acceptance is reported. Safety and belonging is achieved by the group context itself; the interaction and presence of others with similar backgrounds and knowledge of living with stroke help validate survivors’ own experiences, whilst group transparency offers security within the environmental setting.

These foundational factors work towards increasing confidence in one’s ability to attend to and apply ACT material. Survivors show greater willingness to assimilate ACT material into their current knowledge-base, affording many to extend these ideas into practicing the skills (i.e. translating knowledge into practice). The more exposure survivors have to ACT, the more confident they become in integrating and experimenting with strategies that enable greater flexibility and choice in how to respond to internal events (i.e. painful thoughts or emotions). This in turn can allow survivors to become freer from distressing events; thus those who are not rigidly tied to unhelpful thoughts, feelings, or unrealistic expectations about their recovery report greater acceptance of their situation and reality.

Some survivors may continue to oscillate between acquiring and practicing skills for some time before progressing forward; perhaps due to initial difficulty transferring knowledge into practice or in practicing certain techniques. For others they may be unwilling or resistant to incorporate new ideas due to an inflexibility around their recovery goals. For these individuals, levels of acceptance improve marginally yet then remain at a fluctuating level without progressing any further.

This pathway varies considerably for each survivor and in addition, within individuals the process is fluctuating and non-linear. The degree of acceptance fluctuates for survivors as they work towards accepting a changed reality; a process dictated by time, ability to acquire and implement skills, and the individuals' readiness to change. Survivors largely reported moving back and forth between phases of acquiring knowledge and practicing ACT skills, and with this came to recognise a shift in their responses (i.e. greater flexibility) in living with stroke limitations; subsequently moving towards improved acceptance of their changed reality.

Figure 1.2 A conceptual framework for stroke survivors in working towards acceptance of a changed reality.



4.0 DISCUSSION

The main concern central to survivor's narratives and to the conceptual framework developed in this study relates to a difficulty in accepting a changed reality following stroke. This outcome is perhaps unsurprising, given the wide-ranging implications of stroke, its unpredictable nature and the vast disruption it can cause to survivor's lives (Falvo, 1999; Newton *et al.*, 2015). Findings are considered in relation to existing literature; clinical and service implications will also be discussed.

It should be emphasised that these findings only exhibit perspectives of stroke survivors interviewed in this study. Whilst these findings may not generalise outside of this sample, it is hoped the conceptual framework developed and emergent categories may be modified, or used to guide research across other stroke samples or settings.

4.1 Findings in relation to existing literature

4.1.1 Negotiating Challenges of Stroke

Participants need to situate themselves in the study helped capture the challenges faced when living with the effects of stroke; highlighting issues pertaining to increased distress, disrupted self-identities and loss of meaningful activities. This feedback substantiates past literature on mood disturbance post-stroke (Donnellan *et al.*, 2011; TSA, 2013), grief associated with identity change (Carroll & Coetzer, 2011; Ellis-Hill & Horn, 2000; Levack *et al.*, 2014), and reduced life satisfaction (Cloute *et al.*, 2008). Identity specifically was raised as a main challenge by survivors, with large discrepancies between pre and post-stroke self linked to negative affect and increased resistance or non-acceptance of symptoms. This echoes outcomes from brain injury studies where disruptions to self were linked to decreased mood

and poor QoL (Carroll & Coetzer, 2011). All challenges, regardless of primary aetiology (i.e. physical or psychological), were reported to negatively impact on adjustment and recovery within stroke (Mukherjee *et al.*, 2006).

4.1.2 Conceptual Framework

Grounded theory analysis revealed a pathway towards ‘accepting a changed reality’ as the principal challenge experienced. This pathway was reported as a non-linear process, with survivors describing a fluctuation between acquiring knowledge, implementing skills and greater psychological flexibility. Fluctuation in adjusting to physical illness is evidenced in past literature; with adjustment described as a dynamic path that is neither linear nor lockstep (Stanton *et al.*, 2007). Our framework postulates oscillation is important for improved acceptance of stroke, and supports past research by highlighting variability and heterogeneity in the pathway towards acceptance of a changed reality. The emphasis on oscillation corroborates other theoretical frameworks on adjustment, including posttraumatic growth (PTG; Calhoun & Tedeshi, 1999, 2013; Cann *et al.*, 2011; Gangstad *et al.*, 2009; Hallam & Morris, 2014; Kelly, 2015; Kuenemund *et al.*, 2014) and grief (Strobe & Schut, 2010) models. It argues against linear-stage theories of adjustment; although evidence in favour of these is scant (Wortman & Silver, 2001).

Safety and belonging were identified as necessary prerequisites to applying ACT skills; these factors are reported as strong determinants of improved wellbeing and successful adjustment to chronic illness (Ambrosio *et al.*, 2014; Repper & Carter, 2011). Establishing a sense of belonging through meeting peers has been linked to increased feelings of personal empowerment, hope, reduced isolation (Cruwys *et al.*, 2014; Tomaka & Palacios, 2006), and opportunities to re-build a sense of self and identity (Amarshi & Reid, 2006). As interaction

was not actively encouraged within the group, it may suggest mere proximity to others in a shared experience can induce beneficial outcomes. Likewise, social comparisons may contribute as most survivors reported positive comparisons enhanced their self-perceptions, self-esteem (Collins, 2000; Festinger, 1954; Wills, 1981), and elicited optimism about the future (Chambers & Whindschitl, 2004). Survivors with more severe disabilities however were seen to make more pessimistic comparisons against others; resulting in reduced affect, hope and motivation to change (Moore & Small, 2007).

Increased exposure and practice of ACT strategies helped facilitate greater capacity to tolerate distress and control in how to respond when confronted with the challenges of stroke (i.e. flexibility); consistent with research on adjustment post-stroke (Alaszewski *et al.*, 2006; Kessler *et al.*, 2009) and outcomes of ACT in other physical health domains (Graham *et al.*, 2015). Similar to PTG (Tedeschi & Calhoun, 1999, 2004) where transformative changes are experienced as a result of struggling with a traumatic event, change occurred through survivors attempts at reappraising personal goals and painful internal experiences in light of their stroke. This in turn supported improvements in acceptance. Taylor's (1983) cognitive adaptation model similarly stresses the flexibility of cognitions in allowing individuals to consider positive views in the face of traumatic experiences, and in encouraging personal growth and development. Folkman (2001) further emphasises the importance of finding positives from challenging experiences, suggesting cognitive re-framing supports successful coping and increases positive affect.

However, not all survivors followed this trajectory with some ruminating on their pre-injury self, thus reporting greater resistance in using ACT concepts and greater fluctuations in acceptance. Within PTG literature, rumination can be perceived as either a destructive or

constructive strategy depending on whether it perpetuates distress or aids understanding of the trauma (Calhoun *et al.*, 2010). This appears to be closely associated with the concept of ‘denial’ coping within health, grief models and psychodynamic frameworks (Christensen *et al.*, 1997; Telford *et al.*, 2006). For example, in cancer contexts, denial has been viewed as a defence strategy to help manage the difficulty of integrating distressing changes after life-threatening events (Brennan, 2001). Here, denial functions adaptively allowing individuals to slowly integrate information and assimilate new assumptions about the self, world and others into their life narratives (Brennan, 2001). Interestingly, survivors who described these ruminative processes were facing a life of permanent paralysis. This may suggest adjustment processes or trajectories occur for those whose impairments are markedly different from the life they previously identified with. Future research exploring how stroke survivors come to make meaning of their residual disabilities and how this differs depending on the severity of stroke would be of interest.

4.2 Strengths and Limitations

The present study possessed several strengths, including a large sample suitable for achieving data saturation (Evans, 2013), triangulation of the data to reduce interpretation bias, inclusion of a broad range of stroke survivors, and maintenance of high ethical standards; all markers of good quality research.

However, there are important limitations to the study that should be considered. Firstly, lack of sample diversity may limit generality of the data to wider stroke contexts; the sample was unrepresentative of ‘oldest old’ adults, ethnic minorities and survivors with severe disability or in long-term care facilities. Inclusion of only two female participants suggests female

perspectives were also underrepresented. This in part was due to screening criteria, theoretical sampling and study withdrawal, however collaboration with more diverse populations in future may reflect different experiences not captured in these data. Caution should be taken when extrapolating these findings to other contexts, particularly considering ethnic backgrounds, cultures, generational beliefs and religion may influence responses. Interviewees also differed on their duration post-stroke and most were first time stroke survivors; comparisons against stroke survivors who have experienced recurrences and who are at various stages in adjustment to their disability are proposed. Secondly, the researcher completed external credibility checks with other academics and professionals to support the methodological quality of the study; ideally credibility checks with participants via use of a focus group would have also been completed to reflect on emerging data categories. The flexibility of the conceptual framework however, means it can be modified in future to account for any new, emerging information from stroke survivors. Finally, interviews were conducted at least one month after completion of the course to allow for practice and consolidation of the material. Unfortunately, unexpected challenges regarding cognitive impairments were encountered; cognitive decay affected recall abilities. Future extensions of this research should account for memory difficulties to ensure the overall framework is inclusive for all stroke survivors.

4.3 Clinical and Service Implications

To the best of the researcher's knowledge this is the first qualitative study exploring survivors' experiences of ACT, and processes involved in adjustment to stroke. Narratives suggest ACT is a valuable and effective resource for the stroke community; however certain adaptations are recommended to support the physiological-neurocognitive needs of survivors

(e.g. pain; hemianopia; noise sensitivity, cognitive deficits etc.). This includes adaptations to the environment and presentation of the ACT material (refer to box 1).

In addition, the framework acknowledges a fluctuating trajectory towards accepting a changed reality; suggesting facilitators need to consider the element of time, readiness-to-change and ability to acquire/implement ACT skills. Some survivors may benefit from attending a rolling ACT programme to aid material recollection, comprehension and application; although this would need to be balanced against realistic service demands. Modifications to the environmental context (box 1) and the importance of meeting others are reported to help facilitate a sense of safety and belonging. The psychological response related to these foundational components implies feeling safe and connected through a shared experience may indicate the level of support gained in this context is perhaps different that obtained from other people (e.g. family, friends, staff). It perhaps emphasises group interventions should feature as a standard component of post-stroke rehabilitation.

Findings contribute to the growing ACT literature, and are useful in considering future redesigns of stroke practice, policy and service developments. Advocating ACT in stroke could broaden the prospective benefits of rehabilitation, extending support beyond physical care to address the wider and long-term needs of survivors. Astute recognition of long-term needs is vital for clinical practice; better understanding of the psychosocial implications of stroke may enable survivors to access services quicker, which in turn could reduce the probability of chronic complications emerging later on. Acknowledgement of these needs would enhance current provisions, could support the pending updating of the National Stroke Strategy and address concerns of survivors who describe a strong feeling of “*being set adrift*”

upon discharge from hospital. It may also have economic benefit in reducing long-term dependency on stroke and mental health services in future (O'Neill *et al.*, 2008).

Box 1: Recommendations for adapting ACT groups for stroke.

- Review font size, slide formatting and slide colours when delivering the group via PowerPoint presentation.
- Use of personal examples can aid comprehension of abstract concepts and make material relatable.
- Different teaching methods should be used (e.g. psychoeducation, metaphors, and experiential exercises) to aid the learning process; this will accommodate different needs and learning styles.
- Facilitators delivering ACT groups should have good knowledge of the ACT model.
- Make practical modifications to account for physical and neurocognitive limitations.
- Be transparent with group agendas (e.g. break-times and degree of involvement) as this will help manage survivor's expectations and anxieties.
- A good balance between didactic teaching and interaction/discussion.
- Provide easy-to-read handouts summarising the sessions content; particularly useful for survivors with cognitive impairment.

5.0 CONCLUSION

This study describes experiences of support through attending an ACT group, in adjusting to residual stroke symptoms or disability. Improved understandings of how stroke survivors come to accept a changed reality have been highlighted, with findings offering significant insight into the ongoing psychosocial needs of this population. Further replication and extension of the current study is recommended. It is hoped these findings can stimulate further developments to improve the quality of stroke care following discharge from hospital and support future revisions of stroke policies and guidelines.

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Paper 3: Critical Appraisal and Reflections

Rebecca Large

Paper 3 – Critical Appraisal and Reflection

The aim of this paper is to provide a reflective account and critical appraisal of the decision-making processes involved in the systematic review and empirical study. Commentary on the research process will be presented initially, including how the research came to fruition, the experience of working with stroke survivors, and the experience and process of using a qualitative design. Reflections on personal and professional development as a result of undertaking doctoral research and the influence of this project on clinical practice will be outlined. Subheadings have been used throughout this paper for ease of reading. Use of both first and third person accounts will be provided.

1.0 APPRAISAL OF SYSTEMATIC LITERATURE REVIEW

As part of the overall project a systematic review was conducted (paper 1). This allowed the researcher to explore literature currently published within a chosen field, to assess the quality of these studies and to use the outcome to inform future research investigations. The researcher was initially interested in exploring the role of psychological flexibility on functioning within a stroke or neurological context, however the paucity of research in this area meant the investigation needed to be broader. Due to the breadth of research around psychological flexibility generally within the realms of physical and mental health, the researcher decided to focus on one particular condition to ensure the review was manageable. Chronic pain was selected specifically as it has received considerable attention within Acceptance and Commitment Therapy research and is reported as being life-restricting, long-standing and in some cases untreatable – this was likened to some of the residual symptoms

or disabilities stroke survivors might face. Although the review and empirical paper are unrelated, it was hoped completing a review close to the main body of research being undertaken as part of this doctoral thesis, would further inform or provide supplementary information to share back to local services to assist in enhancing the development of future stroke provisions. The researcher was also aware that to the best of her knowledge no systematic review currently exists of this nature; with the majority instead focusing upon the effectiveness of ACT either collectively on different mental/physical health complaints, specific conditions (e.g. social anxiety, chronic pain), or in comparison to other psychotherapeutic interventions (e.g. Cognitive Behavioural Therapy, Applied Relaxation etc.). As such, it was hoped completing a review in a new area would help synthesise findings from individual studies, explore the consistency of the data and add to the current literature base.

It should be emphasised that the researcher largely delayed starting the systematic review process until after data collection and analysis of her empirical study (paper 2), to prevent outcomes from reviewed articles biasing her interpretation of the results. This has been suggested when conducting certain qualitative methodologies such as grounded theory. This ensured the researcher could remain as close to her data as possible without being influenced by extraneous factors (e.g. newly acquired knowledge of ACT, opinions from other researchers etc.). Nonetheless, despite the researcher's best efforts, time constraints meant full compliance with this delay was not completely feasible, and consequently, near the end of the data collection/analysis stage there was some overlap between these processes. Unfortunately, due to the scheduled running of the ACT groups, the time it took to complete and transcribe interviews (along with managing unexpected complications), and the pending thesis deadline, it was not completely practical on this occasion. Use of a reflective journal

helped the researcher to remain grounded in her data and to remain alert to any potential influences that might have jeopardised her interpretation of the findings. If the researcher was faced with a similar situation in future she would hope time would be factored into this process to ensure the recommended guidelines can be followed successfully.

1.1 Inclusion Criteria

The inclusion criteria was carefully considered in collaboration with the researcher's academic supervisors, to ensure the most relevant articles to the review question were obtained, and that the criteria did not unintentionally exclude articles pertinent to this review. Rationales for each inclusion criteria are detailed below:

1.1.1 Articles must be peer-reviewed

As articles are scrutinised by field experts against multiple quality control measures within the peer-review process and are typically revised on a number of occasions prior to publication, these articles were recognised as being scientifically robust and more likely to have strong validity and reliability components. It should be noted however that unpublished articles, dissertations and 'grey' literature can also contribute useful findings; use of only peer-reviewed texts can introduce issues with publication bias.

1.1.2 Adult population (>18 years+)

To the best of the researchers knowledge this is the first systematic review in this area, thus an adult population was deemed most relevant in the first instance. This decision was also guided by the differences reported in physiology and pain assessment measures of working with paediatric populations. Paediatric samples were therefore excluded.

1.1.3 Patients experiencing non-specific pain

Literature into chronic pain is extensive, with studies recognising many different forms of the condition exist (International Association for the Study of Pain, IASP, 2002). Since the breadth of pain literature would have been unsurmountable to review together, articles were restricted to samples where the majority of patients experienced non-specific pain (i.e. not attributable to a known pathology such as infection, deformity, tumour, inflammatory disease etc.). Studies where there was a primary/known aetiology to participant's pain were therefore excluded.

1.1.4 Articles must be reported in English

Lack of time and resources to translate articles in other languages, meant included texts were restricted to English-only publications. Again, this may open the study up to publication bias.

1.1.5 Outcome measures relating to psychological wellbeing, disability and/or functioning.

The review sought to explore how psychological flexibility influences individual's functioning when living with chronic pain; measures pertaining to physical, emotional, psychological and social dimensions were therefore deemed necessary to include. It should be noted that although wellbeing measures were used as an inclusion criteria, for studies exploring process of psychological flexibility following an ACT intervention the researcher is aware that improvements in mood/wellbeing are not intended outcomes of the approach but related more secondary gains.

1.1.6 Psychological Flexibility must be evaluated in some form

As the main entity being studied articles using measures assessing psychological flexibility either collectively (e.g. though the Acceptance and Action Questionnaire) or via its individual facets (e.g. Committed Action Questionnaire) were included.

1.2 Quality appraisal tool

Inclusion of a quality appraisal tool has been emphasised when completing a systematic review. Despite this recommendation, no ‘gold standard’ currently exists; rather a collection of appraisal instruments have been devised that either evaluate diverse designs (e.g. different methodologies) or appraise single methodological approaches, such as the Consolidated Standards of Reporting Trials (CONSORT; Schulz *et al.*, 2010) for Randomised Controlled Trials (RCTs). Although this affords greater choice around what appraisal measure can be used, the researcher found this brought its own dilemmas which left her feeling both overwhelmed and confused when deciding on which tool was most appropriate for her review.

The researcher’s final decision was to use the Quality Assessment Tool for Studies with Diverse Designs (QATSDD; Sirriyeh *et al.*, 2012); a tool comprising of 16 evaluative indicators covering both quantitative and qualitative designs. Guidance notes around the quality scoring criteria was also provided to reduce subjectivity. The rationale for using this particular instrument was based on its previous use in health-contexts by other clinicians and health-service researchers, and the benefit it had of being applied to a range of methodologies. Since this systematic review included papers with that were cross-sectional, randomised-controlled, cohort/prospective and longitudinal in nature, this quality measure

therefore felt most appropriate. It also enabled all papers to be rated on an identical scaling system (i.e. 0 - 3) which aided comparisons between the quality ratings of particular articles.

On reflection, despite believing the quality checklist criteria was initially quite clear, as the researcher progressed with the tool boundaries between scales appeared to 'blur' making it harder to differentiate the quality of papers. Improved clarity of the scoring categories would have assisted in appraising the credibility of the data; instead the researcher was fortunate enough to work with an independent rater to determine the quality ratings of the reviewed articles. This helped to reduce bias in the interpretation process; it also offered useful dialogues around the articles design, sample, measures, reliability etc., and discussions around differences in scores until a consensus was met. It appears similar criticisms have been raised elsewhere in the literature (Fenton *et al.*, 2015).

2.0 RESEARCH PROCESS OF EMPIRICAL PAPER

2.1 Reasons for undertaking this research project.

The early development phase of this research was based largely on the researcher's interest in pursuing a project within clinical health psychology, and her desire to develop a better understanding around a therapeutic model she had limited knowledge of, in this instance, Acceptance and Commitment Therapy (ACT). It was hoped that combining the two fields would enable the researcher to develop a project she was enthusiastic and passion about, as well as advancing her knowledge of a new psychological model which could later be applied in her clinical practice. As the research proposal developed further and the project came to fruition, it was felt that given limited existing literature in this field the outcome could have strong clinical implications for the future development of stroke services and refinement of guiding policies. As such, it was an exciting opportunity for the researcher to contribute to the evidence-base and establish the utility of this model within a stroke context.

The researcher's interest in physical health largely stemmed from her previous employment as an auxiliary nurse during her undergraduate degree where she supported individuals with a range of life-threatening and chronic illnesses, and subsequently, as a senior assistant psychologist supporting the development of a physical health psychology service. More specifically her interest in stroke was sparked from working clinically on a stroke rehabilitation unit during her doctoral training; this revealed the immense scarcity, inequity and variation of community rehabilitation services across the different Welsh University Health Boards (UHBs). The placement also increased the researcher's awareness of the government's drive to concentrate healthcare funding on the short-term physical

rehabilitation needs of stroke survivors, and the sheer lack of support currently available to address the long-term psychological needs of this population. This was surprising to the researcher given the recommendations within the National Stroke Strategy (Department of Health, 2007) and other clinical guidelines (NICE, 2013) which accentuate the need to confront the long-term psychosocial aspects of living with stroke. Similar visions are reported in the recent Welsh Stroke Strategy plan (Welsh Government, 2017) with reports of improving long-term care for stroke survivors over the next 4 years; current provisions available however are not consistent across all UHBs. The researcher felt that from hearing first-hand experiences from stroke survivors about the psychological difficulties that ensue after stroke, better integration and availability of psychological services within multi-disciplinary teams would inform a more holistic care approach and help improve stroke recovery.

To address this apparent gap and to increase availability of psychological services, the notion of running a four-session ACT group was formulated in collaboration with a Clinical Psychologist, Professor Neil Frude. Professor Frude's involvement on the project materialized from his previous work in developing an ACT package for the general population and those accessing primary care services in England and Wales. Professor Frude was keen to adapt his ACT program for stroke survivors in partnership with service-users and a Consultant Clinical Psychologist (Prof. Reg Morris) who is renowned for his psychological and research contributions in stroke. The researcher's interest in pursuing this particular therapy model came from some brief teaching she received on her clinical training course, which highlighted its broad applications and trans-diagnostic nature. ACT was felt to be a promising intervention for this population given some survivors may understandably experience realistic illness beliefs, or be confronted with ongoing health complications or

permanent disability. Opportunity to modify relationships with private events (e.g. thoughts, feelings, sensations etc.) rather than challenging the events directly (as witnessed in Cognitive Behavioural Therapy, CBT) was therefore deemed more appropriate in serving this client group. The researcher was optimistic that listening to stroke survivors experiences of ACT would provide valuable insight into how the approach applies to this population, which in turn could be utilized to improve service delivery.

2.2 Experience of working with stroke survivors

The final decision to interview only stroke survivors, rather than include carers, partners or families, was based on the fact that currently little evidence exists (either quantitative or qualitative) relating specifically to stroke in the context of Acceptance and Commitment Therapy. It was hoped this research could provide a platform on which future research could be based, and that further enquiry into the validity of ACT could be extended in future to support carers and wider support networks of the stroke survivor.

Working with stroke survivors offered the researcher rich, detailed and personal accounts of what it was like to live with the effects of stroke. These first-hand perspectives helped her to understand the devastating impact stroke can have on an individual's life (both physical and psychological), the wider influence stroke has on surrounding networks and systems (such as family, friends, work etc.), and frequently brought her attention back to her own health and wellbeing. The difficulties reported by most stroke survivors radiated throughout the research interviews, with many recounting loss across all life dimensions, living in a constant state of vulnerability and feeling far removed from their familiar reality. On reflection, the dialogue with stroke survivors at times was highly emotive and indicated significant

existential issues. Although the researcher is extremely grateful for the powerful, insightful and sincere reflections of these lived experiences, unsurprisingly the feedback led her to question her own morbidity and mortality, and to reflect on the unpredictable nature of life.

Although the researcher had relatively sufficient knowledge of stroke limitations following her six-month placement on the stroke rehabilitation unit, discussions that unfolded during the research interviews helped to highlight other factors that perhaps had not been considered in preparation of the groups. Admittedly every effort had been made to adapt the ACT material to ensure its relevance to stroke populations, however on reflection more forethought needs to be given to the practicalities of the group (e.g. venue temperature, lighting, space and room comfort) to account for the considerable diversity in residual stroke symptoms. This information has already been shared back to the group facilitators to ensure necessary adjustments are adopted for future roll-out of the ACT groups across the UHBs.

2.3 Reflections on the ACT group

2.3.1 Design

As reported in paper 2, stroke survivors (who work as peer supporters, stroke ambassadors or who had close ties to stroke organisations across south-west England and south Wales) were invited to contribute to the development and adaptation of our ACT group. These people had no other connection with the group and were consulted specifically as “expert patients” to adapt the ACT PowerPoint slides and homework sheets (refer back to paper 2 for more information on group specifics). This co-productive relationship was deemed good practice (Needham & Carr, 2009) and constructive in aiding stroke survivors engagement and experience of the upcoming ACT group. As knowledge is created by experience, the active

role of “experts” in adapting group material was considered crucial in transforming the quality of this intervention (Needham & Carr, 2009). Although this was a time-consuming process requiring plenty of discussion and negotiation around group formatting and content, listening to different perspectives of these individuals allowed gaps, pitfalls and benefits of the group design to be voiced and amended prior to full delivery. It was hoped that co-production would promote “more effective onward learning” (Topping, 2005, p638).

2.3.2 Group Format

The ACT group was advertised as a psycho-educational course, which comprised of teaching theory and experiential components. From participant interviews, opinions around the group format were highly discrepant; some favouring the didactic nature of the group whilst others expressed a keenness for more interaction and discussion. Prior to this study, I possessed limited knowledge of ACT and could appreciate the rationale of both viewpoints. In light of my most recent placement in oncology services however, I have been socialized more to the ACT model and have since questioned the mode of delivery of this model in our stroke context. I am aware that ACT can be delivered in many formats and further acknowledge our psychoeducation course had approval from Stephen Hayes (founder of ACT) as being an appropriate intervention. However, I am left wondering whether stroke survivors may have benefitted more from a stronger experiential component and opportunities to reflect on these exercises. I feel further discussion around these exercises may have allowed stroke survivors to understand these concepts better, which potentially may have increased their adherence to the homework component.

2.4 Experience of Qualitative Research

My decision to undertake a qualitative research project was not taken lightly, given my research background was dominated by quantitative designs. I knew investigations of ACT in stroke had not yet been conducted and that a qualitative project in this field would provide rich insight into stroke survivors' experience of ACT and elicit certain processes within the group that could orient future research and aid the development of psychological provisions in stroke. Nonetheless, despite the initial excitement of completing a novel project, I was indecisive about my research proposal given my lack of confidence in undertaking qualitative research, and anxiety around the subjectivity of the data analysis process. Even though it felt uncomfortable to move away from the familiarity and security of quantitative study, the current project provided a challenge that helped to broaden my research competencies and enabled me to contribute to the existing literature. It was also refreshing to conduct research that moved away from exploring treatment effectiveness; instead this study allowed me to consider how the experience of ACT could offer a detailed explanation of what processes helped to engender psychological flexibility and support participants in living effectively with residual stroke disability. In particular, I was struck by how open, honest and willing participants were in sharing their accounts, and despite my initial reservations I enjoyed the freedom and avenues of exploration this research allowed which would have been overlooked within a quantitative project.

2.5 Process of Qualitative Research

2.5.1 Ethics

To ensure I was satisfied with the overall research design and topic area, a considerable amount of work was spent finalising the research proposal and navigating the ethics process. Multiple drafts and revisions of the application form were completed prior to submission, in the hope that it would help minimize the amount of amendments needed following review by the research panel. Scrutinising all parts of the ethics form and ensuring the information was as detailed as possible, meant my application was thorough and provided opportunities to think about any potential limitations that may be encountered as the research was undertaken.

The ethics process was lengthy, daunting and pressures to get feedback from the research panel so as not to delay the running of the groups was extremely demanding. Despite starting this process prematurely, the demands were perhaps amplified due to a poor understanding of time needed to complete this procedure. Groups and venues had been arranged reasonably far in advance, however due to unexpected challenges from the Research Ethics Committee (REC) and the local Research and Development (R&D) departments, access to the first group participants was nearly jeopardized. Fortunately, co-working with another trainee throughout the ethics process helped to alleviate some of these pressures. Joint ownership of the application helped to feel equally supported, particularly in the absence of any teaching on to how to proceed with ethics and to navigate difficulties that presented in the panel's feedback. In hindsight, despite efforts to minimize disruptions a number of delays were experienced throughout. This was an important learning-curve within the research process; not only was I able to familiarize myself with the ethics process and procedures of the REC, I came to appreciate the length of time this process takes and the challenges that can arise when least

expected. This experience has provided valuable insight and knowledge into the ethics system, and will support me greatly in any future research endeavours as a qualified psychologist, such as service evaluations or development projects.

2.5.2 Recruitment and Sampling

The researcher advertised this study to stroke survivors during their attendance at the ACT group and those interested were contacted at least one month after the group finished. The decision to enforce a one-month delay was made to ensure survivors had chance to assimilate, practice and consolidate knowledge and skills acquired from the group (Star, 2000); and could therefore offer accurate reflections on what elements they found most or least helpful in supporting adjustment to stroke. Contemporary theories of adult education support this decision, suggesting experiential learning and time to self-reflect play key roles in the acquisition of new skills (Burns, 1995; Kolb, 1984). However, despite the justification behind not immediately interviewing participants, the researcher became aware of certain difficulties this delay caused some stroke survivors. It became apparent during the interview process that a small minority were struggling to recall much information about the ACT group due to cognitive impairments. On reflection, it's possible this relates to differences in episodic and procedural memory (i.e. for skills); information may have been learned at a performance level that could not be recalled in terms of events – for example, you know how to ride a bicycle, you have remembered the skills and can perform it with relative ease, however you may struggle to consciously recall the date, venue and nature of your first lessons. Although the research excluded individuals with severe cognitive impairments for the very reason that cognitive processing difficulties may affect their ability to engage with the group, those with mild-to-moderate deficits were included. As a consequence of this some interviews contained little information, and to ensure adequate numbers for the study,

another research site (a charity organisation) was contacted and approved by the ethics committee, to aid recruitment. The fact some individuals could not recall much information is valuable data in itself, and suggests revisions to the adapted ACT course may need to be considered in light of these problems. As mentioned in paper 2, research suggests psychological interventions should aim to be as inclusive as possible (Cadilhac *et al.*, 2016); consultation with survivors identified as having memory difficulties may enlighten services about what adjustments can be made to ensure they gain maximum benefit from this resource.

As well as recruitment, the researcher needed to consider what constituted an adequate sample size, as she was keen to ensure the sample produced sufficient and detailed data to help cultivate a '*nuanced grounded theory*' (Charmaz, 2006, p18). Unlike quantitative research, which focuses on participant numbers, qualitative researchers consider the concept of saturation is most important in determining sample size (Baker & Edwards, 2012; Charmaz, 2006; Glaser & Strauss, 1967). Data saturation "*entails bringing new participants continually into the study until the data set is complete, as indicated by data replication or redundancy*" (Bowen, 2008). As there are no published guidelines quantifying how many participants are required to reach saturation (Guest *et al.*, 2006), the 13 participants involved in this study was viewed as an adequate sample size. This decision was based on the opinion that data saturation was reached after the twelfth interview on the basis that no new properties to the identified categories were provided by interview thirteen. In retrospect, its possible data saturation may have been achieved sooner had individuals with any cognitive impairment been excluded from the study. However it was agreed that this would reduce the face validity and transferability of the data as many stroke survivors experience some degree of cognitive impairment (Patel *et al.*, 2002). Charmaz (2014, p215) further warns that if

saturation is reached too quickly it can affect the criticality and complexity of the analysis, thereby limiting the content validity of the grounded theory. The benefit of this sampling method helped alleviate pressures on the researcher to recruit a certain number of participants, and thus enabled her to focus fully on emerging categories and on future lines of questioning to either support or refute the data. However, lack of guidance around sample size suggests it is an arbitrary process determined largely by the researchers' experience in analysing and evaluating the quality of the information collected. This has the potential to introduce bias to the data-set, and therefore highlights the utmost importance of adhering to qualitative research credibility checks and where possible triangulating the data with colleagues and peers to help eliminate interpretation bias. For the researcher, lack of guidance around how to adequately reach saturation and the discrepancies in the literature around its definition, caused some anxiety about the procedure being followed correctly. Supervision at this stage to ensure the method was being followed as closely as possible was paramount. Interestingly, it appears many researchers struggle with the poor clarity around the process of achieving saturation, and attempts to "get it right" can impinge on how successfully researchers familiarise themselves with their data and quality of the analysis (Piantanida *et al.*, 2004).

Due to the lack of guidance around data saturation, the researcher also took into account the idea of "theoretical sufficiency" (Dey, 1999). Dey (1999) favours the term 'theoretical sufficiency' to saturation (p257), which is the researchers ability to reach a sufficient depth of understanding of both the emerging categories and the processes between them (opposed to reaching a final end-point with no new data arising; saturation). The following qualifies how theoretical sufficiency was accounted for in this study, and how the sample and emergent codes were deemed sufficient in supporting the construction of the grounded theory.

2.5.2.1 Sample diversity

The diversity of the sample enabled different perspectives from stroke survivor's to be captured in the context of this adapted ACT group. Thirteen interviews were conducted with stroke survivors; they represented:

- Perspectives from both females (2) and males (11)
- Perspectives from stroke survivors of different ages
- Perspectives from stroke survivors with a range of residual disabilities, of differing severity
- Feedback from stroke survivors either living alone, with a carer or with family.
- Feedback from stroke survivors who attended the group with a carer versus attending alone.

Nonetheless, given the current profile of stroke survivors, extension of this grounded theory in future would benefit from incorporating experiences of participants with greater ethnic diversity, and further insight from female survivors. This would support the current literature who find certain populations are more at risk of experiencing stroke (National Heart, Blood and Lung Institute, 2017).

2.5.2.2 Decreasing Interrogation, Increasing Abstraction

The researcher transcribed all audio-recordings and read/re-read transcripts alongside audio playback. This kept the researcher immersed in the data and kept stroke survivors dialogue 'real' during the coding process.

Increasing abstraction throughout coding supported movement away from surface-level descriptive codes to understanding more about the relationship and interaction between

emergent codes and categories. This included greater insight into survivor's main concern (i.e. difficulty accepting a changed reality); the conditions under which categories occurred, were maintained and changed; and its consequences. For example, in order for survivors to assimilate ACT material different conditions were reported to assist the learning process; including material being relevant/relatable, use of real-life examples, or the need for safety to aid engagement and participation, etc. These conditions enabled survivors to experiment with ACT ideas and as a consequence (for some) they were able to develop greater flexibility around their responses to stroke limitations. For those who were unable or unwilling to apply techniques, emotional pain was maintained and/or intensified.

2.5.2.3 Reliability/Validity

Codes were initially formed through careful line-by-line analysis, where text was reduced to a short phrase or sentence. The micro-scrutiny of all transcripts supported an accurate interpretation of survivor's narratives, and helped minimise any undue influence from the researcher's perspective (Charmaz, 2006).

Systematic data checking and the process of iteration ('cycling' between interpretation and collection of data; Charmaz, 2006) further ensured the fit and sufficiency of the data. The depth of focused codes and categories were supported further with the use of reflective journals and memo-writing, alongside triangulation of the data.

2.6 Grounded Theory Methodology

Whilst grounded theory is not the focus of this paper, a brief discussion of the framework is necessary to elucidate reasons behind the researcher's decisions of using this methodology.

Compared to traditional scientific forms of enquiry, which look to establish causation, qualitative methodologies aim to understand ‘*how*’ individuals create meaning of lived experiences and ‘*what*’ social processes underlie them. Understanding the drivers of human phenomenon can offer detailed information that guides future investigation; thus they are typically employed to explore areas not otherwise researched or where minimal literature exists (Fossey *et al.*, 2002). Grounded Theory is one qualitative approach designed to support researchers in interpreting complex social phenomena. Although different permutations of grounded theory exist based on their core foundational assumptions and philosophical orientations, globally they all start with inductive logic and rigorously analyse responses to construct theories *grounded* in the data (Charmaz, 2006; Glass & Strauss, 1967; Strauss & Corbin, 1998). Early grounded theory (both classic and straussian) has been criticised for its objectivist or positivist assumptions (i.e. viewing truth as a single and universal reality). In contrast, constructionist theorists advocate the researcher as a ‘co-constructor’ of experience and meaning, thus framing the idea of a shared reality between participants, their context and the researcher (Breckenridge *et al.*, 2012; Charmaz, 2006).

In its application, grounded theory offers a systematic method of data collection and analysis; occurring through a process of coding, categorisation and interrogation of the data until a theory emerges (Charmaz, 2014). Prominent patterns within the data are constantly compared against each other to capture any discrepancies, and are analysed in light of both supporting and contradicting evidence to help refine the overall theory, and to ensure it is grounded in empirical data (Charmaz, 2014; see figure 1.3). The process of identifying which grounded theory approach was best suited to this study was one of the major challenges first encountered by the researcher; an observation consistently reported on for novice grounded theorists (Heath & Cowley, 2004; Howell, 2013). The apparent difficulties defining the

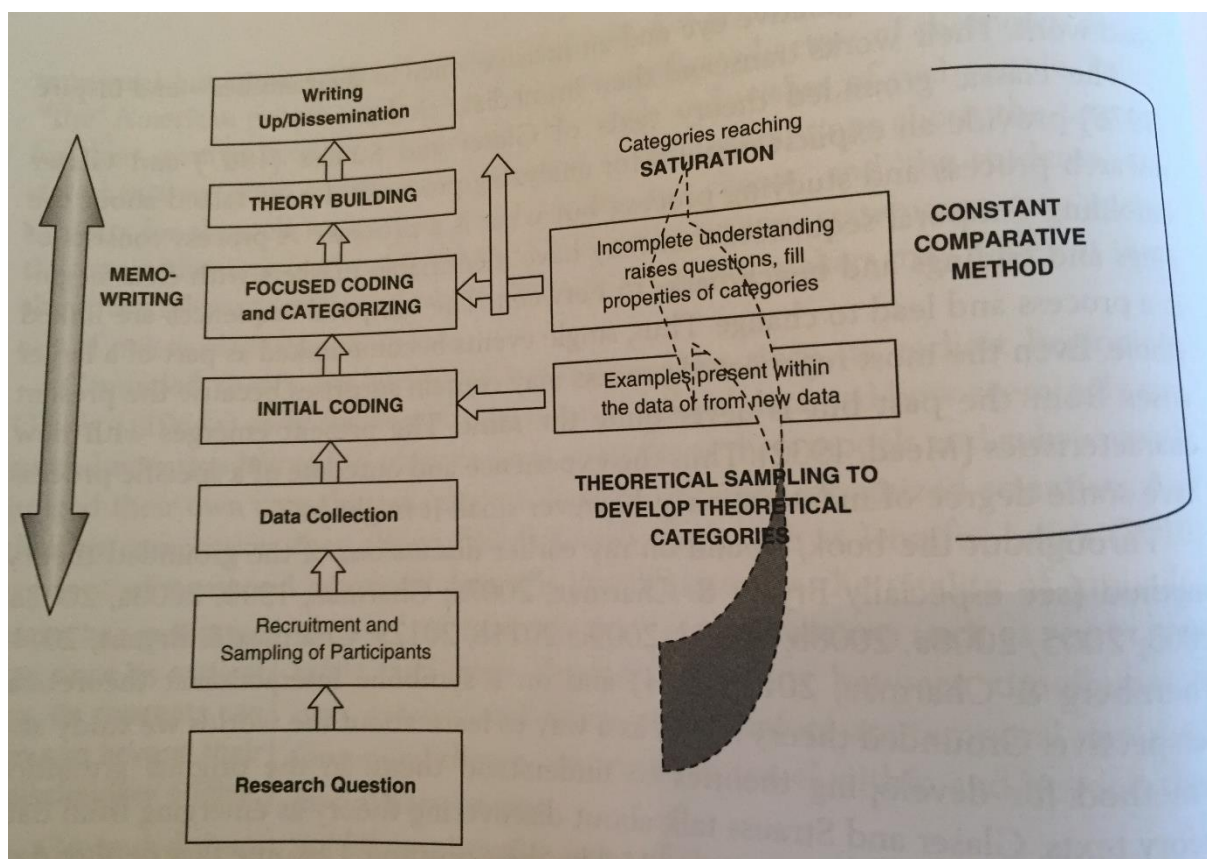
various grounded theory approaches within the current literature, and the lack of clarity or merging of approaches regardless of their inherent incompatibilities ('method slurring') made it difficult to entangle the appropriateness of the models to this research. After considerable reading around the three main approaches, the constructivist model (i.e. seeing the researcher as a 'co-constructor') was adopted as this 'fitted' best with the research question and the researchers own ontological and epistemological position (Willig, 2008). It was particularly important for the researcher to recognise the influence of her own beliefs and values on the data analysis, as she vehemently disagrees with Glaser's claim that researchers can remain neutral and unbiased during the interpretation of findings. In addition, the researcher was attracted to the principles of grounded theory and the freedom or creativity this allowed her when working with the data. Unlike other research methodologies, operating without any preliminary hypotheses or preconceived ideas about what the data may generate (Myers, 2009), provided a sense of excitement about what could arise from stroke survivors' narratives and what potential this information may have in shaping future care provisions.

Despite the initial enthusiasm in using grounded theory, the researchers' lack of knowledge in the chosen methodology and the need to ensure she was remaining true to the model raised a number of challenges throughout the research project. This included: timing issues; feeling "lost" or overwhelmed in the data at times; and duplication of processes to ensure coding was conducted systematically and at the correct level per stage of analysis. To prevent repetition, the aforementioned challenges have been discussed in more depth in subsequent sections of this paper (see section 2.7).

It should be noted that alternative qualitative designs were considered during the research proposal phase, including Interpretative Phenomenological Analysis (IPA) and Thematic

Analysis (TA). IPA captures idiographic subjective experiences and explores an individual's personal perceptions of those experiences (Smith & Osborn, 2003), whilst TA aims to identify emerging trends (themes) within the data-set (Braun & Clark, 2006). Whilst both methodologies would have offered rich insight into the lived experiences of stroke and highlighted commonalities between stroke survivors, the intention of the current research was to identify key underlying processes or mechanisms that support individuals in living with the effects of stroke following attendance at an ACT group. Grounded theory was therefore deemed most fitting in supporting the research aims.

Figure 1.3 Visual representation of the Grounded Theory Process (Charmaz, 2014, p18)



2.7 Data Collection

Within grounded theory data collection and analysis occur simultaneously. For the purpose of this paper however, the researcher has separated these processes to share her reflections on the individual components.

2.7.1 Interviews

During the data collection process, establishing a good rapport with stroke survivors and nurturing a trusting relationship was of upmost importance (Norcross & Wampald, 2011). Drawing extensively on communication and interpersonal skills helped to facilitate this process, given interviews were one-off contacts. These skills were therefore a particular strength to the researcher, since she was effectively ‘unknown’ to the stroke survivors she visited. The researcher had only met survivors briefly during session 1 of the ACT group when she was promoting her project; she avoided any involvement in the delivery or presentation of the groups to eliminate the possibility of bias within the interviewing process. As such, I found offering regular reflections, acknowledging reported difficulties, showing a genuine curiosity in participant responses and normalizing events helped create an atmosphere that was safe and containing, which in turn enabled survivors to be more open and honest in their feedback. This was particularly important as some survivors appeared reluctant to share criticisms of the group experience, for fear of offending the researcher. The tendency for ‘interviewer effects’ or socially desirable responses was highlighted as a significant limitation of individual interviews, and should be given more forethought in future research about how such challenges should be addressed. In an attempt to reduce the likelihood of participants either withholding or embellishing their feedback, the researcher remained as transparent as possible throughout the interview process. Stroke survivors as a

result appeared to be more amenable in discussing their experiences, both positive and negative (Westbrook *et al.*, 2007).

The location of these interviews were also discussed with survivors, with all participants requesting home-visits. The researcher was able to acknowledge the benefits of this request (e.g. comfort, convenience, security), but in her effort to remain person-centred did not anticipate the associated limitations. Challenges of home-based interviews included interruptions from family members, the telephone, and dogs barking, along with partners contributing to the interview questions. These disruptions were seen to affect the flow of conversation, meant some survivors responses were influenced by their partners' feedback and raised issues around confidentiality. The researcher was particularly mindful of confidentiality since many survivors shared narratives around the psychological impact of their stroke and recovery process. These reports were emotionally charged, with some survivors reflecting that they had not shared their deepest feelings with loved one in the fear of upsetting them. In future, the researcher would benefit from explicitly recapping expectations of the interview, and clarifying a mutually convenient time where chance of interruption is minimized. On balance, the choice to conduct interviews within participants' homes where they would feel more relaxed contributed to the quality of the data and outweighed the challenges presented by the interruptions. In addition, observing participants within their natural environment offered a contextual understanding which added to the wealth of the data.

The interview method itself served a useful function in understanding the complexity of stroke and the unique and personal factors contributing to stroke adjustment. Conducting interviews individually enabled the researcher to grasp the most candid representations of the

survivors' experience (Macdonald, 2006), and to minimize external influences on feedback (with the exception of a few interviews where partners shared their opinions). Although the advantages of using alternative qualitative methods were considered during the proposal phase, their associated limitations outweighed their use. For example, the researcher recognized the potential value of focus groups in ascertaining collective perspectives on the underlying processes involved in adjusting to stroke, and how discussions with other group members could stimulate new avenues of interest that may be overlooked during individual interviews. However, consideration of geographical limitations, group dynamics and the wide-ranging impact of stroke (e.g. auditory sensitivity; aphasia etc.), may have prevented a more representative sample from being obtained.

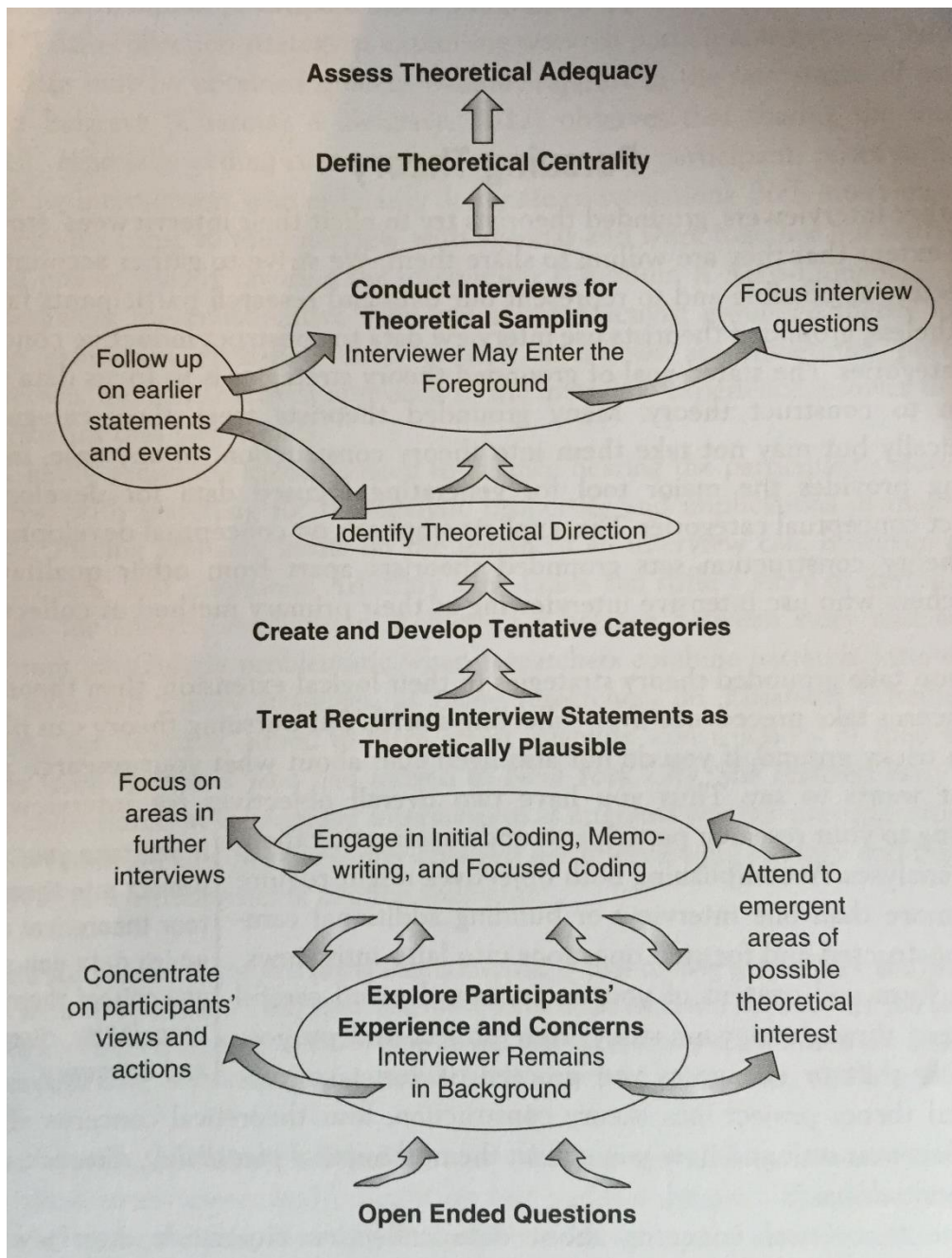
Lastly, as previously aforesaid, the researcher aimed to induce a sense of safety and acceptance within her interviews, and interestingly, she noticed all survivors needed to share their "stroke story" before answering her questions in more depth. It felt like survivors needed to situate themselves in relation to the ACT group and were partially justifying their reasons for attending. On reflection, I wonder whether part of this process centres on the fact that current stroke provisions focus on restoring physical functioning and fail to adequately acknowledge the psychological implications of the condition (McKevitt *et al.*, 2011; O'Neill *et al.*, 2008). For some, if not many, of the survivors this interview may have been their first experience of being able to share the psychology of their stroke, to feel listened to and to feel validated. At times, these interviews were seen to invoke strong emotional reactions; interestingly, I noticed I was less inquisitive during these times and tended to steer away from asking more exploratory questions. It's possible the distinction between my "researcher" and "psychologist" roles became blurred, and instead I would orient towards alleviating or containing participants' distress. This was definitely the case on two occasions where feelings

of suicidality were expressed. In retrospect, further measures should have been incorporated into the research to screen for risk, particularly in supporting the researcher during her home-visits for interviews. In these instances, comprehensive risk assessments were completed, although overall the process highlighted the importance of allowing time to debrief and planning for additional support (both for the survivor and researcher) if needed.

2.7.2 Interview Schedule

The core questions comprising the interview schedule were constructed jointly with both academic and clinical supervisors. I was extremely grateful to be able to consult with one particular supervisor during the initial phases, given her sound knowledge and understanding of grounded theory. The constructive feedback she offered helped to ensure questions were process-focused in accordance with grounded theory methodology (Charmaz, 2006), and assisted me in developing a standardized template for interviews. As interviews progressed, additional questions were added to the original schedule to explore new categories that were emerging from the data. The flexibility offered by this approach helped clarify certain themes permeating the data, and helped direct the research enquiry (see figure 1.3 for interviewing process). This part of the research was exciting and it was interesting to see how the questions evolved following survivors' responses. Although I had little knowledge of ACT prior to starting the research, I was mindful that I had received teaching on it that had introduced me to the model, and was conscious of suspending that knowledge so as not to influence my interpretation of the data and for that to affect the line of questioning. Surprisingly, participants' feedback seemed to be quite similar regarding their experiences of ACT and the processes they deemed most helpful or effective in supporting their acceptance of a changed reality.

Figure 1.4. *Interviewing Process in Grounded Theory Studies (Charmaz, 2014, p88)*



2.8 Data Analysis

2.8.1 Data Management

Grounded theory literature emphasizes the importance of staying as close to the data as possible and immersing oneself in the data collection and analysis phase (Charmaz, 2006). To maintain fidelity to the model, I decided to transcribe all the interviews myself rather than use a third party. This was largely a positive experience since it allowed me to reflect on survivors' narratives, immediately identify categories emerging from the data and to redirect my line of questioning following new information. It further heightened my awareness and sensitivity to the interview process; enabling me to identify times I had either missed opportunities to follow-up on significant statements that could have provided further insight and support for the emerging categories, or revealing times where questions were asked that did not relate directly to what was being studied. A major criticism of transcription, however, was how time intensive the process was, varying between five and nine hours per audio-recording. Alongside the clinical demands of a busy placement and other academic commitments, this process at times was immensely frustrating and my initial enthusiasm to independently transcribe interviews often waned. My frustrations were perhaps additionally compounded by concerns of delaying time between interviews given the aforementioned difficulties in those identified as having mild-to-moderate cognitive deficits. There appeared to be a fine balance between rigidly adhering to my methodology which advocates transcribing and coding interviews simultaneously before moving on to the next interview, and loss of valuable information given the cognitive difficulties reported in this population and the consequences of delay for recall of the sessions. At times, the researcher had to make difficult decisions about how to proceed with managing the data-set, and on occasions this did mean completing a couple of interviews alongside each other without completing the full

coding of transcripts; instead opting to read the transcripts and highlight the most pertinent themes emerging from them. In hindsight, although the formal process wasn't adhered to fully on a couple of occasions this meant feedback from survivors with known impairments could be incorporated into the overall model and thus increase validity of the emerging theory. In future, working qualitatively with this population in the context of neurological damage should be considered more thoroughly. Again, co-production with other stroke survivors to understand the variability of stroke effects and the challenges they face, may help researchers structure their projects in a way that facilitates adherence to their chosen methodology whilst still collecting data that represents the collective stroke community.

Other methods available to support the researcher in transcribing and managing the data, such as NVivo software or Strauss & Corbin's (1998) conditional/consequential matrix, were considered but deemed unnecessary. NVivo software programme manages the data by organising, analysing and identifying common themes amongst the data-set, whilst the matrix is used to locate repeated interactions within the data. Although these approaches had the advantage of being less time-consuming, it was felt, particularly with the software, that it would detract from the researcher establishing a meaningful connection with the data. This was important given qualitative literature emphasises the importance of the researcher being immersed in the data and the central role they should take in data interpretation. Use of specialised software may have highlighted key themes within the data-set, but equally may have missed more subtle cues or areas of interest that could steer the research question and support the development of a substantive theory (Bergin, 2011; Robson, 2002).

2.8.2 Coding

In accordance with a constructivist framework, coding occurred in three stages: line-by-line coding, focused coding (which illustrated greater analytical abstraction across emergent codes) and categorising data based on conceptual similarity (refer back to figure 1.3 for grounded theory process). Use of a reflective journal and memo-writing throughout aided the conceptualisation and refinement of emerging codes and categories (Charmaz, 2006); provoking thoughts about the interaction between categories, their properties and dimensions, and their consequences. Memo-writing was deemed particularly useful in elaborating on participants' narratives, and tentatively exploring the processes around an identified code, that could potentially shape future enquiries during interview. This supported the researcher in moving away from surface level constructs and delving deeper to explore tacit meanings about stroke survivors' attributions, values and beliefs (Charmaz, 2006). At times, the codes elicited from the data were overwhelming and the researcher on occasion noticed herself losing sight of the research question. As a result, she frequently returned to her research question to ensure she didn't drift from the intended aims and objectives of the study. Sticking close to the data and remaining 'active' in the coding process helped to facilitate this, and also ensured participants voices remained visible within the final grounded theory model (Fossey *et al.*, 2002).

Use of a reflective journal enabled the researcher to comment on information derived from participants' transcriptions (thus aiding category and theory development) and to also reflect on process issues; the latter was viewed as essential in increasing transparency throughout the analysis. Not only did reflecting upon process issues allow the researcher to become more aware of what participant responses elicited within her (therefore enabling her to manage its potential influence on data interpretation), it also provided space to reflect on implicit

characteristics of the interview such as participant's body language and the atmosphere during interviewing etc. The broad applications of using a reflective journal to support the research process helped to ensure the researcher focused on constructing a theory that was grounded in the data and gave her greater freedom to explore new areas that may contribute to the overarching model (Charmaz, 2006). The journal also enabled her to remain aware of any existing knowledge and assumptions that may have influenced interpretation of the results. This was particularly important halfway through the research process when the researcher began an elective placement in oncology services where one of the main therapeutic models delivered was ACT. Despite starting the research project with limited knowledge of the model, her elective placement meant she was required to explore this model in more depth; the journal was therefore useful to document the researchers views, reflections and ideas to ensure she was not influenced by information derived from her current clinical work.

As a novice in grounded theory, at times coding felt overwhelming, and perfectionistic tendencies of 'wanting to get it right' sometimes distanced the researcher from the data. It was apparent from supervision that the researcher's first attempts to code happened at the wrong level – i.e. she jumped straight to focused coding before completing line-by-line coding. To ensure none of the participant's data was missed, transcripts were re-analysed. Despite being an exhaustive process it was helpful for the researcher to immerse and familiarise herself more with stroke survivor's narratives. This experience emphasised the paramount importance of supervision during the analysis stage, particularly since a number of issues would have been encountered had the coding error not been identified – including: missing data that may have steered the emerging theory in a different direction and the development of an ill-fitting and unrepresentative grounded theory model. Fortunately,

regular discussions in supervision were useful in remaining true to grounded theory, in refining codes and categories, and identifying areas that required greater elaboration. In hindsight, establishing a trainee/peer supervision group would have been beneficial in providing a forum to discuss emerging codes from our respective data-sets, to obtain different outlooks and perspectives that might not have been considered, and to assist in quality assurance of the study (i.e. triangulation). This may also have built the researcher's confidence in using grounded theory by gaining support from others in a similar situation. Although this was discussed within the current trainee clinical psychologist cohort, progress of research (i.e. different stages of analysis, unforeseen set-backs with interviews, etc.) meant timing of these groups was difficult to arrange. Use of a grounded theory support network in future would be worth considering. The value of gaining other people's perspectives on your research is recognised in opening up new trains of thought or fields of exploration. This may particularly be the case in qualitative studies where researchers can become grossly immersed in their data that at times it can be hard to remove yourself from the process (i.e. not being able to see the wood for the trees).

2.8.3 Conceptual Framework

From coding and theory building, the final framework developed from the data (see paper 2, figure 1.2.) offers useful insight into the components of the ACT group that supported stroke survivors in moving towards accepting a changed reality. Of interest, was the notion that certain prerequisites were needed to optimise survivors learning potential (i.e. a sense of safety and belonging); particularly as interaction was not actively encouraged within the group. This framework should be considered in a tentative manner as it is open to revision in future from any new investigations or research that may be conducted in this field.

It is important to acknowledge the pathways throughout this framework fluctuate, based on individual differences between stroke survivors and the challenges they face; it should not be interpreted as a linear path. This trend appears to be consistent with research in other health domains that suggests individuals move back and forth whilst learning to live with physical disabilities or symptoms (Paterson, 2001). Paterson (2001, p4) describes it as “*an ongoing, continually shifting process in which people experience a complex dialectic between themselves and their world*”. In addition, some individuals were either unable to acquire knowledge or utilise ACT skills to become freer from unwanted events; for these individuals acceptance was seen to improve slightly but remained at a fluctuating level without progressing further. It would be useful to consider how the group context could support these individuals in future or whether further investigations are warranted around why this difference may result (e.g. resistance from survivors; avoidance; cognitive deficits etc.).

Lastly, the framework developed is situated in the responses of the survivors involved in the empirical study, however the researcher acknowledges there could well be potential feedback loops or setbacks that may alter the course that is depicted here. This was not identified within survivors’ accounts but is something to hold in mind for future reference, as acceptance was considered to relate to time. Its possible interviews conducted later, for example 6 months after the ACT group, may reveal different insights, and so again, the model could be revised in future in light of new findings.

2.9 Quality Assurance

To ensure the quality of this research different approaches were adopted to counteract the reported criticisms associated with qualitative research. Both the validity (Glaser, 1998) and

reliability (Elliot *et al.*, 1999) of the data was considered; I will elaborate on them here due to space constraints within the empirical paper.

2.9.1 Validity of Theory

Ground Theory aims to ensure the emerging concepts and theory are grounded in the data to which it will be applied. Glaser (1998, p18) suggest that in doing so, it needs to have 1) fit, 2) workability, 3) relevance, and 4) modifiability.

2.9.1.1 Fit

This concept focuses on ensuring the emerging categories and concepts ‘fit’ with the data from which it was derived, opposed to being shaped by pre-existing knowledge or literature. The researcher ensured through the use of reflective journals, memo-writing and supervision that she remained as close to the data as possible to support the emerging framework. Constant comparisons at each level of analysis further ensured the ‘fit’ of the data.

2.9.1.2 Workability

“Work” relates to how well the theory explains the central dilemma being studied. In this case, the framework developed highlights the main concern reported by survivors and offers a theory about how participants work towards resolving that concern through their attendance at an ACT group.

2.9.1.3 Relevance

This concept relates to how well the theory resonates with the real concerns of participants; and considers the wider application of the theory outside of academic interest. Listening to stroke survivors stories, constantly comparing the data throughout the analysis phase and

sticking close to the data, ensured their main concern of ‘accepting a changed reality’ was heard. Nonetheless, sharing the theory back with survivors or triangulating the data with participants via a focus group to elicit feedback on the overall framework would have improved the validity of this study.

2.9.1.4 Modifiability

This idea suggests the theory should be flexible and adaptable to any new information that emerges. As mentioned previously, the framework developed should be considered tentatively, given the study only examines survivors responses within a brief time-frame.

2.9.2 Reliability of Theory

Guidelines by Elliot *et al.*, (1999) to ensure the methodological rigour of this study was applied. Each component is outlined below:

2.9.2.1 Owning one’s perspective

Reflexive attempts should be made by the researcher to stipulate their own values, interests, assumptions and theoretical orientations, to acknowledge the potential influence these factors may have on the research process. This ensures transparency throughout data analysis and interpretation; in this study it was achieved by outlining the researcher’s position prior to the study and ‘checking in’ throughout the research process through reflective writing.

Owning one’s perspective:

The researcher is a single 30-year old, white British female from a middle-class background in South-West England, who is currently undertaking a doctoral programme in clinical

psychology. Her professional journey in this field, began with the completion of a Bachelor and Masters degree in psychology, punctuated with employment in various clinical settings across England and Wales prior to training. This included voluntary and paid employment within tier 1 (primary care) and tier 3 (specialist care) mental health services, and work as a nursing auxiliary within a local general hospital. Specifically, the researchers' first encounter of working with stroke survivors was in a physical capacity during her time in this hospital, however she was able to recognise the profound impact a stroke could have both on the individual and their families. These experiences sparked her interest in understanding more about the psychological interface between physical and mental health; which followed her onto and throughout clinical training.

As a psychologist in training, the researcher has undertaken core placements where physical and mental health difficulties have frequently coincided, including clinical work on a stroke rehabilitation unit in South Wales. This background has enabled the researcher to develop a better understanding of what it means to live with a physical health condition or the aftermath of acute illness, as well as gaining insight into the emotional disturbances that can result from life-changing events. Interest in the current research topic was stimulated by these past experiences, her clinical work and its relationship to personal life events. The researcher was further motivated to engage in this study as it promoted the voice of stroke survivors and has the potential to develop or modify current stroke rehabilitation provisions, which we currently know are lacking or largely ineffective in supporting the long-term psychological complaints associated with stroke. The aforementioned details highlight the researcher has some experience of working within a stroke context and was familiar with psychologists working within neuro-rehabilitation services; however she had not had contact with any of

the research participants within her professional capacity. This research was completed after she had left the stroke rehabilitation unit.

Prior to the present study, the researcher had a basic awareness of Acceptance and Commitment Therapy (ACT), but had no formal training or in-depth knowledge of this theoretical model. The researcher became fascinated in this model after teaching on the doctoral programme and case presentations of both adult and paediatric cases. This led to an initial exploration of the literature, and a basic understanding of its application. It was during this initial period that the researcher discovered ACT had been applied to a number of clinical health contexts, but had not been considered in psychologically supporting stroke survivors. She believed ACT would have valuable utility within a stroke context, given its premise of changing relationships with unwanted events, opposed to changing the events themselves. This was considered relevant to stroke survivors living with permanent disability or the emotional struggles of living with stroke limitations. It was anticipated stroke survivors attending the ACT group would learn to tolerate their distress better and develop strategies that could support them in adjusting to the effects of their stroke.

In addition, the researchers understanding that ACT is typically delivered experientially, contrasted with the delivery of this specific stroke-adapted intervention. Assumptions were raised about whether a didactic approach could elicit the same therapeutic gains compared to an interactive/discursive format, and whether limiting the experiential component would be detrimental in supporting participants. The researcher acknowledged these beliefs were based on past experiences of facilitating psycho-educational CBT groups, the feedback received from service-users in that context and the personal value she attributes to reflective practice.

The researcher further identified beliefs around stroke survivors' capacity to assimilate ACT concepts into everyday activity; acknowledging assumptions related to participant age and generational differences, educational status and degree of cognitive impairment.

The researchers' interest in this model and in clinical health psychology led her to undertake an elective placement in oncology services; it was during the later phases of analysis and write-up stage of the study that the researcher commenced this placement.

2.9.2.2 Situating the sample

It is proposed that sufficient details about participants should be collected to help situate the researcher to the range of individuals involved in the study and to assess how findings may translate to other situations. Patient demographics and stroke histories are provided in Table 1.3 (paper 2).

2.9.2.3 Grounding in examples

This principle suggests the reader should be able to appraise the fit between the data and the researcher's interpretations of the findings. A detailed summary of the grounded theory method and verbatim quotes within the research are provided in paper 2. Additional conversations around the use and frequency of quotes from certain participants with academic supervisions were facilitated to reduce the potential for bias in terms of alliance with individuals (Ahern, 1999.) Other illustrations of how the data is grounded in examples are evidenced in the appendices i.e. coded interview transcripts; category structures gained from the data and excerpt of memo-writing.

2.9.2.4 Providing credibility checks

Credibility of the developed theory and interpretation of the data should be assessed throughout the research process, either through checking understandings with original

informants or with multiple analysts. In this study, regular discussions of the analysed transcripts, resulting categories and the overall framework were held with both academic supervisors. This helped organise, refine and develop categories into a coherent structure. Triangulation with peers or with a sample of participants could have enhanced quality assurance. It is hoped disseminating the results at conferences and back to local services may facilitate discussions which could lead to the theory being modified in light of new feedback if necessary.

2.9.2.5 Coherence

This guideline proposed that presentation and analysis of the data should be conveyed in a coherent, integrated manner. This was achieved in the current research, through a coherent and clear narrative account with supporting quotations. A visual diagram depicting the emergent theory is also provided.

2.9.2.6 Accomplishing general vs specific research tasks

Researchers should provide clarity over the intended aims of the research and report on limitations associated with the applicability of the data. The current study considers stroke survivors experiences of attending an ACT group and what processes might support adjustment to living with residual stroke symptoms. The sample was derived from south-west England and south Wales. Whilst it is not intended that findings should be generalised outside of this sample, it is suggested the theory may be modified, or used to inform research within other settings. Participant's details and methodological limitations are provided in paper 2 so the reader can make an informed choice of whether the findings can translate to other contexts.

2.9.2.7 Resonating with the reader

This criterion states the emergent theory should be clear and contribute to the readers understanding of the topic area. To ensure clarity and understanding of the theory, both academic supervisors were consulted throughout the analysis phase for feedback. The introduction section of paper 2 should also orientate readers to why this research was undertaken.

2.10 Supervision

As stated above, the role of supervision was critical in supporting the researcher through the analysis phase; a notion corroborated by research reviewing the role of supervision within qualitative methods (Harper *et al.*, 2008). It is also important, however, to reflect on the use of supervision across the entire project (Maunder *et al.*, 2012). Supervision varied greatly throughout this project depending on the supervisor and the stage of the project the researcher was at. The researcher initially started with an academic and clinical supervisor, both with known expertise and specialist interest in working with stroke populations. These supervisors shared a wealth of information around working in the context of stroke and in project design, which helped facilitate ideas for the research, help gain access to the target audience and supported the quality of the work undertaken.

Things became slightly more difficult during the data collection/analysis phase of grounded theory and the support that could be offered around using this methodology. It was apparent that supervision was required more during this stage than at any other time. At this time, the clinical supervisor had gone on maternity leave and was therefore uncontactable, whilst the academic supervisor had reported having only generic knowledge of the chosen methodology

(instead having a strong portfolio of supervising quantitative research projects). A third (academic) supervisor was consequently consulted who possessed a strong research background in using qualitative methods. Although extremely grateful to receive this level of support a number of challenges were noted from having different supervisors involved in the study; namely difficulties in communication (“crossed-wires”) and differing perspectives on grounded theory and the subsequent write-up. This experience led me to reflect on the supervisor’s role and how important it is for them to be proficient in the chosen research topic and methodology (Maunder *et al.*, 2012). The researcher can appreciate that academics are drawn to specific research orientations, however it raised questions as to whether all potential supervisors at doctoral level should be relatively skilful in applying both quantitative and qualitative research, or whether this was an unrealistic expectation of the researcher.

Issues around availability and accessibility were also recognised with one academic supervisor due to their other commitments and responsibilities. Best efforts were made to try and resolve these issues by scheduling regular meetings, telephone calls and “touching-base” emails. Regardless of this particular challenge, generally the researcher has been incredibly impressed by the level of support she had received. At times it felt the supervisors went above and beyond their role to support their supervisee and to ensure the research went as smoothly as possible. Aside from the aforementioned criticism, supervision was useful in strengthening the supervisee’s qualitative research skills and developing her position as a ‘scientific-practitioner’ (useful qualities and competences that contribute to future employability), and in helping the researcher feel contained during times which were anxiety-inducing and overwhelming.

3.0 RESEARCH AND CLINICAL IMPLICATIONS

Navigating the research process has been a rewarding, yet challenging experience. Despite appraising and reflecting upon the rollercoaster journey of undertaking this research, it is apparent from the study outcomes that the proposed theory on '*accepting a changed reality*' could have positive, wide-ranging implications for stroke survivors, stroke services and national healthcare guidelines.

3.1 Research

Despite my initial ambivalence in undertaking a qualitative study, my research experience has emphasised how valuable and necessary it is to collect first-hand participant experiences, and how this can be used either independently to aid the evidence-base or to provide a foundation for further investigations. The power of participants' voices can help capture the complexities and intricacies around specific phenomenon, which might otherwise be missed within quantitative research. The outcome of the empirical study implies the following research implications:

- ❖ The sample utilised in the study was considered relatively broad regarding age, type of disability and varying duration since stroke; however, it was somewhat limited by inclusion of only two female participants and a lack of cultural-social diversity.

Although grounded theory literature places more emphasis on transferability of the data opposed to its generalisability, the current literature may struggle to be extrapolated more widely given these factors. The lack of cultural diversity was somewhat determined by the geographical location of the study, and despite efforts to theoretically sample females,

a couple of women who expressed interest in participating either withdrew at a later date or were uncontactable. As such, the proposed grounded theory may benefit from extensions in future to include more perspectives from females and culturally diverse participants, as well as targeting other geographical areas to see whether any different categories emerge.

- ❖ To the best of the researcher's knowledge, this is the first qualitative study exploring stroke survivors' experiences of ACT and the underlying processes that support adjustment to residual disability and living with a changed reality. Although the effects of stroke are highly individualised, some of the core categories to emerge from the grounded theory provide evidence for ACT in helping survivors reclaim their lives following the devastating and sudden events of stroke. These findings therefore contribute and extend the applicability of ACT and establish the ACT model as being compatible with the realms of neuropsychological rehabilitation. Other core categories to emerge from the data-set focused on contextual factors and the importance of meeting other stroke survivors; this information offers useful considerations for ensuring stroke survivors get the optimal learning environment to support them in improving their psychological wellbeing.
- ❖ In addition to the above, improved 'acceptance' of stroke (both the event itself and its limitations) were reflected throughout participant's narratives, and raised the question as to whether future research should look to delineate what processes are not useful in supporting stroke survivors. Insight into whether certain processes (e.g. values, acceptance, defusion) are more effective in initiating change or whether the model is

collectively valuable in stroke contexts, could support the delivery of stroke provisions and maximise outcomes for group members.

3.2 Clinical

In light of the research into accepting a changed reality, adjusting to stroke limitations and the use of an ACT framework within this context, it is important to consider the wider clinical implications of this work.

Most importantly, the research had revealed the significance of recognising the long-term needs of stroke survivors and how pivotal psychological services can be in improving an individual's wellbeing, psychosocial functioning and quality of life. Recognition of these needs could ensure survivors access the necessary support earlier on in their recovery pathway, which in turn may prevent chronic difficulties with adjusting to stroke effects. Alternatively, the ACT group could also function as a preventative strategy, supporting survivors in building their psychological resilience should they encounter any health changes in future or difficulties living with the impact of stroke.

Although not anticipated by the ACT model, the grounded theory to emerge from the data recognised the value of meeting other stroke survivors in improving acceptance of their current situation and residual symptoms. The clinical utility of this information emphasises the significance of group-based interventions for those living with life-altering conditions such as stroke, where meeting others can offer a sense of belonging, validation and opportunities to learn coping strategies from others going through the same lived experience.

Since ACT in stroke remains in its infancy, and stroke survivors report wide-ranging deficits, psychologists need to consider different ways of teaching skills to aid their learning and understanding of this model. The conceptual framework developed from this research offers some support around the contextual processes that can aid better clinical outcomes (e.g. use of simple metaphors to explain abstract concepts), although further research in this area is warranted. The findings from this study offers promising insight into ways individuals use ACT principles and the group to move towards accepting a new or altered reality. This has the potential to develop stroke rehabilitation services and should encourage organisations to adopt a more holistic approach in the way they support their service-users. Incorporating psychological care into the wider multi-disciplinary team will help inform clinical practice. Given the current NHS climate where funding is limited, innovative ways of working to embrace these suggestions need to be carefully considered.

Moreover, one key area the researcher reflected on throughout the study was around how valuable it was to gain the stroke survivor's perspective. It is typically acknowledged that despite the current drive for co-production, particularly within the Welsh NHS at present, service-users voices still get lost within the healthcare system. This is perhaps best illustrated by some of our survivors' narratives who described being "set adrift" by services despite expressing the need for ongoing support. As such, I am proud that this research offered an opportunity to amplify stroke survivors' voices and needs; and recognise this feedback has an important role within clinical practice and service delivery. I feel it further accentuates the need for more partnership working between professional and service-users; opposed to the "us" and "them" mentality. Personal experiences of co-working with stroke survivors on adapting resources leads me to believe that co-production should be a mandatory requirement

across all physical and mental health organisations to promote services and to ensure funding is being best spent on the needs of the client group.

Lastly, the opportunity to undertake a large research project within the context of clinical health psychology has further highlighted the importance of applying research skills within the workplace. From acknowledging the clinical implications of conducting research and the value this can have in shaping future care and service provisions, it is imperative as a profession that we promote these skills to improve services, healthcare standards, national guidelines and governing policies. As a result, findings from this research will be shared back with local services to encourage them to consider the value of implementing psychological interventions after stroke, and to acknowledge the long-term needs of this population. It is hoped this will improve local service delivery in the near future. The researcher also endeavours to publish her research in a psychology journal, in the hope this will fuel further investigations into this field (including stroke care, neuropsychological rehabilitation or advancing studies that explore the utility of ACT in neurological populations). The Journal of Contextual Behavioural Science was identified as the main choice for publication and was selected for a number of reasons: (1) the journal contributes to the expanding ACT literature base by regularly publishing articles on this approach and thus the researcher assumed publication in this journal would have a high impact in the field – i.e. people looking for ACT studies are most likely to consult this journal; (2) in addition, the journal is the official publishing source for the Association for Contextual Behaviour Science (ACBS). As a worldwide association, it was hoped publishing research here might stimulate interest not just within the UK but be of interest to other ACT experts at an international level; and (3) the target audience of this journal is believed to be largely clinical psychologists and other allied health professionals. From the researcher's knowledge, either

ACT groups or training in ACT, are typically facilitated by psychologists; as such, they may be able to use this research to aid training packages, or in adapting, enhancing or developing future ACT groups they are involved with. Interestingly, having shared these results back to my current placement supervisors who work in oncology, they reflected the findings of this grounded theory analysis could very much apply to cancer contexts as well. Psychologists may therefore be able to extrapolate some of these ideas, categories and processes to support the development of future ACT group in other health settings.

It should be noted that although the publishing guidelines have largely been adhered to for this journal, the British Psychological Society (2004) style guide has been used throughout. This was to ensure consistency in referencing style across the three papers, and as it is the recommended referencing system by the South Wales Doctoral Programme in Clinical Psychology.

This research will additionally be distributed at the Division of Clinical Psychology (DCP) Conference in January 2018 (as part of their ACT symposium) and has been submitted to the Welsh Stroke Conference (WSC).

4.0 PERSONAL & PROFESSIONAL DEVELOPMENT

Reflecting on the entire experience of completing this project I am astounded at the journey over the past 18 months – the emotional rollercoaster of writing this doctoral thesis, conducting the research and hearing both the heart-wrenching and inspirational stories of stroke survivors; the steep learning curve of undertaking qualitative research; overcoming obstacles and challenges that presented throughout the research process; and the opportunities this research has offered in terms of my professional competence and personal development.

Firstly, this project has undoubtedly increased my confidence in conducting systematic literature reviews, in understanding the minutiae of grounded theory processes, and has generally made me more appreciative of what qualitative findings can offer the empirical database. Having embraced the move from the familiarity of quantitative research, despite feeling largely overwhelmed, confused and uncertain at times, this entire process has given me a new-found appreciation of the time, organisation and analytic skills necessary to complete high-calibre qualitative research. Professionally, this experience in itself has ignited interest to pursue other qualitative research in future. The valuable contribution this type of study can make towards understanding the importance of different therapeutic processes or certain phenomenon, can hopefully support the development and refinement of our NHS services; making them more economic, efficient, and effective in supporting the needs of specific clinical populations. In conjunction, the richness and power of survivor's narratives obtained in this study, has highlighted the upmost importance of working collaboratively with service-users to help shape and inform service development. This idea of coproduction is something I endeavour to take forward into my own clinical practice upon qualifying. It seems intuitive that service-users, regardless of the context (i.e. physical and/or

mental health), should be involved throughout the conception, delivery and evaluation of the services they will be accessing, to ensure support is targeting the intended audience effectively. Overall, I feel completion of this project has enhanced my research repertoire and capacity for self-awareness, has strengthened my position as a reflective scientist-practitioner, and has provided me with a strong foundation on which to build further research expertise; all useful qualities that will serve me well as a qualified clinical psychologist.

As well as enhancing research competencies, undertaking this project has been clinically beneficial in enabling me to familiarise myself with a new therapeutic approach. As mentioned previously, I possessed limited knowledge or understanding of the ACT model prior to undertaking this research; however, knowledge acquired throughout this process has since been applied both professionally and personally. The distinctively different perspective of this model (e.g. engendering psychological flexibility, non-pathologising, perceiving distress as inevitable human experiences) is a refreshing take on some of the other therapeutic models I have socialised to throughout training, such as those that are symptom-reductionist like CBT. Learning more about ACT, and putting the model into practice, has enabled me to witness the pragmatic benefits it offers in supporting people living with chronic and intractable conditions. Despite my strong interests in clinical health psychology, I can appreciate the application of this model within mental health contexts, and am both excited and enthusiastic about taking this approach into my clinical practice following training.

Conducting this research has also contributed to my personal development. Firstly, my capacity for self-awareness has grown significantly; this project has afforded many opportunities to reflect on internal processes, views, assumptions and beliefs either via the research itself (e.g. through a reflective journal, discussions etc.), or from hearing survivor's

stories, which at times were considerably emotive and raised their own existential issues for the researcher. Use of supervision extended this capacity for self-awareness, enabling me to recognise these views/assumptions don't necessarily hinder research or clinical work, but can actually be used to enrich my interactions with the data or service-users. Alongside self-awareness, opportunities to self-reflect further enabled me to acknowledge areas of particular strength and to pinpoint areas that required further attention. This developed my own self-knowledge and alerted me to new learning opportunities. Secondly, this experience overall has enhanced my ability to concurrently manage stress and heavy workloads; related to challenges of research and the demands of a busy and emotive clinical placement. Above all, this taught me the importance of self-care and the importance of maintaining a strict work-life balance. Learning more about ACT from this research and self-practice of some of its underlying principles, such as defusing from unwanted thoughts and living in the moment (mindfulness), further supported this idea of self-care and helped me to cope more effectively with some of the difficulties I was facing.

Lastly, liaising with stroke survivors, course facilitators, ethics committees and professionals in multidisciplinary teams, I believe I have strengthened my interpersonal communication skills. Interacting with different individuals and professional bodies has enriched my ability to create a safe therapeutic alliance, along with professionally developing my assessment, consultation and training competencies.

Collectively, I feel these skills have made me a more resilient individual, and enabled me to remain a regulated, reflective and reflexive individual. Although relating to my personal development, I equally feel these skills can translate to support me in my professional capacity. For example, extrapolating these skills could allow me to work more effectively

with complexity, work robustly during a tough transitional phase for the NHS, and promote my own self-care in the workplace to prevent burnout.

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Appendices

Appendix A

SEARCH TERMS FOR SYSTEMATIC REVIEW

These search terms were combined using Boolean Operators (i.e. ‘and’, ‘or’).

Terms used in relation to Psychological (In)Flexibility

- Acceptance and Commitment Therapy/ ACT/ Contextual Behavioural Science
- Psychological Flexib*/ Psychological Inflexibility
- Acceptance/ Experiential Avoidance
- Fusion/ Defusion
- “Self-as-context”
- “Values-based action”/ Values
- Mindfulness
- Committed Action

Terms used in relation to Pain

- Chronic pain
- Persistent pain
- Long-term pain

Terms in relation to change

- Change
- Adjust*/ Emotional Adjust*
- Function*
- Mechanism
- Mediat*
- Predict*
- Process*
- Correlat*
- Associat*

Appendix B

QATSDD Quality Assessment Results

	Review Papers (* Numbers correspond to articles in Table 1.1)																						
Article No:	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
Explicit theoretical framework	3	1	3	3	3	3	3	3	3	3	3	3	3	3	2	2	2	2	2	2	2	1	1
Stated Aims/Objectives	3	3	3	2	1	3	2	2	3	2	2	2	2	1	2	2	2	1	1	3	3	1	2
Clear desc. Of research setting	3	3	3	3	2	3	3	1	0	3	3	3	1	1	2	2	2	3	1	3	2	1	1
Sample size considered in terms of analysis	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Representative sample of target group	2	2	2	2	2	2	2	1	2	2	2	3	2	2	2	2	1	2	2	2	2	2	2
Description of procedure for data collection	2	2	1	3	2	3	3	1	2	1	2	1	1	2	3	2	2	3	1	2	2	1	1
Rationale for choice of data collection tools	2	3	3	3	3	2	3	2	2	2	3	3	2	2	2	2	2	2	1	2	3	3	2
Detailed recruitment data	3	1	1	1	1	1	3	1	2	1	2	3	0	3	2	2	1	2	1	2	2	1	2
Quan: Statistical ax of reliability/validity of outcome tools.	3	2	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	2	1	2
Quan: fit btw research Q and method of data collection	3	3	3	3	3	3	3	2	3	3	3	3	2	3	3	3	3	3	3	3	3	3	3
Qual: fit btw research Q and format/content of data	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Quan: Fit btw research Q and method of analysis	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3
Good justification for analytical method selected	3	3	1	2	2	1	3	3	2	2	3	3	2	2	0	0	0	2	1	2	3	1	2

Qual: Ax of reliability of analytical processes	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Evidence of user involvement in design	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Strengths and limitations critically discussed	2	3	2	3	3	2	2	2	3	2	2	3	2	2	2	2	2	2	1	2	3	2	2
Total Score (out of 42)	32	29	27	29	26	27	31	22	26	25	29	31	21	25	24	23	21	26	18	27	30	20	22
Percentage (%)	76	69	64	69	62	64	74	52	62	60	69	74	50	60	57	55	50	62	43	64	71	48	52

Appendix C**Participant Demographic Questionnaire**

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 if you don't want to.

Thank you.

Today's Date: _____

Participant # (Office Use): _____

Age: _____

Gender (Please Tick)

Have you had more than one stroke?

Yes ☐

No ☐

Male ☐

Female ☐

Date of first stroke ____/____/____

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

Type of Stroke (if known) _____

Location of the Stroke (if known) _____

Are you Employed?

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 received treatment for any psychological condition (e.g. anxiety or depression) since your stroke?

Yes ☐

No ☐

If yes, what was the condition and what treatment did you receive?

Appendix D

Activate Your Life After Stroke (AYLAS) Course Leaflet

To find out more, or to
book a place contact:

**Helping you
re-build your life
after stroke**

ACTivate Your Life After Stroke

Acceptance and Commitment
Therapy for people and carers
living with stroke.



A short course to help you get
on with your life after stroke.



What is ACTivate Your Life After Stroke?

This course has been created
especially for people who feel
distressed or anxious after a stroke.

A stroke affects everyone
differently but it can cause physical,
emotional and social upheaval, not
only for the person but for those
closest to them.

The distress can often make
people feel unable to get on with
their lives.

Carers can have similar feelings and
this course is also suitable for them.

How can the course help me?

The ACTivate Your Life After Stroke
course is based on a novel
approach for helping called
Acceptance and Commitment
Therapy (ACT). ACT teaches that
trying to get rid of our distress and
pain only serves to increase it. It is
often better to accept things that we
cannot control.

Such acceptance is not easy, but
this course will teach you ways of
accepting painful and distressing
thoughts and feelings.

ACT also shows us how to make
a commitment to act in ways that
improve and enrich our lives
despite having had a stroke or
caring for someone who has had
a stroke.

What is the course like?

ACTivate Your Life After Stroke is
a four-week course. Each session
is two hours long.

It is an educational course that
will teach you simple ways of
dealing with thoughts and feel-
ings.

And think what you could gain:
reduced suffering, greater control
over your actions and increased
inspiration to help you change
your life for the better.

If you attend the course, you
won't be asked anything about
your personal circumstances or
problems. Simply come along and
see what you can take away.

The course consists of four sessions:

ACT 1: How the Mind works

ACT 2: Facing up to Life

ACT 3: Being Mindful

ACT 4: Living Wisely, Living Well

I'm interested—how do I book a place?

Details of the next course are
given below.

When:

Where:

Appendix E

ACTIVATE YOUR LIFE AFTER STROKE

COURSE OUTLINE

*Alongside ACT theory, experiential exercises and demonstrations are offered throughout.

ACT 1: YOU ARE NOT YOUR MIND

Introduction to the course – Activate Your Life After Stroke (AYLAS)

Exploring and understanding the impact of Stroke

How the mind works

- Autopilot
- The mind gets things wrong
- The mind is cautious
- The mind is very critical
- Rumination
- The mind tries to stay in control

Home Activities

ACT 2: FACING UP TO LIFE

Summary of ACT 1 content

Things you cannot change

Struggling makes things worse

- Metaphors: e.g. Quicksand Effect
- Thought Suppression

Responding to Pain

Don't put your life on hold

- Metaphors e.g. Passenger on the Bus

Avoidance

Acceptance

The Problem with acting naturally

Reacting vs. Responding

Responding to Physical Pain

- Urge Surfing

Home Activities

Appendix E

ACT 3: BEING MINDFUL

Summary of ACT 2 content

Descriptions vs. Evaluations

Thoughts and Reality

- Confusion; Fusion and Defusion

Mindfulness

- What Mindfulness is not
- Mindfulness and Sleep
- Practicing Mindfulness
- Mindfulness and ACT

Home Activities

ACT 4: LIVING WELL, LIVING WISELY

Brief Recap ACT 1; ACT 2 and Summary of ACT 3 content

Goals

Values

- Values and Feelings
- Identifying your values
- Living by your values
- Values and Actions

Commitment


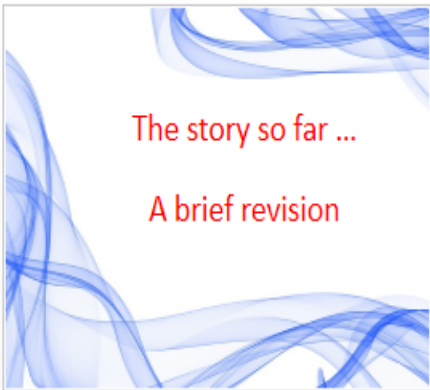
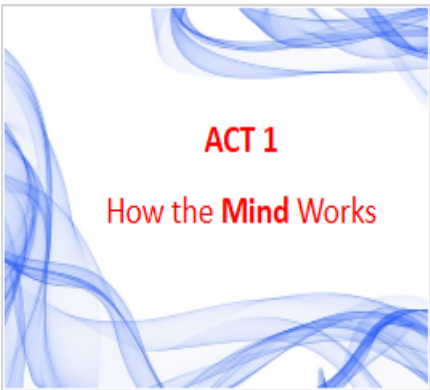


- Patterns of Commitment





Breaking Free

- Whose Life is it Anyway?
- Greater Flexibility
- Increasing Flexibility

Home Activities

Appendix F Activate Your Life After Stroke (AYLAS) Example Presentation Slides

			<p>GET WISE TO YOUR MIND</p> <p>The Mind is always trying to make sense of things and to predict what will happen</p> <p>It often contributes to our suffering because it can be pessimistic, critical and controlling – and it often gets things wrong</p> <p>So our Mind can cause us a lot of unnecessary worry and distress</p>
<p>GET WISE TO YOUR MIND</p> <p>We often leave many of our actions to the Mind's control ("autopilot")</p>	<p>GET WISE TO YOUR MIND</p> <p>We often leave many of our actions to the Mind's control ("autopilot") but in many cases it would be better if we took control and acted consciously and 'wisely'</p>	<p>THE CAUTIOUS MIND</p> <p>Taking active control can give us the freedom to explore new possibilities</p> <p>This is because our ultra-cautious Mind prefers to stick to the same old routine – which limits us and holds us back</p>	<p>WHAT CAN YOU DO ABOUT THIS?</p> <p>... You cannot switch your Mind off </p> <p>... so it's best just to "let it carry on"</p> <p>NOTICE what it is getting up to ... and get wise to how your Mind works </p>

<p>YOU CAN CONTROL YOUR OWN ACTIONS</p> <p>Recognise that your Mind doesn't have the ultimate control over your ACTIONS –</p> <p>YOU DO!</p> <p>YOU</p> 	 <p>ACT 2</p> <p>Facing Up to Life</p>	<p>THE SERENITY REQUEST</p> <p><i>May I have the strength to change the things that I can change;</i></p>	<p>THE SERENITY REQUEST</p> <p><i>May I have the strength to change the things that I can change; the courage to accept the things I cannot change; and the wisdom to know the difference</i></p>
9	10	11	12
<p>THINGS YOU JUST CAN'T CHANGE</p> <p>You cannot change your FEELINGS at will</p> <p>So it's no good telling someone to</p> <p><i>"Cheer up" "Pull yourself together"</i></p> <p>We can't switch our feelings on and off</p> 	<p>THINGS YOU JUST CAN'T CHANGE</p> <p>Struggling to get rid of unwanted feelings often makes things worse</p>  <p> And when we try to suppress an unwanted thought this usually makes the thought much stronger</p>	<p>DON'T PUT YOUR LIFE ON HOLD</p> <p>Whether you are depressed, in physical pain, or have a disability</p>	<p>DON'T PUT YOUR LIFE ON HOLD</p> <p>Whether you are depressed, in physical pain, or have a disability, ACT suggests that you can minimise your suffering by ACCEPTING what can't be changed and carrying on living as full a life as possible</p> 
13	14	15	16

AVOIDANCE

Avoidance (or escape) can bring immediate relief from anxiety, but in the long run it makes things worse – the best thing to do is to face up to your problems

FEEL THE FEAR AND DO IT ANYWAY!

And don't rely on
"Quick Fixes"



17



WHAT NEEDS TO CHANGE?

We can reduce our suffering by changing our **RESPONSE** to pain, disability, anxiety, etc.

The key change we need to make is from ...

FIGHTING

i

to

ACCEPTANCE

18



DOING WHAT NEEDS TO BE DONE

We often automatically do just what we feel like doing, although we **KNOW** that this is not the best thing to do ...

We feel uncertain

We feel frustrated

It's much better to take control and do what **YOU** decide is the best thing to do

19



DO IT ANYWAY!

The distinction between what you **FEEL** like doing and what you **Mindfully CHOOSE** to do is reflected in such statements as ...

"Feel the fear and do it anyway"

"Feel the lack of motivation and do it anyway"

"Feel the urge but DON'T do it anyway"

20



TIME TO BE A REBEL

Your **Mind** will try to control and steer your actions

But you don't have to follow its instructions or "orders"

Your actions are under **YOUR** control –
YOU can decide what to do

21



ACT 3

Being Mindful

22



DESCRIPTIONS AND EVALUATIONS

The **Mind** often confuses ...

DESCRIPTIONS and **EVALUATIONS**

Description

Evaluation

The woman ... is aged 60

is old

The man ... has had a stroke

is in a bad way

23



DESCRIPTIONS AND EVALUATIONS

There is no 'truth' (or 'falsehood') about whether you are *old, incapable*, etc. – these are just **judgements (evaluations)**

24



DESCRIPTIONS AND EVALUATIONS

There is no 'truth' (or 'falsehood') about whether you are *old, incapable*, etc. – these are just **judgements (evaluations)**

So if someone (or your own **Mind**) tells you that you are *old or incapable*, you should recognize that this is just name-calling – it is an evaluation

25



THOUGHTS AND REALITY

Thoughts, feelings and worries are just events inside our head



If we really appreciated this we would never be upset by our own thoughts or feelings

26



THOUGHTS AND REALITY

A thought that just "pops into your head" (however weird or vicious it may be) is something that **happens TO you ...** it is **NOT "something you DO"**

27



FUSION

We often suffer from the consequences of **FUSION**

THOUGHTS and **REALITY**
IMAGES and **REALITY**
WORDS and **REALITY**

"DE-FUSION" techniques help people to overcome **FUSION**



28



DEFUSION

One way to achieve **DEFUSION** is to remind ourselves that thoughts are just thoughts (etc.)

*"I am having **THE THOUGHT** that I'm incapable"*

You can also focus on the sounds or words (or letters in a word, or style of drawing, etc.)

Examples: *Paper, paper, paper*
Speech distortions (slow, weird, singing)

29



DEFUSION – LEAVES ON A STREAM



30



DEFUSION AND MINDFULNESS

The ultimate tool for defusion is **Mindfulness**

This is because it emphasizes the distinction between ... **YOU** and **YOUR MIND**

Attention is completely focussed on what is happening in the moment – here and now!

31



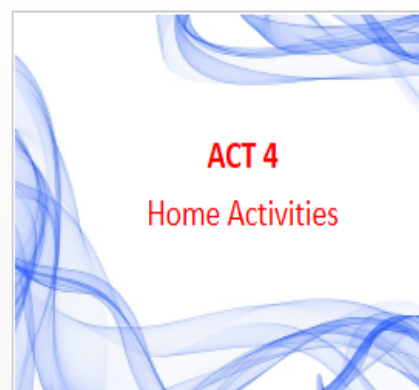
MINDFULNESS

MINDFULNESS - simply noticing what is going on with openness, curiosity and detachment

32



<p>MINDFULNESS</p> <p>MINDFULNESS - simply noticing what is going on with openness, curiosity and detachment without getting involved or caught up in thoughts and feelings</p> 	<p>PRACTISING MINDFULNESS</p> <div>   </div> <p>Brief Body Focus The Three Minute Breathing Space</p>	<p>INFORMAL MINDFULNESS</p> <p>Informal Mindfulness activities include ...</p> <p>Mindfully walking</p> <p>Mindfully watching waves on the shore</p> <p>Mindfully watching clouds</p> <p>Mindfully tying your shoe laces</p> <p>Mindfully drinking a glass of water</p>	<p>BRIEF MINDFULNESS PRACTICES</p> <table border="1"> <tbody> <tr> <td>Mindful candle-watching</td> <td>Mindful listening</td> </tr> <tr> <td>Mindful showering</td> <td>Mindful eating</td> </tr> <tr> <td>Mindful focus on physical support</td> <td>Mindful nature focus</td> </tr> </tbody> </table>	Mindful candle-watching	Mindful listening	Mindful showering	Mindful eating	Mindful focus on physical support	Mindful nature focus
Mindful candle-watching	Mindful listening								
Mindful showering	Mindful eating								
Mindful focus on physical support	Mindful nature focus								
33	★	34	★	35	★	36	★		
<p>MINDFULNESS AND ACT</p> <p>Mindfulness increases our flexibility</p> <p>Being Mindful gives us greater freedom to do the things we want to do</p> <p>This is why Mindfulness is such a key element in ACT – and why ACT is described as a Mindfulness-based therapy</p>	 <p>The story continues ...</p> <p>ACT 4</p>	<p>VALUES AND FEELINGS</p> <p>Most people aren't able to just tell you what their values are</p> <p>They can tell you their name, address and mobile number, but if you asked ...</p> <p><i>"What are your values?"</i></p>	<p>VALUES AND FEELINGS</p> <p>It can be very difficult for us to answer general questions such as:</p> <p><i>"What do I want my life to be about?"</i></p> <p><i>"What do I stand for?"</i></p> <p>But there are easy ways of finding the answers to these important questions</p>						
37	★	38	★	39	★	40	★		



153



HOME ACTIVITY 4 A – YOUR OWN VALUES

You can discover some of your own values using **Home Activity 4 A** ...

“Your 100th Birthday Party”



154



HOME ACTIVITY 4 B – INCREASING FLEXIBILITY

To increase our flexibility we need to do some new things and to do some things differently

This will mean stepping outside our comfort zone and accepting some discomfort

Three **Activities** are designed to loosen you up and to increase your flexibility. They progress from gentle “nudges” to suggestions for more ambitious and challenging activities

155



HOME ACTIVITY 4 B – INCREASING FLEXIBILITY

Activity 4 B (i) “Just to be different”

Take conscious control over some things that you usually do out of habit – and do them in a different way

Sit in a different chair to watch TV
Buy a different newspaper for a change
Try to manage without so many pain killers
“Just to be different”

156



HOME ACTIVITY 4 B – INCREASING FLEXIBILITY

Activity 4 B (ii) “Beyond the Comfort Zone”

Step beyond your comfort zone and do three things that are “challenging” and “brave”

Think of three things that you **WANT** to do but have avoided doing because they might make you feel embarrassed or anxious

And then – be brave, go ahead, accept any uncomfortable feelings but **DO** the things that take courage and commitment

157



HOME ACTIVITY 4 B – INCREASING FLEXIBILITY

Activity 4 B (iii) Being ‘Outrageous’

This **Activity** is the most challenging – but if you are brave enough to do it, it could really increase your flexibility and show you that you are in control and can steer your life in the direction you want

Do something way beyond your comfort zone, something “out of character,” something a little outrageous!

158



HOME ACTIVITY 4 B – INCREASING FLEXIBILITY

Activity 4 B (iii) Being ‘Outrageous’

Of course, the whole point of this **Activity** is for you to deliberately put yourself in a position in which you **FEEL AND ACCEPT** negative feelings such as anxiety or embarrassment

give you a real sense of achievement and increase your flexibility considerably

159



HOME ACTIVITY 4 C – MAKING COMMITMENTS

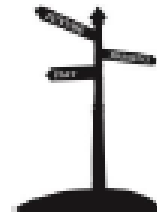
Think of things that you might do (or changes that you might make) that would increase your ability to live the life you want to live

Make **THREE SOLID COMMITMENTS** about how things will be different from now on

160



Appendix G Activate Your Life After Stroke (AYLAS) Example of supplementary material and home activities.



ACTivate Your Life – Handout

ACTivate Your Life is a psychology course that will help you to understand yourself better, and to understand your **Mind**.

The course is based on a relatively new approach to therapy.

‘Acceptance and Commitment Therapy’ (ACT).

ACT helps people to overcome their suffering using ‘**Mindfulness**’ and by helping them understand how to live in accordance with their own important values.

The course is all about you having a better life!

The course is in 4 sessions – we call these **ACTS**



ACT 1 – ‘You are not your **mind’**

- Some of our actions are under **OUR OWN** (conscious, deliberate) control.
- But many of our actions are directly controlled by our **Mind**.
- For example, it is often better for us to shop **Mindfully** (or ‘wisely’) rather than impulsively.
- It is often a bad idea to allow our **Mind** to decide what we will do and this can lead to a lot of unnecessary suffering.
- **Action after Stroke** will help you to be more thoughtful about what you do – and to suffer less.

How the **Mind** works

- Your **Mind** does its own thing – you have no control over many of the things that it does
- You can't direct your **Mind** to **STOP** doing something, but you **CAN** direct it to **DO** something
- Your **Mind** constantly judges, compares and searches for meaning and patterns
- Your **Mind** always tries to figure out “what’s going on” and often jumps to conclusions
- Your **Mind** wanders (it travels through time and space)
- Your **Mind** is very clever (but it often gets things wrong)
- Your **Mind** is always looking out for threats (and, to avoid danger, it is very cautious)
- Your **Mind** is often highly critical (and it is likely to be very critical of YOU)
- Your **Mind** always tries to maintain control (and it will resist YOU taking control)

The **Mind** ruminates



Through the power of language and the ability to create detailed images, the **Mind** can make past events “happen again” – triggering powerful emotional responses including repeated (“endless”) suffering.

- The **Mind** constantly compares things – and it often makes negative comparisons which can bring us down. So even when things are fine, your **Mind** may well suggest that ...

“It won’t last”

“It could be a whole lot better”

“It’s not as good as your sister’s”

- The **Mind** often makes mistakes e.g. the Lines Illusion



- It often tells us that things are dangerous when we know that they are not – or that we should check something when we know that there is no real need to do so.
- So our **Mind** worries us unnecessarily and often holds us back from doing things that could make our life better.

The key thing is what we DO

When we know that our **Mind** has got it wrong, the sensible thing to do is to ignore our **Mind's** silly warnings and to do the **WISE** thing. But this may not be easy and it may take a lot of courage.

Feel the fear



and **do it** anyway

It is very important for you to recognise that you are not bound to believe everything that your **Mind** tells you or to go along with its ideas.

Our **Mind** is always looking out for danger

- Our **Mind** evolved to keep us safe, and this means that it is always on the lookout for any possible threat.
- But **Minds** tend to be over-sensitive – they may become alarmed too easily and may worry us and frighten us when there's no real danger.
- Because your **Mind** is very sensitive to any potential threat – now or in the future – the **Mind** tends to be very cautious ("better safe than sorry") and often tries to hold us back from doing anything different or daring.

Our Critical **Mind**

Our **Mind** is very critical – and it is often especially critical (and even insulting) towards us.

We can't stop this happening but we can learn to live with it so that we are no longer hurt when our **Mind** has a go at us!

- We would be better off if we were more thoughtful and took over more control of our actions!
- Our actions would become
 - less “automatic”
 - less “on autopilot”
 - less “Mindless”
 - and ... more Mindful – this is possible!!



Your **Mind** travels here and there, then back and forth in time

But you the observer are always here and in the present – for you it is always NOW.

The **Mind** likes to be in control, but

Your **Mind** doesn't have the power to control what you do

YOU are not **YOUR MIND**



Don't miss next week: **ACT 2 – “Facing Up to Life”**



ACTivate Your Life – Home Activities

ACT 1 'You are not your mind'

Activity 1A What my mind thinks about me – sentence completion

- When you hear the words "There's no place like ..." the first thing that is likely to come to your mind is "home" because this word completes a very common saying.
- The mind is primed to come up with that particular ending.
- We all have a large stock of "ready-made" phrases and sentences.
- Some of the strong verbal patterns in your mind may be very negative or critical.



'Getting wise to your mind'

This activity will help you recognize that your ever-so-critical mind just churns out many negative thoughts.



Complete each of the following sentences, instantly:

I'm not the person I was, I'm _____

I'm so disabled, I think I will just _____

I hate the fact that I'm _____

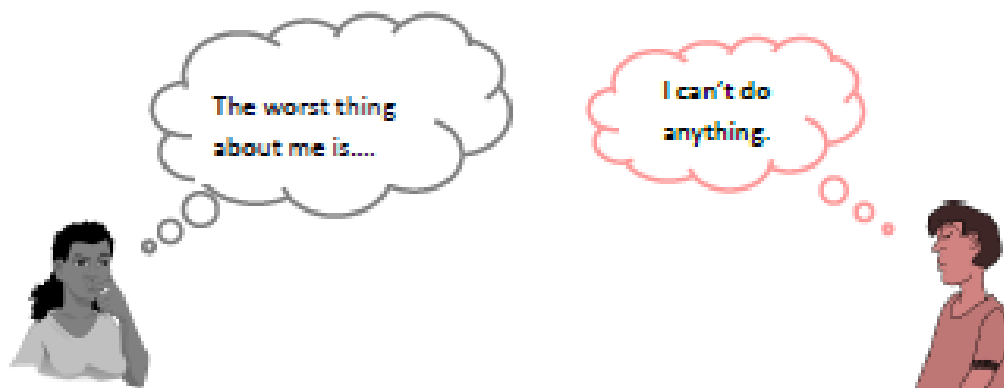
Now think about why you completed the three sentences in the way you did.

Why did you choose these thoughts and words first?

Your answers may echo familiar self-criticisms.

Critical remarks that have hurt us in the past, maybe from parents, by a school bully or by a teacher, may remain quite close to the surface of our memory.

- Your mind is likely to latch on to critical remarks that other people have made and recycle them.
- Your mind may have been recycling critical remarks for a long time, close to the surface of our memory. It is upsetting to recall such negative statements.
- The emotional impact will be reduced if you understand where these judgements come from and really see that "words are just words".



- These sentences beginnings for this activity suggested negative endings.



Let's finish on a more positive note by completing this sentence...

The best thing about me is _____

I can _____

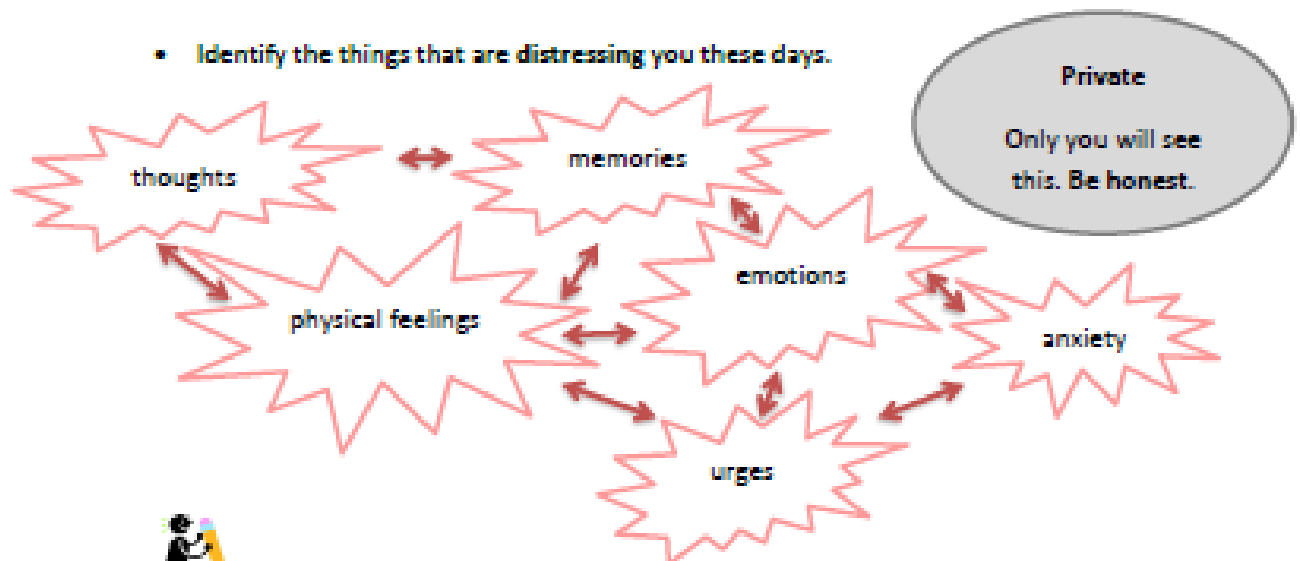


Activity 1B The thoughts and feelings that really bother me

- Think about the thoughts and feelings that are distressing you and spoiling your life.
- Focus on the things that are 'inside you' or on your experiences rather than situations.

Example – "I am worried about money" rather than 'debt problems'.

- Identify the things that are distressing you these days.



Below, write down how long each of them has been affecting you – it might be weeks, months or years.

The current painful thoughts and feelings that are spoiling my life.

How long has this been a problem?

1.	w/m/y
2.	w/m/y
3.	w/m/y
4.	w/m/y
5.	w/m/y
6.	w/m/y

(You can continue the list on a separate sheet)

4

Try looking at your list more closely. You may want to look at the following questions:

- Which issue has been with you for the 'longest' ➡ 'shortest'?
- Think about the similarities and differences between your issues.



- How are some of the issues related to each other?

Example – 'having fights with my partner' might be related to 'feeling low' following my stroke/partners stroke.

- Which of these emotional problems has had the strongest effect?
- How have you tried to overcome these problems in the past?

Each of these ideas suggests ways for you to explore your own problem issues.

This will help you to apply the '**ACTivate your Life**' course material to your own situation.



One of next week's **Home Activities** follows from this one, so keep this list safe.

3



Introducing Mindful Activities

ACT is a Mindfulness-based therapy. It will be discussed in detail in ACT 3.

However, we would like you to practice it throughout the course.

We will suggest Mindful activities for you to do each week.

This week we would like you to begin your practice by doing two simple Mindfulness activities.

Mindfulness simply involves just noticing what's going on in the here and now, without making any judgements.

This Week's Activities

Mindful Breathing

At least two or three times a day, take a Mindfulness mini-break.

Focus on your breathing as you take just five or six breaths.

Don't attempt to control or change your breathing in any way

Experience the breathing directly, without thinking about what is happening and without analysing what you are doing or judging anything.

Just focus on your breathing - notice all of the sensations as the air passes in and out of your body.

Mindful Body Scan

Get into a comfortable position somewhere where you won't be disturbed and then begin a 'body scan'.

This means directing your attention to each part of the body in turn, so that you experience the full range of sensations coming from each part of your body.

This activity is all about noticing sensations: it is not about relaxation.

Don't do anything to control your body. Just attend to different parts of your body in turn.

Example - you may move from your feet and hands to the centre of your body, or you may move your attention slowly from your feet up to your head.

As you move the focus of your attention to different parts of your body, notice all of the sensations coming from that part. Scanning your body in this way is likely to take between 10 and 15 minutes.

ACTivate Your Life – NOTES

Use the space below to write down any thoughts and feelings that you have about your own problem issues and about something you have learned from the **ACTivate Your Life** course.

Reflecting on things in this way will help you to get the most from the course.

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

The Home Activity sheets are just for your personal use and we won't collect the sheets or mark your answers.

Because some of the notes you make on these sheets may be very sensitive, please make sure that you keep them in a safe and private place.

Appendix H

ETHICS

- **REC Ethics Form**
- **Favourable Opinion Letter**
- **Sponsorship**

Reference:
16/LO/0224

IRAS Version 5.2.1

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
An evaluation of an adapted ACT group for stroke survivors

1. Is your project research?

☒ Yes ☐ No

2. Select one category from the list below:

☐ Clinical trial of an investigational medicinal product

☐ Clinical investigation or other study of a medical device

☐ Combined trial of an investigational medicinal product and an investigational medical device

☒ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice

☐ Basic science study involving procedures with human participants

☐ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

☐ Study involving qualitative methods only

☐ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

☐ Study limited to working with data (specific project only)

☐ Research tissue bank

☐ Research database

If your work does not fit any of these categories, select the option below:

☐ Other study

2a. Will the study involve the use of any medical device without a CE Mark, or a CE marked device which has been modified or will be used outside its intended purposes?

☐ Yes ☒ No

2b. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation? ☐ Yes ☒ No

b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☒ No

c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☒ No

Date: 14/01/2016

1

187893/920173/1/578

NHS REC Form

Reference:
16/LO/0224

IRAS Version 5.2.1

3. In which countries of the UK will the research sites be located? (Tick all that apply)

☒ England
☐ Scotland
☒ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

☐ England
☐ Scotland
☒ Wales
☐ Northern Ireland
☐ This study does not involve the NHS

4. Which review bodies are you applying to?

☐ HRA Approval
☒ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☒ Research Ethics Committee
☐ Confidentiality Advisory Group (CAG)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

☒ Yes ☐ No

6. Do you plan to include any participants who are children?

☐ Yes ☒ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

☐ Yes ☒ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

☐ Yes ☒ No

Date: 14/01/2016

2

187893/920173/1/578

NHS REC Form	Reference: 16/LO/0224	IRAS Version 5.2.1
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9. Is the study or any part of it being undertaken as an educational project?

☒ Yes ☐ No

Please describe briefly the involvement of the student(s):
 Doctoral research for the CI's doctorate in clinical psychology

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

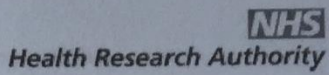
☒ Yes ☐ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

☐ Yes ☒ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

☐ Yes ☒ No

NHS REC Form	Reference: 16/LO/0224	IRAS Version 5.2.1						
Integrated Research Application System Application Form for Other clinical trial or investigation								
								
Application to NHS/HSC Research Ethics Committee								
<p>The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.</p> <p>Please define any terms or acronyms that might not be familiar to lay reviewers of the application.</p>								
<p>Short title and version number: (maximum 70 characters - this will be inserted as header on all forms) An evaluation of an adapted ACT group for stroke survivors</p>								
Please complete these details after you have booked the REC application for review.								
<table style="width: 100%;"> <tr> <td style="width: 33%;">REC Name: [REDACTED]</td> <td style="width: 33%;"></td> <td style="width: 33%;"></td> </tr> <tr> <td>REC Reference Number: 16/LO/0224</td> <td>Submission date: [REDACTED]</td> <td></td> </tr> </table>			REC Name: [REDACTED]			REC Reference Number: 16/LO/0224	Submission date: [REDACTED]	
REC Name: [REDACTED]								
REC Reference Number: 16/LO/0224	Submission date: [REDACTED]							
PART A: Core study information								
1. ADMINISTRATIVE DETAILS								
<p>A1. Full title of the research:</p> <p>A mixed-methods evaluation of an adapted Acceptance and Commitment Therapy (ACT) group for stroke survivors and their carers: ACTivate Your Life After Stroke.</p> <p>N.B. Please note change of name from 'ACTion after Stroke' to 'ACTivate your life after stroke'. The former name appears on the sponsors letter, however the documents provided for review are the same. The name was changed to remain consistent across all research sites.</p>								
<p>A2-1. Educational projects</p> <p>Name and contact details of student(s):</p> <table style="width: 100%; border: 1px solid black;"> <tr> <td style="width: 20%;">Student 1</td> <td> <p>Title Forename/Initials Surname [REDACTED]</p> <p>Address South Wales Doctoral Programme in Clinical Psychology 11th Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff</p> </td> </tr> </table>			Student 1	<p>Title Forename/Initials Surname [REDACTED]</p> <p>Address South Wales Doctoral Programme in Clinical Psychology 11th Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff</p>				
Student 1	<p>Title Forename/Initials Surname [REDACTED]</p> <p>Address South Wales Doctoral Programme in Clinical Psychology 11th Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff</p>							

NHS REC Form

Reference:
16/LO/0224

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Post Code

E-mail

Telephone

Fax

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

Doctorate in Clinical Psychology

Name of educational establishment:

South Wales Doctoral Programme, Cardiff University

Student 2

Title Forename/Initials Surname

Address

South Wales Doctoral Programme in Clinical Psychology 11th Floor, School of Psychology,
Tower Building, 70 Park Place,

Post Code

E-mail

Telephone

Fax

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

Doctorate in Clinical Psychology

Name of educational establishment:

South Wales Doctoral Programme, Cardiff University

Name and contact details of academic supervisor(s):

Academic supervisor 1

Title Forename/Initials Surname

Address

South Wales Doctoral Programme in Clinical Psychology 11th Floor, School of Psychology,
Tower Building, 70 Park Place,

Post Code

CF10 3AT

E-mail

Telephone

Fax

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)**Academic supervisor(s)**

Student 1 Miss Sarah Harris

☐ Dr Reg Morris

NHS REC Form Reference: 16/LO/0224 IRAS Version 5.2.1

Student 2 Miss Rebecca Large ☐ Dr Reg Morris

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

☒ Student
☐ Academic supervisor
☐ Other

A3-1. Chief Investigator:

Title Forename/Initials Surname [REDACTED]
Post [REDACTED]
Qualifications [REDACTED]
Employer Cardiff and Vale University Health Board
Work Address South Wales Clinical Psychology Doctoral Programme 11th Floor, Tower Building, 70 Park Place Cardiff
Post Code CF10 3AT
Work E-mail [REDACTED]k
* Personal E-mail [REDACTED]m
Work Telephone [REDACTED]
* Personal Telephone/Mobile [REDACTED]
Fax [REDACTED]

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.*

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

Title Forename/Initials Surname [REDACTED]
Address [REDACTED]ad
Post Code [REDACTED]
E-mail [REDACTED]
Telephone [REDACTED]
Fax [REDACTED]

A5-1. Research reference numbers. Please give any relevant references for your study:

ate: 14/01/2016 6

NHS REC Form		Reference: 16/LO/0224	IRAS Version 5.2.1
Applicant's/organisation's own reference number, e.g. R & D (if available):	n/a		
Sponsor's/protocol number:	1494-15		
Protocol Version:	1		
Protocol Date:	11/12/2015		
Funder's reference number:	N/A		
Project website:	N/A		
Registry reference number(s): <i>The Department of Health's Research Governance Framework for Health and Social Care and the research governance frameworks for Wales, Scotland and Northern Ireland set out the requirement for registration of trials. Furthermore: Article 19 of the World Medical Association Declaration of Helsinki adopted in 2008 states that "every clinical trial must be registered on a publicly accessible database before recruitment of the first subject"; and the International Committee of Medical Journal Editors (ICMJE) will consider a clinical trial for publication only if it has been registered in an appropriate registry. Please see guidance for more information.</i>			
International Standard Randomised Controlled Trial Number (ISRCTN): ClinicalTrials.gov Identifier (NCT number):			
Additional reference number(s):			
Ref.Number	Description	Reference Number	
A5-2. Is this application linked to a previous study or another current application? <input type="radio"/> Yes <input checked="" type="radio"/> No <i>Please give brief details and reference numbers.</i>			
2. OVERVIEW OF THE RESEARCH			
<i>To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.</i>			
A6-1. Summary of the study. <i>Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.</i>			
<p>Stroke is one of the main causes of acquired adult disability in the UK (Scarborough, et al., 2009). Many psychological problems can also occur including: depression (Hackett et al., 2005), anxiety (Campbell Burton et al., 2013), fatigue (Glader et al., 2002), apathy (Angelelli et al., 2004) and post-traumatic stress disorder (Edmondson et al., 2013). This has a marked impact on health service usage (Naylor et al., 2012).</p> <p>Psychological intervention for post stroke care has been incorporated into national guidelines (Royal College of Physicians [RCP], 2012; Welsh Government, 2012). Despite this, there is an outstanding need to increase and improve psychological resources within these services (National Audit Office [NAO], 2010).</p> <p>We propose to adapt and evaluate the effectiveness of an acceptance and commitment therapy (ACT) group intervention for adult stroke survivors and their carers. The benefit of ACT is that it is transdiagnostic (Lang et al., 2012) therefore applicable to the very wide range of psychological problems found in carers and survivors after stroke. The group will hence endeavour to promote positive adjustment and reduce levels of depression and anxiety.</p> <p>ACT has a well-established evidence base for reducing psychological distress in individuals with mental illness (Ruiz, 2010, 2012) and physical health conditions including: diabetes (Hadlandsmayth et al., 2013), chronic pain (Alonso et al., 2013), epilepsy (T. Lundgren et al., 2008), cancer (Feros et al., 2013), irritable bowel syndrome (Ferreira et al., 2013) obesity (Weineland et al., 2012) and HIV (Silver, 2012).</p>			
Date: 14/01/2016		7	187893/920173/1/578

16/LO/0224

This study will have two parts. Part 1: a quantitative phase evaluating the effectiveness of the ACT group using questionnaire outcome data in comparison to a waiting list control across three time points. Part 2: A qualitative phase exploring stroke survivors experiences of the ACT group and their perceptions of any change from group attendance.

A6-2. Summary of main issues. Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Clear inclusion and exclusion criteria have been developed. Both stroke survivors and carers of stroke survivors are included. Participants must be aged over 18 years and must not have communication or cognitive impairments that would prevent them from participating fully or from providing their informed consent. Participants' capacity to remain in the study will be monitored throughout the different stages of the study by the research team.

Participants will be recruited into the study without pressure and with a full understanding of the requirements and potential implications of the research. Participant information sheets will clearly outline the nature and requirements of the study, along with associated benefits and potential risks. Researchers contact details will be attached to the information sheet, enabling participants to seek further or additional clarification if necessary and to ensure they are fully informed of all aspects of the study. Freedom to withdraw at any stage of the study will be made explicitly clear. Once all considerations are met, consent will be gathered from each participant. Debrief forms at the end of the study will also be provided, reiterating research aims.

Participant information sheets will also clearly explain the limits of confidentiality. The researchers will adhere to the "Caldicott Principles" for confidential management of identifiable data. All data will be anonymised and participants will be randomly allocated a number to protect their identity. Any identifiable data will be kept in a locked filing cabinet within a Cardiff University building, until they are fully coded, at which point they will be destroyed (within 2 years of the start of the study). The project is in fulfilment of a University Doctorate and must follow university research governance which requires anonymised data to be securely kept for 15 years.

Any concerns raised from participants will initially be addressed by the researchers and supervisor. If external involvement is required they will be communicated in a confidential manner to relevant services. The participant information sheets will explain that participants may experience distress associated with talking about their condition (or that of significant others); however attempts will be made to minimise risk were possible and local support numbers will be provided. Participants will be informed of their right to withdraw at any stage of the study. They will also have the opportunity to discuss their concerns with the researchers during and at the end of sessions. If required, participants will be provided with information detailing local services (e.g. Stroke Association Wales) that may be helpful to their well-being.

The main findings of the study will be made available via written feedback and also, subject to approval, within scientific journals.

There are no conflicts of interest between the role of the researchers and that of a health care professional.

3. PURPOSE AND DESIGN OF THE RESEARCH

7. Select the appropriate methodology description for this research. Please tick all that apply.

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis

<p>NHS REC Form</p>	<p>Reference: 16/LO/0224</p>	<p>IRAS Version 5.2.1</p>
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☐ Epidemiology
☐ Feasibility/ pilot study
☐ Laboratory study
☐ Metanalysis
☒ Qualitative research
☒ Questionnaire, interview or observation study
☒ Randomised controlled trial
☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

Part 1 of the study (quantitative):

Is this adapted version of an ACT group an effective intervention for enhancing well-being and mood of stroke survivors and/or their carers?

Is this adapted version of the an ACT group an effective intervention for enhancing quality of life of stroke survivors?

Part 2 of the study (qualitative):

How do stroke survivors experience the acceptance and commitment therapy group?
 What are the perceived effects on them of being in the group?
 What do stroke survivors identify as the key elements that produced any change they experienced?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

Part 1 of the study (quantitative):

How do the findings compare to previous studies of ACT groups with chronic health conditions?

Part 2 of the study (qualitative):

Do the results from the data map onto current ACT models (e.g. Steven Hayes ACT)

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Stroke is a major health problem. In England and Wales, over 900,000 people are living with the chronic illness, which can cause sufferers to be highly dependent on others for their care (National Audit Office [NAO], 2005). A wide range of psychological problems have been reported to develop post stroke (e.g. low mood, Hackett et al., 2005; Campbell Burton et al., 2013), which have a marked impact on usage of health services (Naylor et al., 2012).

Psychological intervention post stroke has been incorporated within national guidelines (Royal College of Physicians, 2012). However, there is sparse evidence for the efficacy of psychological interventions for commonly reported difficulties post stroke (Lincoln et al., 2011), such as depression (Hackett et al., 2008), anxiety (Kneebone & Jeffries, 2013) and posttraumatic stress disorder (Edmondson et al., 2013). Whilst there is emerging evidence that some psychological interventions improve wellbeing post stroke (Williams et al., 2007; Mitchell et al., 2009; Watkins et al., 2011; Thomas et al., 2013), there remains an outstanding need to demonstrate further the effectiveness of psychological interventions within stroke services (NAO, 2010; Care Quality Commission, 2011). This is of particular importance given that pharmacological treatments have been reported to increase adverse events (Hackett et al., 2008). The current lack of robust evidence for psychological approaches has a detrimental impact on the quality of stroke care provided (Watkins & French, 2009).

This research aims to contribute to this area by evaluating the effectiveness of an ACT group for stroke survivors and their carers, and identifying important therapeutic mechanisms that enhance change after stroke. The ACT group will be adapted from the already existing 'ACTivate your life' course, which is being used in NHS mental health services across South Wales. The course endeavours to promote positive adjustment and reduce levels of depression and anxiety, using the core tenets of ACT. These concern the way in which individuals engage with events in the world around them, understand their thinking processes, be more aware of their values, and how they shape their goals and

actions. ACT teaches these new perspectives and methods in a way that does not require the memory load to carry lots of factual information, or to remember specific techniques applicable to different symptoms; it relies on experiences and on general perspectives that can be practised. As such, ACT has demonstrated encouraging outcomes for mental illness (Ruiz, 2010, 2012) and physical health conditions including: diabetes (Hadlandsmayth et al., 2013), chronic pain (Alonso et al., 2013), epilepsy (T. Lundgren et al., 2008), cancer (Feros et al., 2013), irritable bowel syndrome (Ferreira et al., 2013) obesity (Weineland et al., 2012) and HIV (Silver, 2012).

A13. Please summarise your design and methodology. It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.

Part 1 of the study (Quantitative):

Study Design: The study will employ a longitudinal randomised design using a questionnaire methodology. For obvious reasons the study will not be blind. Outcome measures will be taken pre, post and at a two month follow up.

Validated outcome measures have been chosen in order to obtain reliable and valid data for function and participation.

Participants will be recruited across five NHS University Health Boards/Trusts: Cardiff and Vale University Health Board, Cwm Taf University Health Board, Aneurin Bevan university health board, North Bristol NHS Trust and University Hospitals Bristol NHS Foundation Trust. Bristol Area Stroke Foundation charity (BASF) will also assist in the recruitment across Bristol and will also host the course for all Bristol participants. The individuals may be recruited at any stage of the care pathway after discharge from hospital.

Potential participants will be identified by clinicians or from the stroke register against the inclusion and exclusion criteria. All interested participants will be provided with a course flyer, written participant information sheet and consent form. The participant information sheet will detail an overview of the study, its rationale, requirements, exclusion / inclusion criteria, potential benefits and risks associated with participating. All interested participants will give their consent either verbally or in writing (which will be indicated on the consent form) depending on how the clinical team are communicating with them. Once consent has been obtained, participants will be randomly allocated into the treatment group or placed on a waiting list (control group). Carer/stroke survivor pairs will be allocated together.

Letters will be sent to participants to let them know which group they have been randomised to and what the next steps are e.g. for the treatment group details of the course dates and venue and the control group when we will next be in contact for questionnaire data and when they can access the treatment group.

The intervention group will attend a four-week, 2.5 hour (maximum) educational group that focuses on assisting stroke survivors and carers to learn a set of simple, and teachable, techniques that focuses on changing patterns of experience and thinking. The learning will involve understanding the principles of ACT via PowerPoint presentations which have been adapted to include stroke specific examples and have been simplified to allow for potential cognitive impairment. As part of the programme they will have the opportunity to engage in simple exercises in class and as homework. Psychological flexibility will be encouraged by the teaching of basic techniques that aim to help movement in the direction of acceptance and understanding of life-goals.

Both the control group and the intervention group will be asked to complete the measures listed below, at the same time points. The primary measure will be mood and well-being changes in the outcome measures from before the intervention (time 1), directly following the intervention (time 2) and two months after the course has finished (Time 3). We hope to have at least 15 participants in each group, across the four sites (Bristol, Cardiff, Newport, and Cwm Taf), with a total of 120 participants.

After the follow up data is collected, the waiting list control group will be offered the intervention which will consist of the exact same material over the exact same period as the first group. The control group participants who go on to attend the intervention will be asked to complete the questionnaire measures at the same time points: at the start of the intervention, at the end and two months after the course has finished. It will take 20 minutes to complete one battery of questionnaires.

Questionnaires: In addition to these standardised questionnaires, demographic information will be obtained at the start of the study including: the participant's age, gender, time since stroke etc. (see appendix for stroke survivor and carers demographic forms).

Data for the study will be anonymised with randomly allocated codes. Identifiable personal data will be stored separately in a locked unit.

<p>NHS REC Form</p>	<p>Reference: 16/LO/0224</p>	<p>IRAS Version 5.2.1</p>
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Statistical analyses: A mixed model (within and between participants) MANOVA will evaluate the group x time interaction between the experimental and control. A mediation analysis of the ACT specific processes (e.g. acceptance) will be conducted.

Part 2 of the study (qualitative):
Qualitative methodology will be employed during the second part of the study.

Semi-structured interviews will be conducted to explore stroke survivors' subjective experiences of the ACT group. These interviews will be led by the researcher and will be framed around 8 main questions (see attached "draft interview schedule"). Interviews will be undertaken in consultation rooms across the research sites or in the participants' own home, lasting no more than 1 hour. The number of interviews conducted will depend upon the length of time it takes to reach data saturation (i.e. when no new information is emerging from the dataset), which is recommended for the type of qualitative analysis being performed (Charmaz, 2006, 2014). We envisage data saturation will be achieved with 25 participant interviews. These interviews will occur >1 month after the group.

Similar to above, participants will be recruited from the University Health Boards (UHBs) and at any stage of the care pathway following discharge. The three UHBs (Cardiff & Vale, Cwm Taf & Aneurin Bevan) in particular have been selected for part 2. Participants for this phase of the study will consist only of stroke survivors. Sampling will begin purposefully in the first instance to offer maximum variation in stroke survivors reported experiences of the group i.e. a diverse range of participants who express interest to partake will be interviewed. Theoretical sampling will then be used for subsequent interviews, whereby participants are selected based on the emerging theory.

The researcher will briefly introduce herself and part 2 of the study during the first ACT session of each group across the UHBs. This will allow potential participants to meet the researcher, especially if she intends to make some home-visits later on (i.e. help 'put a face to the name'). Following this introduction, detailed participant information sheets will be provided. Contact slips will be provided by group facilitators, allowing participants to either leave their contact details or to decline part 2 of the study. For those who do not respond, group facilitators will follow up by telephone contact.

Interviews will be audio-recorded to support the researcher with transcription and data analysis. Participants will be made aware of this in advance on the consent form. All data will be stored on a password-protected and encrypted USB device for the duration of the study, and will subsequently be destroyed after use. Participants will be assigned a numerical identifier during transcription to protect their identity.

Design: Grounded Theory (GT) will be used in phase 2, for both data collection and analysis which will occur simultaneously. GT aims to identify emerging themes from the data and develop new, contextualised theories (i.e. "grounded" in the data). As such, data collected after each interview will be transcribed and reviewed in an evolving process. Interview questions will be revised to progressively focus on the emerging theory. This process is in line with the inductive nature of the GT approach (Strauss & Corbin, 1997).

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

☒ Design of the research
☐ Management of the research
☐ Undertaking the research
☐ Analysis of results
☒ Dissemination of findings
☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.

Meetings to discuss the ACT course design and delivery have included stroke survivors. The adaptation of the ACTivate your life after stroke course to make it stroke specific was done in collaborative with service users. We aim to involve service users when disseminating the findings.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

All participants must be 18 years of age or older.
Clinical diagnosis of stroke (or be carers of someone who has experienced a stroke)
Must be able to understand English and communicate responses
The target volunteer has been referred to this stroke-adapted ACT course by a clinician

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Patients with any other acquired brain injuries, such as traumatic brain injury, encephalitis, tumours, etc.
Patients with a diagnosed degenerative condition e.g. dementia
Significant cognitive / language impairment that would prevent them from engaging with the group
Those experiencing severe psychotic symptoms
Those who are receiving other therapies, as part of a multi-component intervention which would prevent any changes specific to group psychotherapy to be estimated (with the exception of drugs for depression and anxiety).

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Seeking informed consent (Part 1)	1	0	5 mins	Clinical team, face-to-face/telephone.
Seeking informed consent (Part 2)	1	0	5 mins	Clinical team, group session/telephone
Information Sheet (Part 1)	1	0	10 mins	Clinical team, face-to-face/telephone.
Information Sheet (Part 2)	1	0	10 mins	Clinical team, group session/telephone.
Demographic information sheet	1	0	5 mins	Researcher, group session/telephone.
Part 1 questionnaire: PHQ-9 & GAD-7	3	0	5 mins	Researcher, group session/telephone
Part 1 questionnaire: EuroQol 5D (Brooks et al., 2003)	3	0	5 mins	Researcher, group session/telephone
Part 1 questionnaire: Adult State Hope Scale (ASH) Snyder et al. (1996)	3	0	5 mins	Researcher, group session/telephone
Part 1 questionnaire: Warwick-Edinburgh Mental Well-Being Scale (WEMWBS), NHS Health Scotland, University of Warwick and University of Edinburgh, 2006.	3	0	5 mins	Researcher, group session/telephone

16/LO/0224

Part 2: Interview Questions (from Interview Schedule)

1 0 45-60 mins Researcher, at participants home or in one of two main research sites.

Part 1 debrief form

1 0 5 mins Researcher, group session

Part 2 debrief form

1 0 5mins Researcher, at participants home or at main research sites.

A19. Give details of any clinical intervention(s) or procedure(s) to be received by participants as part of the research protocol. These include uses of medicinal products or devices, other medical treatments or assessments, mental health interventions, imaging investigations and taking samples of human biological material. Include procedures which might be received as routine clinical care outside of the research.

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days).
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention
or
procedure

1 2 3 4

ACT course in a group format: 2.5 hours over 4 sessions.

1 0 10 hrs The groups will take place within the UHB's in Wales, either within hospital premises or in community venues and within the Bristol Area Stroke Foundation charity (BASF) for Bristol participants. The Bristol group will be facilitated by the charity (i.e. not NHS employees). The Welsh groups will be facilitated by clinical psychologists already working within the stroke teams. The hope is, depending in this research findings, these ACT groups will continue to be delivered to patients in these services beyond the research and will be become a routine intervention offered by the psychology team within the stroke departments.

A20. Will you withhold an intervention or procedure, which would normally be considered a part of routine care?

☐ Yes ☒ No

A21. How long do you expect each participant to be in the study in total?

Part 1(quantitative):

Intervention group: Completing the questionnaires at each time points: 25 mins. Therefore across three time points = 75mins plus 20 mins of reading time for the consent form, information sheet and debrief form.

Control group: for those that also go on to access the intervention, a further 75mins for questionnaires across the three time points during the course.

Attending the treatment group: 2.5hrs x 4 weeks = 10 hours (maximum)

Part 2 (qualitative):

Reading information sheet, consent and debrief forms: 20 minutes

Interviews will last no longer than one hour per interview.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Completing questionnaires, attending ACT sessions or participating in interviews, where issues around stroke are discussed and the impact it has had on survivors' lives, has the potential to cause distress. To minimise the risks to participants, the potential for distress will be clearly outlined in the participant information sheet provided before they give consent to take part in the study. If participants find completing the questionnaires distressing, they will be offered time with the researcher who is a clinical psychology trainee or if necessary with her supervisor (a registered clinical psychologist). Participants will be clearly informed of their rights to discontinue participation in the study at any stage of the research.

Information detailing local support services (e.g. Stroke Association Wales and Clinical Psychology Outpatient services) will be provided.

In order to minimise risks associated with breaches of data protection, personal identifiable information will be stored securely in a locked cabinet on NHS premises.

There is also a small potential for disclosure of risk issues during completion of the questionnaires. The consent form will explain the circumstances when confidentiality would be broken, such as risk to themselves or others, in accordance with NHS policy and procedures. Should the potential for risk arise, the Clinical Supervisor, will be notified immediately for further assessment and management of the risk.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

☒ Yes ☐ No

If Yes, please give details of procedures in place to deal with these issues:

Responding to questionnaires or interview questions may potentially be upsetting to participants. Prior notice of this possibility will be documented in the participant information sheet. Participants will have the opportunity to discuss any concerns they have during or after completing the battery of questionnaires, or the interviews. They will be informed from the start of their right to stop at any time during this process.

Attending group sessions may include topics that individuals find upsetting (e.g. the impact of stroke on their well being). Any adverse reactions may be addressed during the sessions or in confidence outside sessions (by the researcher or his supervisor if necessary). The limits of confidentiality will be made explicitly clear on the information sheet.

Disclosure of criminal or other sensitive information is unlikely, since this is not a focus of the research nor the group sessions.

A24. What is the potential for benefit to research participants?

The research aims to explore the benefits of Acceptance and Commitment therapy (ACT) on the wellbeing of stroke survivors and their carers. It is hypothesised that participants will find that this stroke adapted ACT course enhances their quality of life and decreases distress. ACT models are cost effective methods for clinical services to utilise, particularly as they are designed to be group based. This work has the potential to demonstrate the effectiveness of ACT groups after stroke and thereby to inform improvements in community stroke services.

A25. What arrangements are being made for continued provision of the intervention for participants, if appropriate, once the research has finished? May apply to any clinical intervention, including a drug, medical device, mental health intervention, complementary therapy, physiotherapy, dietary manipulation, lifestyle change, etc.

All of the course facilitators across the sites will receive a 2 day training package on how to deliver this stroke specific ACT group. All the groups will be run by staff already working within the UHB's/BASF charity, all of whom are willing to make this intervention a routine intervention offered to stroke survivors and their carers across all the sites.

A26. What are the potential risks for the researchers themselves? (if any)

Potential for home visits during phase 2 of the study, could present as a potential risk for the researchers. All

<p>NHS REC Form</p>	<p>Reference: 16/LO/0224</p>	<p>IRAS Version 5.2.1</p>
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measures will be taken to ensure the safety of the researchers, including familiarisation and implementation of the lone-worker policy. In addition, participants will have been screened by the inclusion/exclusion criteria and will already be known to stroke service practitioners who will be able to provide background information on the participants involved in this phase of study, if there is cause for concern.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).

Potential participants will be identified through nomination by clinical staff. In part 1, both the control group and the intervention group will be recruited using the same inclusion / exclusion criteria. We are working closely with the clinical psychologists in each of the Welsh Health Boards (Cardiff and Vale, Aneurin Bevan and Cwm Taf) and they will assist in recruitment within these areas. In part 2, potential participants will be self-identified.

Professor Reg Morris, Consultant Clinical Psychologist (and Academic Supervisor for this project) has strong links with the Bristol Area Stroke Association (BASF) and clinical teams across both of the Stroke Bristol NHS Trusts. We are working closely with a representative from BASF to run these adapted ACT groups with them within the Bristol area.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

☒ Yes ☐ No

Please give details below:
Yes, but only by the clinical teams to nominate appropriate people for the course.

A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?

☐ Yes ☒ No

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

☐ Yes ☒ No

A29. How and by whom will potential participants first be approached?

Potential participants will be contacted initially by letter/phone call by clinicians within the stroke rehabilitation services.

A30-1. Will you obtain informed consent from or on behalf of research participants?

☒ Yes ☐ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

<p>NHS REC Form</p>	<p>Reference: 16/LO/0224</p>	<p>IRAS Version 5.2.1</p>
<p>Part 1 of the study: Patients and carers who are identified by the clinical team as interested in attending the ACT group will be put on a waiting list. The clinical team will alert the patients to the study and if they are interested to hear more about the nature and purpose of part 1 of the study, as well as any potential risks and benefits, and their rights as a participant. It will also briefly introduce part 2 of the study (see notes below).</p> <p>At a further time point (so that the patient has at least 24 hours to read the information sheet), the patient will be contacted and will have the opportunity to ask any questions or discuss any concerns they might have about their involvement in the study. If they are willing to be involved in the study they will be asked to sign a consent form or the indicated on the consent form. If they do not wish to participate in the study, they will still access the treatment group as usual but questionnaires will not be administered to them.</p> <p>Part 2 of the study: Eligible participants will receive an information sheet in advance of the group, detailing in length part 1 of the study and briefly highlighting the aims of part 2. This ensures participants are not overwhelmed by inordinate amounts of information in the first instance.</p> <p>Facilitators of the ACT groups at each of the three sites (used in part 2) will reiterate the aims of the qualitative study during the first ACT session and will provide participant information sheets. A verbal reminder will be given to participants about this part of the study in the penultimate ACT session. Contact slips will also be presented throughout the ACT group allowing participants to express interest or decline part 2 of the study. Those who do not respond will be followed up and contacted via telephone by the group facilitators.</p> <p>Participants interested in the second part of the research will be given the opportunity to ask any questions or discuss any concern they might have about their involvement in the study. If participants are happy to complete the consent form before finishing the ACT course this will be made available. If participants wish to be contacted after the group, informed consent will be gathered prior to commencing the interviews.</p> <p>(NB: We have liaised with the Research Liaison Manager, Louise Hesp, of Cardiff & Vale UHB regarding consent procedures for part 1 and part 2 of the study. This method was approved by their team; see attached email).</p> <p><i>If you are not obtaining consent, please explain why not.</i></p>		
<p>Please enclose a copy of the information sheet(s) and consent form(s).</p>		
<p>A30-2. Will you record informed consent (or advice from consultees) in writing?</p> <p> <input checked="" type="radio"/> Yes <input type="radio"/> No </p>		
<p>A31. How long will you allow potential participants to decide whether or not to take part?</p> <p>At least 24 hours will be allowed for this decision.</p>		
<p>A32. Will you recruit any participants who are involved in current research or have recently been involved in any research prior to recruitment?</p> <p> <input type="radio"/> Yes <input checked="" type="radio"/> No <input type="radio"/> Not Known </p>		
<p>A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)</p> <p>Any prospective participants who have communication or cognitive impairment (as judged by staff or those who know them) will not be eligible to take part in the study. Individuals who cannot communicate fluently in English or Welsh, will not be able to take part in the study. If required, a translator for Welsh speaking</p>		

<p>NHS REC Form</p>	<p>Reference: 16/LO/0224</p>	<p>IRAS Version 5.2.1</p>
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participants will be sourced.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

The questionnaires proposed for the study are only validated in English. If Welsh translations become available, they will also be provided as alternatives.

A34. What arrangements will you make to ensure participants receive any information that becomes available during the course of the research that may be relevant to their continued participation?

Should information come to light during the research, the researchers will discuss with their academic supervisor to plan how ensure participants are made aware of this information, for example whether the research should contact them directly or if it would be more appropriate for a member of their care team to contact them, depending on the nature of the information.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

☒ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

☐ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

☐ The participant would continue to be included in the study.

☐ Not applicable – informed consent will not be sought from any participants in this research.

☐ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:
Capacity is susceptible to change and will be continuously monitored throughout the study.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)

☐ Access to medical records by those outside the direct healthcare team

☐ Access to social care records by those outside the direct social care team

☐ Electronic transfer by magnetic or optical media, email or computer networks

☐ Sharing of personal data with other organisations

☐ Export of personal data outside the EEA

☒ Use of personal addresses, postcodes, faxes, emails or telephone numbers

☒ Publication of direct quotations from respondents

☐ Publication of data that might allow identification of individuals

☒ Use of audio/visual recording devices

<p>NHS REC Form</p>	<p>Reference: 16/LO/0224</p>	<p>IRAS Version 5.2.1</p>
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☒ Storage of personal data on any of the following:

- ☒ Manual files (includes paper or film)
- ☐ NHS computers
- ☐ Social Care Service computers
- ☐ Home or other personal computers
- ☒ University computers
- ☐ Private company computers
- ☐ Laptop computers

Further details:
As the study will be sponsored by Cardiff University, the academic supervisor (Prof, Reg Morris) at Cardiff University will have access to the data. This is explicitly stated in the participant consent forms.

A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.

Adherence to the NHS code of conduct will be followed. Identifiable personal data will be destroyed once it has been anonymised; within 2 years of the start of the project.

A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.

The lead researchers (who are Cardiff and Vale UHB employees and trainee clinical psychologists) and their supervisor (who is a Cardiff and Vale UHB employee and Registered clinical psychologist) will have access to personal data collected in the study. This is clearly outlined in the participant information sheet and consent forms.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

☐ Less than 3 months
☐ 3 – 6 months
☐ 6 – 12 months
☒ 12 months – 3 years
☐ Over 3 years

If longer than 12 months, please justify:
In line with Cardiff University's data retention and archiving policies for clinical research relating to public health, all research data (after anonymisation) must be stored for 5 years. This is made explicitly clear within participant information sheets.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

☐ Yes ☒ No

Date: 14/01/2016	18	187893/920173/1/57
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NHS REC Form

Reference: 16/LO/0224

IRAS Version 5.2.1

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

☐ Yes ☒ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

☐ Yes ☒ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

☐ Yes ☒ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

The Department of Health's Research Governance Framework for Health and Social Care and the research governance frameworks for Wales, Scotland and Northern Ireland set out the requirement for registration of trials. Furthermore: Article 19 of the World Medical Association Declaration of Helsinki adopted in 2008 states that "every clinical trial must be registered on a publicly accessible database before recruitment of the first subject"; and the International Committee of Medical Journal Editors (ICMJE) will consider a clinical trial for publication only if it has been registered in an appropriate registry. Please see guidance for more information.

☐ Yes ☒ No

Please give details, or justify if not registering the research.

No suitable register exists.

Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

☒ Peer reviewed scientific journals

☒ Internal report

☒ Conference presentation

☒ Publication on website

☐ Other publication

☐ Submission to regulatory authorities

☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

☐ No plans to report or disseminate the results

☐ Other (please specify)

A53. Will you inform participants of the results?

187802/020172/4/574

NHS REC Form

Reference: 16/LO/0224

IRAS Version 5.2.1

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

☐ Yes ☒ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

☐ Yes ☒ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

☐ Yes ☒ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

The Department of Health's Research Governance Framework for Health and Social Care and the research governance frameworks for Wales, Scotland and Northern Ireland set out the requirement for registration of trials. Furthermore: Article 19 of the World Medical Association Declaration of Helsinki adopted in 2008 states that "every clinical trial must be registered on a publicly accessible database before recruitment of the first subject"; and the International Committee of Medical Journal Editors (ICMJE) will consider a clinical trial for publication only if it has been registered in an appropriate registry. Please see guidance for more information.

☐ Yes ☒ No

Please give details, or justify if not registering the research.
No suitable register exists.

Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

☒ Peer reviewed scientific journals

☒ Internal report

☒ Conference presentation

☒ Publication on website

☐ Other publication

☐ Submission to regulatory authorities

☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

☐ No plans to report or disseminate the results

☐ Other (please specify)

53. Will you inform participants of the results?

NHS REC Form

Reference:
16/LO/0224

IRAS Version 5.2.1

☒ Yes ☐ No

Please give details of how you will inform participants or justify if not doing so.
Participants will be provided with written feedback, detailing a summary of the research. Participants will be provided with the researcher's contact details, should they wish to discuss anything further. If appropriate, findings may also be published on the NHS university health boards and NHS trust website and if so, participants will be informed of how to access this information at the web address.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? Tick as appropriate:

☐ Independent external review

☐ Review within a company

☐ Review within a multi-centre research group

☒ Review within the Chief Investigator's institution or host organisation

☐ Review within the research team

☒ Review by educational supervisor

☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
The scientific quality of this research has been reviewed by the Doctorate of Clinical Psychology supervisory team at Cardiff University.

A copy of the email confirming scientific review (from Cardiff University) are included.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A56. How have the statistical aspects of the research been reviewed? Tick as appropriate:

☐ Review by independent statistician commissioned by funder or sponsor

☐ Other review by independent statistician

☐ Review by company statistician

☐ Review by a statistician within the Chief Investigator's institution

☐ Review by a statistician within the research team or multi-centre group

☒ Review by educational supervisor

☐ Other review by individual with relevant statistical expertise

☐ No review necessary as only frequencies and associations will be assessed – details of statistical input not required

In all cases please give details below of the individual responsible for reviewing the statistical aspects. If advice has been provided in confidence, give details of the department and institution concerned.

Title Forename/Initials Surname
[REDACTED]

Department
Institution
Doctorate Programme in Clinical Psychology
Cardiff and Vale UHB

20

187893/920173/1/57

NHS REC Form		Reference: 16/LO/0224	IRAS Version 5.2.1
Work Address	11th Floor, Tower Building, 70 Park Place Cardiff		
Post Code	CF10 3AT		
Telephone	02920870582		
Fax			
Mobile			
E-mail	[REDACTED]		
Please enclose a copy of any available comments or reports from a statistician.			

A57. What is the primary outcome measure for the study?

Part 1 of the study (quantitative): Primary outcome will be from PHQ-9 and GAD-7, analysed together by MANOVA.

Part 2 of the study (qualitative): No specific psychometric measures will be utilised in part 2, however a grounded theory approach will evolve across the course of the study regarding data collection and analysis.

A58. What are the secondary outcome measures?(if any)

Part 1 of the study (quantitative): Mediation analysis will be conducted using the ASH and EURO-QOL questionnaire data.

Part 2 of the study (qualitative): Not applicable.

A59. What is the sample size for the research? How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.

Total UK sample size: 120

Total international sample size (including UK):

Total in European Economic Area:

Further details:

part 1 of the study (quantitative): at least 120 people (15 people in each of the two groups (intervention and control) over four sites

Part 2 of the study (qualitative): For part 2, a sample size of 25 people will be used to ensure data saturation is achieved. This conforms to the guidelines of grounded theory research(Denzin & Lincoln, 2005; Creswell, 2007).

A60. How was the sample size decided upon? If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.

part 1 of the study (quantitative):

A power analysis was conducted using Gpower software. Information input into this programme is:

test family: F-Test

Statistical test: MONOVA repeated within-between interactions

Type of power analysis: A priori

Effect Size: 0.4 (for a large effect), 0.25 (for a medium effect size)

x err prob: 0.05

Power: 0.8

Number of groups: 2 (control and intervention group)

Number of measurement: 2 (PHQ-9 & GAD-7)

Total sample size given by Gpower: 52 for a large effect size, and 128 for a medium effect size.

Therefore our aim is for at least 120 participants but we would still be satisfied with a figure of at least 52 participants, considering the calculations outlined above.

Part 2 of the study (qualitative):

NHS REC Form

Reference: 16/LO/0224

IRAS Version 5.2.1

The same size was decided upon given the current literature around grounded theory and from researching sample sizes in studies that follow a similar format to the one presented here.

A61. Will participants be allocated to groups at random?

☒ Yes ☐ No

If yes, please give details of the intended method of randomisation:

part 1 of the study (quantitative): Using a Microsoft excel spreadsheet each participant will be given a number in ascending order (for each site). Internet software (www.randomizer.org) will be used to randomly generate a numbers list for group 1 (treatment group) and group 2 (waiting list control group) which will corresponded against the participants numbers. Therefore the computer software will determine which participant goes into which treatment group. Carer and stroke survivor partnerships will be grouped together (i.e. given the same number) to ensure they are allocated into the same group due to logistical reasons as well as ensuring the control group does not gain access to the course materials before the course is offered to them.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

part 1 of the study (quantitative):
Two way (time and condition), repeated measures MANOVA will be used to analyse any changes in the variables between the different stages of measurement (pre, post and follow up) and any differences in change across the intervention and waiting list control conditions (interaction).

Mediation analysis using PROCESS (Hayes, 2013) will be used to determine the roles of the mediating variables.

part 2 of the study (qualitative):

In part 2, Grounded Theory will be used to analyse the dataset. This method will help to explore emerging themes from the data and to generate theory, in an area where little is already known. It has been chosen to help develop a deeper understanding of stroke survivors experiences of the ACT group and to gain insight into potential change processes which might result from group attendance.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

	Title Forename/Initials Surname
Post	Clinical Psychologist
Qualifications	
Employer	
Work Address	
Post Code	
Telephone	
Fax	
Mobile	
Work Email	

South Wales Doctoral Programme in Clinical Psychology 11th Floor, School of Psychology,
Tower Building, 70 Park Place,
CF10 3AT

A mixed-methods evaluation of an adapted Acceptance and Commitment Therapy (ACT) group for stroke survivors and their carers: ACTivate Your Life After Stroke. N.B. Please note change of name from 'ACTion after Stroke' to 'ACTivate your life after stroke'. The former name appears on the sponsors letter, however the documents provided for review are the same. The name was changed to remain consistent across all research sites.

16/LO/0224

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187893

Thank you for your letter of [REDACTED] responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Mr Rajat Khullar, nrescommittee.london-cityandeast@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

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

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

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

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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management

permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [sponsorship insurance certificate]		
Interview schedules or topic guides for participants [part 2: interview schedule]	2	14 December 2015
Letter from sponsor [Sponsorship letter]		22 December 2015
Other [Rebecca Large (CI) CV]		
Other [Part 2: Participant information sheet and consent form]		
Other [Email from Louise Hesp re: consent process]	2	13 January 2016
Other [part 2: debrief form v1]		
Other [Part1: debrief form v2]	1	11 December 2015
Other [demographic form for carers v3]	2	29 November 2015
Other [demographic form for stroke survivors v3]	3	29 November 2015
Other [ASH sample]	3	29 November 2015
Other [EUROQOL 5D sample]		
Other [Warwick and Edinburgh mental wellbeing scale sample]		
Other [PHQ-9 & GAD-7 sample]		
Other [Reply to REC panel]		
Participant consent form [part 1: consent form v2]	1	10 February 2016
Participant information sheet (PIS) [Part 1: Participant information sheet]	2	29 November 2015
REC Application Form [REC_Form_14012016]	3	08 January 2016
REC Application Form [REC_Form_12022016]		14 January 2016
Referee's report or other scientific critique report [supervisors letter of scientific review]		12 February 2016
Research protocol or project proposal [protocol]	2	10 February 2016
Response to Request for Further Information [Cover Letter]		15 February 2016
Summary CV for Chief Investigator [REDACTED]		
Summary CV for supervisor [REDACTED]		

Statement of compliance

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

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

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/LO/0224

Please quote this number on all correspondence

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

Yours sincerely



pp

Chair

Email: n 

Enclosures: "After ethical review – guidance for researchers"

Copy to:



Research and Innovation Services
Director Geraint W Jones
Gwasanaethau Ymchwil ac Arloesi
Cyfarwyddwr Geraint W Jones

22 December 2015
Professor Reg Morris
School of Psychology
Cardiff University
South Wales Clinical Psychology Doctoral Programme
11th floor,
Tower Building
70 Park Place
Cardiff, CF10 3AT



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Prifysgol Caerdydd
Llawr 7
30 - 36 Heol Casnewydd
Caerdydd CF24 0DE
Cymru Y Deyrnas Unedig

Dear Professor Morris,

Title: A mixed-methods evaluation of an adapted Acceptance and Commitment Therapy (ACT) group for stroke survivors and their carers: ACTION after Stroke

Short title: An evaluation of an adapted ACT group for stroke survivors

I understand that you are acting as Chief Investigator for the above ClinPsy PhD project to be conducted by Rebecca Large [REDACTED]

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

Scientific (Peer) Review

I can also confirm that Scientific (Peer) Review has been obtained from Professor Reg Morris – South Wales Clinical Psychology Training Programme, Cardiff University.

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 (for NHS REC and NHS R&D approvals), you will be required to obtain signature from the Sponsor ('Declaration by the Sponsor Representative').

Please then submit the project to the following organisations for approvals:

- An NHS Research Ethics Committee;
- Health & Care Research Wales Permissions Coordinating Unit (formerly known as NISCHR PCU) -to arrange host organisation R&D approval for Welsh NHS sites);
- English NHS Site R&D Approvals:
 - [REDACTED]
 - [REDACTED]

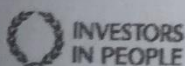
Once Research and Innovation Services has received evidence of the above approvals, the University is considered to have accepted Sponsorship and your project may commence.

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 Research Governance Framework for Health and Social Care. In accordance with the University's Research Governance Framework, the Chief Investigator is also responsible for ensuring that each research team member is qualified and experienced to fulfill his delegated roles including ensuring adequate supervision, support and training.



UNIVERSITY OF WALES
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Registered Charity: 1136855 Elusen Gofrestredig

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

Roles and responsibilities are adequately detailed in the research protocol – no contract required.

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


- ensure you are familiar with your responsibilities under the Research Governance Framework for Health and Social Care;
- undertake the study in accordance with Cardiff University's Research Governance Framework for the principles of Good Clinical Practice;
- ensure the Research complies with the Data Protection Act 1998;
- inform Research and Innovation Services of any amendments to the protocol or study design, including changes to start /end dates and ensure any such amendments are submitted to, and approved by, the relevant bodies (e.g. RECs and/or R&D offices);
- co-operate with any audit inspection of the project files or any requests from Research & Innovation Services for further information.

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

SPON 1494-15


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

Yours sincerely





D 274

Cc Rebecca Large 

Appendix I**Consent Form**

Name of Researcher: XXXXX, Trainee Clinical Psychologist

Participant Identification Number:

You are here today as you attended the four-week '*ACTivate Your Life After Stroke*' course. I am conducting a project to see if this course was useful in reducing distress and improving well-being. If you agree to be part of this study I will aim to ask you a few questions about your overall group experiences. Before agreeing to participate in this interview it is important you have read the attached participant information sheet carefully. Please feel free to ask any questions you may have.

Please tick the box if you agree with the following statement:

1. I confirm that I have read and understood the 'Participant Information Sheet' 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 at any time without giving a reason and without it affecting my care or rights in any way. ☐
3. I understand that the researcher will hold all information and data collected securely and in confidence, and that all efforts will be made to ensure that I cannot be identified. ☐
4. I am aware that sessions will be audio-recorded and that these recordings will be shared only with the research team. These recordings will be kept confidential at all times and stored securely in locked and protected files. ☐
5. I am aware that excerpts from these recordings, or descriptions of them, will be used by the researcher for the purpose of research. I give permission for the information to be used in reports with the understanding that it will remain anonymous. ☐
6. I understand that if the researcher is concerned about my safety or the safety of others, she will share this information with her supervisor who may request to speak with me to assess this risk further. Action may then be taken to ensure a duty of care. ☐

Participant Signature Date.....
 Name (please print)

Researcher Signature Date.....

OPTIONAL

I **would** like a summary of the findings of this study sent to my email or postal address below, once the project has been written.

Email Address:

.....

Postal Address (including postcode):

.....

.....

Appendix J

- INFORMATION SHEET INTRODUCING QUANTITATIVE RESEARCH PRIOR TO START OF ACT GROUP; A SMALL SUBSECTION DETAILS INFORMATION ABOUT THE CURRENT QUALITATIVE STUDY SO AS NOT TO DECIEVE PARTICIPANTS/GROUP MEMBERS

Participant information sheet

We would like to invite you to take part in a research study to help us learn more about how to support people after stroke. There are two parts to this study, the details of which are explained below.

Before you decide to take part, it is important for you to understand *why* the study is being done and *what* you need to do. Please read this leaflet carefully.

Take time to decide whether or not you want to take part - talk it over with your family and friends, or ask us if you would like things explained or need more information.

Thank you for reading this!

Part 1 of the Study

What is the study?

We understand that a stroke can be life-changing for some survivors and their carers. Many stroke survivors find that they feel anxious or low in mood. We think that a model of therapy called Acceptance and Commitment Therapy (ACT) could be helpful in improving mood and well-being after stroke. This study aims to determine if ACT is effective to stroke survivors and carers.

ACT teaches people to accept what is out of our personal control. It is **based on the idea that, generally, trying to rid ourselves of pain and distress only serves to increase it. The alternative then, is to accept it - but that doesn't mean being defeated or tolerating suffering. ACT is about learning skills and ways of managing to make room for painful feelings, thoughts, and sensations - allowing them to be there, without having to struggle against them. But it is more than just this, it is also about committing to action that improves and enriches our lives.**

The aim of this project is therefore to look at how effective this therapy is in reducing levels of anxiety or depression, and improving well-being. In order to evaluate the effectiveness of this therapy properly, people who register their interest to participate in this study will be randomly allocated into one of two groups. Group one: will be invited to attend the ACT therapy course as soon as possible. Group two: will first go on a waiting list to receive ACT and then will be invited to attend the ACT course at a later date.

Why are you doing this?

When conducting research, there are lots of factors that may lead to change in how a person feels, for example, a person may simply feel better with time. One of the ways in which we try to 'control' for things like time, is to also include a 'control' or comparison group in the study. The people randomly allocated to the 'control' group serve as a comparison for the group that receive ACT. The two groups are assessed in the same ways. Therefore, any difference between the two groups can be

attributed to the intervention itself. The group assigned to the waiting list initially will then be invited to receive the intervention at a later date.

What will the course be like?

The course is a four week therapeutic course called '*ACTivate Your Life After stroke*'. It is very important that you can commit to attend all four sessions of this course since the sessions are closely linked. The sessions will last two hours per week (except the first and last session which will be two and a half hours). There will be a break included at the middle of each session. The layout of the sessions will be the same. There will be a presentation given and you do not have to contribute or speak at all if you do not wish to do so. We just ask that you listen to the session content with an open mind.

Can both the stroke survivor and his/her carer/spouse take part?

Yes! Either one, or both are welcome to attend, but we do ask that ALL participants come to ALL four sessions.

What exactly is involved if I do agree to take part?

If you decide to take part in the research there will be five questionnaires to complete. These should take no longer than 30 minutes in total. Both carers and stroke survivors will be asked to complete the same questionnaires at the start of the course and on completion of the course. We will ensure there is time to complete these questionnaires within the first and last session of the course. We would also like you to complete these questionnaires again two months after you finished attending so we can see how the benefits of ACT have been maintained. We may contact you via the telephone or post to complete these forms for the final time if you are willing for this.

If you are allocated into the waiting list group, we will ask you to complete the same questionnaires at the same three time points as the treatment group, as outlined above. This allows us to determine if ACT is better than no treatment. When you do attend the course, with your permission, we will ask you to complete the questionnaires three more times, at the start and end of the course and two months after the course has finished, as above. This will help us to evaluate the usefulness of the treatment.

How will my information be used?

The results of the research will be written up as a thesis and an article and submitted as part of a Doctorate in Clinical Psychology. It is important that you know that no participants will be identified in any way as part of this process.

Do I have to take part?

There is absolutely no requirement to participate in the research, and if you wish to join the course but not take part in the research you will still be welcomed as a valuable member. Whether you chose to participate in the study or not, this will have no impact on your treatment you receive from the stroke team.

If I agree to participate in the study, can I change my mind later on?

Yes, if you wish to withdraw from the study you can do this at any time. All your identifiable information and data collected from you, to date, will be destroyed and your name removed from all study files.

Will my participation in the study be confidential?

Your participation in the research will be kept strictly confidential. The questionnaires will be seen only by myself and my research supervisor (XXXXX) and will be kept in a locked filing cabinet and identifiable information will be destroyed after 2 years.

I have a duty of care to protect people from harm, so there are some legal and ethical rules I must obey which could require me to over-ride confidentiality in the very unlikely event that there is a risk of harm.

Will I be paid for this study?

There is no payment for taking part in this study.

Who has reviewed the study?

This study has been reviewed by the London - City & East Research Ethics Committee. This means that the study processes involving the questionnaire data collection have been reviewed and given a favourable opinion by this NHS ethics committee (reference: 16/LO/0224).

Part 2 of the Study

The second part of the study involves Stroke Survivors and will take place once the “ACTivate Your Life After Stroke” course has finished. We hope to learn more about the effectiveness of this psychological intervention by asking you some questions and exploring your personal views and experiences of the group.

We will invite some of you (>25) to a short interview, approximately 45 minutes, in a location convenient to you. If you are keen to participate and would like to share your experiences of the group, or would like to know more information before consenting, please speak with your group facilitator. They will happily provide you with a participant information sheet detailing part 2 of the study in more depth, ensuring you are fully informed before making your decision.

Are there any risks in participating in any part of this study?

People vary in how they get on with different kinds of psychological treatments and we do not know whether or not you will find the Activate Your Life After Stroke course helpful. It is possible that completing questionnaires, the content of our ACT sessions or participating in interviews, where issues around stroke are discussed might be upsetting for you. To minimise this, if at any point you feel distressed please come and speak to one of the facilitators at the group who would be happy to support you. If you notice your mood worsens over the group, we expect you to discuss this with the facilitators so that they can arrange extra help and support for you through your GP, or local support services, as appropriate.

What if I have a concern about the treatment I have received?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions [contact details below]. If you remain unhappy and wish to complain formally, you can do this by contacting the XXXXXX NHS Complaints Procedure on XXXXX XXXXXX.

Further information

If you have any further questions about taking part in the study or need further information please do not hesitate to contact the researcher (contact details below).

Thank you very much for taking the time to read this information sheet, your help is greatly appreciated. If you would like to participate in this study, please let your stroke clinician know.

XXXXX XXXXXXXX

If you would like more information about the project, please feel free to contact us:

Researcher (Part 1 of the study):

[CONTACT DETAILS]

Researcher (Part 2 of the study):

[CONTACT DETAILS]

Academic supervisor:

[CONTACT DETAILS]

- INFORMATION SHEET SPECIFICALLY FOR QUANTITATIVE PROJECT

Participant Information Sheet

We would like to invite you to take part in a research study to help us learn more about the effectiveness of a psychological intervention for stroke survivors. Before you decide to take part it is important for you to understand *why* the research is being conducted and *what* it will involve for you.

Please take the time to read the following information carefully and discuss it with others if you wish. Please don't hesitate to ask us if there is anything that is not clear or if you would like more information, before deciding to take part or not.

What is the purpose of this study?

We understand that for some people having a stroke can cause drastic and unexpected changes to their lives, both physically and psychologically. Most people will recognise the physical limitations caused by stroke such as limb weakness or speech difficulties, but stroke can also cause psychological changes. These changes might be expressed in the way we think, feel or behave, and have the potential to affect our quality of life. Stroke survivors may feel depressed or anxious, be frustrated or feel overwhelmed by their current situation. All these feelings are common, and although they usually dissipate with time, in some individuals they can persist. As such, we hope to explore ways to help reduce this by offering support to promote positive adjustment after stroke. We believe a therapy called Acceptance and Commitment Therapy (ACT) could be beneficial in this instance.

ACT is a therapy based on the idea that, generally, trying to rid ourselves of pain and distress only serves to increase it. It teaches people to accept what is out of our personal control – but that doesn't mean being defeated or tolerating suffering. ACT is about learning skills and way of managing to make room for painful feelings, thoughts, and sensations – allowing them to be there, without having to struggle against them. But it is more than just this, it is also about committing to action that improves and enriches our lives.

As such, I am looking to recruit up to *twenty-five* stroke survivors to explore your personal views of the ACT group and to gain feedback on what elements you found most or least helpful. This will involve a short interview, which should last approximately 45 minutes to an hour.

Do I have to take part?

It is up to you to decide to join the study. The researcher will describe the study and go through this information sheet with you. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive and you would still be welcomed to the group as a valued member.

What will I need to do?

You will need to commit to an interview session, which will be held approximately one month after the ACT course. Each session should last approximately 45 minutes. These sessions will be audio-recorded to support the researcher in transcribing and analysing what you want to tell them.

How will my information be used?

The results of the research will be written up as a thesis and submitted as part of my Doctorate in Clinical Psychology. It is also hoped that these results will be published in a scientific journal and presented at Stroke Conferences. You will be given the opportunity to receive a summary of the findings after the research is complete. You will not be identified in any report/publication related to this research.

What are the benefits of this research?

We hope you will find some benefit from these interviews by reflecting on your experiences of the group and consolidating the material you have covered so far. However, we also hope that participation may benefit you and other stroke survivors in future. That is, as a new research area in Stroke we hope your direct feedback and views can help contribute to the development of new psychological and support services for stroke survivors.

Are there any risks in participating in any part of this study?

People vary in how they get on with different kinds of psychological treatments and we do not know whether or not you will find the Activate Your Life After Stroke course helpful. It is possible that completing questionnaires, the content of our ACT sessions or participating in interviews, where issues around stroke are discussed might be upsetting for you. To minimise this, if at any point you feel distressed please come and speak to one of the facilitators at the group who would be happy to support you. If you notice your mood worsens over the group, we expect you to discuss this with the facilitators so that they can arrange extra help and support for you through your GP, or local support services, as appropriate.

What if I have a concern about the treatment I have received?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions [contact details below]. If you remain unhappy and wish to complain formally, you can do this by contacting the XXXXXXXX NHS Complaints Procedure on XXXXX XXXXXX.

Will my taking part in the study be kept confidential?

All information collected from you during the interview will be kept strictly confidential. The audio-recordings will only be heard by myself and members of the research team whilst transcribing the material, and all data will be anonymised to protect your identity. These recordings will be stored as a locked and encrypted file, and identifiable information will be destroyed within 2 year.

As an exception, if I am worried about your safety or the safety of others, there are legal and ethical rules I need to obey which would then require me to override confidentiality. However, I would always try to discuss this with you in the first instance.

Will I be paid for this study?

No, there is no payment for taking part in this study.

Who has reviewed the study?

This research has been reviewed by the South East Wales NHS Research Ethics Committee (reference: 16/LO/0224) who have given it a favourable ethical opinion for conduct. This project

has also been reviewed, according to procedures specified by Cardiff University Research Ethics Committee, and allowed to proceed.

Contact for further information

If you are potentially interested in taking part in this study, please either phone XXXXXX XXXXX (Researcher) on XXXXX XXXXXX or email XXXXXXXXXX.

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

Please feel free to discuss this with others and feel free to contact myself or my supervisor to ask any questions if there is anything you are unsure about or would like more information on. If you agree to take part in the study, you will be asked to sign a consent for and will be given a copy for your own records.

Researcher:

[CONTACT DETAILS]

Academic Supervisor:

[CONTACT DETAILS]

Appendix K

Draft Interview Schedule

FIRST: Reiterate confidentiality policy and check that consent form is signed.

- 1. Having attended the ACT group, what were your initial expectations of the group?**

Prompt: What were you hoping to gain from attending this group?

- 2. Can you describe your experience(s) of attending the ACT group?**

- 3. What if anything did you learn?**

Prompt: What did you take away from the group? What sense did it make in regards to living life after stroke?

- 4. (If something) what helped you learn/understand/do things differently?**

- 5. If nothing, why wasn't it helpful? What were the barriers to learning new things or making change?**

- 6. How, if at all, has your way of coping with life after stroke changed since attending the group?**

Prompt: What does coping look like now? How does this compare to the way you were coping before the group?

- 7. What has most contributed to this change?**

- 8. If you could sum up what it was like being part of the group to someone considering attending, what would you say?**

Finish with: Is there anything else I have missed you think I should know to understand your experience of the group better? / is there anything I have missed that you would like included?

Appendix L **Memo Writing Excerpt**

Losing one's Prior Life

This survivor is talking about loss of a prior life since his stroke, and living with a permanent paralysis. He reports feeling disjointed or disconnected from all that he has known, which causes overwhelming emotional suffering and devastation when he thinks back on times he was more able, seeing himself as capable, independent, in control. He alludes to floating in a dark abyss of uncertainty and hopelessness – wondering if he will make contact with his old self or old life in future. He is seen to question the permanency of his disability in attempts to retain hope of an improved future; regardless of what advice medical professionals have given him.

Suffering loss in personal, social, relational domains and feeling isolated as a result. Is this caused by the residual symptoms or by the actions of the individual i.e. taking himself away because of his own criticisms, judgements etc?

Describing a fight against reality – a dilemma that is faced; do you accept the situation you are in now even though you are not happy or where you want to be; or do you continue fighting and holding on to hope as that propels you in your thoughts of getting back to “me”/ “my old self”. Seeing acceptance of symptoms as “giving up”, “being less able”, “resigning oneself to a lesser life”; rather than noticing this may open up more opportunities and reduce the restrictions that have been self-imposed?

- How does this impact on identity? Sense of value or worth?
- Difficulties compounded further my daily reminders of stroke effects? – me now vs. me then; me vs. others.

Appendix M Data Analysis – Full Category Structure

Figure A.1

CORE CATEGORY 1: NEGOTIATING CHALLENGE OF STROKE

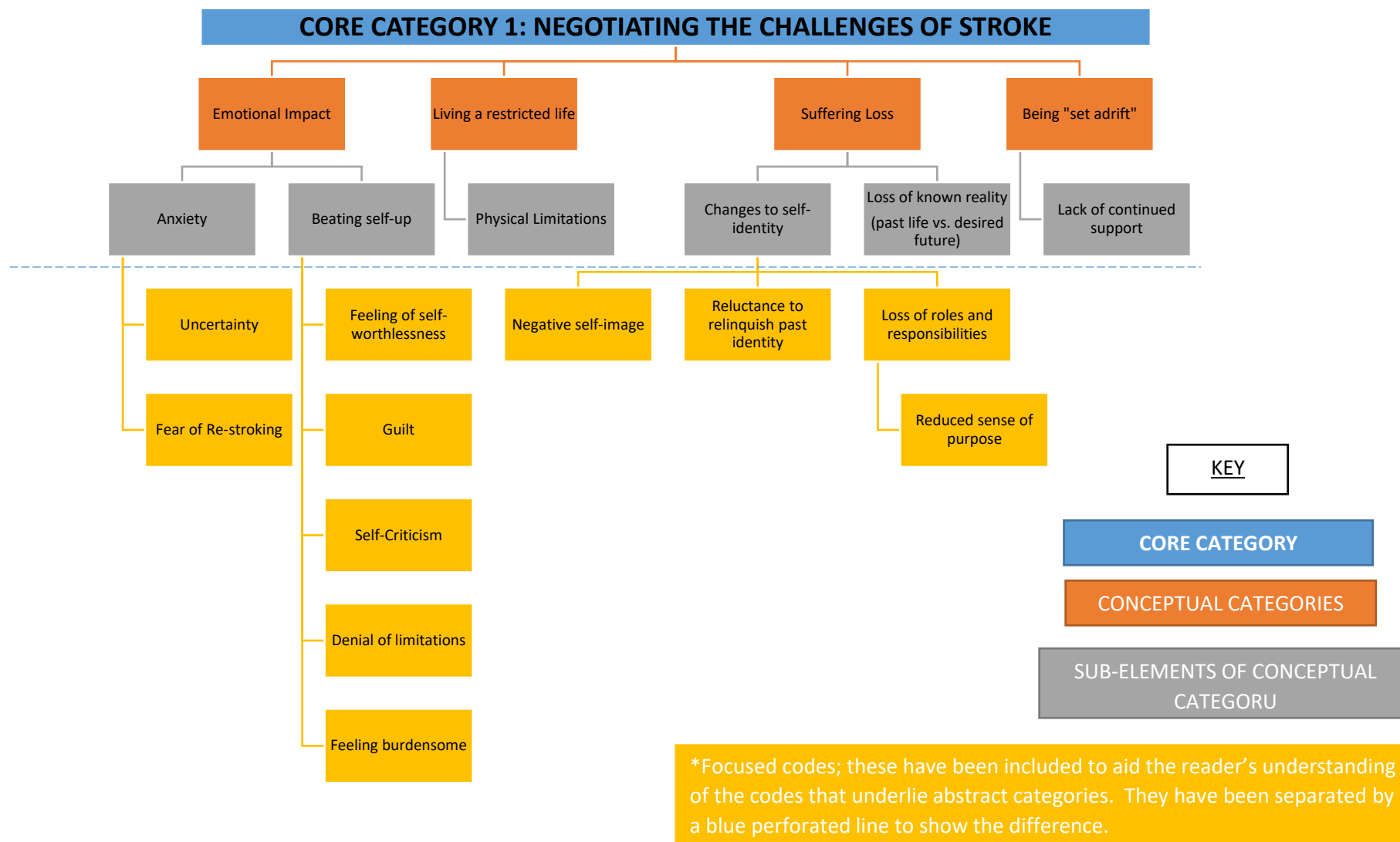


Figure A.2

CORE CATEGORY 2: CONTEXTUAL FACTORS

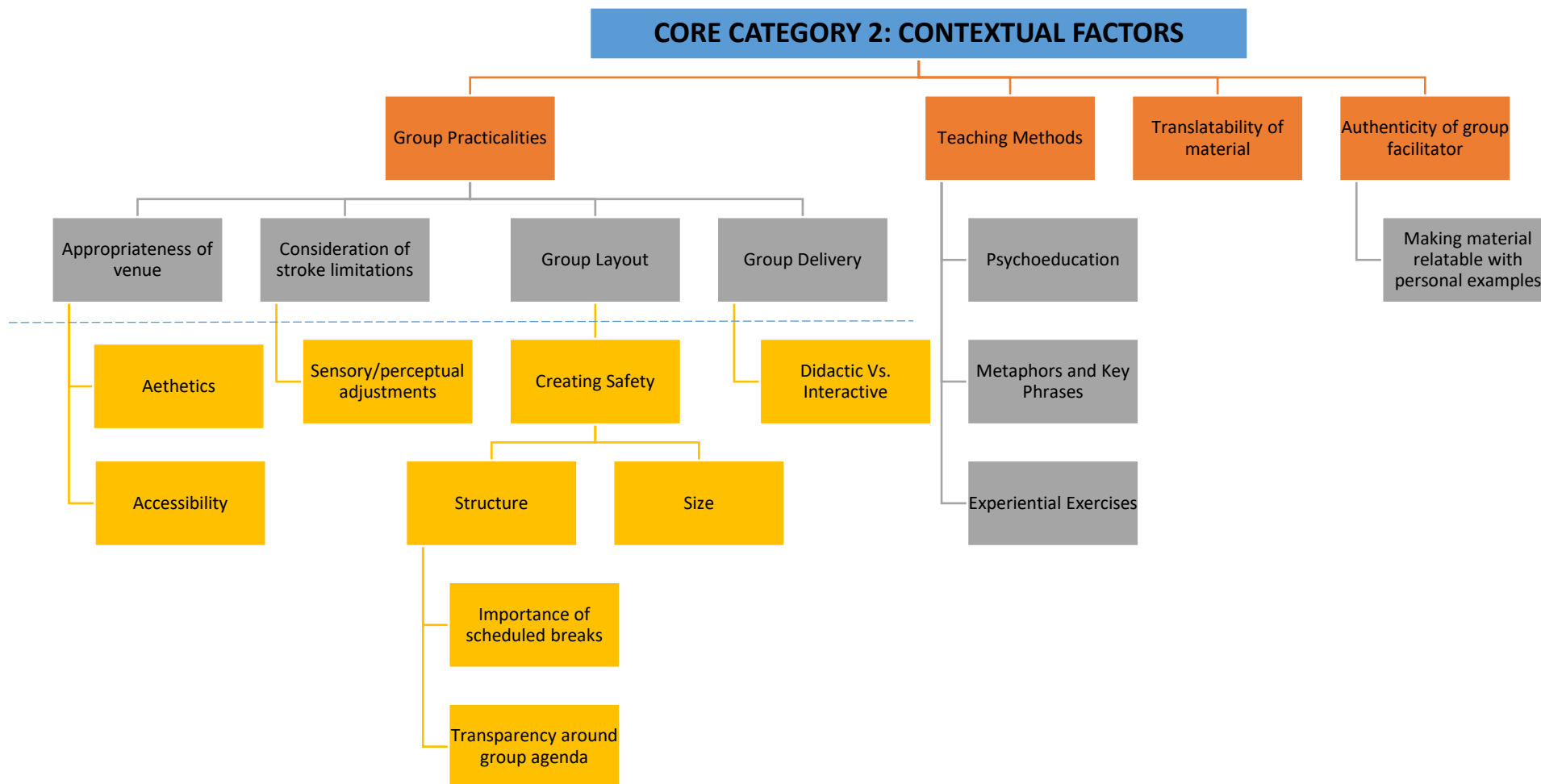


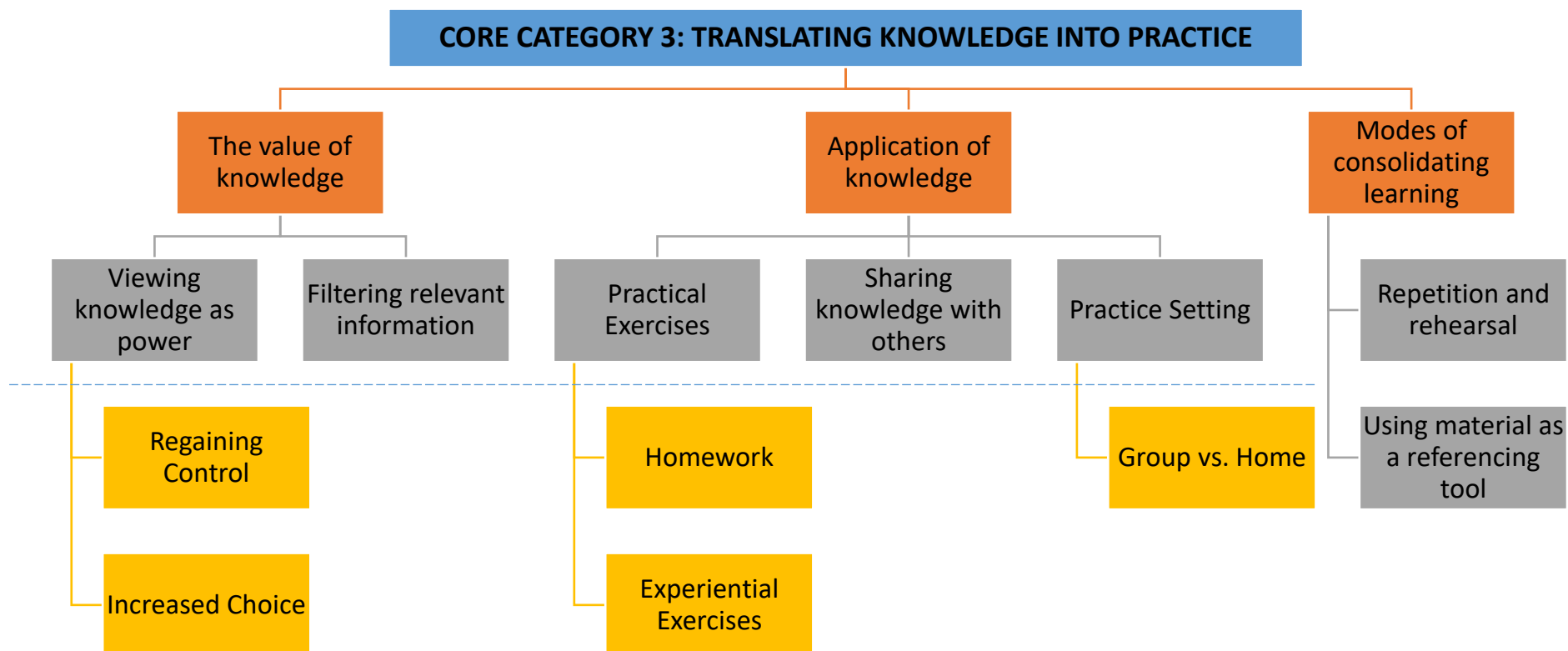
Figure A.3**CORE CATEGORY 3: TRANSLATING KNOWLEDGE INTO PRACTICE**

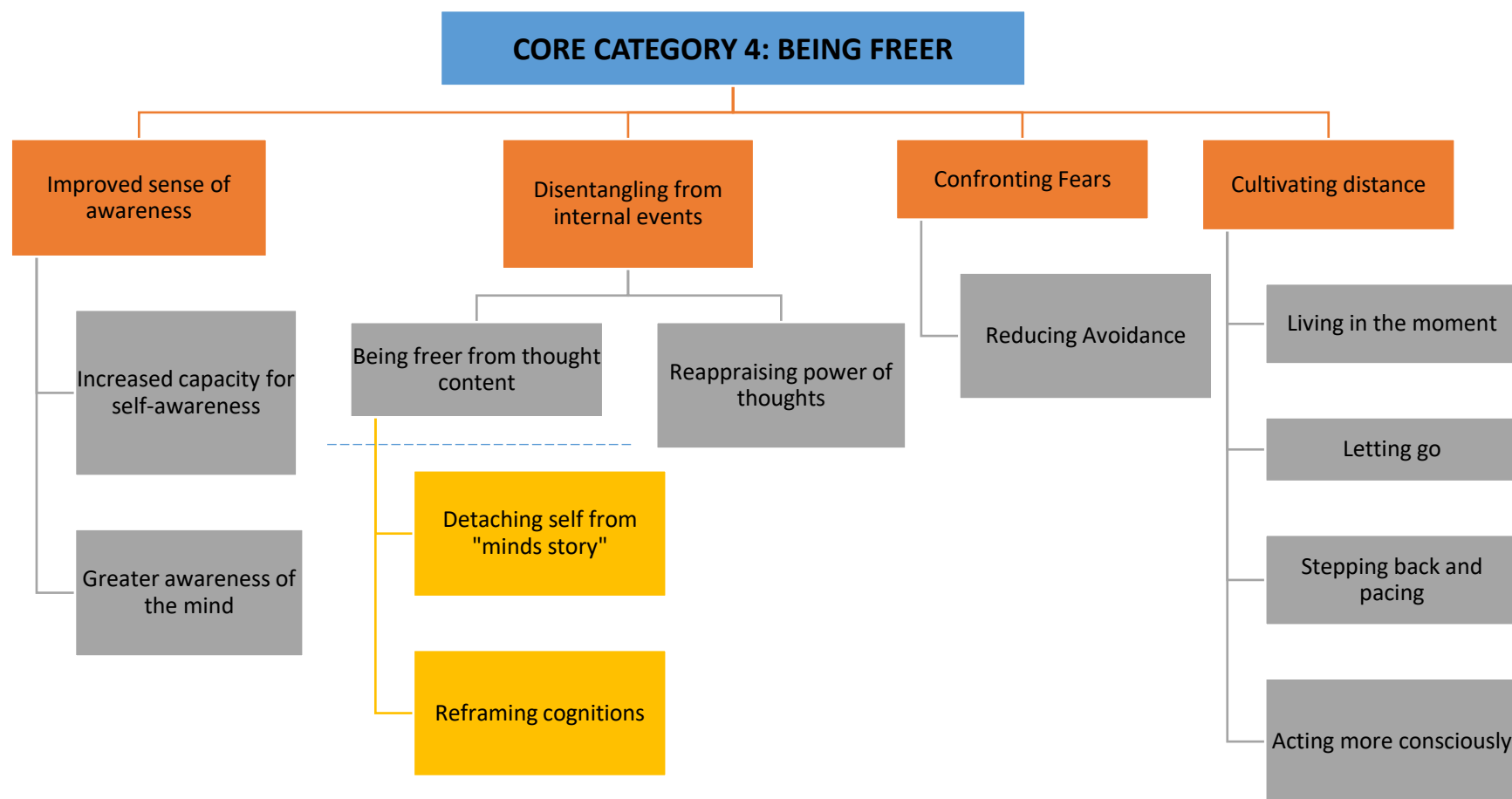
Figure A.4**CORE CATEGORY 4: BEING FREER**

Figure A.5

CORE CATEGORY 5: VALUING OTHER STROKE SURVIVORS

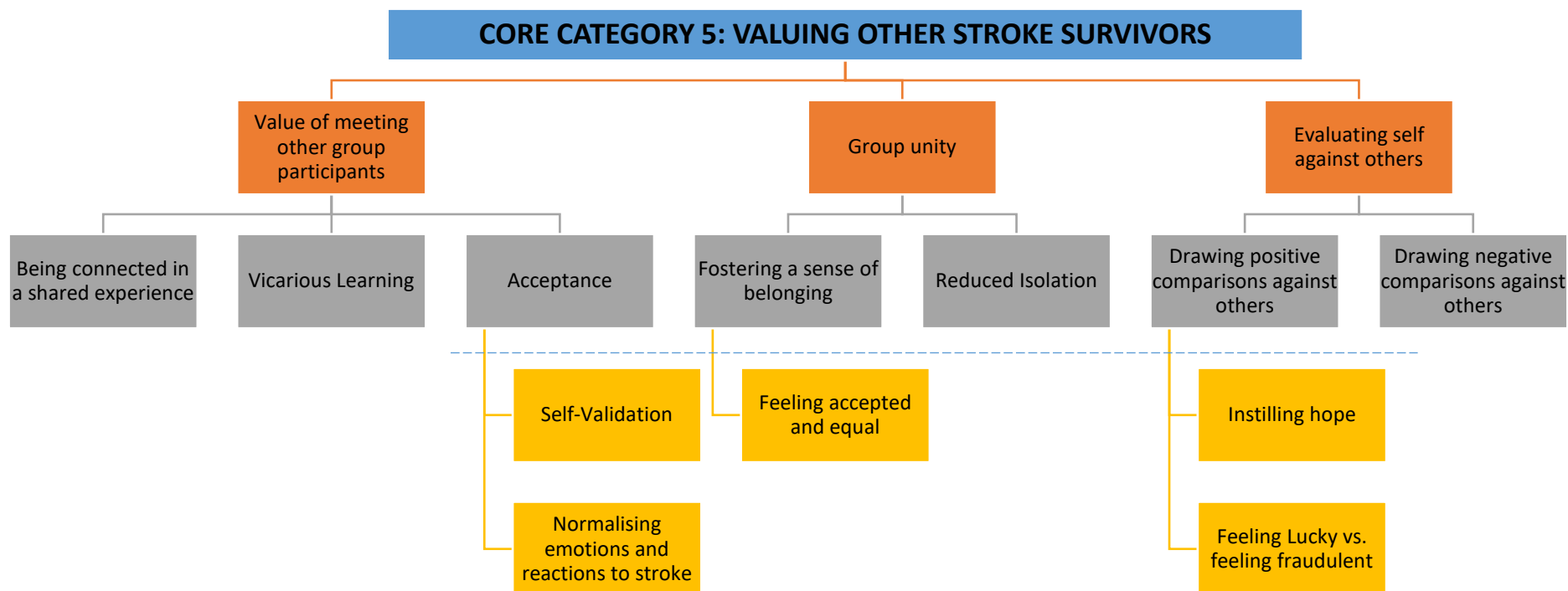
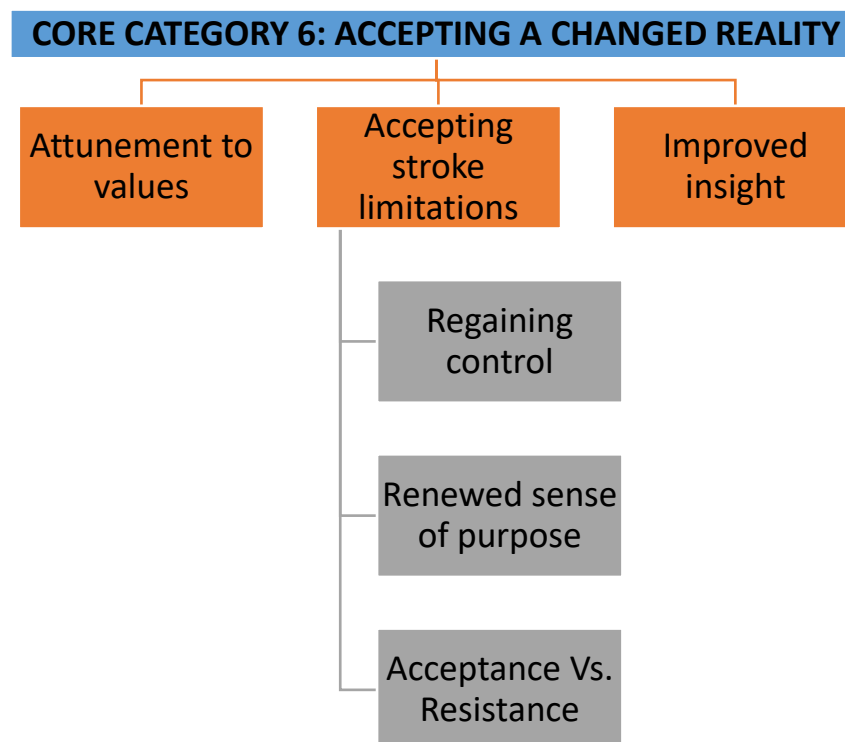


Figure A.6

CORE CATEGORY 6: ACCEPTING A CHANGED REALITY



Appendix N

Email Response from Dr. Stephen Hayes

Dear Neil,

I finally went through the slides in presentation mode and they are really nice.
I like them a LOT. (With your permission can I borrow some for workshops?
I will credit you of course)

The language of your blurb looks right on to my eyes ... in actually expressing my feelings toward this project and your work:

I welcome the fact that Neil Frude's "ACTivate Your Life" course will bring many of the key ideas of ACT, and many effective strategies for helping people to live with their emotional and physical pain, to a wide audience in Wales and beyond. I am very pleased that there is such enthusiasm for this approach, that the course will be delivered widely and that the effects will be carefully evaluated

You can list my affiliation as below or edit it down. Sometimes for things like this people also add "Co-developer of Acceptance and Commitment Therapy" or more specific things (e.g., author of *Get Out of Your Mind and Into Your Life*)

Feel free to do what works best in these areas

Please do send me the rest of the course as it is worked out!

Best of luck with the project

- S

Steven C. Hayes
Foundation Professor and Director of Clinical Training
Department of Psychology
University of Nevada










"Love isn't everything, it's the only thing"

hayes@unr.edu or stevenchayes@gmail.com





Fax: (775) 784-1126
Psych Department: (775) 784-6828
Home (use sparingly): (775) 746-3121
Cell (even more so): (775) 848-0689

Appendix O Example of Coded Transcripts

B.1 Example Extract 1 (Mark)

	I: Ok, so my next question, is what if anything did you learn from attending the group?	
Judging the mind.	C: I learnt that the mind is an absolute buggar. I learnt that it has so	 becky large Understanding the mind.
Identifying the persuasiveness of the mind.	much sway over you and although it's your mind, and you would think actually that because it's your mind that if you like, the subconscious	 becky large Understanding the mind.
Identifying limits of control.	part should have no sway on how you consciously think, but actually it's a complete flip because the subconscious just drives everything.	
Recognising power of the mind.	When those little doors open and the things you are scared about come whittling out, it's so powerful and unless you know how to plug it or	 becky large Learning to train the mind.
Wanting to train the mind	deal with it, it can overtake your complete mind-set. You know, like now I walk around and if someone was to ask me what was I thinking	 becky large Being present.
Being in the present moment.	I'd probably say nothing, I'm not thinking anything. I'm just enjoying the moment. there's nothing going through my mind at all. Um,	
Describing a busy mind.	whereas before everything was going through my mind - you can't do this because of this, you can't do that because of that. And now it's like,	
Noticing a shift in the "busyness" of the mind.	you can't do that but the other bit of me says well I am going to do it, so if you don't like it shut up because I'm going to do it. Then if something happens, you can tell me 'I told you so'.	 becky large Challenging own self-doubt; confronting fears.
Describing a determination/focus.		
Describing freedom from a restrictive mind.	I: So, it's about overriding some of those thoughts?	
	C: A little bit like that yeah. These thoughts would have definitely	 becky large Awareness of power of thoughts.
Recognising change pre- and post- group.	stopped me doing things before, um really had a big sway on my everything. So, I think it was the second session when we were talking about how powerful the subconscious bit was, and what I love the best was that, it goes in one ear and comes out the other ear, so just let the	 becky large Defusing thoughts. Being Mindful.
Reducing battle with thoughts.	thoughts flow. And it's quite natural to have good thoughts, bad thoughts... Whereas if I had bad thoughts before I'd have been like	 becky large Normalising thoughts.
Normalising types of thoughts.	'ooh, I might burn in hell for this' or 'if gods watching.....' But, they are quite normal and they just flow, they just flow out. I don't hang on to	
Describing past reactions to 'bad' thoughts.	them.	 becky large Defusing thoughts.
Unhooking from thoughts.		

B.2 Example Extract 2 (Abigail)

	I: What if anything did you learn from the group?	
Realising life continues after stroke. Reducing struggle with self. Accepting limitations. Learning to accept self-identity has changed.	C: The fact really that there is life after a stroke. You know, that you don't need to beat yourself up, that there are going to be limitations to what you can do, but those limitations are fine. You've got to come to accept the fact that you aren't the same person you were before, doesn't mean to say you are a lesser person, um but just understand where your limits are and what you can and can't do now. And accept them, accept you don't have to beat yourself up about it you know, and that's the one thing I did I felt very guilty and you know, felt I can't do that I've got to ask someone. And the feeling of failure in having to ask for help, I was a very independent person before and would always do things for myself, and will still try to do things for myself. But I haven't got to feel bad if I can't do it, you know I can say to someone "well, I need your help". That's something I took away from the group, you know you aren't a failure just because you've got to ask for help.	 becky large Improved acceptance of stroke. Developing self-compassion
Recognising boundaries of limitations.		
Feeling failure when depending on others. Loss of independence. Fighting to regain independence.		 becky large Maintaining independence -> having purpose.
Reducing struggle with emotions if unable to do something. Being more open to receiving help/support. Identifying change in perception; no longer equating failure with asking for help.		 becky large Taking a different perspective.
Connecting with group material. Evaluating material as relevant and relatable. Drawing similarities between group material and lived events.	Some of the things we covered, I couldn't help but sit in the group and smile, because I was thinking "gosh, that's so me". The things that they covered were spot on, you know they targeted the areas that apply to lots of people. It was just the fact that you could completely relate to it. I was thinking 'I've done that so many times' when I've put the coffee jar back because I couldn't take the lid off, so it's easier just to lift the lid up off the tea.	 becky large Connecting to group material.

B.3 Example Extract 3 (Charles)









Acknowledging passive group approach.	C: Yeah good, I didn't talk to many people because we'd just go in and do the course but I used to go to the stroke group in XXX and talk about our strokes and that was very good.	 becky large Critiquing passive approach.
Describing minimal interaction. Valuing shared experiences. Comparing groups; less personal.	I: so there was less of that in this group by the sounds of things. C: yeah definitely. I don't think there was a lot of interaction and describing each other's situations which I would have found helpful. It wasn't go personal as the stroke group I attended.	 becky large Requesting interaction.
Reading through hand-outs.	I can't really remember..... I know at the time I found it informative, definitely, but I just can't remember. I know we were given handouts at the time and I looked through those, but I've not looked at them for a while...[long pause]...I'm sorry, I really can't remember anything.	 becky large Making comparisons to other support groups.
Taking ideas on but not applying. Making no change to life.	I: That's ok, don't worry. One of my questions was about what were the barriers to learning new things. It sounds like at that time you were able to take ideas and concepts on board, but perhaps due to the difficulties you've experienced since the stroke does that make it harder to put those ideas in place? C: Yeah, I took the ideas on board but I haven't really applied them. I haven't made any changes to my life since attending I don't think.	
Making change.	I: Ok, so the ideas were informative, but.....	
Motivating self to make positive change.	C: I know that I have, um, started to go to the gym. I um, used to play rugby a lot before, but then I stopped and obviously put loads of weight on. So I've started going to the gym... that's a mind thing you know. I need to get myself motivated to go up there. I've never really been a physical person but I go twice a week now, get a sweat on you know.	 becky large Making life adjustments.

Figure B.4 Example Extract 4 (Liam)

Removing feelings of guilt. Identifying uncontrollability of the mind. Finding alternative strategies to manage the mind. Increased awareness	I think for me the first one [first session] when they talked about the mind took some of the guilt away. I thought well you can't control it [the mind], you can design different strategies but definitely...I think it was something I knew but I hadn't thought of. Um, so I found that helpful. Again, not just for me but for other people I have spoken to, there's a guilt to having a stroke [laughs] and how it affects others, you can't help it.	 becky large Viewing knowledge as power Dropping control
Identifying usefulness of metaphors.	The passengers on the bus exercise was useful, and one thing that does stick out in my mind [laughs] because I was doing it on my motorbike, was saying words you don't like. It must have been the week I went on my own, I was going up the motorway on my bike and shouting things into my crash helmet. Repeating it you know, and there was one	 becky large Distancing self from Thoughts Reappraising the power of thoughts
Getting distance from thoughts.	element where you say a sentence but you'd say it slowly, or sing it. It took you away from the thought. The day I remember doing it on the motorbike, I think the word was "stroke" because it was pissing me off for some reason.	
Practicing exercises.	We were also given a [mindfulness] CD but they only played part of it,	 becky large Practicing skills
Evaluating mindfulness tasks as helpful.	but I try to use it every night. I find it very helpful if I can remember to do it. You know, sometimes things go wrong or something bad has	
Forgetting to use mindfulness when faced with adversity.	happened and you don't think about using it until afterwards, and I think I wish I had done it, or wish I could think about it when I'm out.	
Wanting to override automatic reactions.	I: Ok, so you've mentioned about learning some things from the group, largely about the role of acceptance in your recovery, so with regards to that what helped you understand and apply those ideas?	
Learning to unhook from what the mind says. Evaluating grp as covering large quantity of information. Not overthinking.	C: Um, I think part of it was the mind thing, because I don't know.... I might think "is that bloody true" and it probably isn't. I don't have to listen to my mind, so that helps. Obviously talking to others outside of the course. I'd forgotten how much was involved in the group....It's trying not to overthink things.	 becky large Identifying choice in how to proceed Benefitting from talking to others.

Appendix P Reflective Journal Extract

Extracts

August 2015

Met with Reg today to discuss the potential of doing a research project with him in stroke. He's got a couple of ideas that could be launched - think this could be a really good piece of work, with impact. Sounds like an ACT group for stroke survivors might be the way forward for this project – really glad to see how enthused he is by this idea, must mean it's something worth pursuing. And actually, as I think about it, I think that's something I really want with this project is a supervisor who is committed and engaged throughout the whole process.

I'm feeling really excited about this. I had decided before today that I wanted to complete a project in a physical health setting but hadn't decided whether to focus on adults or paediatrics. I'm guessing the ethics process might be slightly more straight-forward with adults, given my knowledge and experience with ethic committees from the past.

I don't know much about ACT though... I hope that doesn't matter... actually it could be a good learning opportunity for me. From the little I do know, I think this could definitely have potential in supporting stroke survivors. In fact, it's frustrating something like this didn't exist when I was on my placement at the Stroke Unit, this could have worked wonders with some of my old patients. Lots to go away and think about now.....

August/September 2015

Met with Reg again... think this project area is a GO-ER, although I've just found out that one of the other trainees is doing the effectiveness study Reg advertised. DRAT! This means if I continue down this route I'm going to have to do a qualitative project alongside [trainee]. I'm not sure how I feel about this – in fact, I'm quite anxious about it. Will I be able to do a good qualitative project? I've not done qualitative research before will this go against me? I have so many thoughts going round in my head now – I'm trying to balance this out with the fact I'd get a research project in an area that interests me. But, I also need to feel comfortable with the method process don't I? There is so little time left before I need to make a final decision – may be it will be good to branch out from my comfort zone?

September 2015

I decided, against my better judgement, to go for the qualitative project. Eeek! Fingers-crossed this works out ok.

October 2015

Met with Reg and Neil today to formalise the idea for my research project. I'm feeling slightly better about the idea of qualitative research now and am looking forward to getting going with the ethics process. [Trainee] and I are going to do the application form together as a two-phase study. Having done ethics forms before and knowing how long and arduous they can be, it will be nice to share this experience together and to support each other with it. Sounds like the groups are intended for March 2016 though; means it's a bit of a rush to get the ethics process sorted.

February 2016

Yay! After many, many amendments both for the REC and the individual R&D departments for the UHBs we finally have ethics approval! I can't believe it... that was close; I was really concerned we might need to delay the start of the group so that we can ensure enough numbers for our study.

March 2016

Trying to get my head around Grounded Theory. I chose this method as it seems to relate best to my research question, but I'm struggling to understand Charmaz's book – it's so floundery and long-winded. I'm having to read chapters three times over – this is ridiculous! Is this what qualitative researchers are like? My anxiety about doing a qualitative project has shot up again, I'm not sure I'm cut out for this.

April/May 2016

I conducted my first interview today. I was both nervous and excited to see what this interview might reveal. He was lovely and very chatty, although my initial assumptions about what might come up in the interview weren't supported. He didn't seem to offer much content about the group material, instead he seemed to perseverate on issues with the group format (i.e. it being teaching based rather than a 'therapy' group) and the venue layout. That's not to detract from what he was saying; group factors were obviously something he felt were very important and it seems this may have been dictated by his expectations and past support groups he has attended.

I guess it made me wonder whether this is something all stroke survivors will comment on and whether I will get enough richness in my data to develop a theory or framework (am I jumping too far ahead after just one interview??), or whether my questions aren't structured very well. I guess this is something I will need to keep in mind. The interview questions evolve as part of grounded theory anyway so I guess I'll just have to see whether these interviews take me. Note to self, withhold those assumptions!

May 2016

Wow, that interview was hard. I've just met a young gentleman not much older than me – he has a young family, is fit and healthy, and this has understandably knocked him for six. It felt really hard to listen to him talk about the challenges he faced during the acute stroke phase, but I was inspired by his resilience, determination and drive to make changes for the future. I was aware throughout the interview that I was drawn into certain processes, and noticed myself feeling sad, frustrated, and hopeful at times, alongside a strong sense of injustice. This is something I need to reflect more on in future interviews; it's not just the content that I need to be paying attention to but other processes going on in the room too; this might open up new avenues for questioning.

June 2016

I am transcribing and analysing the data as I go along, but I'm learning how laborious this process can be. Some transcripts are taking me 7 hours to type up... I have thought about hiring an external party but I want to stay as close to my data as possible; unfortunately, this just makes it harder (especially with the demands of my new, and very, very, busy clinical placement). That said, I am enjoying

reflecting back on the interviews when I come to type them up, and am starting to see common themes and trends emerging from the data. My codes are developing in light of this, which are producing some really interesting results – information re: group practicalities, the material, comparison processes, and relevance of certain ACT principles. The one thing I am unsure about is how far to take the coding process, how far do I go beyond the participants words to make meaning out of their narratives, without leading or misrepresenting the data? Vic has recently joined my supervisory team with her expertise in grounded theory – I think I might need to consult with her more on this.

August 2016

I keep going over my analysis and interpretation, so it was good to get a different perspective on it again today. Vic and I have met a couple of times now to discuss the codes I am developing, and to make sure they are process-focused and grounded in the data as much as possible. We've talked about the more abstract concepts and categories that are coming through the data, to support the development of a framework. Struggles with residual disabilities and needing to accept current limitations (but finding this challenging), appears to be the main dilemma or concern coming out of survivors narratives.

Appendix Q Criteria for Research Journal



JOURNAL OF CONTEXTUAL BEHAVIORAL SCIENCE

AUTHOR INFORMATION PACK

TABLE OF CONTENTS

• Description	p.1
• Abstracting and Indexing	p.2
• Editorial Board	p.2
• Guide for Authors	p.4



ISSN: 2212-1447

DESCRIPTION

The *Journal of Contextual Behavioral Science* is the official journal of the *Association for Contextual Behavioral Science (ACBS)*.

Contextual Behavioral Science is a **systematic and pragmatic approach** to the understanding of behavior, the solution of human problems, and the promotion of human growth and development. Contextual Behavioral Science uses **functional principles and theories** to analyze and modify action embedded in its historical and situational context. The goal is to **predict and influence behavior**, with precision, scope, and depth, across all behavioral domains and all levels of analysis, so as to help create a behavioral science that is more adequate to the challenge of the human condition.

Contextual behavioral science is a strategic approach to the analysis of human behavior that proposes the need for a **multi-level** (e.g. social factors, neurological factors, behavioral factors) and **multi-method** (e.g., time series analyses, cross-sectional, experimental) exploration of **contextual and manipulable** variables relevant to the prediction and influence of human behavior.

The journal considers papers relevant to a contextual behavioral approach including: Empirical studies (without topical restriction - e.g., clinical psychology, psychopathology, education, organizational psychology, etc.) Brief reports on preliminary, but provocative findings Reviews (systematic reviews and meta-analyses are preferred) and Conceptual and philosophical papers on contextual behavioral science

We are particularly interested in: Papers emphasizing the study of core **behavioral processes** that are relevant to a **broad range of human problems** Papers **bridging different approaches** (e.g., connecting behavioral approaches with cognitive views; or neurocognitive psychology; or evolutionary science) Papers that **challenge** a contextual behavioral science approach from an informed perspective

The journal welcomes papers written by researchers, practitioners, and theoreticians from different intellectual traditions. What is distinctive is not a narrowly defined theory or set of applied methods but whether the methodology, conceptualization, or strategy employed is relevant to a contextual behavioral approach.

Special Issues

GUIDE FOR AUTHORS

Types of article

All manuscripts must clearly and explicitly be of relevance to CBS. You may find the JCBS article "Contextual Behavioral Science: creating a science more adequate to the challenge of the human condition" helpful in assessing whether your manuscript is likely to be of interest to readers of this journal.

Articles should fall into one of seven categories:

1. Empirical research (up to 6000 words)
2. Brief empirical reports (up to 3000 words)
3. Review articles (up to 10,000 words)
4. Conceptual articles (up to 6000 words)
5. In practice (up to 3000 words)
6. Practical innovations (up to 3000 words)
7. Professional interest briefs (up to 3000 words)

Word limits exclude references, tables and figures but include the abstract

1. Empirical research. JCBS welcomes manuscripts across a breadth of domains from basic behavioral science to clinical trials. Research concerning the measurement and testing of process of change is particularly welcome. Potential methodologies include but are not limited to: randomized controlled trials, single case experimental designs, cross-sectional and prospective cohort studies, mixed-methods designs, small scale analog studies. Papers reporting null findings are also welcome if their methodology is sound and their power sufficient. Authors of such papers will need to emphasize the implications of their findings for future research and practice.

2. Brief empirical reports. Manuscripts in this section may report preliminary, provocative or replicated results. Empirically sound methodology and adequate power remain important considerations.

3. Review articles. Manuscripts reviewing a wide range of topics are encouraged as long as their content is directly relevant to CBS. Systematic reviews and meta-analyses are particularly welcome. Authors are advised to consult relevant MARS (<http://www.apa.org/pubs/authors/jars.pdf>) and PRISMA resources (<http://www.prisma-statement.org/>) when preparing such manuscripts.

4. Conceptual articles. Manuscripts in this section should address conceptual or theoretical issues relevant to CBS. This may include papers that discuss relevant philosophical assumptions and traditions, or conceptual papers which explore aspects of or inconsistencies in contextual behavioral theory and science.

5. In practice. Manuscripts in this section are designed to make CBS useful to practitioners from a wide variety of areas. Manuscripts must be written in an accessible style and should be easily understood by practitioners who are not experts in research or basic behavioral science. Manuscripts should provide both clear insights for new practitioners as well as stating the questions that remain to be answered by future research.

6. Practical innovations. Manuscripts in this section seek to apply the findings and applications of CBS to under-studied, under-served or novel areas. The scope of these manuscripts is limited only by the journal's broad mission: creating a science more adequate to the challenge of the human condition.

7. Professional interest briefs. Manuscripts in this section highlight professional issues of relevance to those working in the field of CBS. Examples include manuscripts related to training and supervision, assessment methods in professional settings or opinions on contemporary issues.

The Journal welcomes suggestions for Special Issues. Proposals for a themed Special Issue should be sent to the Editor-in-Chief, Emily Sandoz at emilysandoz@louisiana.edu, and should include suggested Executive, Advisory or Guest Editors, a proposed call-for-papers, 6-10 provisional authors and topics (specific titles or general areas), a proposed timeline for submission, peer-reviewing, revision and publication. All manuscripts in a special issue will be subject to the normal process of peer-review.

To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

Article structure

Subdivision - unnumbered sections

Divide your article into clearly defined sections. Each subsection is given a brief heading. Each heading should appear on its own separate line. Subsections should be used as much as possible when cross-referencing text: refer to the subsection by heading as opposed to simply 'the text'.

Introduction

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

Material and methods

Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

Theory/calculation

A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.

Results

Results should be clear and concise.

Discussion

This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

Conclusions

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

Essential title page information

- **Title.** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
- **Author names and affiliations.** Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
- **Corresponding author.** Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.**
- **Present/permanent address.** If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Abstract

A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

Graphical abstract

Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. You can view [Example Graphical Abstracts](#) on our Information site.

Authors can make use of Elsevier's Illustration and Enhancement service to ensure the best presentation of their images and in accordance with all technical requirements: [Illustration Service](#).

Highlights

Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). You can view [example Highlights](#) on our Information site.

Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

Abbreviations

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

Formatting of funding sources

List funding sources in this standard way to facilitate compliance to funder's requirements:

Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

If no funding has been provided for the research, please include the following sentence:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Math formulae

Please submit math equations as editable text and not as images. Present simple formulae in line with normal text where possible and use the solidus (/) instead of a horizontal line for small fractional terms, e.g., X/Y. In principle, variables are to be presented in italics. Powers of e are often more conveniently denoted by exp. Number consecutively any equations that have to be displayed separately from the text (if referred to explicitly in the text).

Footnotes

Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

References

Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

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11

Web references

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

Data references

This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your Reference List. Data references should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

References in a special issue

Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

Reference management software

Most Elsevier journals have their reference template available in many of the most popular reference management software products. These include all products that support Citation Style Language styles, such as Mendeley and Zotero, as well as EndNote. Using the word processor plug-ins from these products, authors only need to select the appropriate journal template when preparing their article, after which citations and bibliographies will be automatically formatted in the journal's style. If no template is yet available for this journal, please follow the format of the sample references and citations as shown in this Guide.

Users of Mendeley Desktop can easily install the reference style for this journal by clicking the following link:

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When preparing your manuscript, you will then be able to select this style using the Mendeley plug-ins for Microsoft Word or LibreOffice.

Reference style

Text: Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 978-1-4338-0561-5, copies of which may be ordered online or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK.

List: references should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

Examples:

Reference to a journal publication:

Van der Geer, J., Hanraads, J. A. J., & Lupton, R. A. (2010). The art of writing a scientific article. *Journal of Scientific Communications*, 163, 51–59.

Reference to a book:

Appendix R Debrief Form

Debrief Letter

Dear Sir/Madam,

Thank you for participating in this research, it is greatly appreciated.

The aim of this study was to explore whether the Acceptance and Commitment Therapy (ACT) group was helpful for stroke survivors and their carers. We hope the feedback you provided will give some insight into some of the reasons why you may or may not have experienced benefit, which will inform future groups for stroke survivors and carers.

If you wish to have information about the results of the study please contact XXXXXXXXX (see details below) and she will send you a summary of the results as soon as they are available.

Please be assured that the data you provided will be kept strictly anonymous. If you have any concerns about the research, please feel free to contact the researchers. If you remain unhappy and wish to complain formally, you can do this by contacting XXXXXXXX on XXXXX XXXXXX or XXXXXXXXXXXXXXXX

Yours Faithfully,

XXXXXXXXXX

Trainee Clinical Psychologist

Supervised By: XXXXXXXXXXXXXXXX

Consultant Clinical Psychologist

Researcher:

[CONTACT DETAILS]

Academic Supervisor:

[CONTACT DETAILS]