Acceptance and Commitment Therapy for Chronic Fatigue Syndrome: a case series approach

By
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Submitted in partial fulfilment of the requirements of the Doctorate of Clinical Psychology
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Portfolio abstract

Background

Acceptance is understood to be an important element in coping with chronic illnesses, linked to positive outcomes such as reduced symptoms and greater quality of life. Chronic Fatigue Syndrome (CFS) is a disabling syndrome that is associated with a poor reported quality of life even in comparison to other chronic conditions. Given that Acceptance and Commitment Therapy (ACT) is a psychotherapeutic model aimed at increasing psychological flexibility, with an emphasis on experiential acceptance and the pursuit of values, this approach holds potential for living and coping with CFS.

Methods

This study used a mixed method multiple single case design to explore the effects of a six week self-help ACT intervention with six participants with CFS.

Results

Significant increases in ‘engaged response style’ was replicated in four out of six participants and maintained at follow up, with the qualitative data adding further validity to the importance of the values component of the intervention. Low initial acceptance scores improved in four participants but were not maintained. Overall measures of psychological flexibility indicated improvements maintained at follow up for three participants. All participants wearing the activity monitor showed increased physical activity post-intervention, three of which maintained this at follow up. Five participants reported less symptoms and disability, which was maintained for three participants. The implicit measure indicated that underlying beliefs remained stable.

Conclusion

This study was largely exploratory but it seems that this intervention might be of benefit to some individuals with CFS, particularly in the promotion and pursuit of individual values. This study adds support to the role of acceptance in CFS however in this format at least it seems that any benefits from the intervention are difficult to maintain. Although improvements in overall psychological flexibility were replicated in
three out of six participants, this prompts discussion about the ineffectiveness of the intervention for other participants.
Statement of Contribution

In all parts of this thesis the majority of the responsibility concerned with searching and reviewing the literature, designing the projects, recruiting participants, collecting and analysing data, and writing up findings lay with the Trainee Clinical Psychologist.

Advice was given throughout on many aspects by Dr David Dawson and Dr Nima Moghaddam, research tutors at the University of Lincoln. Dr Mark Gresswell and other tutors at the University contributed to the conceptualisation and refinement of the project in its early stages. Fellow trainees Joe Priestley and Mary Jinks had similar project designs and we worked closely together to develop the project, assisting with the change interviews and developing means of presenting the results, such as the figure depicting the procedure.

Dr Anne Abey and others in the Physical Health Psychology Team contributed by providing extensive clinical knowledge and specialist experience, in supporting my work within the service and also aiding in the recruitment of participants.
Journal Paper

An Acceptance and Commitment Therapy (ACT) intervention for Chronic Fatigue Syndrome (CFS): A case series approach

*ACT for CFS*

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Abstract

Objective

Acceptance is an important element in coping with chronic illnesses, linked to positive outcomes such as reduced symptoms and greater quality of life. Chronic Fatigue Syndrome (CFS) is a disabling syndrome associated with a poor reported quality of life. Given that Acceptance and Commitment Therapy (ACT) is a psychotherapeutic model aimed at increasing psychological flexibility, emphasising experiential acceptance and the pursuit of values, this approach holds potential for living and coping with CFS.

Methods

This study used a mixed-methods multiple single-case design to explore the effects of a six week self-help ACT intervention for six participants with CFS.

Results

Significant increases in 'engaged response style' was replicated and maintained in four participants, with qualitative data adding further validity to the importance of the values component of the intervention. Low initial acceptance scores improved in four participants but were not maintained. Overall measures of psychological flexibility indicated improvements maintained at follow up for three participants. All participants wearing the activity monitor showed increased physical activity post-intervention, three of which maintained this at follow up.

Conclusion

This study was largely exploratory but it seems that this intervention might be of benefit to some individuals with CFS, particularly in the promotion and pursuit of individual values. This study adds support to the role of acceptance in CFS however in this format at least it seems that any benefits from the intervention are difficult to maintain. Although improvements in overall psychological flexibility were replicated in three participants, this prompts discussion about the ineffectiveness of the intervention for the other participants.
Keywords

Acceptance and Commitment Therapy, Chronic Fatigue Syndrome, case series, psychological flexibility, values
Introduction

Chronic Fatigue Syndrome

Chronic Fatigue Syndrome (CFS) is not well understood medically or psychologically (Wessely, 2001), with an uncomfortable association with somatoform disorders. Diagnostic systems characterise CFS by medically unexplained fatigue alongside a range of neurological and rheumatologic symptoms, persisting for at least six months (Fukuda et al., 1994). This syndrome is understood to be chronic and disabling, with lower reported quality of life than other chronic conditions (Anderson & Ferrans, 1997); there is a clear need to consider how positive outcomes can be achieved with this population. This would have both individual and societal impact in terms of improving effectiveness of care and service provision, and reducing the broader impact of the disability.

Psychosocial factors

Research into aetiology is ongoing and an important effort to further our understanding of this syndrome. There is also an understanding that a range of psychosocial factors may play a part in maintaining the experience, and should therefore be considered targets for intervention. For example, high levels of a personality factor described as ‘maladaptive perfectionism' have been noted in this population, with conflict between high standards for self and fatigue thought to enhance symptoms and distress (Brooks, Rimes, & Chalder, 2011). Cognitive Behavioural Therapy (CBT) models of CFS suggest that unhelpful beliefs and thinking patterns in response to initial symptom experience may lead to a reduction in activity, which in turn exacerbates symptoms, creating a ‘vicious circle' of disability; similarly, previous research has suggested that individuals often use avoidance-based coping strategies in an attempt to manage their condition, which can in turn lead to increased disability (Heins, Knoop, Burk, & Bleijenberg, 2013). CBT interventions seek to target and adapt underlying beliefs that are thought to be functionally linked to avoidance-based coping and associated physical deconditioning processes. CBT and Graded Exercise Therapy (GET), focused more

1 For a more detailed review of CFS please see Extended Introduction, CFS: Diagnosis and Prevalence
2 For more information on current models of CFS, please see Extended Introduction, CFS: Aetiology
3 Psychosocial factors are explored further in Extended Introduction, CFS: Psychosocial Factors
specifically on increasing physical activity, are evidenced based recommended interventions (National Institute of Clinical Excellence (NICE), 2007; White et al., 2011), with recent research indicating that beneficial effects can be maintained in the longer term (Sharpe et al., 2015). Despite this promising research, these findings are controversial and have received significant criticism from the CFS community: they report methodological concerns with the research as well as the implications for understanding CFS within these models, concerned that treatments trivialise the experience (Shepherd, 2015; Tuller, 2015). Research into alternative interventions remains lacking (McCracken & Gutiérrez-Martínez, 2011).

Emerging findings from a range of studies suggests that ‘acceptance’ is a key process in living well with chronic illness. Acceptance does not equate to passive resignation or submission, but instead refers to an active psychological strategy aiming to disrupt the negative cycle between avoidance and reduced quality of life. As such it is commonly defined as willingness to live with illness without reactance, disapproval or attempts to reduce or avoid it (Bogaerts et al., 2007); this is opposed to attempts to control the uncontrollable (Brooks, Rimes & Chalder, 2011). Whilst this conceptualisation is compatible with an understanding of psychosocial factors as perpetuating distress within CFS, it offers an broader intervention strategy to that suggested by CBT models, not assuming that change can be achieved by directly challenging thoughts – as such, it may address some of the concerns with CBT models highlighted above.

Acceptance has been linked with positive physical and psychosocial outcomes, including fewer symptoms, lower levels of distress, lower perceived severity of illness and higher reported quality of life (Rankin & Holttum, 2003). Significant findings to this effect have been found in chronic pain patients, as well as emerging positive results with other patient groups including cancer (Feros, Lane, Ciarrochi, & Blackledge, 2013), epilepsy (Lundgren, Dahl, & Hayes, 2008) and diabetes (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007). Amongst the limited number of studies that have examined acceptance amongst individuals with CFS, results were in line with findings from other populations: lower acceptance was associated with higher

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4 For more information on current interventions and further exploration of the criticisms of these, please see Extended Introduction: CFS, Intervention.
fatigue and impaired physical functioning (Brooks, Rimes & Chalder, 2011), whilst increased acceptance has been related to better psychological well-being and decreased fatigue (Van Damme, Crombez, Van Houdenhove, Mariman, & Michielsen, 2006).

Considering the findings from other physical health populations, as well as the issues associated with currently recommended treatments for CFS, the potential of acceptance based approaches warrants further examination.

**Acceptance and Commitment Therapy (ACT)**

ACT is a third wave psychotherapeutic approach, with the primary aim of facilitating behavioural change in line with individual values, by increasing psychological flexibility. In contrast to predominant therapeutic techniques aimed at cognitive restructuring or changing the content of thoughts, ACT suggests changing the client’s perspective regarding the value and power of thoughts; flexibility is fostered in order to broaden the behavioural repertoire, so that the focus is not on avoiding thoughts or aversive experiences but on engaging in meaningful, valued behaviour. ACT interventions aim not for clients to be free of symptoms, but to allow them to behave in a valued way in spite of them.

Developing literature suggested six core processes within the overarching concept of psychological flexibility: acceptance, present moment awareness, cognitive defusion, self-as context, values and committed action (Hayes, Strosahl, Bunting, Twohig & Wilson, 2004). There are a number of questionnaires that have been designed to measure these contributing processes, a selection of which were chosen for this study and are described in more detail in the ‘Methods’ section below.

In this context, acceptance is seen as the opposite of experiential avoidance, whereby individuals employ strategies to control or minimise aversive experiences. This can be functional in the short term in specific contexts but becomes problematic when it interferes with engagement in rewarding behaviours and goal attainment (Eifert et al., 2009); there is a body of literature documenting experiential avoidance as a maladaptive strategy that ultimately increases the frequency and saliency of

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5 ‘Acceptance’ is discussed further in the Extended Introduction: Acceptance
avoided experiences (Wegner, 1994). Experiential avoidance is correlated highly with distress and psychopathology (Hayes, Wilson, Gifford, Follette & Strosahl, 1996; Kashdan & Kane, 2011).

Maintaining contact with the present moment and developing the ‘self-as-context’ are concepts that link to the practice of mindfulness, which is increasingly linked with improved well-being in a number of domains (Academic Mindfulness Interest Group, Melbourne, 2006).

Cognitive fusion is the tendency to get caught up in the content of thoughts, with decreased ability to see alternative options or maintain a sense of self as independent to these (Strosahl, Hayes, Wilson, & Gifford, 2004) – defusion on the other hand can be seen as the ability to distance yourself from private events such as thoughts and emotions, reducing the influence of these on behaviour. This therefore increases the ability to act independently of thoughts which may be unhelpful or discouraging.

Finally, ACT promotes the clarification of values, and commitment to behaviour in ways that are consistent with these valued ends. Values can usefully be understood as ways of responding that give increased access to relatively stable, long term sources of positive reinforcement (Blackledge & Barnes-Holmes, 2009). This aspect of the model differentiates ACT from CBT and mindfulness based interventions.

In summary, by promoting psychological flexibility, including increasing acceptance, ACT aims to foster an active coping strategy as a means to enable people to engage in activities that are personally meaningful to them, with attendant experiences of reward and vitality (Hayes, Strosahl, Bunting, Twohig & Wilson, 2004). As outlined above, this may support better living with chronic conditions including CFS. There is strong research support for the efficacy of ACT with chronic pain (APA Presidential Task Force on Evidence-Based Practice, 2006; Chambless et al., 1998) and a recent meta-analysis concluded that ACT may be as effective as established psychological interventions, potentially with added value in terms of quality of life.
outcomes and processes of change (Davis, Morina, Powers, Smits, & Emmelkamp, 2015). 

ACT appears suited to a range of delivery formats, including self-help (Ljótsson et al., 2014); there is also evidence to suggest that brief interventions of between three and eight weeks can be effective (Nijhof, Bleijenberg, Uiterwaal, Kimpen, & van de Putte, 2012). A number of ACT texts have been developed, including the text used in this study ‘Get out of your mind and into your life’ (Hayes & Smith, 2005).

**Aims**

There were two objectives of this study:

1. To examine effects of an ACT self-help intervention on self-report and behavioural measures of change in people with CFS, specifically in relation to core processes outlined by the model underpinning ACT.
2. To begin to assess whether this intervention might be feasible and acceptable for this population.

This project utilised a multiple single-case design with repeated and comprehensive mixed method measures to begin to identify and understand the change processes involved. This design has been used as means of gaining rich data about a client and in response to some of the disadvantages of other evaluative methodologies, such as Randomised Control Trials, in which individual change processes are likely to be masked by the results of the whole (Elliott, 2002). Using multiple single cases allows the demonstration of replicable mechanisms across cases, addressing concerns of internal validity (Kazdin, 1981). This design was therefore chosen to facilitate a comprehensive exploration of a relatively un-researched area, and to acknowledge contextual factors, considering the noted heterogeneity of CFS.

The study includes self-report measures as well as a behavioural outcome measure; this recognises the importance of functional improvement in evaluating CFS

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6 For more information on this therapeutic model, as well as more specifically application to this population, please see Extended Introduction: Acceptance and Commitment Therapy, and Extended Introduction: ACT and CFS.
7 Please see Extended Introduction: Self help
8 For more information please see Extended Introduction: Purpose of investigation
9 More detailed information regarding the epistemological position and methodological choices made in this study is included in Extended Introduction: Epistemology and Extended Introduction: Methodology.
treatments, is used within the study to overcome limitations associated with self-report and to improve ecological validity.10

We hypothesised that following the ACT intervention measures of psychological flexibility, as well as individual processes within this, would improve in line with the model. Furthermore we hypothesised that this would be reflected in increased physical activity levels11.

Method

This research was approved by the University of Lincoln Research and Ethics Committee, the NHS Trust Ethics Committee and the East Midlands National Research Ethics Service Committee (REC Ref 14/EM/1086)12.

Design

A mixed-method multiple single-case series was implemented. Each individual completed baseline data collection until stable trend-lines were evident in key outcome measures. These individual baselines acted as control periods; intervention then took place across six to seven weeks, with a follow up at three months.

Participants

Six participants were recruited from an established CFS service in the UK via written and verbal advertisement from the primary researcher and multi-disciplinary team members working within the service13. Written informed consent was obtained from each participant prior to the study commencing.

Five participants were female, one was male; ages ranged between 19 years and 62 years (mean = 38.5 years, SD 15.22). CFS is diagnosed more frequently in women, so the gender imbalance in this sample is reflective of that documented within the broader CFS population (Afari & Buchwald, 2003). Participants were recruited after

10 We also included an implicit measure to examine secondary interests relating to implicit change at the individual level; this is discussed in more detail throughout the extended paper, beginning with Extended Introduction: Implicit responses.
11 A secondary hypothesis related to the implicit measure would be that this would indicate a move towards more flexible responding; for more information please see Extended Method, Measures: Implicit measure.
12 More detailed outline of the ethical considerations within this study are included in Extended Method: Ethics
13 Recruitment is outlined further in the extended paper, which also includes recruitment materials within the appendices.
having received the standard service treatment of a 10 week group programme, all within the last 12 months: this programme was based on psychoeducation, socialising participants to a neurobiological model whereby different lifestyle factors are individually explored, then conceptualised as part of a ‘jigsaw’ of CFS. The reported duration of CFS symptoms varied between participants (2-29 years) as did time since diagnosis (1-27 years).

**Inclusion criteria**

Participants were required to be aged 18 years and above, to have received treatment as normal, and to be able to give informed consent throughout the research in order to take part.  

**Measures**

**Quantitative Measures.**

A comprehensive battery of standardised self-report measures was implemented once a week (see below); four ACT process measures and two CFS measures were compiled into one online questionnaire totalling 79 items. A condensed battery of these measures was developed to be administered a further two times each week, in consideration of participant fatigue and burden. For this condensed questionnaire, key items were selected from the full ACT process measures based on the highest factor loadings (indicating construct validity), and through expert consensus between three Clinical Psychologist ACT practitioners (indicating face/content validity), with further reference to key texts (for example, Hayes, Strosahl & Wilson, 2011). This adapted questionnaire comprised 12 questions.

**ACT process measures.**

*The Philadelphia Mindfulness Scale (PHLMS; (Cardaciotto, Herbert, Forman, Moitra, & Farrow, 2008)*

This questionnaire is designed to measure two ACT processes: acceptance and present moment awareness (mindfulness). In this study another measure focuses on mindfulness (the MAAS: see below) and so the PHLMS was largely chosen to

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14 More information on the recruitment and inclusion of participants can be found in Extended Method: Participants
monitor acceptance. Participants rate 20 items addressing experience with thoughts and emotions on a five point Likert scale (1 = never and 5 = very often), for example:

‘There are aspects of myself I don’t want to think about’

Odd items are summed for the awareness score, and even items are reversed and summed for the acceptance score. Scores can range from 10 to 50 on each scale: higher scores indicate higher levels of the components being measured. The two subscales were not correlated in previous studies, suggesting that they can be examined independently; Cronbach’s alpha was found to be .85 and .81 respectively, suggesting good internal consistency for both (Cardaciotto, Herbert, Forman, Moitra & Farrow, 2008).

This scale has been shown to be able to distinguish between clinical and non-clinical samples, where clinical samples included mixed psychiatric outpatients and student counselling outpatients; clinical samples display lower levels of both components measured (Cardaciotto, Herbert, Forman, Moitra & Farrow, 2008).

*The Cognitive Fusion Questionnaire (CFQ; Gillanders et al., 2014)*.

This is a seven item self-report questionnaire assessing cognitive fusion. Items are rated on a seven point Likert scale (1 = never true and 7 = always true), with higher scores indicating higher cognitive fusion; for example:

“I got so caught up in my thoughts that I was unable to do the things that I most wanted to do”

There is good preliminary evidence of the CFQ’s psychometric properties: one month test-retest reliability was found to be .80; Cronbach’s Alpha ranged between .88 and .93 across five different samples, including a large community sample (.90), a sample of women with MS (.93) and a mixed mental health sample (.88); and elevated levels of fusion have been reliably identified amongst clinical samples, in contrast to nonclinical samples (Gillanders et al., 2014).

*The Mindfulness Attention and Awareness Scale (MAAS: Brown & Ryan, 2003).*
The MAAS is a 15-item self-report inventory designed to measure attention to and awareness of what is occurring in the present moment. Items such as:

“I found myself doing things without paying attention”

are rated on a six point Likert scale (1 = almost always and 6 = almost never), and the mean of these items is calculated to give a score from 1-6, with higher scores indicating greater mindfulness. The MAAS has been found to have good internal consistency, with Cronbach’s alphas of .82 and .87 in clinical and non-clinical samples; clinical samples have been found to report lower levels of mindfulness on this scale, indicating less attention to and awareness of what is occurring in the present moment (Brown & Ryan, 2003).

The Engaged Living Scale (ELS; Trompetter et al, 2013).

Designed to assess an engaged response style, this questionnaire relates to the values and committed action aspect of the ACT model. Participants are asked to rate 16 statements on a five point Likert scale from 1 = not at all to 5 = totally agree, for example:

“I have values that give my life meaning”

Total scores range from between 16 and 80, with higher scores indicating a more engaged response style. The psychometric properties have been evaluated on a clinical sample of chronic pain patients undergoing an online ACT intervention, a sample not dissimilar to those included here: it has been demonstrated to have good internal consistency and construct validity and clinical samples have been found to score less highly on this scale, indicating greater discrepancy between values and behaviour than normative populations (Trompetter et al., 2013).

CFS Measures.

SF-12 Physical Function subscale (Ware Jr, Kosinski, & Keller, 1996).
Participants are asked to measure on a three point Likert scale (0 = not limited at all, 5 = limited a little and 10 = limited a lot) the extent to which their health limits their ability to participate in 10 activities, for example:

“Lifting or carrying groceries”

Scores can range between 0 and 100, with higher scores indicating higher disability.

The SF-12 is itself a short version of the SF-36, a generic and widely used health-related-Quality of Life measure evaluated for use within general population samples as well as across a number of health diagnoses. It was decided in this study not to include the full SF-12 in order to minimise participant burden and fatigue. For the specialist clinic where this sample was obtained, the mean average at admission to the service is 39.5 (SD 25.0).

*Chalder Fatigue Questionnaire (Chalder et al., 1993)*.

This is an 11 item scale which asks patients to rate their fatigue symptoms on a four point Likert scoring system (0 = less than usual and 3 = much more than usual), for example:

“Do you need to rest more?”

Total scores range between 0 and 33, with a score of 11 indicating no change from usual and higher scores indicating higher levels of fatigue. It has been shown to be able to reliably discriminate between clinical and non-clinical samples. Within the specialist service from which this sample was recruited, the mean average at admission is 27.6 (SD 4.8)\(^{15}\).

**Behavioural Measure.**

Participants wore a ‘Fitbit’ Zip Activity Tracker, a portable bracelet device monitoring physical activity. This information is uploaded to a computer via a USB device and accessed via the Fitbit website. Data were uploaded by the primary researcher with

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\(^{15}\) Psychometric properties of these measures are summarised in Extended Method, Measures.
participants receiving no feedback until completion of the study to limit any confounding effects of self-monitoring\(^\text{16}\).

**Change Interview.**

At the end of the intervention participants took part in a change interview, based on guidelines by Elliot, Slatick & Jones (2001) and Elliot (2002), designed to garner which aspects of the intervention, if any, had promoted change and/or were useful from the participants’ perspectives. The interview was conducted by telephone by an individual external to the research team in order to limit demand characteristics and to encourage open self-reflection. It was recorded and transcribed by the primary researcher\(^\text{17}\).

**Procedure**

**Baseline.**

Baseline measures were completed for a minimum of two weeks: visual analysis was used to determine whether trends were either stable or declining across three data points before the intervention began.

**Intervention.**

Each week, a section of text from the book ‘Get out of your mind and into your life’ (Hayes and Smith, 2005), was sent via email or post to participants. Each section was chosen and ordered by its relation to underlying ACT processes (see Table 1 below); participants did not read the book sequentially\(^\text{18}\). Participants were encouraged to read the material each week and complete the exercises therein. The primary researcher checked comprehension and adherence via a phone call each week.

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\(^{16}\) This measure is discussed further in Extended Method, Measures: Behavioural measure

\(^{17}\) Please see Extended Method, Measures: Change interview

\(^{18}\) Please see Extended Method, Procedure: Intervention
<table>
<thead>
<tr>
<th>Intervention Stage</th>
<th>ACT Process</th>
<th>Chapters</th>
<th>Content</th>
<th>Measures monitoring target process</th>
</tr>
</thead>
</table>
| Overview of ACT (Orientation phase) | N/A | 1/2/3 | • Introduction  
• Human suffering  
• Why language leads to suffering | N/A |
| Week 1 | Willingness (Acceptance) | 4/9/10 | • Avoidance  
• Willingness | PHLMS |
| Week 2 | Cognitive Defusion | 5/6 | • Trouble with thoughts  
• Having a thought vs. buying a thought | CFQ |
| Week 3 | Self as Context | 7 | • Three senses of self | MAAS |
| Week 4 | Present Moment Awareness | 8 | • Mindfulness | MAAS |
| Week 5 | Values | 11/12 | • What are values?  
• Choosing your values | ELS |
| Week 6 | Committed Action | 13 | • Commitment / barriers | ELS |

Table 1: An outline of the intervention, including book chapters read each week, correlating ACT processes targeted, and the measures used to evaluate change in each of these.

Follow up.

All participants agreed to complete the follow up three months following completion of the intervention. The three phases of the study are graphically represented in Figure 1.
Baseline Follow up

**Daily Measures:**
- ACT specific
- CFS specific

**Weekly measure:**
- Psychological Flexibility

**Behavioural Measure:**
- Fitbit

**Qualitative measure:**

**Week:** 0 1 2 3 4 5 6 7 8 \(\ldots\) 20

**Figure 1:** Diagram outlining procedure and measure collection throughout the study. Throughout the baseline and intervention phase participants received an email link to the online questionnaires three times each week - these are marked by an x in the figure. The Fitbit was worn throughout. Post-intervention participants completed the change interview. The complete battery of measures was completed at follow up.

**Analysis**

The condensed questionnaire items were summed to produce an overall score of psychological flexibility. Other questionnaire items were scored according to the original measures (the CFQ was reversed so that higher scores reflect positive attributes as in all other ACT measures).

Quantitative results were analysed using visual analysis procedures informed by Lane and Gast (2014), and through the calculation of reliable and clinically significant change indices (Jacobson & Truax, 1991). These were then considered in conjunction with qualitative data from the change interviews.¹⁹

**Results**

The scores from the condensed questionnaires represented overall psychological flexibility. The data were highly individual for each participant, as can be seen from

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¹⁹ Please see Extended paper, Method: Analysis
two examples included here, with a positive trend noted throughout intervention for participant two, and a negative trend throughout intervention for participant five.\(^{20}\)

\(^{20}\) The other results graphs are depicted in the Extended Results.
Figure 2: Example graphs showing a positive trend (P2) and a negative trend (P5) in overall psychological flexibility during the ACT intervention for CFS, indicated by the solid line. Baseline trends are indicated by the dashed line.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Trend throughout intervention</th>
<th>Data at follow up</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Improving</td>
<td>Improvement not maintained</td>
</tr>
<tr>
<td>2</td>
<td>Improving</td>
<td>Improvement maintained</td>
</tr>
<tr>
<td>3</td>
<td>Stable</td>
<td>Stable</td>
</tr>
<tr>
<td>4</td>
<td>Improving</td>
<td>Improvement maintained</td>
</tr>
<tr>
<td>5</td>
<td>Declining</td>
<td>Decline not maintained</td>
</tr>
<tr>
<td>6</td>
<td>Improving</td>
<td>Improvement maintained</td>
</tr>
</tbody>
</table>

Table 2: A summary of the overall psychological flexibility measures collected from participants twice weekly throughout the intervention.

Overall, psychological flexibility appears to have increased upon introduction of the intervention and maintained at follow up beyond what might have been expected from baseline trends in three of six participants.21

As demonstrated by the graphs below, scores on ACT process measures were also variable.

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21 Further results are reported in Extended Results: Overall psychological flexibility
Figure 3: Scores on key outcome measures pre and post a self-help ACT intervention, and at follow up. Asterisks on the ACT process measures and the Chalder Fatigue Questionnaire indicate change from baseline that was calculated to be clinically significant.
Five participants were below the average score on the ELS at baseline (60.8): four of these showed clinically significant improvements that were maintained at follow up. On the acceptance scale of the PHLMS, five participants were below the normative mean at baseline (30.19) and four were below the clinical mean (24.62). Four participants indicated clinically significant change from baseline to post-intervention; two participants maintained this at follow up.

Participants indicated variable fatigue levels; five participants indicated clinically significant improvement at post-intervention, four of which indicated that this was maintained or further improved at follow up. Levels of daily impairment indicated via the SF-12 subscale indicate varying levels of disability, which appeared to decrease at post intervention in five participants but was not maintained at follow up.

There was an observed increase in recorded physical activity at post-intervention in all five participants; this appeared maintained at follow up in three participants.

In line with guidelines demonstrated in Elliot (2002) data from the change interviews was evaluated with regards to the support it gave for the validity and reliability of the other measures. Overall, participants’ reports appeared to be largely congruent with quantitative measures in all but one participant who spoke about positive changes that were not evident in the process data. Where change was otherwise noted, participants were able to give detailed examples of applying strategies and real life change, including job changes and direct efforts to increase valued activity (physical activities and activities with family), indicating good engagement with and comprehension of the material, adding support to the validity of the results. Three participants attributed important changes directly to the intervention: a further two thought improvements would have happened naturally but this intervention facilitated it more quickly. Half of the participants noted that the timescale was challenging considering the demand of the intervention: two participants had a week mid-intervention where data collection was ongoing but no additional reading was introduced. These difficulties were notably exacerbated by the participant’s cognitive symptoms of CFS including reduced memory, attentional ability and increased mental fatigue. Despite these difficulties, participants spoke about revisiting the text.

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22 Results across each measure are discussed in more detail in Extended Results: Results by measure. Results are also summarised per participant.
in their own time, indicating that they saw some value in it for managing their CFS in the longer term, but that the format of this intervention was difficult – the implications of this are considered further in the discussion. Four participants recommended this text to others with CFS, indicating good acceptability of the content of the intervention.

**Discussion**

We investigated the relationship between a self-help ACT intervention and a number of outcome measures in six participants with CFS. The participants were demographically representative of the service from which they were recruited.

Measures of overall psychological flexibility were complex. We hypothesised that these would increase during the intervention, which was the case in three participants: this is enough to satisfy replicability criteria as suggested in the literature (Kratochwill et al., 2010) allowing some ability to conclude that these processes are demonstrable across cases. However, with only half of the participants improving there are clearly questions remaining about this differential responsiveness and clinical and theoretical implications. Potential explanations might include factors associated with the study design, limitations of measures and individual factors – these are discussed in further detail below.

Within the individual process measures, it was notable that significant, positive change occurred and was maintained in four out of six participants on the Engaged Living Scale. This was further supported by qualitative data, with similar numbers of participants reporting that the values aspect of the intervention was most useful. ACT allows a highly idiographic approach to facilitating behaviour change aligned with personally meaningful activities, which may contrast with a more structured CBT approach; explicit values work is not a focus of either CBT or GET as currently recommended interventions for CFS and so this finding indicates an important area of potentially added value.

Another interesting finding was the increase in physical activity noted in all participants wearing the Fitbit activity monitor. Previous interventions have noted

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23 Change interview responses are summarised in the Extended Results section. Please also refer to this for the results of the implicit measure (Extended Results: IRAP).

24 Please see Extended Results: overall psychological flexibility.
increased activity as a target for intervention: physical activity has beneficial effects on general health and mood (Penedo & Dahn, 2005), and the more specific processes of building up physical strength and resilience are thought to be important for a positive prognosis with CFS (White et al., 2011). Nonetheless interventions specifically targeting this are controversial, with even detrimental effects noted. Increased activity was not an explicit focus of this intervention, and there was a limited dose of intervention in terms of time and format, yet there was a notable increase in physical activity. Within the ACT model the change seen in activity could be understood as increased commitment to valued behaviours, reflecting scores on the ELS. From this perspective an increase in engaged living is a key outcome in its own right, which adds further promise to this approach.

There are some limitations of the Fitbit data – for example, they were necessarily condensed into a weekly average due to variable data collection. The baseline therefore comprises a single measure, limiting the ability to reliably assess change following the introduction of the intervention. Although the role of the activity monitor itself as a mechanism of change is possible, participants did not have access to feedback about the data during the intervention and so the role of reinforcement was minimised, which is thought to be the common change mechanism in other similar devices (Fritz, Huang, Murphy, & Zimmermann, 2014); similarly, the maintenance of change in three participants over three months without the continual presence of the Fitbit indicates that there are other underlying change processes. None of the participants cited the Fitbit as an important mechanism of change.

Replicable clinically significant change was noted on one other ACT process measure, the Acceptance scale of the PHLMS. Participant’s baseline scores were lower than a comparable clinical mean, which is in line with previous literature suggesting that acceptance is an important consideration for this sample (Van Damme et al., 2006) and a key target for intervention. Clinically significant increases in levels of acceptance in four participants are promising but the lack of maintenance perhaps again raises questions about the format of this intervention. Future research

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25 Change on individual ACT process measures is discussed further in the Extended Discussion: ACT process measures
26 Further discussion around this measure and the increase seen in activity is included in the Extended Discussion: Behavioural Measure.
could look to determine whether additional clinician input or a longer time period
could maintain this positive effect.

Change during the intervention in terms of symptom impact on the SF-12 subscale
reflects the pattern of change in acceptance scores: directionality is unclear from the
observed data, although previous data and ACT theory would suggest the primacy of
acceptance - this finding is compatible with previous literature indicating that
increased acceptance can have a positive impact on symptom experience (Van
Damme et al., 2006)27.

Focusing instead on second order change, symptom reduction is not a primary goal
of ACT, although it is commonly noted as a secondary benefit. The overall trend was
one of decreasing fatigue throughout the intervention, largely maintained at follow
up, with a sharp increase in participant five being the exception. Reporting of
disability did not correlate with fatigue, with a trend of reduced disability post-
intervention reverting back to baseline levels at follow up. The change in fatigue
scores mirrors the increase in activity, and although there isn’t a clear pattern across
participants about which preceded the other, it seems likely that they might be
interlinked, with increased activity likely to have a positive effect on other systems
such as sleep, mood and energy (Penedo & Dahn, 2005).

Limitations of the study design include the potential for selection bias as individuals
volunteered themselves, perhaps indicating high levels of motivation. There is little
evidence to suggest that this sample is systemically atypical in comparison to the
wider service sample, however it is not known how individual personality traits might
have had an effect on the complex results. Data from the change interviews
indicated that all participants were actively engaged with the material provided; given
high levels of perfectionism noted in this population and the recruitment procedure, it
is possible that these participants were highly motivated to achieve target outcomes.
Further exploration of individual factors within the context of this therapeutic
approach would be beneficial in facilitating an understanding of who could benefit
most and potential barriers to change.

27 Please see Extended Discussion: Fatigue and symptoms. The implicit measure is also discussed in the
Extended Discussion.
The psychological flexibility measure used in this study was developed from validated questionnaires drawn together in a novel format; the psychometric properties should therefore be further evaluated with regards to the underlying model and the results of this study interpreted with these limitations in mind. Daily full measures would have given a more detailed understanding of individual change processes, however this ideal design would have increased participant burden and have a potentially negative impact on study engagement, particularly in view of feedback suggesting that participants found the applied procedures to be demanding. Also, the less frequent use of measures may have helped to balance any threats to validity resulting from the instrumentation effects of frequent assessment over time.

A strength of the design is its ecological validity, with participants representing the complexity of the clinical picture of CFS, reporting other health concerns and ongoing external events. This also means however that there was less experimental control in the study; although steps were taken to collect detailed information through frequent and mixed measures, ultimately the results gave a multifarious picture, a recognised characteristic of such designs (Elliot, 2002). There remain limits to our ability to explicitly state the particular conditions by which change might occur.

This study was largely exploratory, building upon a body of research suggesting that increased acceptance in chronic health conditions leads to positive psychosocial and physical outcomes. Despite some limitations and a complex picture of results, there are some important implications for further research. ACT might be a more acceptable way of promoting physical activity with an idiographic emphasis on personally meaningful values with this notably heterogeneous participant group. It would be clinically useful to establish whether an adapted format could promote stable increases in acceptance and engaged living over time. A longer follow-up period would be useful to determine whether valued behaviour change was maintained. Finally a more detailed understanding of who would benefit from this intervention could improve client outcomes and service provision.

*Word count: 6,155*

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28 A more detailed discussion of strengths and limitations of this study is included in the Extended Discussion.
Conflict of interest

There is no conflict of interest to declare by the authors.

Role of funding source

The University of Lincoln provided funding support for this research study but had no involvement in the study design, data collection, analysis or interpretation, or in the writing of this report.

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References


Appendix 1: Journal of Contextual Behavioural Science Guidelines

The guidelines for submitting a journal to this paper and an author information pack can be found here:

https://www.elsevier.com/journals/journal-of-contextual-behavioral-science/2212-1447/guide-for-authors
1.1 Chronic Fatigue Syndrome

Diagnosis and prevalence.

Chronic Fatigue Syndrome (CFS) is a controversial syndrome, with no clear medical or diagnostic definition and no comprehensive account of aetiology. Also called Myalgic Encephalopathy or Encephalomyelitis (ME) in the NHS in England and Wales (National Institute of Clinical Excellence (NICE), 2007), and with ongoing debate about an appropriate name for this syndrome (Nicholson, Brown, Jason, Ohanian, & O’Connor, 2016), for the purpose of this study the term CFS will be used, as it is in the specialist service from which the participants were recruited.

Whilst fatigue is the key symptom of this diagnosis, it is distinguished from common experience as chronic and disabling rather than contextual and time-limited (Afari & Buchwald, 2003). The comorbid rheumatologic and/or neuropsychiatric symptoms necessary for a clinical diagnosis can include pain, poor sleep and cognitive difficulties (see Appendix 1 for full diagnostic criteria) (NICE, 2007). Chronic Fatigue Syndrome is a complex diagnosis, a heterogeneous clinical picture that is further complicated by high rates of association with many other chronic physical health conditions, including most commonly Fibromyalgia, Irritable Bowel Syndrome, chronic pain and chemical sensitivities (Aaron et al., 2001). CFS has an estimated population epidemiology of 0.2-0.4 % (NICE, 2007) (National Institute of Clinical Excellence (NICE), 2007), although it is acknowledged that it is very difficult to calculate this given controversies with diagnosis and limited understanding of its presentation. Generally literature reports a preponderance of young, white women with this diagnosis (Afari & Buchwald, 2003).

Following diagnosis, there is a continued recognition that CFS is a heterogeneous syndrome with highly individual pathways, timescales and symptomology that are difficult to predict (ME Association, 2007). Overall levels of disability associated with chronic fatigue syndrome tend to be higher on average than other chronic conditions such as diabetes; it is estimated that between 25% and 50% of people with CFS are in part-time or full time employment or education (ME Association, 2007). A distinction is made between mild, moderate and severe CFS, ranging from those
able to maintain employment and self-care to those severely restricted physically including in their ability to walk and to leave the house: the prognosis for those at the severe end of the spectrum is significantly poorer (ME Association, 2007).

Given the extent of the individual cost of CFS, the economic cost of this diagnosis has also been evaluated: one study estimated that the total three month costs for individuals with chronic fatigue syndrome was £3515, over 90% of which was accounted for by care from family and friends and lost employment: those with more severe symptoms and with more dependants had associated higher costs (McCrone, Darbishire, Ridsdale, & Seed, 2003). An American study estimated between two and seven billion dollars total annual cost to society (Jason, Benton, Valentine, Johnson, & Torres-Harding, 2008). It is recognised that service use tends to be higher in individuals with CFS than other populations (McCrone, Darbishire, Ridsdale, & Seed, 2003) and given this, in conjunction with our knowledge of the chronicity of the syndrome and the lack of understanding about management and care, it has furthermore been suggested that CFS places a disproportionate burden on the healthcare system (Reynolds, Vernon, Bouchery, & Reeves, 2004). This context highlights the importance of further research into prevention and treatment.

**Aetiology.**

Contemporary understandings of CFS are increasingly building on a biopsychosocial model whereby chronic stressors, both physical and psychological, lead to neurobiological dysregulation, including low vagal tone and hyperactivity of the hypothalamic pituitary adrenal axis (Kempke & Claes, 2015). This model is inclusive of several proposed triggers including clear physical causes such as a viral infection, or accumulated psychological stressors: the common mechanism is then the management of these stressors by the body, with psychosocial factors contributing to the maintenance of the initial stress response beyond that which would be considered biologically healthy or adaptive. Many of the symptoms of CFS can therefore be understood via hormonal and chemical changes and disruption of neurobiological systems: this includes for example sleep patterns, appetite, the immune system and memory systems. This model understands the physical aspect of the syndrome whilst positing psychosocial factors as integral to its development and maintenance and as such it deals with the uncomfortable reputation of this
syndrome as ‘somatoform’ or psychosomatic. It is a key role of psychologists working with this diagnosis in communicating the dynamic interplay between physical and psychological factors, so that individuals feel validated and understood and are able to access services effectively: this involves addressing this within the social world of the individual as well as explicit psychological interventions designed to target key maintaining processes outlined by the model.

It was mentioned in the introduction that there is ongoing debate about an appropriate nomenclature for this syndrome: it is a key concern for individuals with CFS that healthcare providers are better able to understand the diagnosis and to acknowledge that this is a serious and real condition (Nicholson, Brown, Jason, Ohanian, & O’Connor, 2016). The patient voice indicates that including fatigue in the name exacerbates stigma and trivializes the syndrome (Ibid): an alternative suggestion, ‘catastrophic multi-system dysfunction’ fits particularly well with emerging research and the neurobiological model outlined above. There are undeniably complex physical changes as well as psychosocial elements to this experience as in any chronic illness, with such complexity and dynamics between multiple factors perhaps indicating why it is such a heterogeneous clinical picture.

**Psychosocial factors.**

Several specific psychosocial factors have been investigated in relation to the development and maintenance of CFS, both within a CBT model as well as more widely.

One factor investigated in the literature that may complicate and add stress to the experience of CFS is the documentation of high rates of stigma reported in this client group (Ware, 1992). This includes higher reported rates than in comparison to people with fibromyalgia and IBS; collectively these ‘somatic’ samples also reported higher rates than a sample with accepted medical conditions such rheumatoid arthritis and multiple sclerosis (Looper & Kirmayer, 2004). This effect was hypothesized to be due to increasingly uncertain medical status and understanding of underlying mechanisms of the somatic disorders and CFS especially. High rates of perceived stigma within CFS have been associated with increased length of
illness and unemployment, higher symptom severity and greater relational difficulties with partners (Green, Romei, & Natelson, 1999).

Coping is generally understood to be a fundamentally important concept in understanding how people experience and are affected by stress, and a proliferation of research indicates that ‘coping’ can affect the clinical picture and outcome of chronic illness (Aldwin & Park, 2004). Within CFS, coping strategies and illness attitudes are noted to be equally as important as in other chronic illness populations: for example, they are thought to be more predictive of illness outcomes than are immunological markers (Wilson et al., 1994). Given the central role of stress responses in the biopsychosocial model outlined above, this seems a coherent assumption and research finding. Other research has also suggested that this population are more likely to use maladaptive coping strategies (Ax, Gregg, & Jones, 2001; Creswell & Chalder, 2001; Nater, Maloney, Lin, Heim, & Reeves, 2012). This has been linked with beliefs about the illness - a sense of control was associated more with problem-focused coping strategies than avoidant coping strategies (Heijmans, 1998) and as discussed previously, the lack of understanding of this disorder and the associated stigma may well lead to a depleted sense of control with this chronic diagnosis in particular. Beliefs about control, the severity of the disorder and the seriousness of the consequences were found to mediate the relationship between pain severity and adjustment to result in different levels of physical and social functioning as well as mental health (Heijmans, 1998; Jensen, Turner, Romano, & Karoly, 1991), providing further support for the role of complex dynamics between psychological and physical processes. Similarly, it is known that the use of less adaptive coping strategies may be related to increased disability among individuals with chronic fatigue syndrome (Ax, Gregg, & Jones, 2001; Moss-Morris, Petrie, & Weinman, 1996; Ray, Jefferies, & Weir, 1995), although a causal direction between coping and disability has not been established.

An individual personality factor that has received significant interest in relation to CFS is that of perfectionism. More specifically ‘maladaptive perfectionism’, whereby a high achievement orientation is coupled with self-critical thoughts, is hypothesised to lead to more maladaptive coping strategies (Sirois & Molnar, 2014) and has been used to predict daily pain and fatigue symptoms (Kempke et al., 2013). One study
indicated that perceived activity was important in subjective distress ratings rather than objective activity, which may further indicate the saliency of cognitions in the maintenance of this experience (Wiborg, Knoop, Frank, & Bleijenberg, 2012), with higher discrepancy between the ideal self and the perceived self leading to higher distress. This once again highlights the dynamic relationship between psychological and physical factors, and examples one mechanism by which chronic stress may be a maintaining factor in this diagnosis.

It has been noted that individuals with a diagnosis of CFS perceive higher levels of fatigue than a normal sample taking the same exercise (Gibson, Carroll, Clague, & Edwards, 1993) – there are several hypotheses as to why this may be the case, including higher distress increasing perceptions of fatigue, or a lack of sleep or physical deconditioning leading to increased physical effort and consequent fatigue. These hypotheses are all coherent with the neurobiological model described briefly above, and it once again seems likely that a combination of these factors could be contributing to the experience of CFS.

**Intervention.**

It is evident that there are complex interplays between cognitions, behaviours and physiological processes in this disorder, each of which could be targets for change in psychotherapeutic intervention. Despite the high personal costs of the diagnosis outlined in the introduction, it is nonetheless recognised that disability and quality of life can be significantly improved for all individuals with CFS (ME Association, 2007).

One of the indicators of a good prognosis is a holistic management approach, encompassing physical and psychosocial elements that allow a stepwise approach to functional improvement (ME Association, 2007); this is coherent with the biopsychosocial model of understanding CFS, clearly indicating the role for psychology in intervening, and places an emphasis on behavioural and functional change as outcome measures.

The evidenced based role of Graded Exercise Therapy (GET) works explicitly on the hypothesis that the physiological changes of deconditioning and avoidance are reversible and treatable through the initial establishment of a realistic physical baseline before adding achievable increments (White et al., 2011). This can be seen
to target the frequent ‘boom and bust’ pattern of activity seen in this population, whereby on a ‘good’ day individuals push themselves to complete higher levels of activity, which then results in excessive fatigue in forthcoming days and/or weeks. Given the hypothesised role of psychosocial factors outlined above this pattern may well link to maladaptive perfectionism for example, with behaviour driven by self-critical thoughts and high achievement standards. This pattern presents a barrier to improvement as the stress response associated with this factor and the physical deconditioning are maintained. Whilst recognising that there may be links to underlying psychological factors, GET does not seek to address this and focuses on physical activity only, a key critique and potentially an explanation for some of the damaging effects noted by some members of the CFS community (ME Association, 2015). CBT interventions would include some similar processes to GET including the development of behavioural baselines and behavioural experiments but would also include cognitive challenging and other structured techniques to more explicitly target underlying maladaptive beliefs and psychological factors and to address social and emotional barriers to change (White et al., 2011).

Graded exercise therapy is noted to be useful in other physical health conditions that may result in deconditioning, having positive physical and psychological side effects – the first RCT evaluating GET with a CFS population in 1997 reported similar beneficial effects in this population, beyond those of relaxation and flexibility exercises which were the comparable treatment as normal groups (Fulcher & White, 1997). More recently these results were echoed in a large and influential ‘PACE’ trial of 641 participants, with significant improvements noted in physical functioning and in decreased fatigue scores following the CBT and GET interventions, with comparatively greater improvements in post-exertional malaise than other treatments – this was considered important because this is frequently cited as a reason not to use GET (White et al., 2011). Five participants in these treatment groups experienced serious adverse reactions, although it was deemed that this was not related to treatment. Recently a longer term follow up of this study, a median of 2.5 years later in which 75% of the original participants responded, indicated that the improvements originally documented in the CBT and GET groups were maintained (Sharpe et al., 2015).
Despite the seemingly positive reporting of these interventions for the CFS population, the study and the implications of the research have been significantly controversial in the wider health community. The ME Association and key members within it have formulated a number of “indefensible” methodological concerns, including a lack of transparency, dismissal of key outcomes in the interpretation of results, and undeclared conflicting interests (Shepherd, 2015). There are further charges that this approach reduces treatment of CFS to simply developing of a positive mental attitude, which does not comprehensively address the physical abnormalities, in brain and immune functioning for example, that are found in CFS. In support of these concerns, the ME Association cite a recent survey suggesting that 70% of respondents felt that GET had in fact made them worse.

The ME Association summarises that the illness has an individual element - those treatments which have helped reduce particular symptoms in some people have unfortunately proved ineffective or even counterproductive in others (http://www.meassociation.org.uk/about/the-treatment-of-mecfs/). Interventions need to be broadly able to recognise and validate the undeniable physical changes associated with CFS, as well as helping individuals ideographically to ‘come to terms with the restrictions imposed by the illness’, to remain positive, and to identify their own goals and apply the principles of pacing in order to achieve these (Ibid). These aims, outlined by the ME Association, further justifies the use of a flexible intervention such as ACT to address psychosocial maintenance factors, which are present in all physical health conditions, but in a way that is arguably more client-centred and potentially a better fit for this complex population.

1.2 Acceptance

The largest body of research into acceptance within health is with chronic pain, prompted largely by a need to further clarify the conceptualisation of ‘coping’ and patient factors in the development and maintenance of this disabling and prominent diagnosis (McCracken & Eccleston, 2003). Literature has since proliferated in this particular field and across a number of chronic health conditions. It is important to reiterate that acceptance is qualitatively different from passive acceptance, or resignation: in the frequently used ‘COPE’ measure for example, designed to assess an individual’s typical responses to stressful events, acceptance is distinguished
from other coping strategies such as denial and disengagement (Carver, Scheier, & Weintraub, 1989). This is validated both across the health literature and specifically for the CFS population (Nakamura & Orth, 2005).

It is thought that both physiological and psychological outcome measures are mediated by acceptance processes and improved self-management strategies (Gregg, Callaghan, Hayes, Glenn-Lawson, 2007; Lundgren, Dahl & Hayes, 2008). Increased acceptance was conceptualised in one qualitative study as a mechanism for integrating CFS into identity, with adjusted values and goals, as well as links to other positive attributes of mental health such as an increased sense of self-worth (Dickson, Knussen, & Flowers, 2008). A small qualitative study looking at the process of patient empowerment in individuals with a diagnosis of CFS, noting the benefits of such in clinical outcomes, describe this as a dual process both “holding on” to previous self-identities and learning to manage the illness, whilst simultaneously “letting go”, by accepting that some control must be relinquished (Aujolat, 2008). The end result is a reconciled self, coherently integrating illness mastery and different identities in a meaningful narrative. It is also mentioned that clinicians can play an important role in facilitating this via the approach they use with patients. A shift of attention and cognitive focus from avoidance or combatting of illness to acceptance and integration may well facilitate more effective behavioural change and consequent functional outcomes - informed and self-endorsed behavioral regulation has long been associated with well-being enhancement (Ryan & Deci, 2000).

1.3 Acceptance and Commitment Therapy (ACT)

ACT is a model of change processes and intervention that is built upon a comprehensive, basic theory of language and cognition known as Relational Frame Theory (RFT: Blackledge & Drake, 2013; Hayes, 2004). This deductive development from a previously established evidence based model of normative human functioning is considered by some as a strength of this approach over others such as Beck’s cognitive theory (a contributor to CBT), which was inductively developed from specific observations of depression (Beck, Rush, Shaw & Emery, 1979). In any case
ACT itself is increasingly recognised as a more user friendly and clinically applicable model of the underlying extensive and complex behavioural theories (Hayes, Levin, Plumb-Vilardaga, Villatte & Pistorello, 2013).

There is an increasing evidence base for ACT as a psychotherapeutic treatment with a diverse range of psychological problems including depression, substance abuse and psychosis, as well as improving quality of life in other distressed but non-diagnosed populations (Blackledge & Barnes-Holmes, 2009). As a third wave Cognitive Behavioural Therapy it has been suggested that ACT addresses a number of conceptual difficulties with more traditional approaches, although there is ongoing debate about whether or not it is more effective than established psychotherapeutic treatment protocols in all applications across the literature (Levin & Hayes, 2009). It can be challenging to compare such models because the different approaches necessitate different outcome measures, of either first order or second order change; this can skew data in meta-reviews and evaluations. Further research is needed to fully establish which therapy might work best and for whom: given the primary focus on decreasing experiential avoidance and improving acceptance, alongside facilitating value-based living, ACT might be more suitable for populations or individuals with high levels of experiential avoidance and lower levels of meaning in life (Veehof, Oskam, Schreurs, & Bohlmeijer, 2011). It has been previously suggested that ACT may not work quite as well for minor problems and less entangled and avoidant clients (Forman, Herbert, Moitra, Yeomans, & Geller, 2007).

To conceptualise the six core processes hypothesised to form psychological flexibility, the ACT community have developed a model known as the ‘hexaflex’, portrayed in the figure below. ACT is described as a functional approach rather than a collection of techniques (Eifert et al., 2009) therefore should be flexibly applied for an individual and their context: acknowledging then that all components are key to change and there is no prescriptive way in which they should be targeted, there remain some questions about precisely how these concepts might combine and work collectively to form psychological flexibility. Within this specific population, we might hypothesise from previous literature that the acceptance factor would be low, but the status of other factors alongside this is not known.
Figure 4: The hexaflex model of six core processes contributing to psychological flexibility as proposed by Acceptance and Commitment Therapy.

**ACT and CFS.**

The functional goal of an ACT intervention with CFS would be movement in the processes of the model, so an increase in flexible ways of relating to fatigue, and ability to change behaviour when it is not allowing the achievement of desired goals in a specific context. Balancing acceptance processes with behavioural commitment, clients would be encouraged to reduce experiential avoidance of distressing thoughts and evaluations about self and fatigue as well as feared bodily sensations, and to find ways to move towards valued life directions even when unpleasant fatigue thoughts and symptoms are present.

**Self Help**

Chronic illness models place emphasis on the need for self-management, to maximise an individual’s self-efficacy and control and to minimise dependency on health services (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Nodhturft et al., 2000). Programmes teaching self-management skills as part of treatment have been linked to improved clinical outcomes and reduced costs in a number of chronic physical health conditions (Bodenheimer, 2006). Self-efficacy is defined as the confidence to carry out a behaviour necessary to reach a desired goal (Ibid) – this
seems compatible particularly with the values and committed action component of the ACT model. Similarly, self-management education teaches problem solving as a transferable skill beneficial to daily living with a chronic illness, which could be seen as akin to or perhaps facilitated by psychological flexibility.

When a ‘cure’ is not a realistic goal, instead the focus shifts to the maintenance of pleasurable and independent living, which emphasises the individual’s role as their own experts in determining what is pleasurable and meaningful for them – the role of healthcare providers then becomes one of consultancy in supporting them to do this (Holmand and Lorig, 2000). Research suggests that we are much more likely to make and maintain behaviour changes if they are personally meaningful and freely chosen; similarly, ‘activating’ the patient in their own treatment as part of a patient centred approach is consistently associated with improved physical health outcomes (Anderson, Funnel & Arnold, 2002).

This paradigm of chronic illness is compatible both with a self-help approach, as well as with an ACT model, given its unstructured and idiographic approach. This is potentially more important than ever with CFS given the noted heterogeneity of the population, the chronicity of the diagnosis as well as the associated low levels of control. A self-help format could also improve accessibility for individuals whose physical and cognitive symptoms may make regular travel and attendance at clinics difficult.

Implicit responses.

There are a number of self-report measures which have been designed to access the ACT specific processes, with good psychometric properties but which by their nature remain susceptible to demand characteristics. Noting the controversies and the stigma associated with a CFS diagnosis, this may be particularly relevant to this consider within this client group. We do not know how these would influence participants explicit responding, but evidence to date indicates that implicit measures are more divergent for socially sensitive concepts (Fazio & Olson, 2003). Furthermore, it might be hypothesised that within this diagnosis automatic processing, such as illness beliefs and responses to physical stimuli or aversive thoughts, may play a role in the maintenance of maladaptive behaviours and as such be a target for intervention. This study therefore included the Implicit Relational
Assessment Procedure, a response measure that has been shown to access implicit relations across a growing number of domains; it has furthermore been shown to capture and predict behaviours not accounted for by self-report procedures (McKenna, Barnes-Holmes, Barnes-Holmes, & Stewart, 2007). Moreover, evidence suggests that participants cannot manipulate this measure even when given direct instructions to do so (Ibid). For more information see Measures section below.

1.4 Local service

The collaborating NHS Specialist CFS service was able to offer expert advice and guidance with regards to the client group and service need.

It is not currently understood what specific aspects of the group treatment programme are helpful, although service providers hypothesise that belongingness, validation and emotional processing are key to facilitating change. Within the service there is also a hypothesis that most change is noted on psychological measures rather than symptoms or disability within the groups, a process which would be coherent with an ACT model of understanding distress (A. Abey, personal communication, Jan 17 2014).

We know something about the characteristics of the individuals accessing this Specialist service (which are reported in the ‘Participants’ section below), but outcome data across the service is not readily available.

1.5 Purpose of Investigation

It is acknowledged that psychological flexibility is useful in improving psychiatric conditions. The initial section outlined the potential role for acceptance in the experience of CFS; conclusions from these studies advocated further research into ACT interventions with this client group. It is not clearly understood how the processes outlined above may interact to effect a change in psychological flexibility. Similarly, there is little evidence currently addressing the relationship of implicit measures with the core psychological processes identified by the ACT model. This research may give some insight as to the clinical utility of this measure in the future.
This project therefore utilised a multiple single case design with repeated and comprehensive mixed method measures to begin to understand the change processes of an ACT intervention with the client group.

1.6 Epistemology

ACT is based on Relational Frame Theory, both of which stem from an explicitly functional contextualist approach. The epistemology behind this is pragmatism, which emphasises the importance of clarifying hypotheses by their practical consequences (Hookway, 2015). This contextual behavioural science approach describes itself as a specific strategy for scientific development, not seeking grand ontological truths but seeing research and all behaviours as part of a context, and aiming to generate more useful (rather than ‘true’) ideas – this can include the development of basic theories, of applied theories, the measurement of theoretically key processes and the testing of effectiveness, over a broad range of levels of analysis (Hayes, Levin, Plumb-Vilardaga, Villatte & Pistorello, 2013).

Functional contextualists distinguish themselves from descriptive contextualists by their pragmatic aim of predicting and influencing events: this involves identifying aspects of the manipulable environment that influence the occurrence, incidence, prevalence, or probability of psychological events (Fox, 2008). Within this framework the truth criterion is ‘successful working’ or workability: it relies therefore on the explicit statement of the aim of the analysis and an evaluation as to whether or not these specified consequences are achieved (Hayes, 1993).

This research looks to assess the efficacy of one particular course of action with a specific sample: as such it can add to the existing literature about what approach might be useful in this context. If this and other studies indicate the utility of this approach, it may be useful in the future to more directly compare ACT with other psychotherapeutic approaches in a different experimental form, adding to a body of literature about which course is most useful in what contexts (Hayes, 1993). This approach to testing the model, by applying it to topographically distinct samples and experimenting with peripheral aspects such as format and length of delivery, allows testing of the boundaries of the model. This then facilitates it to become more clinically and practically useful: the identification of processes of change that are both sufficient and necessary for the benefits observed in treatment, and the further
identification of the methods that impact these processes, are key to the ability to optimize treatment impact (McCracken & Vowles, 2014). In line with pragmatic aims, the explicit goals of this study include evaluating whether or not the underlying processes of psychological flexibility can influence the experience of CFS as targeted by this intervention: there is an interest in the basic science of behaviour change as well as the applied psychology.

The contextual behavioural approach has a number of both strengths and weaknesses: it facilitates evaluation through the ready assessment of goals and aims, which further allows clear communication amongst researchers. On the other hand it can be argued that there are elements of theoretical incoherency, as the model emphasises the importance of context, yet dividing the whole into parts in order to study them is artificial and fragments the context in which the whole exists (Hayes, 1993): this however is a difficulty that faces psychology as a scientific study and must be tolerated from this epistemological position if pragmatic aims are to be achieved.

1.7 Methodology

Contextualism permits many analytic goals and as such doesn't specify a particular methodology; the aims outlined above are nonetheless particularly well achieved by experimental designs (Hayes, 1993). These offer a good way to isolate environmental variables and develop a clear understanding of how they are functionally related to the behaviour.

Single case designs can provide a rigorous experimental evaluation of intervention effects, as well as providing a strong basis for establishing causal inference (Kratochwill et al., 2010). This methodology is useful within this research, beyond that of other methods such as Randomised Control Trials, as it allows a comprehensive exploration of a relatively un-researched area. It is a feasible design both in terms of the scope of this study as well as able to generate appropriate data to answer the hypotheses and achieve the outlined goals.

Single case designs have the following features, which are replicated within this study: they use an individual unit of analysis, therefore comparing data within rather than between subjects. They measure outcome variables across different phases.
This study proposes repeated measures before and throughout the six week intervention, in accordance with the aim to clearly understand any change processes and the functional relation of environmental variables to behaviour. This will begin two weeks prior to the intervention (phase B) in order to gain a stable baseline (phase A): guidelines agree that a minimum of three data points during the baseline is necessary however five data points in each phase are recommended (Smith, 2012). The measures will also be repeated at a three month follow up to begin to assess the time course and maintenance of any change. A normative agreement on replication effects across cases demands three demonstrations at least, although more are preferred (Kratochwill et al., 2010).

Therapy outcome is both qualitative and quantitative (has the client changed, and how much?) – this methodology therefore advocates the use of mixed methods of data collection (Elliott, 2002). This further encourages a detailed analysis as the data is more sensitive: participants may change on some measures but not others due to a range of factors. Mixed methods are further recognised as powerful tools for investigating the complex, multilevel systems and processes often found in healthcare – the advantages of integrating mixed methods include enhancing validity, using each to explain the other, and using qualitative data to generate hypotheses to be tested in further quantitative studies (Fetters, Curry, & Creswell, 2013). This research therefore integrates mixed methods via a convergent design – both measures will be conducted in parallel, and linked or ‘embedded’ at points throughout the study.

2. Extended Method

2.1 Ethics

This project was submitted and approved via the following ethics committees: the University of Lincoln School of Psychology Research Ethics Committee, Lincolnshire Partnership Foundation Trust Ethics Committee and the East Midlands National Research and Ethics Committee (REC Ref: 14/EM/1086: see Appendix 2).

Informed consent.

Participants were informed of all information relevant to participation in this study via an information sheet for them to keep (Appendix 3) and a discussion with the primary
researcher, giving the chance to clarify any questions and concerns. Informed consent was gained and the signed consent form was copied twice: one was kept for study records and consequently stored at University of Lincoln, the other made available for the participants to keep as a record (Appendix 4). Following informed consent, participants took part in the research process as outlined in the journal paper and elaborated on below.

**Right to withdraw.**

It was made clear to participants that they could withdraw from the study at any time throughout the intervention or within four weeks of the end of the intervention, by contacting the primary researcher without any consequence for their care. If participants withdrew current data collected could still be used.

Weekly contact with the researcher allowed monitoring of any additional needs throughout the process.

**Confidentiality.**

This project acted in accordance with the Data Protection Act (1998): participants were allocated a code by which data was collected and stored confidentially. Laptops used for data storage and for the IRAP measure were password encrypted. Any emails containing data were sent via a secure network.

**Compensation.**

Participants were offered reimbursement for their time: this included £50 for taking part in the research and a further £10 at follow up, with proportionate compensation if they withdrew at any stage. As all participants took part in the full research, a total of £360 was paid.

**2.2 Participants**

A total of eight participants were approached to take part; two participants missed the recruitment window due to other time commitments.

Six participants was decided to be a suitable number for this project because it was feasible logistically, within the context of the service and the study, as well as being
able to meet the outlined aims: it allowed ample demonstration of replication effects with allowance for attrition (although this was ultimately not an issue).

**Inclusion criteria.**

All participants had previously taken part in the group intervention that is currently offered as treatment as normal by the service; in light of this being an exploratory study, this was in order that no participants were disadvantaged by not receiving treatment as normal. The ease with which we recruited individuals indicated that there are still service users who feel that they would like to receive further support even after the group. The self-help format of this intervention could be a feasible means of providing this without taking too much clinical time. Furthermore, as an exploratory study, results here could inform future studies which might include a more experimental comparison design of the group versus the self-help intervention.

Participants needed access to the internet and a phone, as well as a good understanding of both written and verbal English, given the nature of the intervention. This was felt to be representative of the local sample if not the wider CFS sample.

Providing participants met the inclusion criteria, they were not excluded on the basis of any demographics or other individual factors. This study was designed to be a balance between a controlled experiment as well one which was ecologically valid therefore individual variation was judged as an inevitable part of this client group. Similarly, as each participant was assessed on an individual basis and functioned as their own control, the significance of individual variations was lessened.

**Service data.**

Assessment data is held for 470 adult patients who used the service between 2010 and 2014, of whom 390 (83.0%) met diagnostic criteria for CFS/ME. Ignoring 10 patients who have missing data for age or sex, the average scores at baseline are as follows:

Chalder Fatigue Scale: mean 27.6, SD 4.8
SF36 Physical Function subscale: mean 39.5, SD 25
Of this patient group, 80.8% (307/380) were female, the mean age was 42.3 (SD 12.9) years, and the median duration of illness was 40 months. Of those who reported impact on paid work (n=289), 27.3% had reduced their working hours, 12.1% were on sick leave and 39.1% were unemployed because of their ill health.

Comorbidities included fibromyalgia (42.1%), migraine (34.5%), Irritable Bowel Syndrome (60.0%), depression (39.1%), and anxiety (55.1%).

2.3 Measures

A parallel psychometric study is being finalised in which the condensed ACT measures, adapted for this study, are further evaluated. The full measures were chosen with an acknowledgement of their psychometric properties, which are displayed in the table below.

<table>
<thead>
<tr>
<th>Test</th>
<th>Sample</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>Internal consistency (Cronbach’s alpha)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHLMS Awareness</td>
<td>Non-clinical - Student</td>
<td>559</td>
<td>36.65</td>
<td>4.93</td>
<td>.75</td>
</tr>
<tr>
<td>PHLMS Acceptance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PHLMS Awareness</td>
<td>Clinical – Psychiatry outpatient</td>
<td>52</td>
<td>35.11</td>
<td>5.39</td>
<td>.75</td>
</tr>
<tr>
<td>PHLMS Acceptance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CFQ</td>
<td>Non-clinical – student and community</td>
<td>1040</td>
<td>22.28</td>
<td>8.3</td>
<td>.90</td>
</tr>
<tr>
<td></td>
<td>Clinical - Multiple</td>
<td>133</td>
<td>21.22</td>
<td>10.63</td>
<td>0.93</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------</td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sclerosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MAAS</td>
<td>Non-clinical</td>
<td>122</td>
<td>4.45</td>
<td>0.77</td>
<td>0.73 – 0.91</td>
</tr>
<tr>
<td></td>
<td>community</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Clinical –</td>
<td>122</td>
<td>4.08</td>
<td>0.74</td>
<td>0.83 – 0.95</td>
</tr>
<tr>
<td></td>
<td>cancer patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ELS</td>
<td>Non-clinical</td>
<td>439</td>
<td>60.80</td>
<td>7.83</td>
<td>0.90</td>
</tr>
<tr>
<td>Chronic Fatigue</td>
<td>General population</td>
<td></td>
<td>14.2</td>
<td>4.6</td>
<td>.89</td>
</tr>
<tr>
<td>Scale</td>
<td>Clinical –</td>
<td></td>
<td>27.6</td>
<td>4.8</td>
<td></td>
</tr>
<tr>
<td></td>
<td>CFS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 3: Information on psychometric characteristics and reference group norms for the ACT measures used in this study.

All questionnaires were designed and administered via the free internet software Esurv.org: they were piloted by colleagues before administration.

**Behavioural measure.**

This measure was included in order to add objective behavioural data to the analysis, given the complex nature of the relationship between behavioural and cognitive factors in both the development and the maintenance of CFS. As an objective rather than a self-report measure of activity, it was possible either that it would corroborate self-report measures or conflict with them: each of these results would have implications for the study and are explored further in the discussion.

This measure was included with acknowledgement and consideration of the potential implications of targeting increased activity with this population: the literature highlights both the importance of trying to achieve this given the physiological changes associated with CFS as well as the controversies and potentially damaging effects of doing so for some individuals. Whilst the gradual reversal of some of the deconditioning processes may be an intervention of merit, this must be targeted
carefully and sensitively to the needs of the individuals. Similarly the boom/bust pattern of activity noted in this client group, likely related to maladaptive perfectionist tendencies, needs to be considered as higher activity in itself does not equate to better outcomes. Given this, physical activity goals were not explicitly set within this intervention and the behavioural measure was used only for monitoring. Within the ACT model it is a key aim to increase valued behaviour but not physical activity per se.

Implicit measure.

**Stem Completion Task.**

At recruitment, participants were asked to complete a stem completion task to develop some idiographic terms, with which the researchers then developed the IRAP (see below). This included six items based on health, and six items based on ill-health. Participants were provided with some example stems, such as

When I am well, I feel….

When I am well, I think…

They were also given the chance to generate their own belief statements within a similar format. For further information please see appendix 5. The full responses generated by participants are recorded in appendix 6.

**Implicit Relational Assessment Procedure (IRAP, [http://irapresearch.org/what-is-the-irap/](http://irapresearch.org/what-is-the-irap/)).**

It can be understood that there is a continuum of responses from explicit, deliberative behaviours, as captured by the self-report measures, to brief, immediate, relational responding. The IRAP was designed to tap into the latter, asking participants to very quickly confirm relations between a target and stimulus. In this case, target and stimulus terms were idiographically developed by the initial stem completion task as described above.

The IRAP software was used to present stimuli and record participant responses. The program included standardised on screen instructions which the participants were able to read in their own time. These instructions included a description of the
process, indicated how to complete the task and emphasised that speed and accuracy of responses is required. They did not indicate which of the tasks were deemed to be consistent or inconsistent. The IRAP consisted of two test blocks, and took around 15 minutes to complete. Any data from practice blocks or in the development of the test was not used in analysis.

On each trial, four stimuli were presented concurrently. One of two label stimuli appeared at the top of the screen, the target appeared in the centre of the screen, and the two response options (true and false) were presented at the bottom of the screen. All four stimuli remained visible on screen until the participant responded: pressing the ‘D’ key selected the left option and pressing the ‘K’ key selected the right option. The positioning of the true/false responses as on the left or right of the screen was alternated randomly across trials.

If a participant gave a correct response all four stimuli disappeared and there was a 400ms blank screen interval. In the case of an incorrect response a red X appeared below the target and remained onscreen until the correct response was given. The IRAP was scored in terms of differences in response latency between consistent and inconsistent trials, with the expectation that inconsistent trials will provoke a slower response.

The IRAP has poor test-retest reliability, but this is a feature of its design: it measures states rather than traits, so responses may be highly dependent on context and could therefore be expected to change. Practice effects should be mitigated by the extended period of time proposed between the IRAP tests in this study. It should also be noted that within this measure participants are their own control, therefore any differences for example in cognitive symptoms should not affect the results.

**Qualitative Measures.**

**Change interview (Elliott, Slatick & Urman, 2001).**

The change interview was part of a practical reasoning process to make ample consideration for contextual factors, including an effort to rule out any other alternative plausible explanations of change (Elliott, Slatick & Urman, 2001; Elliott,
This also allowed for rich data collection, in line with the aims of the study. The change interview schedule is included in Appendix 7.

Based on published guidelines, data from the change interview was evaluated in terms of the following questions: was there any negative impact described? What was the importance of therapy to participants? Are the descriptors of change trivial or significant, with elaborated detail and examples – does this vary and does this match quantitative outcomes? Also it was felt to be important to consider inter-relational dynamics and self-presentational patterns in change interviews – were there any overly positive attributions of change and therapy? What was the participant’s use of language – did any of them resort to culturally stereotyped perceptions or scripts of therapy? Did participants report being surprised? Was change noted in previously chronic problems? What was the context surrounding the intervention; were there any notable extra-therapy events occurring for the participants?

These questions help to evaluate the credibility and validity of the other data collected throughout the study. Participant reports that are in line with data from other measures, that highlight the importance of the research in changing chronic conditions and that use individual language to describe particular applied examples, would add support for any positive effects of the intervention.

Demographics.

The data collected as part of routine measures already in place within the service included brief demographic data, such as age, gender, chronicity of symptoms and diagnosis and any previous interventions: these were useful in this project to describe the sample such that inferences could be made about representativeness and comparability to other CFS samples. This also facilitated analysis of outcome measures with an understanding of context. Minimising the collection of personally identifiable information helped to protect anonymity of obtained data and reduce unnecessary participant fatigue.

2.4 Procedure

Recruitment.
Leaflets and posters were used to advertise the research at the end of the groups currently run as treatment as normal within the service and by members of the multi-disciplinary team with individual clients (copies included in Appendix 8). The contact details of the lead researcher were indicated on the advertisement material. All members of the MDT running these groups had taken part in a short information session led by the researcher in order for them to have some ability to describe the research.

Participants who showed interest in the study met with the primary researcher: they were required to read an information sheet and give signed consent before the intervention began. The participants then completed the STEM completion task and consequently the IRAP computer task, on an encrypted laptop either at an NHS base or the participant’s home.

**Intervention.**

ACT relies heavily on the use of metaphors and exercises designed to encourage the reader to view their problem from a different perspective, to increase flexibility of thought and to experientially connect with the material in direct opposition to experiential avoidance, which of course is hypothesised in this model to be a maintaining factor in distress.

ACT processes are not conceptualised to work sequentially therefore can theoretically be introduced in any order (Blackledge & Barnes-Holmes, 2009); for the purposes of the research design, sequencing by process rather than by chapter structure enabled a clearer understanding of responsivity to the particular processes or techniques, which would otherwise have been obscured.

**2.5 Analysis**

Online data (from eSurv.org and Fitbit.com) was transferred by the primary author to an Excel worksheet, which was consequently used to develop all graphs and further analysis.

Data from the Fitbit activity monitors was calculated to give an average daily step count per week.
ACT measures were adapted where necessary to consistently measure psychological flexibility rather than inflexibility, and are represented as such in the graphs presented in the results sections (positive trends indicate increased psychological flexibility). The two scores reflecting fatigue and disability on the Chalder Fatigue Scale and the section of the SF-36 were left as originally developed: lower scores indicate less fatigue and disability.

In line with the design and epistemology of this study, it was recognised that SCED designs should be evaluated using multiple methods to better understand findings and increase confidence in interpretation (Lane & Gast, 2014). Initially data was analysed by calculating reliable change and clinically significant change in line with quantitative data analysis criteria (Jacobson and Truax, 1991). The reliable change index estimates whether change is greater than might be expected by simple measurement unreliability, and therefore likely to be a result of the intervention. This is calculated using a function of the standard deviation of the measure used. If change is deemed reliable, it can then be further evaluated as to whether it is clinically significant: that is, whether the individual has moved from a position more similar to a typical, clinical sample to that of a ‘normal’, healthy sample. There are three recommended ways of establishing this; where possible in this study evaluations relied on Jacobsen and Truax’s (1991) third method and were calculated using values from clinical samples which were deemed most similar to this sample, such as those with other chronic health conditions or mixed mental health samples. There were some measures, such as the ELS, where clinical sample means weren’t available and so only the mean of the normal sample could be used to evaluate clinically significant change.

Following analysis for clinically significant change, ACT process measures (from the weekly questionnaires) were then further analysed by visual analysis, evaluating trend, level and stability both within and across the two conditions of this study, guided by recommended systematic procedures (Lane & Gast, 2014). Trend is defined as progress and direction over time, level as magnitude of the data, and stability as the variability or bounce of data (Gast & Spriggs, 2014).
Response latency data from the IRAP was transformed into D-IRAP scores, which were extracted from the software output and which then indicated any biases in responding across two domains: a positive/negative bias, whereby participants responded differentially to either ‘well’ (positive) stimuli or ‘unwell’ (negative) stimuli, or a consistent/inconsistent bias.

3. Extended Results

There were large amounts of data collected throughout this study: in addition to those presented in the journal paper, the results are here summarised before being described in more detail by measure and then by participant.

The following tables summarise change per participant across quantitative outcome measures: the first indicates change at post-intervention whilst the second indicates change maintained at follow up.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Overall psychological flexibility</th>
<th>PHLMS - Awareness</th>
<th>PHLMS - Acceptance</th>
<th>MAAS</th>
<th>CFQ</th>
<th>ELS</th>
<th>SF-12</th>
<th>CFQ</th>
<th>Fitbit</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>2</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>3</td>
<td>✓</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>4</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

*Table 4: A summary of positive change across quantitative measures across the sample from baseline to post-intervention*
Table 5: A summary of positive change across quantitative measures across the sample from baseline to post-intervention

As can be seen from this table and as summarised in the journal paper, three participants appeared to maintain improvements in psychological flexibility post intervention and at the follow up. The notable finding within the individual process measures was the clinically significant change maintained in four participants in an engaged response style, measured via the ELS. All participants wearing the Fitbit indicated increased activity. Other measures provide a complex and varied picture.

3.1 ACT process measures

Overall psychological flexibility.

Two example graphs are included in the journal paper for measures of overall psychological flexibility: the remaining four are depicted in the graphs below.

![Participant 1 Graph](image_url)
Figure 5: Graphs depicting overall psychological flexibility scores for participants 1, 3, 4 and 6, to complement the two included in the accompanying journal paper.

The condensed questionnaire was adapted for the purpose of this study therefore has not been previously psychometrically validated in the same format. The scores and averages for the sample in this study are displayed simply for information in the table below.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Score of psychological flexibility</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Average across baseline</td>
<td>Post intervention</td>
</tr>
<tr>
<td>1</td>
<td>27.0</td>
<td>35.0</td>
</tr>
<tr>
<td>2</td>
<td>10.6</td>
<td>26.0</td>
</tr>
<tr>
<td>3</td>
<td>29.0</td>
<td>28.0</td>
</tr>
<tr>
<td>4</td>
<td>12.0</td>
<td>35.0</td>
</tr>
<tr>
<td>5</td>
<td>15.0</td>
<td>12.0</td>
</tr>
<tr>
<td>6</td>
<td>23.2</td>
<td>39.0</td>
</tr>
<tr>
<td>Average</td>
<td>19.47</td>
<td>29.17</td>
</tr>
<tr>
<td>SD</td>
<td>7.95</td>
<td>9.70</td>
</tr>
</tbody>
</table>

Table 6: Average scores within this sample of the condensed questionnaire designed to give an indication of overall psychological flexibility.
Visual analysis.

This was conducted in order to assess the reliability and validity of the data, and therefore the strength of our conclusions.

Within condition.

Stability and level change analyses were conducted on the baseline data and the intervention data.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Baseline</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>2</td>
<td>60</td>
<td>84</td>
</tr>
<tr>
<td>3</td>
<td>100</td>
<td>80</td>
</tr>
<tr>
<td>4</td>
<td>60</td>
<td>50</td>
</tr>
<tr>
<td>5</td>
<td>80</td>
<td>75</td>
</tr>
<tr>
<td>6</td>
<td>80</td>
<td>58</td>
</tr>
</tbody>
</table>

*Table 7: Percentages of data points in each condition per participant that fall within the stability envelope (calculated as 25% either side of the median value).*

Evaluation of each condition indicated data was stable throughout baseline in four participants, and during the intervention phase in three participants, using the criterion that 80% of data was within the stability envelope of within 25% of the median (Gast & Spriggs, 2014).

<table>
<thead>
<tr>
<th>Participant</th>
<th>Baseline</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>-1</td>
<td>5.5</td>
</tr>
<tr>
<td>2</td>
<td>3.5</td>
<td>-6.5</td>
</tr>
<tr>
<td>3</td>
<td>-1.5</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>-11</td>
<td>13.5</td>
</tr>
<tr>
<td>5</td>
<td>0.5</td>
<td>-3</td>
</tr>
<tr>
<td>6</td>
<td>-1.5</td>
<td>14.5</td>
</tr>
</tbody>
</table>

*Table 8: Calculations of relative level change per participant in baseline and intervention phases.*

Evaluation of relative level change, calculated by comparing the median values of the first and second halves of the data set, indicated that psychological flexibility was
deteriorating during baseline for four participants and improving for two. The same calculation during the intervention phase indicated that psychological flexibility improved for four participants and deteriorated for two.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Baseline</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>2</td>
<td>-4</td>
<td>15</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>-5</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>19</td>
</tr>
<tr>
<td>5</td>
<td>-2</td>
<td>-5</td>
</tr>
<tr>
<td>6</td>
<td>-1</td>
<td>14</td>
</tr>
</tbody>
</table>

*Table 9: Calculations of absolute level change per participant across baseline and intervention phases.*

Evaluation of absolute level change, calculated by comparing the first and last value within each phase, indicated a deteriorating trend in psychological flexibility during baseline for three participants, with three improving. During the intervention phase the same calculation indicated improving trends in four participants.

*Between condition.*

The self-help intervention was the only experimental variable introduced across the two conditions.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Percentage of non-overlapping data (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>92</td>
</tr>
<tr>
<td>2</td>
<td>92</td>
</tr>
<tr>
<td>3</td>
<td>17</td>
</tr>
<tr>
<td>4</td>
<td>75</td>
</tr>
<tr>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>6</td>
<td>67</td>
</tr>
</tbody>
</table>

*Table 10: Percentages of non-overlapping data for each participant between baseline and intervention phase.*
Calculations of percentages of non-overlapping data, that is data in the intervention phase that is equal to or higher than the highest value in the baseline phase, indicated that there was variance across participants ranging from 8% to 92%.

The visual analysis is summarised in the table below.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Condition</th>
<th>Direction</th>
<th>Stability*</th>
<th>Multiple paths within trend?**</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A</td>
<td>Accelerating</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>B</td>
<td>Accelerating</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>2</td>
<td>A</td>
<td>Decelerating</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>B</td>
<td>Accelerating</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>3</td>
<td>A</td>
<td>Accelerating</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>B</td>
<td>Decelerating</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>4</td>
<td>A</td>
<td>Decelerating</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>B</td>
<td>Accelerating</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>5</td>
<td>A</td>
<td>Accelerating</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>B</td>
<td>Decelerating</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>6</td>
<td>A</td>
<td>Decelerating</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>B</td>
<td>Accelerating</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Table 11: Summary of analysis of trend, stability and level of data within and between conditions. *Stability analysis based on criterion of 80% of data within 25% of the median. **Trend analysis based on criterion of at least three data points in one direction indicating a trend.

Given the heterogeneity of this sample, these results as highlighting an element of variability across the data is perhaps unsurprising but the findings are discussed with due caution.

**Results by measure.**

Although given the single case design the results per measure cannot be generalised, it was useful nonetheless to consider change across each individual process in each participant, in line with the aims of the study.
On all graphs below, one asterisk indicates reliable and significant change from baseline to post intervention, whilst two asterisks indicate that this is sustained at follow up. The dashed vertical lines represent the different phases: baseline, intervention and follow up.

*Engaged Living Scale.*
All participants indicated reliable and clinically significant change from baseline to post intervention: four of these were in a positive direction. This was maintained in all participants at follow up.

The mean available for this measure, calculated from a normative sample, is 60.8. Pre intervention five out of six participants were below this score. Post intervention, the one participant who had previously been above this score had deteriorated to below the normative mean, whilst two had improved to above the mean, leaving four participants below the normative mean for an engaged responding style.

**PHLMS – Acceptance scale.**

![Participant 1 - Acceptance scale on the PHLMS*](image1)

![Participant 2 - Acceptance scale of the PHLMS*](image2)

![Participant 3 - Acceptance scale of the PHLMS](image3)

![Participant 4 - Acceptance scale of the PHLMS**](image4)
The means for this measure are 30.19 in a normative sample and 24.62 in a clinical sample: pre-intervention, five out of six participants were below this normative mean and four out of six were below the clinical mean. Four out of six participants indicated clinically significant change from baseline to post-intervention. Post intervention three out of six participants scores were higher than the mean of the normative sample.

In three of the six participants there appears to be a slight increase in scores at questionnaire three (the second week of the intervention).

Despite these improvements post intervention, at follow up only one participant had maintained clinically significant change from baseline.

**PHLMS – Awareness Scale.**

The following graphs depict scores from the six participants on the Awareness scale of the PHLMS across this study.
The means for this measure are 36.65 in a normative sample and 35.11 in a clinical sample: three participants (two, three and five) were below the normative mean at baseline, and participants two and three were also below the clinical mean. Four of six participants showed no change on this measure from baseline to post-intervention. Scores for participants three and four indicated clinically significant change pre-post intervention which was maintained at follow up (indicated with asterisks on the graphs above).

There are no key points of change indicated on these graphs.

*Cognitive Fusion Questionnaire.*
The means for this measure in a normative and a clinical sample are 26.72 and 14.69 respectively (these have been reversed to fit with this data, so that higher scores continue to indicate higher defusion rather than fusion). Pre intervention three out of six participants were above the normative mean and all were above the clinical mean. One participant (participant five) deteriorates to below the clinical mean post intervention, whilst all others remain above both the clinical and normative means.
Clinically significant change was noted for just two participants, participants four and six; this was true from pre to post intervention and maintained at follow up.

There are no clear patterns within the data as to change at particular points in the intervention.

*Mindfulness Awareness and Attention Scale.*

![Graphs showing Mindfulness Awareness and Attention Scale for different participants](image-url)
The means for this measure within a normative and a clinical sample are 4.45 and 4.08 respectively. Four out of six participants were below the clinical mean pre-intervention, with participants one and three being above both the clinical and normal mean pre-intervention. Post-intervention, two participants were above both clinical and normative means, three participants were below both means, and the final participant measured between the two.

Four participants indicated clinically significant change from baseline to post-intervention, three in a positive direction (indicated by single asterisks on the graphs above). Change was maintained at follow up in two participants (three and four), one in a positive direction one and in a negative direction.

**SF-36 physical function subscale**

![Graphs of SF-36 physical function subscale for participants 1 to 4](image-url)
As indicated by the graphs above, responses to this set of questions were highly variable between participants, indicating varying levels of disability in the sample. The average score on this scale on admission to the specialist service from which this sample was recruited was 39.5, with a high standard deviation of 25 reflecting that levels of reported disability vary significantly amongst individuals with a diagnosis of CFS. As only a subscale was used, there is not an internal reliability value available for this measure with which to calculate reliable change. The trial protocol for the PACE trial specified 75 as a cut-off point to indicate improvement, although in the published trial change was calculated as a function of the standard deviation of the initial scores (Stouten, Goudsmit, & Riley, 2011): looking at the 75 point cut off, five participants were already below this at baseline, five remained below this at the end of the intervention and four remained below this level at follow up.

*Chalder Fatigue Questionnaire.*
Similarly to the previous measure, these scores indicate a level of heterogeneity across the sample with regards to reported levels of fatigue.

The mean for this measure calculated from a community sample was 14.2 (SD 4.6); in the same study CFS patients had a mean fatigue score of 24.4(SD 5.8) (Cella & Chalder, 2010). Within the specialist service from which this sample was recruited, the mean average at admission is 27.6 (SD 4.8). At baseline, five participants indicated that their levels of fatigue were above the normative mean score, as might have been expected from individuals accessing a specialist fatigue service. Two participants had higher levels of fatigue than the mean fatigue score documented by Cella and Chalder (2010) with only one participant indicating baseline fatigue scores that were higher than the service average on admission. Post intervention, two participants remained above the normative mean despite reliable change in a positive direction; three participants moved from above to below normative mean, and one participant indicated an increase in fatigue, moving from below normative mean to slightly above.
Five out of six participants indicted reliable and clinically significant change on this measure from pre to post intervention, four of which was in a positive direction: at follow up three of these five had maintained this change.

In the recent PACE trial (White et al, 2011), average scores at baseline across the different treatment groups ranged from 27.7 to 28.5. Improvement was evaluated on this scale by change of two or more points from baseline to post-intervention. By this standard, five out of six participants in this study improved on this measure.

**Fitbit.**
Fitbit data was not collected from participant one, due to some discomfort wearing the bracelet and difficulties working the monitor to provide sufficient data.

3.2 Change Interviews

The data gained from the change interviews is summarised in the table below.
<table>
<thead>
<tr>
<th>Question</th>
<th>P1</th>
<th>P2</th>
<th>P3</th>
<th>P4</th>
<th>P5</th>
<th>P6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall experience?</td>
<td>Interesting, some helpful some not, long, frustrating at times</td>
<td>Really good</td>
<td>Quite good, quite interesting</td>
<td>Brilliant, positive</td>
<td>Really good – better understanding now</td>
<td>Very helpful</td>
</tr>
<tr>
<td>Material?</td>
<td>Repetitive, complex, sexist</td>
<td>Waffly but got used to it</td>
<td>Clear, mostly made sense, sometimes questioning it</td>
<td>Generally clear and straightforward</td>
<td>Made sense – a few bits read several times</td>
<td>A lot to do in the timescale, sometimes struggled Beginning confusing, more helpful at the end</td>
</tr>
<tr>
<td>Helpful for others?</td>
<td>If interested, intelligent, and able to commit time</td>
<td>Yes</td>
<td>Don’t know – need to re-read</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Helpful aspects?</td>
<td>More detailed than TAU</td>
<td>Mindfulness, values, learning</td>
<td>Defusion – pain management</td>
<td>Simple exercises Values</td>
<td>Researcher – having someone</td>
<td>All helpful – Mindfulness and</td>
</tr>
</tbody>
</table>

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<p>| Changes? (How important?) | None noticed in everyday life | Yes - big decisions i.e. new job; Listening to myself (5/5 importance) | Minor changes and improvement – 5/5 importance | Yes – detaching from thoughts, present moment awareness, mindfulness (able to give examples; 5/5 importance) | Yes – (4/5 importance) | Yes - more body aware, less dwelling on negatives, able to deal with past issues, have gone back to gym (5/5 importance) | values |
| Attributed to intervention? | / | Yes (1/5 likely to happen without intervention) | Don’t know | Yes (1/5 likely to happen without intervention) | Yes (1/5 likely to happen without intervention) | Likely to have happened anyway but achieved quickly |</p>
<table>
<thead>
<tr>
<th>External events?</th>
<th>Chronic stressors – family, health, relationships</th>
<th>None</th>
<th>Chronic family stressors</th>
<th>Health stressor</th>
<th>None</th>
<th>with intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td>Very determined person</td>
<td>/</td>
<td>Difficulties with cognitive symptoms</td>
<td>Receptive audience – already practice mindfulness/meditation</td>
<td>/</td>
<td>/</td>
</tr>
<tr>
<td></td>
<td>Difficulties with cognitive symptoms</td>
<td></td>
<td>Wants to re-read in own time</td>
<td>Will continue to use</td>
<td></td>
<td>/</td>
</tr>
</tbody>
</table>

*Table 12: Change interview data from six participants summarised by question.*
### 3.3 IRAP

The IRAP software generates overall D-IRAP scores for each trial: these are summarised in the table below.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Data point</th>
<th>Overall D-IRAP score</th>
<th>Bias</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Pre</td>
<td>0.618091</td>
<td>Consistent</td>
</tr>
<tr>
<td></td>
<td>Mid</td>
<td>0.343444</td>
<td>Consistent</td>
</tr>
<tr>
<td></td>
<td>Post</td>
<td>0.520994</td>
<td>Consistent</td>
</tr>
<tr>
<td></td>
<td>Follow up</td>
<td>0.571308</td>
<td>Consistent</td>
</tr>
<tr>
<td>2</td>
<td>Pre</td>
<td>0.448942</td>
<td>Consistent</td>
</tr>
<tr>
<td></td>
<td>Mid</td>
<td>0.178884</td>
<td>Consistent</td>
</tr>
<tr>
<td></td>
<td>Post</td>
<td>0.468416</td>
<td>Consistent</td>
</tr>
<tr>
<td></td>
<td>Follow up</td>
<td>0.374653</td>
<td>Consistent</td>
</tr>
<tr>
<td>3</td>
<td>Pre</td>
<td>0.0538</td>
<td>Consistent</td>
</tr>
<tr>
<td></td>
<td>Mid</td>
<td>0.260114</td>
<td>Consistent</td>
</tr>
<tr>
<td></td>
<td>Post</td>
<td>-0.11114</td>
<td>Inconsistent</td>
</tr>
<tr>
<td></td>
<td>Follow up</td>
<td>0.225424</td>
<td>Consistent</td>
</tr>
<tr>
<td>4</td>
<td>Pre</td>
<td>0.216557</td>
<td>Consistent</td>
</tr>
<tr>
<td></td>
<td>Mid</td>
<td>-0.0635</td>
<td>Inconsistent</td>
</tr>
<tr>
<td></td>
<td>Post</td>
<td>-0.32318</td>
<td>Inconsistent</td>
</tr>
<tr>
<td></td>
<td>Follow up</td>
<td>0.224273</td>
<td>Consistent</td>
</tr>
<tr>
<td>5</td>
<td>Pre</td>
<td>-0.34878</td>
<td>Inconsistent</td>
</tr>
<tr>
<td></td>
<td>Mid</td>
<td>-0.0155</td>
<td>Inconsistent</td>
</tr>
<tr>
<td></td>
<td>Post</td>
<td>-0.12926</td>
<td>Inconsistent</td>
</tr>
<tr>
<td></td>
<td>Follow up</td>
<td>-0.41637</td>
<td>Inconsistent</td>
</tr>
<tr>
<td>6</td>
<td>Pre</td>
<td>-0.65319</td>
<td>Inconsistent</td>
</tr>
<tr>
<td></td>
<td>Mid</td>
<td>-0.20139</td>
<td>Inconsistent</td>
</tr>
<tr>
<td></td>
<td>Post</td>
<td>-0.59314</td>
<td>Inconsistent</td>
</tr>
<tr>
<td></td>
<td>Follow up</td>
<td>-0.08888</td>
<td>Inconsistent</td>
</tr>
</tbody>
</table>

*Table 13: Overall D-IRAP scores at the four points for each participant: scores closer to zero indicate less bias, therefore potentially a more flexible style of responding.*
Data from the implicit measure was highly variable between participants, as indicated in the graph below, but appeared to remain largely stable within participants from pre to post intervention and follow up, with only one participant (P6) indicating a trend towards more flexible responding in relation to wellness and illness beliefs.

![Graph showing D-IRAP scores for each participant at pre, mid, post intervention and follow up.](image)

*Figure 14: D-IRAP scores for each participant at pre, mid, post intervention and follow up: scores closer to zero indicate fewer biases and therefore may indicate increased flexibility in responding.*

Literature from similar implicit procedures suggests cut off points to evaluate response biases as ‘slight’ (.15), ‘moderate’ (.35) and ‘strong’ (.65) (Greenwald 2003).

### 3.4 Results by participant

**Participant one.**

Overall psychological flexibility for this participant appeared to improve upon introduction of the intervention and throughout the six weeks at a greater trend than indicated by the baseline scores, however the follow up indicated that this had deteriorated back to a pre-intervention level.
On the ACT process measures, change was varied. There was no change on the awareness scale of the PHLMS, although a slight increase in scores from pre to post were further built upon at follow up – a non-significant trend, this may represent either error or meaningful change. There was pre-post clinically significant change on the Acceptance scale. The baseline acceptance score was below the clinical mean for this measure. Although the post-treatment score was still within two standard deviations of the mean of the clinical sample, this change was considered clinically significant because it was closer to the normative mean than the clinical mean. The follow up score had deteriorated from post treatment; it did not indicate reliable positive change from baseline, although it had moved from below to above the clinical mean.

Baseline score on the CFQ was already more than two standard deviations above the normative mean; this deteriorated reliably at post-intervention although was not considered significant as the score remained above this mean. At follow up the score had once again improved beyond the baseline score.

On the MAAS, average scores deteriorated reliably from pre to post intervention. Despite this decrease, both pre and post treatment scores were higher than the mean of the clinical population; the pre-intervention score is above the mean of the normative population and drops slightly below post intervention. Scores at follow up however had improved once again, to above the pre—intervention score and above both the normative and clinical mean, although the baseline to follow up change was not calculated as reliable.

The scores from the ELS indicated pre-post reliable change – the pre intervention score was just below the normative average for this measure, and moved to more than two standard deviations above this post-intervention, therefore change was considered to be clinically significant also. Follow up scores indicated some deterioration from post-intervention although it remained higher than the average score for this measure and baseline to follow up change was calculated to be reliable.

Change on the Chronic Fatigue Questionnaire was reliable and clinically significant, moving from more than two standard deviations above the mean at pre intervention
to more than two standard deviations below at post intervention. At follow up fatigue scores had increased but remained reliably and significantly lower than baseline.

In summary, the quantitative measures indicated improvements in overall flexibility, in acceptance, in engaged living and decreases in symptoms.

The D-IRAP score calculated for this participant at baseline indicated a bias towards consistent items on the test, just below the suggested cut-off for a 'strong' bias. The results at post-intervention and at follow up were largely stable, with the mid score dropping to a moderate effect size in the same direction.

Unfortunately no Fitbit data was collected for this participant due to technical difficulties and some discomfort with wearing the monitor.

This participant gave a mixed account of the intervention in the change interview – they were willing and pleased to take part in a research project. They noted that the content of the text was partly repetitive of content that had been covered in the group (treatment as normal); some of the content was not useful and generally the text was too long, but equally there were aspects that they found interesting and helpful. There was no subjectively reported change in fatigue or disability symptoms. This participant noted multiple stressful and chronic external events occurring throughout the intervention and still evident at follow up. They described individual factors such as a very determined personality with perfectionist traits and gave external lifelong examples as well as examples in relation to this research study. Subjective data from researcher process notes indicates little behavioural change but improved mood at follow up.

**Participant two.**

This participant indicated low baseline scores of overall psychological flexibility and an ongoing improvement upon introduction of the intervention. At follow up these improvements had deteriorated slightly although psychological flexibility remained higher than at baseline and as indicated by baseline trend and in line with scores within the latter half of the intervention.

With regards to the individual ACT measures, there was no change on scores pre to post intervention on the awareness scale of the PHLMS. Pre post intervention scores on the acceptance scale changed reliably and were deemed clinically
significant: the pre intervention score was below the clinical mean and the post-intervention score was closer to the mean of the non-clinical sample than the clinical sample. At follow up this score had deteriorated again to below the clinical mean although not back to baseline levels: pre to follow up change although positive was not reliable.

Pre to post intervention scores on the CFQ deteriorated and this change remained at follow up. Scores on this measure for this participant were however above both normative and clinical means at pre and post intervention and follow up despite the deterioration in scores.

Scores from pre to post intervention on the MAAS changed reliably and were judged to be clinically significant, as scores moved from beyond two standard deviations below the mean of the clinical sample at baseline to post intervention within two standard deviations of this mean. This score had deteriorated again at follow up and baseline to follow up change although seemingly positive was not reliable.

On the ELS, pre to post intervention scores changed reliably and were clinically significant: scores went from below two standard deviations of the mean at pre intervention to an average score at post-treatment. This was maintained at follow up.

Fatigue scores on the CFQ changed reliably and were considered clinically significant, moving from pre-intervention at two standard deviations higher than the mean to post-intervention within one standard deviations of this average score. This change had improved further at follow up, with fatigue ratings dropping below the average: baseline to follow up change was reliable and clinically significant.

In summary, reliable change was noted from pre to post intervention on the acceptance scale of PHLMS and all other ACT measures, which was in a positive direction for all except the Cognitive Fusion Questionnaire. Positive change was only maintained at follow up on one measure, the ELS. Reliable and significant change was maintained from baseline to follow up on the fatigue ratings.

D-IRAP scores for this participant follow a similar pattern as for participant 1: the pre, post and follow up trials indicate fairly stable moderate consistent biases, with only the mid-intervention trial indicating a change from moderate to slight.
Fitbit data indicated an increase in physical activity from pre to post intervention, which was further increased at follow up. Evidence of specific increased activity was described in the participation of events such as ‘Tough Mudders’ and sponsored walks.

Participant two described a key behavioural change occurring during the course of this intervention, in securing new job. This was described as an important change (5/5), something they had wanted to do for a while, and was related to the intervention in that it was part of the process of ‘listening to themselves’ – it was rated as 1/5 likely to have happened without this intervention. This change in a chronic situation and the subjective appraisal of the intervention being a key part of this adds support to the positive role of this intervention. This participant did not describe any key stressors or external events that were likely to have influenced participation in this intervention.

**Participant three.**

Scores of overall psychological flexibility for this participant appeared to deteriorate slightly throughout this intervention, although the overall trend was largely in line with and slightly above the baseline trend. Scores at follow up were higher than at immediately post-intervention and in line with estimates from baseline trends.

This participant indicated a higher than average level of acceptance at baseline on the acceptance scale of the PHLMS with no reliable change post-intervention and a consistent score at follow up. Scores on the awareness scale indicate reliable positive change that was nonetheless not clinically significant.

There was no reliable change from baseline to post intervention or follow up on the CFQ; this participant’s scores were above the clinical and normative means throughout.

Pre to post intervention scores on the MAAS indicate reliable and significant deterioration, with post intervention scores closer to the clinical rather than the normative mean, scores that remained largely stable at follow up.

Similarly to the previous measure, scores on the ELS indicate reliable change in a negative direction from pre to post intervention which is largely stable at follow up.
This change was however not considered clinically significant as scores remain with two standard deviations of the mean.

In summary, there were no clinically significant improvements noted on any of the ACT process measures.

Fatigue ratings on the CFQ indicated deterioration from baseline to post intervention, change that was reliable but not clinically significant. This score returned to average at follow up.

All of the D-IRAP scores for this participant indicated a 'slight' bias only, with largely stable results at pre, with a change in the direction of the bias noted at post-intervention only.

The behavioural measure indicated a significant increase in physical activity which was maintained at follow up.

This participant was ambivalent about this intervention in the change interview. Throughout the intervention it was noted that cognitive symptoms associated with CFS, such as reduced concentration and memory and cognitive fatigue, were significantly interrupting engagement, hence in this case it was extended for an extra week to allow additional time for reading. Despite these difficulties this participant indicated interest in reading the text again at a slower pace after the intervention; similarly they felt that in general important changes were taking place, although it was difficult to judge the extent to which this was related to the text. One specific example was described in which this participant was able to engage in a valued activity despite aversive thoughts about pain and fatigue. This participant noted chronic external stressors that were present throughout this intervention.

**Participant four.**

Overall scores of psychological flexibility increased significantly upon introduction of the intervention and throughout the six weeks, in contrast to baseline trend, with post-intervention scores maintained at follow up.

Reliable and clinically significant change was recorded on all of the ACT process measures and was maintained at follow up.
This participant indicated high levels of awareness on this scale of the PHLMS that were maintained, but low initial levels of acceptance that improved throughout the intervention to beyond the normative mean. Scores on the CFQ moved from below the normative mean to above this. MAAS scores moved from below both clinical and normative means at baseline to above both means post intervention and at follow up. Scores on the ELS had continued to rise at follow up and fatigue scores on the CFQ had continued to fall.

The mid and post intervention trials indicated a change in the direction of the bias as recorded by the IRAP, but the baseline and follow up results indicated a fairly stable, slight bias towards consistent responses.

Fitbit data indicates an increase in physical activity from baseline to post intervention that was not maintained at follow up.

This participant noted in the change interview multiple positive changes as a result of this intervention, including an increase in behavioural repertoire and strategy use for difficult situations: they were able to give examples of being mindful when stuck in traffic, changing thoughts related to fatigue and using a variety of techniques to cope with a significant external stressor that occurred in the early stages of the intervention. Changes also included a behavioural consequence of the values work, as the participant applied for and secured interviews for alternative employment in the latter part of the intervention. They felt that the exercises in the text were particularly useful. This participant noted that they were already interested in the content of this intervention such as mindfulness. They also noted pre-existing physical injury that was separate from the CFS which may have affected some of her responses on the SF12 subscale.

**Participant five.**

Overall levels of psychological flexibility were low for this participant at baseline, deteriorated slightly throughout the intervention and remaining at this level at follow up.

There was no reliable change on any of the ACT process measures from baseline to post intervention. Low pre intervention scores were noted on the acceptance scale of the PHLMS, the CFQ, the MAAS and the ELS. From baseline to follow up scores
on the ACT measures remained largely stable, although reliable change was noted on the awareness scale of the PHMLS.

Fatigue scores on the CFQ indicated reliable change in a positive direction from pre to post intervention but this change was not considered clinically significant given that levels remained high and above the mean. Fatigue levels increased to higher levels than pre-intervention at follow up.

The mid intervention trial of the IRAP indicated a drop in biased responding for this participant, but all other results indicated a fairly stable slight bias towards inconsistent items, with the final result just falling into the level of ‘moderate’.

Fitbit data indicates an increase in physical activity from pre to post intervention; at follow up data had deteriorated slightly from post intervention but remained closer to this than to the pre intervention levels, indicating some maintained increase in physical activity.

This participant described that this intervention had improved their insight and understanding as to their experience, rating it as ‘very helpful’. The Fitbit was identified as one of the most important parts of the intervention, encouraging them to notice how much activity was done and the contrast between this and cognitions and evaluations about levels of activity. This participant also noted the importance of the researcher as part of the intervention.

**Participant six.**

Overall levels of psychological flexibility improved from baseline to post-intervention. Scores had decreased again at follow up although they remained higher than would be expected from baseline trends.

There was no reliable change from pre to post scores on the awareness scale of the PHLMS but reliable change in a positive direction on all other ACT process measures. Change on the acceptance scale of the PHLMS and the MAAS was also clinically significant.

Fatigue levels as indicated by the CFQ decreased from pre to post intervention, moving from above to below the mean for this measure; this change was reliable and significant, and had further decreased at follow up.
This participant initially indicated a strong bias on the IRAP towards inconsistent items: this fluctuated at mid and post intervention trials and had dropped to a slight bias in the same direction at follow up.

Fitbit data indicated high levels of activity at pre intervention that increased at post intervention but had returned to previous levels at follow up.

In the change interview, this participant spoke very positively about the intervention. There was a week mid-intervention where data collection was ongoing but no additional reading was supplied, as with participant three: this participant was experiencing severe migraine at this time and was unable to engage in the intervention. It was noted that the material was challenging particularly in the context of the cognitive symptoms of CFS, but value was attributed to the text, with this participant stating they would like to engage more fully in the suggested exercises over a longer timeframe once the study was complete. This participant gave clear examples of increased participation in meaningful activity such as starting the gym again and re-joining a rowing club. They acknowledged chronic work stressors that they felt unable to change.

4. Extended Discussion

4.1 Key finding – an increase in an Engaged Response style

The finding that an increasingly engaged response style was indicated across four participants, and maintained over the follow up period, suggests that this approach may have incremental value over existing interventions. This finding can be understood in the context of literature cited in the introduction regarding the importance of patient activation and empowerment in improving physical and clinical outcomes in chronic illness, and in balancing a commitment to behaviour change in response to illness with an acceptance of illness boundaries into a personally coherent and meaningful narrative – an approach explicitly embodied by the ACT model.

The change interview data added validity to the quantitative data: values work was explicitly mentioned by four out of six participants as a key aspect of the intervention, a number which largely corresponds to the clinically significant and maintained change seen in objective data as measured on the ELS. It should also be noted
however that one participant cited this as important but indicated decreasing scores on the ELS post intervention. Previous literature has indicated that both brief ACT interventions and those in a self-help format can be effective, which was part of the rationale for using this format in this study, however several of the participants highlighted some of the pragmatic difficulties of the values aspect of this intervention in particular. For example, two participants became aware of discrepancies between their work and their values: both actively addressed this within the timeframe of the study, with one successfully gaining an alternative job, whilst the other began applying. It is perhaps understandable that effecting demonstrable change is difficult in only six weeks, given the practical and logistical challenges that may be associated with this. Similarly it is possible that by encouraging reflection on valued living enables such discrepancies to enter awareness and become more salient and perhaps more distressing, particularly if unable to be quickly addressed, which could be reflected in deteriorating scores on the ELS. A longer follow up period and potentially a longer intervention would be interesting to reflect on the timescale of such change. However in this study scores on the ELS did improve and were maintained in four of six participants; whilst further exploration therefore of the barriers to change is necessary, this intervention remains promising.

4.2 Behavioural data – the Fitbit

There are undeniably some concerns about the validity of the Fitbit data, complicated by the data collection methods in which daily feedback was not possible. However, similarly to evidence of change in terms of values, evidence of increased activity from the Fitbit was supported by qualitative evidence from the weekly phone contact and from the change interviews. For example, participants spoke about re-starting the gym, joining a sports club, engaging in a charity race for the first time, and going to the park with family more often. A feature of the average recording of activity across a week is a more stable assessment, with the recognition that there may be a number of external factors contributing to daily fluctuations in activity levels. Some of these were noted in the qualitative data, including changes in routine due to public holidays, work and family commitments and also ill-health: one participant experienced severe headaches for a few days and activity was significantly limited. The average measures in this study give an overall indication of activity on a weekly basis throughout the intervention.
In challenge to the argument that the Fitbit itself might be the mechanism of change, it is recognised that the Fitbit is a self-monitoring form of persuasive technology, and in normal conditions is hypothesised to work with conditioning and reward in the form of feedback and meeting goals and targets, with reinforcement from the software and from online communities – these aspects were not accessible to participants in this study as they were unaware of the passwords required to access the online forum for their data (Fritz, Huang, Murphy & Zimmermann, 2014). Simply wearing an activity monitor without feedback or self-monitoring options has in previous studies been used as a baseline measure – change is seen when self-monitoring is introduced, therefore indicating a functional relationship between activities and monitoring (Ibid). Behaviour, activity and functional outcomes remain challenging to assess in studies conducted outside the laboratory – self report measures are susceptible to unreliability, observation is difficult pragmatically, and biological monitoring is often costly. Although these results should be interpreted with caution considering the possible limitations, the Fitbit is nonetheless an interesting and useful way to gain this information (VanWormer, 2004).

In consideration of previous literature and understandings of this population, such as the boom and bust patterns of activity as well as high recorded rates of maladaptive perfectionism, it seems likely that self-monitoring may be powerful motivator for this population, although not necessarily a helpful one. This may contribute to the argument that GET is found to be unhelpful and even damaging for some individuals with CFS, as explored in the introduction, particularly in the context of a structured, generic intervention, rather than something more idiographic and flexible. Change across participants was variable as in all other measures, although in some the changes in activity levels were marked; it is important to note that within the timeframe of the study, no adverse effects were noted. At follow up there was some evidence that increased activity levels had not been maintained: whether this relates to unsustainable increases throughout the intervention, to the removal of the psychological intervention, or other intervening factors it is difficult to say. The Fitbit default daily target is 10,000 steps a day, a recommendation frequently cited within popular literature (Tudor-Locke, Hatano, Pangrazi, & Kang, 2008): given the increases noted across multiple participants, only one participant was above this level at baseline and one further participant increased activity to above this level at
post-intervention and follow up. It could be seen then that activity increases remained within a normal and non-damaging range.

Even considering the controversies and concerns noted with GET, there may still be a role for increasing physical activity for this population in a reasonable and gentle manner, given the overall beneficial effects of exercise: within an ACT model specifically, an increase in activity is a key outcome as long as that activity is meaningful and values-driven. Physical activity per se is not a key outcome. This is reflected in the study design, in that participants were not explicitly asked before this study about whether they would like to increase their physical activity levels or which types of activity would be meaningful: however, data synthesised from both qualitative and quantitative measures suggests that each participant found different ways of engaging in increased activity, indicating that these had individual value. Perhaps this intervention, without an explicit focus on increasing exercise but instead increasing valued activity, is a more acceptable and an important means of engaging this population – the encouragement of idiosyncratic, values-based goals over the imposition of a protocol may be more congruent with this complex population.

4.3 ACT process measures

In the change interviews, participants two and six cited mindfulness as a particularly important aspect of the intervention and both of these participants experienced clinically significant change on the MAAS from baseline to post intervention (at which point the change interview was conducted); the conjunction of these two results gives some support for their validity. Four participants indicated baseline scores below the mean of a comparative clinical sample on the MAAS, perhaps suggesting that within this sample at least initial levels of mindfulness were low; three individuals indicated clinically significant change post-intervention, but this was only maintained in two. When evaluating clinically significant change, it was clear for this measure that the clinical and normative means are very close, therefore reliability of change was prioritised. Within an ACT model, mindfulness is seen as one of several key processes underlying psychological flexibility; there is also substantive literature documenting the positive effects of mindfulness in its own right (Academic Mindfulness Interest Group, Melbourne, 2006); noting that this sample indicated low scores at baseline, this too could be a key target for intervention. Mindfulness
interventions may be useful, but the change on additional process measures such as acceptance and valued living indicates that this more comprehensive model might have further promise. Mindfulness literature does suggest that benefits increase with time and frequency of practice: as with the acceptance measure there is scope to explore further how this change could be maintained.

The clinical and normative means on the awareness scale of the PHLMS were also close. On this measure, four out of six participants indicated levels of awareness at baseline that were already equal to or greater than the normative mean, indicating generally good awareness. This measure was not prioritised as awareness was conceptualised as part of mindfulness, which was measured independently with an alternative scale (the MAAS). There were however some discrepancies between the results indicated by this scale (good levels of awareness) and by the MAAS (low levels of mindfulness) – further research into the processes underlying the model, the clear operationalisation of these and the development of accurate measurement tools is warranted.

Given the model on which this intervention is based, with increasing evidence to support its use across a range of diagnoses, the lack of change on some of the process measures deserves consideration. On the CFQ four out of six participants were already above a comparative clinical mean, indicating low levels of fusion. It could be that there is more generally a floor effect on this measure, as the scores were already high so there was limited room for improvement; hence the scores from the questionnaire indicated little change. This could also be true for the awareness measure discussed above. Participant 1 for example indicated deterioration on the CFQ, although the post-intervention score remained above the mean score for a comparative sample. This finding could be a result of regression to the mean, considering the extreme value to begin with, or it could represent the participant’s socialisation to the ACT model and therefore a changing understanding as to what fusion is, reflected in the answers to the questionnaire.

Previous studies have suggested that ACT may not work quite as well for minor problems and less entangled and avoidant clients, which perhaps could help to explain varying levels of change (Forman, Herbert, Moitra, Yeomans, & Geller, 2007). However, participant five, indicating least positive change across the
outcome measures, indicated low scores on all of the process measures at baseline. Similarly, levels of fusion were generally indicated to be low therefore a description of the sample as less entangled might be relevant, but low acceptance scores and valued living scores indicates higher levels of avoidance.

A visual analysis of the data across measures and across participants indicates little evidence for event-shift sequences on the individual process measures with change instead appearing to occur in individualised patterns with a stable overall trend. This does not support the initial hypothesis that change would be clearly seen to occur in line with the specific processes targeted by the intervention. It is important to recognise that this hypothesis was based on the implicit assumption that change in specific processes, as targeted by specific text selections, would respond with a similar temporal pattern, that is that by reading about it one week, we would clearly see change the next: upon reflection this is perhaps an assumption that needs further clarification within the literature more broadly, and which doesn’t seem to be supported within this study. This could be for a number of reasons for this finding here including issues with the model but also individual participant factors and limitations of the design, as discussed in more detail below.

Once again considering the previous literature in support of ACT interventions being able to effect change in both brief and self-help formats, it may nonetheless be interesting to further explore whether a longer intervention could facilitate further change in this population, particularly considering some of the cognitive barriers to accessing this intervention as highlighted in the change interviews and discussed further below.

4.4 Overall psychological flexibility

As an overarching mechanism combined of the processes discussed above, there were similar overall trends of change rather than event shift patterns in the measure of psychological flexibility. This may have been expected if as suggested by the model each process contributes equally to the overarching whole and responds predictably to the intervention. However the patterns of changes in psychological flexibility as associated with other outcome measures are not clear: the participant that indicated most change on the overall psychological flexibility measure did not correspond with the largest increases in physical activity for example. The participant
with the lowest scores originally did show most change, ending up with the highest scores at follow up – otherwise variability is evident in initial scores and overall volume and direction of change. There is therefore no clear indication from this study as to which process might be the most important driver of change, or indeed what the common mechanism of change was. Once again there are a number of study limitations that could have contributed to this effect, however there are still questions raised about the precise mechanisms of this model that are deserving of further exploration, if it is to be useful. It may be that the model has veracity but it is limitations of measurement that give rise to ambiguous results. The individual processes do not yield easily to functional analysis, but this kind of work contributes to an increasing body of knowledge to explore this.

A stable or deteriorating trend was required at baseline, as evaluated by visual analysis: this was achieved in all participants within the minimum two week time span, although measures of stability calculated at the end of data collection did vary across the larger data set. The various procedures used to analyse this measure in more detail were chosen to give an indication of how much variation there was in the results, and in turn contribute to the evaluation of how clearly and confidently we can report change; it is recommended that various measures are used in recognition of the limitations of single measures (Lane & Gast, 2014). As suggested by other analyses throughout this study, results varied by participant and by procedure used.

The ACT model conceptualises psychological flexibility as an overarching skill that contributes broadly to effective behaviour and mental health, and that is transferable across situations, hence its claim to be trans-diagnostic – given this, we would expect and hope that indications of psychological flexibility post-intervention were stable. This means that participants were able to employ these skills despite any external or contextual influences. High levels of variability in some participant’s data, for example participant four, may reflect a self-report response style and indeed high levels of variability was evident in baseline as well as throughout the intervention phase. Nonetheless the percentage of non-overlapping data for this participant suggests a high level of change in a therapeutic direction, as suggested by the other analyses too.

4.5 Fatigue and symptoms
Given the pattern of symptom reporting, it is possible that the decrease in reports of symptoms were a result of demand characteristics during the intervention phase of the study. This is not an issue that has been noted in other studies with similar samples and the collection of the measures via an online questionnaire should have limited the influence of the researcher as prompting bias in responding.

Whilst the fatigue scores and symptom scores were lower for some of this sample compared to other CFS samples, the qualitative data indicated the significant impact of the problems for each participant in this sample. The range of difficulties experienced by individuals with a diagnosis of CFS is well documented, and it may have been relevant to incorporate further measures to assess the individual impact of the syndrome, although some of this became apparent in the change interview data. The discrepancy between the desire from these individuals for further intervention and the scores of their fatigue levels and symptoms on the measures is interesting: whether this relates to personality factors such as maladaptive perfectionism and/or a desire for symptoms to be eliminated completely, or whether other factors such as the psychological measures contribute more to perceived levels of distress could be worthy of further investigation and may affect how we conceptualise this diagnosis and services in the future. Whilst symptom reduction is often an individual goal at the beginning of an intervention, the ACT model argues that change in other outcomes such as engaged living and quality of life is in any case both more realistic and more desirable, so these were important outcomes in this study. It is not known how this intervention would have worked with a sample of more physically symptomatic participants.

4.6 Stem completion task

There were two versions of this task developed for the study, one which relied on the participants to generate their own terms and one which provided more structure in order to do so. Each participant in the study completed the first version of the task with ease, being able to quickly generate terms associated with wellness and illness, indicating the saliency and familiarity of these beliefs. Similarly, the content of the answers was remarkably similar across participants and fits with previous literature in that they were evaluative rather than simply descriptive, for example ‘when I am unwell I am useless’. Within the ACT model this could be an example of cognitive
fusion, whereby evaluations become literally interpreted and fused with an individual's sense of self, and having a direct, often unhelpful, influence on behaviour.

4.7 The IRAP

The generation of idiographic terms from the stem completion task was a novel use of the IRAP and a strength of this study in that it allowed fully individualised data in line with the design and aims. This measure was used experimentally, with limited previous research to guide our expectations of change. It was hypothesised that a decrease in biases, indicated by D-IRAP scores closer to zero, might indicate implicit change towards different health beliefs and more flexible responding, a key outcome of the ACT model, as participants adapted their beliefs to more inclusive and dynamic concepts of health, ill health and self. This would also hypothetically be reflected in behaviour change, as has been indicated in other IRAP studies (Nicholson & Barnes-Holmes, 2012). However it would also be possible within an ACT framework to hypothesise that behaviour could change without implicit beliefs changing: this would indicate less fusion with thoughts and beliefs, so that initial beliefs remained that same but the repertoire of behaviour that succeeded these beliefs became greater and more flexible. In this case the D-IRAP scores were actually quite stable, indicating that participant’s implicit beliefs about when they are well or unwell did not change as a result of the intervention. In conjunction with the witnessed increases in physical activity, this adds greater weight to the latter hypothesis.

There are a number of factors to consider when evaluating this novel use of the IRAP. In this study participants generated idiographic target terms related to wellness and illness, as a means of enhancing the validity and the salience of the measure. However it is not known whether the difference in length of the responses generated would have made a difference to results – longer terms would have taken longer to read therefore longer to respond to. However each participant was their own control, therefore any changes over time should still have been noticed.

A further possible complication of the use of the IRAP was the cognitive symptoms noted by the participants: the time limit for responding was increased from 2500ms to 5000ms to allow extra time as several of them struggled on the initial practice
tests. This does have implications for the validity of the results, possibly allowing the argument that a longer timeframe allowed explicit processing rather than accessing implicit beliefs; however, this change was small and as previously described, it was decided that as each participant acted as their own control it was of more importance to keep the test consistent across trials than to be able to compare to the wider population. It is recognised that the response window for implicit responding is variable – in this sample less time to respond visibly increased stress for some participants, which in itself may have impacted on the validity of the results. Higher levels of stress may also have prompted withdrawal from the task. This highlights the potential role of individual personality traits that may have interacted with this specific procedure as well as within the study more generally: several participants notably wanted to focus on getting the answers right rather than responding quickly, and felt increasingly distressed by not achieving this: whether this reflected more strongly held beliefs or high levels of perfectionism for example, is not known, nor how this might interact with the intervention. Cognitive symptoms did appear to fluctuate for the participants and several mentioned at one of the trials of the IRAP that they felt particularly tired or were struggling to concentrate: it is not clear how this might have affected their implicit responding.

There were some fluctuations in terms of direction and magnitude of responding, however the initial IRAP results indicated that most participants were quicker to respond to consistent rules as expected, and that this largely remained stable at follow up. All participants indicated responses within the moderate range, therefore indicating moderate levels of bias or fusion.

The results of the IRAP as used here indicate little evidence in support of the efficacy or importance of measuring implicit change as related to behavioural change, however this is in contrast to some previous research (Nicholson & Barnes-Holmes, 2012) and could be the focus of further investigation, to establish why there is some discrepancy and whether or not this could be a necessary and/or useful measure of therapeutic change in the future.

4.8 Change interviews

One key consideration is the individual factors and context that inevitably influenced this study. Previously, change interviews have been employed within Hermeneutic
Single Case Study designs with an independent judiciary panel assessing the strength of the evidence within cases; in this study the interviewer was independent but the information gathered was considered by the primary researcher. Given that the quantitative data gave clear indications of clinically significant change, this technique within this study allowed a description and further understanding of the context of such change for the individuals involved, in line with the epistemological and theoretical approach.

It is well acknowledged that some people are more likely to benefit from particular interventions than others, as was indicated here. One participant was already engaged with mindfulness practice and had some knowledge of Acceptance and Commitment Therapy previously - their scores were nonetheless low at baseline; they indicated the highest levels of change in overall psychological flexibility and consistently across the ACT process measures. This participant’s initial interest in mindfulness and meditation perhaps indicated that they would resonate with this text, but just as ACT would argue that it is more than just mindfulness practice, so this intervention seemed to have significant positive effects beyond her current practice.

All participants appeared highly engaged in material as previously noted but some agreed with the content more readily than others and a more thorough and structured investigation of personality factors as influencing engagement with and interest in the text would be useful, particularly if they could be used to predict change.

Given the context of the controversies of currently recommended treatments for CFS, it is important to reiterate that no participants stated in the change interviews a negative impact of taking part in this intervention, either physically or psychologically.

The guidelines note that it is important to consider inter-relational dynamics and self-presentational patterns in change interviews – overly positive attributions of change and therapy were certainly noted in participant four, who deteriorated or remained stable on most measures, yet spoke in the change interview about successful and positive change in terms of the processes within the text as well as functionally, in terms of changed behaviour. This participant made particular reference to the importance of the therapeutic relationship; this is very well-documented as being key to psychological therapy, but in this study the self-help format meant that participant-
researcher contact was limited to just one phone call a week of around 10 minutes duration. It was not noted by the primary researcher throughout the intervention that this participant asked for any more support than others or relied any more heavily on the researcher. There were similar demographic factors between the primary researcher and this participant that may have encouraged a positive view of the alliance. Hypotheses as to the discrepancy between the subjective reporting and the objective measures might include wanting to protect the alliance, or individual factors relating to the perceived importance and availability of social support.

The long duration of the problems experienced by some of these participants, including previous and ongoing contact with the specialist CFS service, make it unlikely that self-correctional processes accounted for the change seen in this study; there did not seem to be any relation to duration of the problem and amount of change seen. This further adds some validity to the results. Participants reported various previous self-help strategies: participant one spoke about deciding to continue as normal (i.e. before the diagnosis), which could be understood as low levels of acceptance and high levels of avoidance – this participant reported high levels of symptom experience at baseline and throughout the intervention, although process measures and the overall psychological flexibility measure did indicate some positive change. Other participants, as mentioned, had employed various coping strategies such as mindfulness, distraction and of course the group treatment provided by the service, with varying levels of success. The chronicity of this experience and the challenges associated with treating it are evident; in this context, the changes seen with this brief, self-help intervention are considerable.

Whilst there is previous research as to the efficacy of ACT as a self-help intervention, it is also understood to be a functional psychotherapeutic approach designed to be flexibly applied for an individual and their context (Eifert et al., 2009) – as such there are possibly some limitations of the self-help approach, but all participants seemed able to apply it to their own individual contexts as evidenced by the personal examples of the particular techniques being used. This indicates that this approach and this format has some utility despite the noted heterogeneity of this population.
It would have been interesting to return to the participants and ask further, more targeted questions once the results had been analysed, to seek their own interpretations of their individual results, although the potential for outcome bias would then be high.

4.9 Strengths and limitations

Inclusion of participants into the study relied on self-selection and therefore self-report with regards to the need for further intervention: participants were not included or excluded based on particular levels of symptom reporting for example. The limitations of this include the possibility of self-selecting bias as already mentioned; it similarly limits comparability to other studies which do include such constraints and rely more heavily on objective severity of the diagnosis to inform evaluations of clinical need. However there are ongoing debates as to the utility of such evaluations as accurately reflecting individual levels of distress or functional impairment and so subjective report has some advantage: this also was also an ecologically valid approach in that it reflects the workings of the particular specialist service from which these participants were recruited, which relies mostly on clinical judgement to inform intervention rather strict cut offs on objective measures.

One limitation of this study, and an area in which further research would be beneficial, is in the lack of a quality of life measure – it is noted that this is an important aspect of an ACT approach, with an emphasis on values driven behaviour, and potentially an outcome which could indicate incremental value when compared to approaches such as traditional CBT; this therefore would be an important means of assessing whether or not this approach might have further benefit to the currently recommended alternatives. Within this study, the SF-12 subscale is a means of briefly evaluating the impact of disability, in consideration of participant burden and fatigue, and replicates other studies with this population, such as the PACE trial: however the different model within this study, with a different emphasis on outcomes, would have benefitted from further assessment of quality of life. Despite noting it’s congruence with an ACT model, quality of life is not explicitly included within ACT theory or in specific measures.

Health quality of life (HQOL) measures are increasingly considered valid indicators of service needs and intervention outcomes, in light of a body of literature suggesting
that self-assessed health status is a more powerful predictor of mortality and morbidity than many objective measures of health (Centre for Disease Control and Prevention (CDC), 2011). The main barrier to the use of HRQOL as an outcome indicator is the lack of a common definition and measuring standard – it is recognised as subjective rather than an objective concept, and to be multi-faceted, including but not limited to evaluations of physical health, social status, role, cognitive function, mental health, feelings of vitality and levels of pain (Chen & Li, 2005). Given these conceptual complexities there are a number of possible measures that could have been included in this study. Generic HQOL options recommended by the Centre for Disease Control and Prevention (CDC) include the full SF-36, the Sickness Impact Profile and the Quality of Well-being scale, all of which are comprehensive and lengthy measures (CDC, 2011). The Dartmouth COOP Functional Health Assessment Charts (COOP/WONCA Charts) are shorter and straightforward, but give non-quantitative data which may limit analysis (Chen & Li, 2005). In future research the measure chosen would necessarily depend on the aims and design of the research and the priority placed on a HQOL outcome measure.

A further outcome measure that would have been useful to assess is that of mood. Subjective observations from the primary researcher were that this improved in participants throughout the intervention and at follow up, although this was not a robust enough observation to be considered in the results. A measure of mood would have added validity to the ideas of this approach as improving personally meaningful outcomes, perhaps beyond that of traditional interventions. Similarly, in conjunction with a quality of life measure, this may be a way of comparing degrees of distress and treatment need within the sample as opposed to current clinical measures of disability as indicated by a medical model, which do not consistently correlate with quality of life. There are a number of established comprehensive questionnaires assessing mood, including the Profile of Mood states and the Positive and Negative Affect Schedule (PANAS); this latter scale additionally has an online application named ‘Moodscope’, a more succinct measure that could perhaps have been incorporated into the online measures within this study as a regular measure of mood (Drake, Csipke & Wykes, 2013). Alternatively a simple visual analogue rating scale may have given an indication of mood, although analysis would have been
limited – again, choice of a measure of mood in future research would depend on the aims and design of the study.

Limitations associated with individual personality factor have already been raised: it is possible also that this particular format should be carefully considered in this context too. Recognising the potential utility and/or importance of a self-help and self-management approach with chronic illness generally and CFS in particular, there may also be some interactions with personality factors: for example before key skills are learnt and psychological flexibility built, the high standards associated with maladaptive perfectionism could lead to over-application of elements of the intervention in ways that are unhelpful. Further evaluations testing the boundaries of this model in different applications would contribute further to an understanding of this.

There were some ethical limitations on the design of this research as there was no previous evidence in support of ACT as a beneficial intervention for this population. This research therefore required that participants had already been through treatment as normal in the form of the group intervention. This necessarily becomes a limitation, as the impact of the participants attending the group previously is unknown. Similarly there was some variation in timescale between participants completing the group programme and recruitment for this study. Given the potential benefits of this intervention there may be scope for further research to test this intervention in a more direct comparison of current interventions. There is also a practical question considering how this particular intervention could fit currently within existing services. As a less intensive format, this could be offered as an adjunct to the existing group intervention for those who need or want more input; however, considering the stepped model of care employed across healthcare services currently, this could also be offered as preparation for a more substantial intervention or as an option for those who are less distressed or more able and willing to self-manage. Given the noted heterogeneity of the population and indeed this sample, it could be further investigated as to how this and other psychological interventions could be stratified for the different needs of the populations; this would be complimented by further research into the individual factors of participants and the interactions of this with the intervention.
It is acknowledged that multiple single cases studies have a number of advantages but also that they often present with a mixed picture – they require less resources in terms of participants than designs such as Randomised Control Trials but also require perhaps more from the researcher in terms of in-depth and critical analysis and synthesis of complex information (Elliott, 2002). In this study, whilst there were a number of interesting findings, it is certainly true that the results are mixed and don’t provide a clear answer in terms of the efficacy of this approach for the broader CFS population as may have been indicated by an alternative design.

Visual analysis allows a comprehensive range of methods in evaluating data, which can each tell us slightly different things: this allows breadth of information when it comes to analysis, and high sensitivity to change, but it also highlights the need to interpret the results correctly and synthesise them adequately, which inevitably incorporates an element of subjectivity (Lane & Gast, 2014). This study benefitted from multiple authors, including qualified clinicians who are practised in the use of such statistics. There is still no agreed best method for calculating effect size within single cases, although this methodology is increasing in popularity (Lane & Gast, 2014; Manolov, Solanas & Leiva, 2015).

It is important to understand threats to the internal validity of the study, or other factors that could explain any findings: there were processes in place to maximise control and recognition of confounding variables, such as phone calls weekly to monitor participant fidelity, sending through only specific chapters of reading each week and gathering a range of both quantitative and qualitative data in both self-report and objective forms. These were all put in place to maximise experimenter control and clarity. Similarly, using pre-established and validated measures was useful in that it limited bias from observation. One limitation as mentioned was the novel use of the condensed questionnaire as limiting the ability to compare the results to broader populations: collecting the full questionnaire information daily would have allowed far greater analysis however the function of these measures as indexing day-to-day processes whilst minimising participant fatigue was prioritised. This questionnaire would be more problematic had it been used as the sole outcome measure, but the calculation of therapeutic change and effectiveness through clinically significant change indices utilised the validated full-scale measures completed by participants once a week.
Related to the recognised complexity of data collection in this type of study design, it is noted that stability was assessed on only one outcome during the baseline period rather than across all measures used, with the recognition that it was difficult to achieve optimal stability across these in an applied rather than a laboratory setting. There was a strong rationale behind the study design of focusing on the psychological measures as primary outcomes, however on reflection further analysis from a stable baseline as well as added subjective data in particular regarding the behavioural outcome measure and the increase in activity could have helped to further understand how this occurred and why in our sample.

The scores indicated by participants at the three month follow up have interesting implications for the maintenance and longer term efficacy of this approach. It would be interesting to see over a greater period of time any maintenance of change or improvement; it is a limitation of much psychology research that follow up data is often restricted to three years at best but even that was unfortunately not within the scope of this study. There are some hypotheses about why ACT might work better over the longer term in comparison to other interventions such as CBT, including the learning of meta-cognitive skills that are trans-diagnostic and therefore more transferable, the longer term diffuse benefits of mindfulness, and the idea that values are intrinsically reinforcing, therefore it could be expected that individuals would increasingly engage in valued activity. Longer term data could add further clarity to the debate about the incremental validity of either ACT or CBT, or in fact the common mechanisms of both.

Overall this was an exploratory study aimed at producing some initial data on such an intervention with this population – similarly, it was designed to retain a balance between ecological validity and experimental control. The patients that use the service frequently have other comorbid issues, as is highlighted by the epidemiological research into CFS – theoretically this does not pose a problem for the ACT model because distress is conceptualised and treated a-diagnostically, but practically there are limitations to this approach, which become clear when we attempt to clearly understand the individual differences. Complete experimenter control was not viable ethically or pragmatically and the study design necessitates limits in generalising the results to others.
4.10 Clinical Implications

As noted previously the epistemological position and scientific model of contextual behavioural science advocates multi-level development of research and consequent integration of this (Hayes, Levin, Plumb-Vilardaga, Villatte & Pistorello, 2013) – this study adds to a wider body of literature about the specific application of this intervention to people in this sample but also more broadly to a discussion about the processes underlying change and the overarching theories as suggested by ACT. The clinical implications of this project then included feedback to and extensive discussion with the multi-disciplinary team members of the specialist service from which these participants were recruited. Results were also disseminated to the participants via email and phone calls, with plans to share it further with the wider CFS community at an annual conference and within the ACBS community via the Journal of Contextual Behavioural Science. Any interest and discourse prompted by this enables further exploration and scientific progress.

In terms of direct clinical implication this study includes consideration of the feasibility and the acceptability of this intervention for this sample – it was evaluated as having potential with good feedback received from all participants although a number of considerations and complexities to think on further. The results, particularly in terms of physical activity, were promising given the limited clinician support involved.

4.11 Directions for future research

This has been discussed throughout the previous section: despite some complexity, the results indicate potentially important aspects of this intervention which should be researched further with this population, including efficacy over the longer term, the intervention in different formats, across a broader population sample, and in comparison to other interventions (although with an acknowledgment that key outcome measures might be different across these). Similarly, the theoretical questions raised indicate the need for further exploration of the ACT model and the key processes conceptualised within this.

5. Personal Reflections

An explicit reflective process is not commonly included in quantitative research, potentially due to this being seen as incompatible with the objectivity favoured by the
scientific model on which psychological research is historically based. This is further an approach that is mirrored by the National Health Service as an outcomes, efficiency based service model. Reflection is more commonly included in qualitative research. It is increasingly recognised that healthcare professions and psychology practitioners in particular are in a unique position in that there is a strong emphasis on evidenced based practice, but a co-existent requirement to develop our own practice through reflection (McIntosh, 2010).

The scientist-practitioner model is widely debated as to suitability in practice, particularly considering increasingly complex contextual factors influencing our practice, including advances in technology, an increased emphasis on consumer rights, increasing cultural diversity and political issues relating to how (and which) psychological services are funded (Lane & Corrie, 2007); reflective practice can be seen as one way to acknowledge and incorporate such dynamics into our practice and research to make it more ecologically valid. Although acknowledging that it is not always well defined or understood and can encompass many different ideas, generally reflective practice is considered a ‘dynamic developmental process’ (Taylor, 2011). The hypothesised benefits of reflective practice include the ability to work more effectively with complex information, giving practitioners ‘courage to work competently and ethically at the edge of order and chaos’ (Ghaye, 2007, p7). In a Contextual Behavioural Science approach, utilised within this study, all methods and ideas are assumed to be bound within a values and contextual framework – this is therefore coherent with an approach of open reflection.

5.1 Motivations

This research is important within wider contextual spheres due to the context of the NHS currently, with considerable economic pressures, as well as the changing conceptualisation of mental and physical health and ill-health. Currently separated into separate services, the acknowledgement of the complexity and prevalence of ‘psychosomatic’ experiences and the limitations of current services to deal effectively with these prompts theoretical consideration of the mind-body link, as well as practical consideration of how best to work with this. Attending a conference by the Association of Contextual Behavioural Science to present the initial results of this
study was a stimulating and rewarding experience, allowing me to converse with and further explore these issues with researchers and clinicians in similar fields.

The service that facilitated this research has a number of unique challenges being a community service that covers a very rural county with a small team – whilst there is some interest in enlarging the service to incorporate other somatic and frequently comorbid diagnoses such as fibromyalgia, there are significant logistic and economic pressures to consider, which informed the format of this intervention.

More specifically, this research was contextually important to me as a key part of my doctoral research. It is an area which I am highly interested in, and as such was a project I was personally invested in. This was a strength in facilitating maintained motivation throughout the process. Several participants noted my genuine interest in the project and it is acknowledged that therapist confidence can positively influence outcomes – whilst this may have had some effect throughout the research, the comprehensive measures and analysis with multiple authors maintained the objectivity of the work as far as possible. I hope that my interest and enthusiasm continues to be evident in my professional work. The Doctoral programme too is an important part of my life and one which has challenged me, including this particular assignment: this research then was part of an ongoing learning process, but one which I have thoroughly enjoyed.

Noting my interest in this area, I have nonetheless never known anyone with a diagnosis of CFS before beginning this research. When introduced to the study at the commencement of the course, I was unfamiliar with the literature of CFS – this in many ways facilitated an open-minded approach to the development of the study, although required significant personal reading on my behalf. There may have been some benefits to having prior knowledge in easing the development process and potentially in addressing some of the limitations of this research that I discovered in hindsight – I was similarly unfamiliar with psychological research. Being able to work within the service during the recruitment phase of my study enabled highly beneficial first-hand experience of working with CFS (I had no contact with the participants of this study previously). Similarly, having conducted this research project and been supported by both academic and field supervisors, I feel significantly more confident both in my knowledge of the area and my ability to conduct further research.
As well as an interest in the area of health psychology, I had a pre-existing interest in ACT as a model of psychological flexibility and the increasing literature into the benefits of mindfulness, something I practice personally. My knowledge and my own professional ideas about clinical practice, and ideas of health and ill-health have developed significantly in the three years that I have been involved in the course and in this research.

5.2 Challenges

Completing this project allowed me some insights into the challenges of conducting research whilst also working clinically: it was difficult to organise with only one day a week dedicated to the project and as a largely independent researcher, there were a number of logistical barriers to overcome and other commitments to juggle (from both authors and participants); overall it did require a significant time and cognitive commitment on my behalf. The amount of data was overwhelming and difficult to synthesise and communicate coherently, exacerbated by the fact that this design is new to me – I certainly appreciated the acknowledgement that multiple single case designs require a lot of input from the researcher. This was continued throughout the write up, which required the development of two separate but embedded pieces of work: also given the scale of the extended paper it was difficult at times to keep the whole project in mind as well as being appropriately specific and targeted.

A key learning point for me was that it would have been very useful to conduct a full pilot trial with a voluntary participant or a colleague – this would not only have increased my confidence in conducting the research but may have facilitated the modification of some aspects of the research to combat some of the limitations described above.

Resources employed to overcome

Although this project could not have been completed without significant support from the co-authors, I think I was personally able to contribute a number of skills: I am highly organised and task-focused, with an ability to use time efficiently, which helped in conducting this project within the timescale and also with the synthesis of such large amounts of data. I also have good communication skills and was able to work well with all of the co-authors, both at the university and within the CFS service.
The enthusiastic participants in this study reinforced for me that research directly with the clinical populations we work with is both viable and important, particularly in controversial and complex areas such as this where there is so much scope for further input. Finally, in recognising the relationship between mind and body and being interested in both physical and mental health, I try to maintain a number of self-care practices which help me to manage stress: I consider these important to my professional capacity more generally and they facilitated the completion of this project, in line with my own values, without neglecting other important aspects as my life and without (so far!) any adverse experiences.

Extended paper word count: 21,010
References


and cognitive therapy for anxiety and depression. *Behaviour Modification, 31*(6), 772-799. doi:31/6/772 [pii]


*Evaluation, 320,* 537-540.


Appendix 1: CFS diagnostic criteria (Centres for disease control and prevention., 2012)

Consider a diagnosis of CFS if these three criteria are met:

1. The individual has severe chronic fatigue for six or more consecutive months that is not due to ongoing exertion or other medical conditions associated with fatigue (these other conditions need to be ruled out by a doctor after diagnostic tests have been conducted)

2. The fatigue significantly interferes with daily activity and work

3. The individual concurrently has four or more of the following eight symptoms:
   - Post-exertional malaise lasting more than 24 hours
   - Unrefreshing sleep
   - Significant impairment of short-term memory or concentration
   - Muscle pain
   - Multi-joint pain without swelling or redness
   - Headaches of a new type, pattern or severity
   - Tender cervical or axillary lymph nodes
   - A sore throat that is frequent or recurring
Appendix 2: Ethical approval

NRES Committee East Midlands - Nottingham 1
Royal Standard Place
Nottingham
NG1 6FS
Telephone: 0115 8839428
22 August 2014

Mrs Lauren Roche
Trainee Clinical Psychologist
NHS - Lincolnshire Partnership Foundation Trust
University of Lincoln
Brayford Pool
Lincoln
LN6 7TS

Dear Mrs Roche

Study title: An Acceptance and Commitment Therapy intervention with Chronic Fatigue Syndrome - a case series approach.

REC reference: 14/EM/1086
IRAS project ID: 153862
Appendix 3: Information sheet

(Version 2: 26/9/14)

Title of Study: ACT for Chronic Fatigue Syndrome: a case series approach
Name of Principal Researcher: Lauren Roche

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you.

What is the purpose of the study?

The purpose of this study is to explore how a 6 week guided self-help intervention based on an approach known as ‘Acceptance and Commitment Therapy’ might help people with Chronic Fatigue Syndrome.

Why have I been invited?

You have been invited to take part as you have recently been involved in the local Specialist Chronic Fatigue Service. We are inviting 6 participants like you to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time throughout the study and up to two weeks afterwards. You would not need to give a reason. This would not affect your legal or medical rights.

What will happen to me if I take part?
The research will take around 8 weeks in total. Each week participants will be asked to fill in an online questionnaire three times a week throughout this time. They will be prompted to do this by text, or by email, whichever they feel would be more useful.

There will be a short task to complete on a laptop: this will take at the beginning, the midpoint and the end of the intervention (a total of three times). Participants will also be supplied with a ‘fitbit’ activity monitor to wear.

The intervention itself will last for 6 weeks and participants will be posted a chapter of text each week including some worksheet exercises to think about. The lead researcher will call the participants for around 15-30 minutes each week to offer support with the material.

At the end of the intervention an independent researcher will conduct an interview with you on the phone, lasting around 30 minutes.

Participants will also be invited to complete a three month follow up although this is not essential to the study.

**Expenses and payments**

Participants will be compensated £50 for their time. If they attend the three month follow up, they will be compensated a further £10.

**What are the possible disadvantages and risks of taking part?**

This intervention has not been conducted before with this client group therefore we cannot promise that this study will help you. However, given the evidence supporting this intervention with other client groups, it is not expected that there will be any detrimental effects or risks involved.

**What are the possible benefits of taking part?**
This study may be helpful for you. It may also help to develop future interventions for others who experience CFS.

**What happens when the research study stops?**

We can update you of the results of the study.

**What if there is a problem?**

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. Their contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting NHS Complaints. Details can be obtained from your hospital.

If you are unhappy throughout the study, you can raise these concerns at any time with the researcher.

**Will my taking part in the study be kept confidential?**

We will follow ethical and legal practice and all information about you will be handled in confidence. This study will be conducted in line with the Data Protection Act 1998.

If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Lincoln who are supervising the research. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you will have your name and address removed (anonymised); participants will be asked to generate a unique code that will be used to identify data so that you cannot be recognised from it.
Your personal data (address, telephone number) will be kept for 6 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). All other data will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality.

**What will happen if I don’t want to carry on with the study?**

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. You will be given a unique code and you just need to email the researcher with this in order to withdraw your data. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

**What will happen to the results of the research study?**

The results of this study will be written up as part of the primary researcher’s thesis for Clinical Psychology Training. It will also be submitted for publication. This is likely to happen in 2016. The results may also be presented at a national conference for CFS. Participants will not be identified in any of these cases.

**Who is organising and funding the research?**

This research is being organised and funded by the University of Lincoln.

**Who has reviewed the study?**

This study has been developed by researchers at the University of Lincoln, in collaboration with service providers. This study has been reviewed and approved by an NHS Research Ethics Committee.

**Further information and contact details**
You can contact the lead researcher using the following details:

Lauren Roche – email: 13451705@students.lincoln.ac.uk
Appendix 4: Consent form

(Version 1: 7/3/14)

Title of Study: ACT for Chronic Fatigue Syndrome: a Case Series Approach

REC ref:

Name of Researcher: Lauren Roche

Name of Participant: [Please initial box]

1. I confirm that I have read and understand the information sheet dated................................. for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis.

3. I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorised individuals from the Universities of Nottingham and Lincoln, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential.

6. I agree to take part in the above study.
<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>____________________</td>
<td>__________</td>
<td>____________________</td>
</tr>
</tbody>
</table>

Name of Person taking consent  Date  Signature
(if different from Principal Investigator)

<table>
<thead>
<tr>
<th>____________________</th>
<th>__________</th>
<th>____________________</th>
</tr>
</thead>
</table>

Name of Principal Investigator  Date  Signature

2 copies: 1 for participant, 1 for the research notes
Appendix 5: Stem completion task

An Acceptance and Commitment Therapy intervention for Chronic Fatigue Syndrome: initial questions

Unique code:
Date completed:

Please complete the statements below, based on your personal experiences.

For example, you might complete the sentence “when I am ill, I feel useless”; “when I am ill, I feel resigned”. Or, “when I am well, I feel normal”; “when I am well, I feel energetic”.

1) When I am ill, I feel...

2) When I am ill, I can't...

3) When I am ill, I am...

4) When I am ill, others think I...

5) When I am ill, I want…
6) When I am ill, I think…

1) When I am well, I feel...

2) When I am well, I can’t...

3) When I am well, I am...

4) When I am well, others think I…

5) When I am well, I want…

6) When I am well, I think…

If you feel that your experience would be better captured using different terms, please use the space below to write some similar sentences in your own words:
## Appendix 6: Stem completion responses

<table>
<thead>
<tr>
<th>When I am well….</th>
<th>When I am unwell….</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel really great</td>
<td>I think I am going to die</td>
</tr>
<tr>
<td>I feel sure of myself</td>
<td>I can’t breathe properly</td>
</tr>
<tr>
<td>I am confident</td>
<td>I am pathetic</td>
</tr>
<tr>
<td>I have no limits</td>
<td>Others think I am a burden</td>
</tr>
<tr>
<td>I want to stay this way</td>
<td>I want to get back to normal</td>
</tr>
<tr>
<td>I feel energetic</td>
<td>I question how did this happen</td>
</tr>
<tr>
<td>I feel lively</td>
<td>I feel deflated</td>
</tr>
<tr>
<td>I can’t sit still</td>
<td>I can’t think straight</td>
</tr>
<tr>
<td>I am happy</td>
<td>I am tired</td>
</tr>
<tr>
<td>Others think I am fine</td>
<td>Others think I can’t understand</td>
</tr>
<tr>
<td>I want to be busy doing things</td>
<td>I want to be active again</td>
</tr>
<tr>
<td>I think of what I can do</td>
<td>I think I’ll never be me again.</td>
</tr>
<tr>
<td>I feel energetic</td>
<td>I feel completely washed out and slow</td>
</tr>
<tr>
<td>I can’t stop doing things</td>
<td>I can’t concentrate</td>
</tr>
<tr>
<td>I am happy</td>
<td>I am irritable and snappy</td>
</tr>
<tr>
<td>Others think I am overenthusiastic</td>
<td>Others think I am mardy</td>
</tr>
<tr>
<td>I want to do as much as possible</td>
<td>I want to be left alone</td>
</tr>
<tr>
<td>I think I am better forever</td>
<td>I think it will never get better</td>
</tr>
<tr>
<td>I feel normal</td>
<td>I feel useless</td>
</tr>
<tr>
<td>I can go out with friends</td>
<td>I can’t function</td>
</tr>
<tr>
<td>I am energetic</td>
<td>I am lonely</td>
</tr>
<tr>
<td>Others think I am my normal self</td>
<td>Others think I am faking</td>
</tr>
<tr>
<td>I want to go out</td>
<td>I want to hibernate</td>
</tr>
<tr>
<td>I think positively</td>
<td>I think I’m useless</td>
</tr>
<tr>
<td>I feel joyful</td>
<td>I feel miserable</td>
</tr>
<tr>
<td>I can’t sit still</td>
<td>I can’t be optimistic</td>
</tr>
<tr>
<td>I am happy</td>
<td>I am mardy</td>
</tr>
<tr>
<td>Others think I am better</td>
<td>Others think I’m a pain</td>
</tr>
<tr>
<td>I want to make the most of every moment</td>
<td>I want nurturing</td>
</tr>
<tr>
<td>I think how grateful I am</td>
<td>I think negatively</td>
</tr>
<tr>
<td>I feel great</td>
<td>I feel rubbish</td>
</tr>
<tr>
<td>---------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>I feel normal</td>
<td>I can’t do anything</td>
</tr>
<tr>
<td>I am happy</td>
<td>I am unhappy</td>
</tr>
<tr>
<td>I think ‘let’s go for it’</td>
<td>I want to curl up</td>
</tr>
<tr>
<td>I want to do stuff</td>
<td>I want more energy</td>
</tr>
<tr>
<td>I want to stay this way</td>
<td>I think ‘why me’</td>
</tr>
</tbody>
</table>
Appendix 7: Change Interview Schedule

Below is an example of questions that will be asked in the semi-structured change interview:

What has been your experience of therapy?
Did you find the materials made sense?
Do you think it would be useful for someone else with CFS?
Was any particular aspect more or less helpful?
What changes have you noticed?
Where these changes positive or negative?
Were you surprised by the changes? (Rate the importance of these changes on a five point scale)
How likely would these changes have been without therapy?
What have your previous self-help strategies been?
What extra therapy events occurred during this time period – do you think this had an effect?
What was your perception of the therapist?
Acceptance and Commitment Therapy for CFS:

RESEARCH OPPORTUNITY, Starting September 2014

Who?
- Any one taking part in this group!
- Need access to a phone and the internet

What?
- A six week self-help intervention (total of 8 weeks involved in the research)
- Based on Acceptance and Commitment Therapy
- Weekly phone calls from the researcher
- Regular online questionnaire

Where?
- In your own home

WHY?
- To explore whether this intervention might be helpful for people with Chronic Fatigue Syndrome

FOR MORE INFORMATION:
Contact Lauren Roche on 13451705@students.lincoln.ac.uk
Research background and context

There is a shared understanding in the literature that ward rounds are fundamental in providing high quality care (for example Herring, Richardson & Caldwell, 2013). However it is also recognised that they can be difficult and challenging experiences for service users (for example Lawrence, Labib & Brownell, 2009). Furthermore, there is currently little research into the structure and clinical outcome of ward rounds and it is recognised that there is variability in both purpose and conduct (RCP, 2012). There is an on-going debate as to whether or not there should be nationally standardised codes of conduct (Wagstaff and Solts, 2003). There is some guidance available regarding best practice in review processes: the AIMS Standards for Inpatient Wards - Working Age Adults offers some specific recommendations as well as suggesting that managers and practitioners have agreed standards for reviews/ward rounds (16.6) and that service users are made aware of these standards (16.8). Ultimately, identifying principles for best practice in ward rounds can improve patient safety, patient experience, shared learning, collaborative working and efficient use of resources (Ministry of Health, 2013).

This service evaluation has been conducted as a result of interest from both patient and staff groups. It has also been observed that there is considerable variation in the ward round procedure across the three wards comprising this adult rehabilitation service. This service evaluation aims to incorporate patient and staff perspectives of ward round to develop agreed standards for ward rounds in line with national and local policy (NHS, 2008). These standards would then be shared with patients and staff groups and evaluated on a regular basis, in accordance with AIMS guidance (RCP, 2010).

Research aims
1. To evaluate the current ward round process across three inpatient Adult Mental Health wards including identifying possible areas of improvement.

2. To incorporate the service users perspective alongside that of the staff who experience this process first-hand, in line with both national and local policy (http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/patient_perspectives.html).

3. To develop agreed standards for ward rounds, which can be shared with service users and evaluated on a regular basis in future practice, in line with AIMS guidance (RCP, 2010).

What the research discovered

The analysis of the entire data set uncovered 7 key themes: timing logistics, location logistics, multi-disciplinary team involvement, ward round processes, being patient-centred, patient experience and documentation / feedback. These themes were not mutually exclusive.

The data was analysed and reported for each individual ward in order to incorporate specific information. The findings were then collated into a single ‘Code of Good Conduct’, which consists of a series of guidelines that should be adhered to in order to maintain good standards in ward rounds. This incorporated both suggestions of things that currently worked well in ward rounds as well as aspects that could be improved. It is applicable to all three wards. This document is attached for further reference.

How the findings will be disseminated

The findings were presented via a report made available to each ward (hard copies placed in the nursing offices and communal areas of the ward, as well as email notification to staff teams). A feedback session was held on 26th August 2014 in which both staff and service users were invited to attend a short presentation of the research and offer any feedback. Generally the research was well-received and we updated the report from feedback as appropriate. Finalised reports were then re-printed and disseminated as above. A copy of the Code of Good Conduct is made clearly available on each ward. It is envisaged that an audit may be undertaken by future Psychology Trainee’s. The research was also disseminated amongst the psychology team via the Psychology Team Meeting, and emailed to the LPFT Research department.

This research is currently being revised and written up for potential submission to an academic journal.

Service impact achieved by the research and future plans

The service has benefitted from this evaluation by the generation of recommendations and the establishment of a baseline by which to monitor the ward round processes. Previous research indicates that ward rounds are a key process in providing high quality care and in that the identification of clear principles can aid this. Both staff and service users had the chance to offer an opinion and be involved in this project, and the high rate of responses and
involvement indicates that this was a salient area of development for this particular service. Having attended ward rounds since the development of the Code of Good Conduct, I have witnessed staff groups making a concerted effort to engage in the recommendations outlined. Following the success of this service evaluation, it is being considered to conduct a similar project for CPA meetings held bi-annually for service users.


Trainee’s Signature: ______________________ Date: ______________
Supervisor’s Signature: ______________________ Date: ______________
ACCEPTANCE is understood to be an important element in coping and living with chronic illnesses such as diabetes and chronic pain, and increasing acceptance has been related to a number of positive outcomes such as reduced symptoms as well as greater reported quality of life 1.

Chronic Fatigue Syndrome (CFS) is a disabling disorder that is associated with poor reported quality of life even in comparison to others chronic conditions 3.

Given that ACT is a psychotherapeutic model aimed at increasing psychological flexibility and values pursuance 2 the approach holds potential for coping and living with CFS, with interesting implications for service provision and client care.

AIMS

- The utility of an ACT self-help intervention for this under-researched population
- Whether therapeutic and physical change is driven by predicted ACT mechanisms

RESULTS

- One man and five women (N=6) aged between 19-62 yrs were recruited from a specialist CFS Service in the UK.
- Three out of six participants indicated change on an overall measure of psychological flexibility
- Change across ACT process measures was variable. Analysis found replicable clinically significant change from baseline to post-intervention on two processes: the Acceptance scale of the PHLMS and the ELQ. This change was maintained on the ELQ at three month follow up.
- All five participants for whom we had Fitbit data showed increased levels of activity at post-intervention; three maintained this as follow up.

DISCUSSION

- There is a huge body of literature supporting the positive role of increased physical activity in the management of physical and mental health 4, as well as support for its role specifically in the management of CFS 5. There are interesting implications then for this psychotherapeutic approach in promoting increased physical activity in CFS – an emphasis on values and engaging in meaningful behavior may be a more acceptable way of achieving this in this population.
- The results indicating improvement in psychological flexibility in three participants are promising, however raise some questions about this model as applied to this population, given the variability in processes of change noted throughout.
- Given the self-help format of this intervention, the results are promising – further research is warranted into individual factors that might interact and might improve our ability to predict who would most benefit from this intervention.

REFERENCES