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# **UNIVERSITY OF SOUTHAMPTON**

FACULTY OF SOCIAL, HUMAN AND MATHEMATICAL SCIENCES

School of Psychology

## **Experiences of mindfulness for physical health and asthma patients: a qualitative approach**

by

**Aarti Patel**

Thesis for the degree of Doctorate in Clinical Psychology

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UNIVERSITY OF SOUTHAMPTON

## **ABSTRACT**

FACULTY OF SOCIAL, HUMAN AND MATHEMATICAL SCIENCES

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Thesis for the degree of Doctor of Clinical Psychology

### **EXPERIENCES OF MINDFULNESS FOR PHYSICAL HEALTH AND ASTHMA PATIENTS: A QUALITATIVE APPROACH**

Aarti Patel

The initial part of this thesis comprises of a thematic synthesis of qualitative research followed by a qualitative study. The thematic synthesis aimed to gain an understanding of how participants with long term health conditions and physical health difficulties, experience mindfulness interventions. Thomas and Harden's (2008) three step thematic synthesis method was utilised, in order to synthesise the qualitative findings of 20 qualitative studies. This process revealed five key themes: 1) Perceived barriers to participation and practice: 2) Positive consequences and benefits of participation: 3) Group attributes: 4) Negative experience and 5) Home practice and application to life. Mindfulness based interventions are acceptable for individuals with long term and physical health conditions. Individuals can experience both positive and negative experiences of mindfulness interventions. The group aspects of these interventions are valued by participants for their support and social aspect; however some patients can experience a negative effect, which requires further exploration.

The needs of patients with respiratory conditions and dual mental health difficulties are not adequately catered for. The literature investigating mindfulness and respiratory conditions, especially asthma, is limited. There is only one study to date, which has looked at the effectiveness of mindfulness compared to treatment as usual in a randomised control trial for asthma, which has shown promising results. The present study aimed to explore poorly controlled asthma patients' experience of a brief mindfulness group. A qualitative approach was taken to elicit the views of adults with poorly controlled asthma from a difficult asthma clinic, who attended a four week mindfulness course. A focus group and nine semi structured interviews were conducted and analysed using thematic analysis. The study found four overarching themes including: *Wellbeing, Challenges, Acceptability and Integration*. These results imply that despite the challenges, a mindfulness based intervention is acceptable for poorly controlled asthmatics. Furthermore, it had a positive impact on wellbeing and patients were able to integrate skills alongside existing treatment. Further exploration of tailored mindfulness based interventions for asthmatics would be beneficial. In particular, exploring both subjective experiences and impact on health related outcomes, as well as psychological barriers to attendance and practice.



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## Declaration of Authorship

I, Aarti Patel declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

**Experiences of mindfulness for physical health and asthma patients: a qualitative approach**

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I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission [or] Parts of this work have been published before submission

Signed: Aarti Patel

Date: 31<sup>st</sup> May 2017



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## Definitions and Abbreviations

ACT	Acceptance and Commitment Therapy
AQLQ	Asthma Quality of Life Questionnaire
CBT	Cognitive Behavioural Therapy
CDR	Centre for Reviews and Dissemination
CHD	Coronary Heart Disease
COPD	Chronic Obstructive Pulmonary Disease
DBT	Dialectical Behaviour Therapy
HADS	Hospital Anxiety and Depression Scale
HRQOL	Health Related Quality of Life
HIV/AIDS	Human immunodeficiency virus infection and acquired immune deficiency syndrome
IAPT	Increasing Access to Psychological Therapies
LTHC	Long Term Health Conditions
MBSR	Mindfulness Based Stress Reduction
MBCT	Mindfulness Based Cognitive Therapy
MBI	Mindfulness Based Interventions
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
PCA	Poorly Controlled Asthma
PHC	Physical Health Conditions
PICO	Patient Population Problem Intervention Comparison Outcome
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PTSD	Post Traumatic Stress Disorder
QOF	Quality Assessment Framework
QOL	Quality of Life
RCT	Randomised Control Trial
TAU	Treatment as Usual
UK	United Kingdom



# **Chapter 1: Systematic review of the literature: What are patient experiences of mindfulness based stress reduction and mindfulness based interventions for physical health conditions? A review of qualitative literature**

## **Introduction**

This chapter is a systematic review and thematic synthesis of the qualitative literature around how patients with physical health conditions, experience mindfulness interventions. Research surrounding mindfulness has exponentially grown, with a wealth of evidence for the usefulness of the skill in both physical and mental health settings. Whilst there is an abundance of quantitative systematic reviews (Grossman, 2004; Bohlmeijer, 2010; Hoffman et al 2010; Fjordback et al 2011; Khoury et al 2013), very few qualitative reviews exist (Malpass et al. 2012; Cairns & Murray, 2015). In order to explore the collective experiences of mindfulness based interventions for physical health patients, the current systematic review was undertaken.

Up to 15 million people in England have one or more long-term health conditions (LTHC) (DOH, 2001c) and therefore tend to be the most frequent users of the health care service. LTHCs or physical health conditions (PHCs) can include a wide range of conditions including cardiovascular disease, diabetes, asthma, arthritis, as well as HIV/AIDS and now some cancers. This costs the National Health Service (NHS) 70% of their expenditure (House of Commons, 2014). Mental health conditions can also be considered as LTHCs; however this systematic review refers to physical health conditions specifically.

### **Comorbidity: physical and mental health**

Those with PHC or LTHCs are two to three times more likely to experience mental health difficulties, such as depression and anxiety. This in turn is associated with excess disability and morbidity, and can predict worse medical outcomes in people with LTHCs (Moussavi, Chatterji, Verdes, et al, 2008). Those with below clinical thresholds of depression can predict worse medical outcomes in those with LTHCs such as coronary heart disease (CHD) (Barth, Schummacher and Hermann-Lingen, 2004). For example, for individuals with chronic obstructive pulmonary disease (COPD), mental health difficulties are three times more prevalent and in particular, they are 10 times more likely to suffer with anxiety disorders (Livermore, Sharpe and McKenzie, 2010). Evidence also indicates higher levels of mental health difficulties amongst individuals with conditions such as arthritis, cancer, asthma, HIV/AIDS (Chapman, Perry and Strine, 2005). This suggests that psychological treatments may

be effective interventions in order to support individuals with co-morbid physical and mental health difficulties.

### Recommendations and the gap in treatment

Research suggests that behavioural and psychological interventions can be efficacious and economical, leading to cost saving in overburdened health care systems (Carlson and Bultz, 2004; Blout et al. 2007). There has been some effort to bridge the gap in providing psychological therapies to those with long term health conditions, by introducing Increasing Assess to Psychological Therapies (IAPT) services here in the UK (DOH, 2011). Initial outcomes show positive results, as those referred to IAPT for LTHC are associated with reduced use of emergency services and increased adherence to antidepressants (Lusignan et al. 2013). However, Naylor et al. (2016), for the Kings Fund, report that psychological therapies are still not readily or routinely available for those with LTHCs and multi-comorbidity, and also that staff are not adequately trained in psychological therapies on wards and outpatient departments.

National Institute for Health and Clinical Excellence (NICE, 2004) recommends psychological, emotional and spiritual care for palliative care patients, who often have multiple morbidities. NICE also recommends that patients with a LTHC and depression should be able to access evidence-based treatments such as Cognitive Behavioural Therapy (CBT) (NICE, 2009). CBT has been shown to be effective to help recovery, especially for those diagnosed with pain (Morley, Ecclesoton and William, 1999) chronic fatigue (Malouff et al. 2008), and multiple sclerosis (Thomas et al. 2006). However, small effect sizes are seen for the treatment of anxiety and depression in COPD (Coventry & Gellatly, 2008; Baraniak & Sheffield, 2011). Furthermore, while there is some evidence for the effectiveness for the use of CBT for improved quality of life, asthma control and anxiety levels in people with asthma, the evidence overall is low and not conclusive (Kew, Nashed, Dulay and York, 2016). So whilst the evidence for CBT is strong for some LTHCs, it is weak for others. More recently, the mindfulness based interventions are being trialled for a range of LTHCs and PHCs.

### Mindfulness and the evidence base

Mindfulness has been defined and understood as “paying attention in a particular way: on purpose, in the present moment, and non-judgmentally” (Kabat-Zinn, 1994). Mindfulness is most commonly known as stemming from Buddhist tradition, but has been taught for thousands of years by many other religions. It was first developed without its spiritual connotation, for the treatment of pain for hospital patients by Jon Kabat Zin (1982). It involves a willingness to notice where the attention of one’s mind is at any given moment in time. This attention may be on thoughts about the past or future, body sensation and or emotions (McKay, Wood, Brantley, 2007). Mindfulness sees

these as mental events not to be analysed, changed, or manipulated but simply to be noticed that they are fleeting events in the mind's awareness. It conveys a non-striving stance, with no particular outcome other than to observe and witness without judgment whatever comes in one's field of awareness. The regular practice of Mindfulness will allow individuals to regulate their attention, allowing an increase of recognition of mental events, adopting curiosity, openness and acceptance (Bishop et al. 2004). Mindfulness promotes awareness and non-judgmental thinking with sustained moment-to-moment awareness, with health benefits such as reduced pain, anxiety and stress (Grossman, Niemann, Schmidt and Walach, 2004).

Although mindfulness is not a therapy in itself, in recent years it has been integrated with a number of other approaches and several therapy programmes have emerged such as; Mindfulness Based Stress Reduction (MBSR); Mindfulness Based Cognitive Therapy (MBCT); Dialectical Behaviour Therapy (DBT); and Acceptance and Commitment Therapy (ACT), all of which consider mindfulness an integral component of their own therapy (Baer, 2003). These programmes have shown positive outcomes, at reducing both mental health and physical health outcomes, especially MBSR and MBCT, which are more commonly available.

There are a number of studies that provide the evidence for the application of mindfulness based interventions (MBI). Hofmann, Sawyer, Witt, & Oh, (2010) convey the effectiveness of mindfulness based therapies for anxiety and depression. Additionally, Khoury et al. (2013) also demonstrates, in a comprehensive meta-analysis, how mindfulness based therapies are beneficial for anxiety and depression. MBIs have also shown to be effective for individuals with physical health or LTHCs. Carlson, Speca, Patel & Goodey (2003) and Carlson and Bultz (2004) indicate how mindfulness for cancer patients has improved quality of life, mood and stress. Furthermore, acceptance based approaches have been beneficial for rheumatic disease (Hayes et al 2004), which challenges the traditional dominance of CBT (Morely, Eccleston & Williams, 1999). Additionally, case studies have demonstrated the beneficial use of ACT when working with asthma (Fellows et al. 2015).

MBSR, which is the mostly commonly reported method of mindfulness training, was developed by Jon Kabat-Zinn in 1982, for the treatment of pain and stress related disorders in hospital settings. It involved an eight to ten week course for up to 30 individuals. Each session would last two, to two and half hours each, comprising of being taught mindfulness meditation skills such as a body scan and sitting meditation and also a group discussion of coping, stress and homework assignments. At week six, an all-day intensive session would be held. Participants are also encouraged to practise the skills for at least 45 minutes per day, outside of the group setting. Furthermore, participants are instructed to focus attention on their breath or movement, and to be aware of it from moment to

moment. Thoughts, emotions and external events are to be considered as passing events, to be observed non-judgementally (Kabat-Zin, 1990) and attention is brought back to the present moment, if they notice their mind has wandered onto thoughts or memories (Baer, 2003). MBSR has been shown to be effective for a range of different chronic health conditions such as Fibromyalgia (Lauche et al.2013), Psoriasis (Kabat-zinn et al, 1998), Pain (Randolph, Calder, Tacone and Greak, 1999) and Cancer (Speca, Carlson, Goodey and Angen, 2000) as well as for mixed chronic health conditions (Crowe et al 2016).

Whilst MBSR was initially developed for physical health conditions, Segal,Williams,&Teasdale, (2002) developed MBCT as a psychological relapse prevention for recurrent depression. MBCT, combines the content of MBSR with a focus on cognitive therapy, emphasising the importance of challenging thinking styles. Having been based on MBSR, it is similarly an eight-week group intervention, designed to prevent relapse of depression by encouraging participants to take a detached view of their thoughts. MBCT was introduced and is recommended by NICE (2004) for those who have had three or more major depressive episodes. In a meta-analysis, Fjorback, Ardent, Ornbol, Fink, & Walsh (2011) demonstrate a medium effect size for the application of MBSR and MBCT. While MBSR improved mental health in 11 studies in comparison to treatment as usual (TAU) or waiting list controls (WLC), MBCT reduced the risk of depression relapse in two studies, in comparison to TAU demonstrating their differentiating respective effects.

A number of recent systematic reviews have been published in the field of mindfulness for LTHCs, which will now be summarised. Baer (2003), in a meta-analysis reviewed 21 studies and concluded that MBIs may be helpful in alleviating mental health difficulties and improving psychological functioning. Additionally, Grossman et al (2004), in a meta-analysis of 20 studies found that controlled and uncontrolled studies showed similar effect sizes to each other and that MBSR may help a broad group of individuals with a broad range of clinical and non-clinical difficulties including pain, cancer, heart disease, depression and anxiety and non-clinical stress. Carson (2012) provides empirical evidence to support the efficacy of mindfulness based interventions for a range of different PHCs including pain, cancer, cardiovascular disease, diabetes, HIV/AIDS and irritable bowel syndrome, providing a level of evidence for each condition. Many of these conditions appear to have their own systematic or meta-analyses or RCTs, indicating level one and level two evidence respectively. Crow et al. (2016) conducted a systematic review of MBSR for long-term physical conditions. They reviewed 15 studies, concluding that there may be some evidence that MBSR may be helpful for pain conditions, as well as primary insomnia and irritable bowel syndrome. They found small to moderate effect sizes for asthma, pain, tinnitus, and fibromyalgia and somatization disorder. Mindfulness seems to help manage such conditions by reducing anxiety and depression via a number of processes, including

acceptance, relaxation, exposure, cognitive change, relapse prevention and self-management (Baer, 2003). Shapiro (2006) conveys that a process of 're-perceiving' occurs which is primarily, a shift in perspective, alongside improving self-regulation of attention, which anchors attention in the current experience thereby reducing or preventing rumination (Bishop et al, 2004). Furthermore, Chidea, Serretti & Jakobsen, (2013) describe mindfulness as both top down and bottom up emotional regulation strategies. All of which can help with anxiety and depression and the self-management and acceptance of the difficulties of living with a physical health conditions.

### **Existing qualitative reviews of mindfulness and the need for a qualitative synthesis**

Research in regard to LTHC, is now replete with systematic reviews and meta-analysis, due to the abundance of empirical studies, reporting outcomes from observational studies and RCTs. What has not been summarised well in the literature is service user's experiences of MBI. A small number of independent qualitative studies exploring patient experience of mindfulness exist. For this reason, even fewer qualitative syntheses are available. Due to the apparent bias in the current literature, the lack of qualitative synthesis means that links and connection can be lost, studies are left in isolation, and audiences are unable to reach higher analytic understanding. Furthermore, if qualitative studies can be systematically reviewed like quantitative studies, they have the potential to inform the development of treatments, interventions, and policy and practice (Campbell et al. 2003).

Malpass et al. (2012) in a meta-ethnography, brings together qualitative studies exploring patient experiences of MCBT and MBSR for both mental health and physical health conditions. Their synthesis describes patients' experience of the mindfulness process. They conceptualised the way participants develop a new understanding of their illness over time, and the role mindfulness approaches have in helping patients manage their difficulties better. They reported three main phases: 1) Phase one is a period of exposure, 2) Phase two is a period of learning new skills and developing a steadiness and persistence in inquiring into experience. 3) Phase three is a period of transformation in the illness experience. More recently, Carins and Murray (2015) in another meta-ethnography, sought to gain an understanding of how MBCT contributes to positive therapeutic change. Their process of reciprocal translation identified the following five major themes: 1-Taking control through understanding, awareness and acceptance; 2-The impact of the group; 3- Taking skills into everyday life; 4-Feelings towards the self and 5- The role of expectations.

Therefore, whilst existing qualitative systematic reviews have already looked at either MBCT alone, or MBCT and MBSR for both mental health and physical health populations, reviews have not as of yet, aimed at synthesising the existing qualitative literature around physical health patients' experiences of MBSR or MBI alone. For this reason, MCBT was excluded from the current review, as

were patients with mental health conditions. This review therefore fills the gap with a systematic review of physical health patient's experience of MBSR and allows us to identify if experiences are specific to MBSR or similar or different to MBCT. Additionally, a qualitative synthesis enables service providers to understand service user experiences and therefore adapt and develop services accordingly, with the aim of enhancing service delivery and patient outcomes.

### Scoping and planning

Scoping and planning highlighted some recent quantitative systematic reviews of psychological interventions for respiratory conditions (Harrison et al. 2016) and for asthma (Yorke, Fleming & Shuldhham, 2006; Yorke et al. 2015). However, it also highlighted a lack of research for mindfulness and asthma specifically, as research in asthma and mindfulness is in its infancy. It was agreed that searching more broadly would result in more published qualitative literature and hence the current review.

### Review Aims

The aim of this systematic review was broadened to explore the various experiences of participating in a mindfulness intervention, for individuals with long-term health or physical health conditions. Informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Guidelines (Moher et al 2009) (Appendix A) the current systematic review aims to examine the extent to which patient experiences of mindfulness interventions for physical health conditions have been explored, in order to summarise and answer the following objectives:

### Objectives:

1. Identify what patient experiences are of participating in mindfulness interventions for long-term or physical health conditions;
2. Identify similarities or difference between experiences;
3. Critically evaluate the current findings within the qualitative literature; and
4. Identify clinical implications and/ or suggestions that emerge from the findings of the review

A Patient/Population, Intervention, Comparison, Outcomes, Study type (PICOS) model was utilised to guide the literature search (Appendix B).

## Methodology

The systematic review had several stages: 1) locating literature: 2) appraising included studies: 3) thematic synthesis of the themes. Each will be described in turn.

### Location of literature and Search strategy

This literature review has been conducted in a systematic way. In order for the search strategy to be replicable, it has been described in detail (Boland, Cherry & Dickinson, 2014). Databases PsychINFO, MEDLINE, CINAL and Web of Knowledge were searched through EBSCO using key terms.

A search was conducted on 6<sup>th</sup> January 2017 using the following terms:

*'Mindfulness' or 'mindfulness based stress reduction' or 'mindfulness based intervention' or 'Mindfulness intervention' AND 'Chronic illness' or 'chronic disease' or 'Long term health condition' or 'Physical health'.* This search resulted in 2604 papers.

As the indexing of qualitative papers are not as accurate as the indexing of quantitative studies (Centre for reviews, & dissemination (CRD), 2009), it was decided that searching using 'qualitative', as a search term would limit the results. It is preferable for search strategies to consist of solely topic and subject terms, without specifying the method of study (CDR, 2009). Therefore, limits were not put on the type of study, so as not to disregard relevant research that may not have been indexed correctly, even if this resulted in a large number of records. This resulted in a 2604 possible papers. After duplicates were removed, 2062 titles, and where relevant, abstracts were read to determine the most relevant articles. 124 full papers were read, and the reference list and citations of 37 relevant papers were examined to discover any further studies. The reference and citation searches resulted in an additional eight relevant articles, resulting in 45 full text papers being read.

At this point, articles were excluded because there was no evidence of clear mindfulness intervention (4), the intervention was MBCT or based on cognitive therapy (4), participants' primary condition was a mental health condition (3), the main intervention was yoga (2), the intervention was mindfulness mixed with another intervention (8), the population were adolescents (1) or healthy individuals (1) or the full text papers were not accessible (2). It was agreed that mixed method papers would be included, as without these the review would fail to acknowledge existing qualitative studies which could be relevant. Twenty studies were included in the final review, based on the inclusion and exclusion criteria below.

## **Inclusion criteria**

Studies had to meet the following criteria in order to be included in the review;

- I. Published academic journal
- II. Studies included a qualitative methodology
- III. Participants received either a MBSR, or an intervention based predominantly on mindfulness, or mindfulness based intervention, or variant of MBSR, or the intervention included mindfulness
- IV. Participants were adults over the age of 18
- V. Studies had a qualitative methodology or were mixed method with a qualitative element
- VI. The population had a diagnosed or self-reported physical health condition

## **Exclusion Criteria**

Papers were excluded if:

- I. The study was quantitative
- II. The sample included children, students, adolescents, professional groups, staff, or health professionals who did not have a long-term health condition
- III. The study was purely quantitative (RCT, correlational, predictor, cohort, population, cross sectional based studies)
- IV. The intervention did not include a substantial mindfulness element
- V. The intervention included a multimodal intervention e.g. sex therapy, physiotherapy, consultation, exercise
- VI. The study focused on MBCT alone
- VII. The participant's primary diagnosis was a mental health condition
- VIII. Abstracts, conference paper, book chapter, book review, workshops, reviews, meta-analyses, presentations, theses, dissertations

## **Search Results**

Results are illustrated graphically in Figure 1. This figure shows that the original search terms retrieved 1099 from Psych INFO, 517 from Medline, 268 from CINAHL, 46 from PsychArticles and 657 from Web of Science.

514 duplicates were removed in EndNote, 28 duplicates as identified by the electronic programme Covidence were also removed, leaving 2062 articles for screening. 1920 articles were removed after the initial screening, leaving 142 full text papers. Once initial inclusion and exclusion criteria were

applied, 45 papers remained for full text review. 24 papers were further rejected for the reasons specified above and in the figure below.



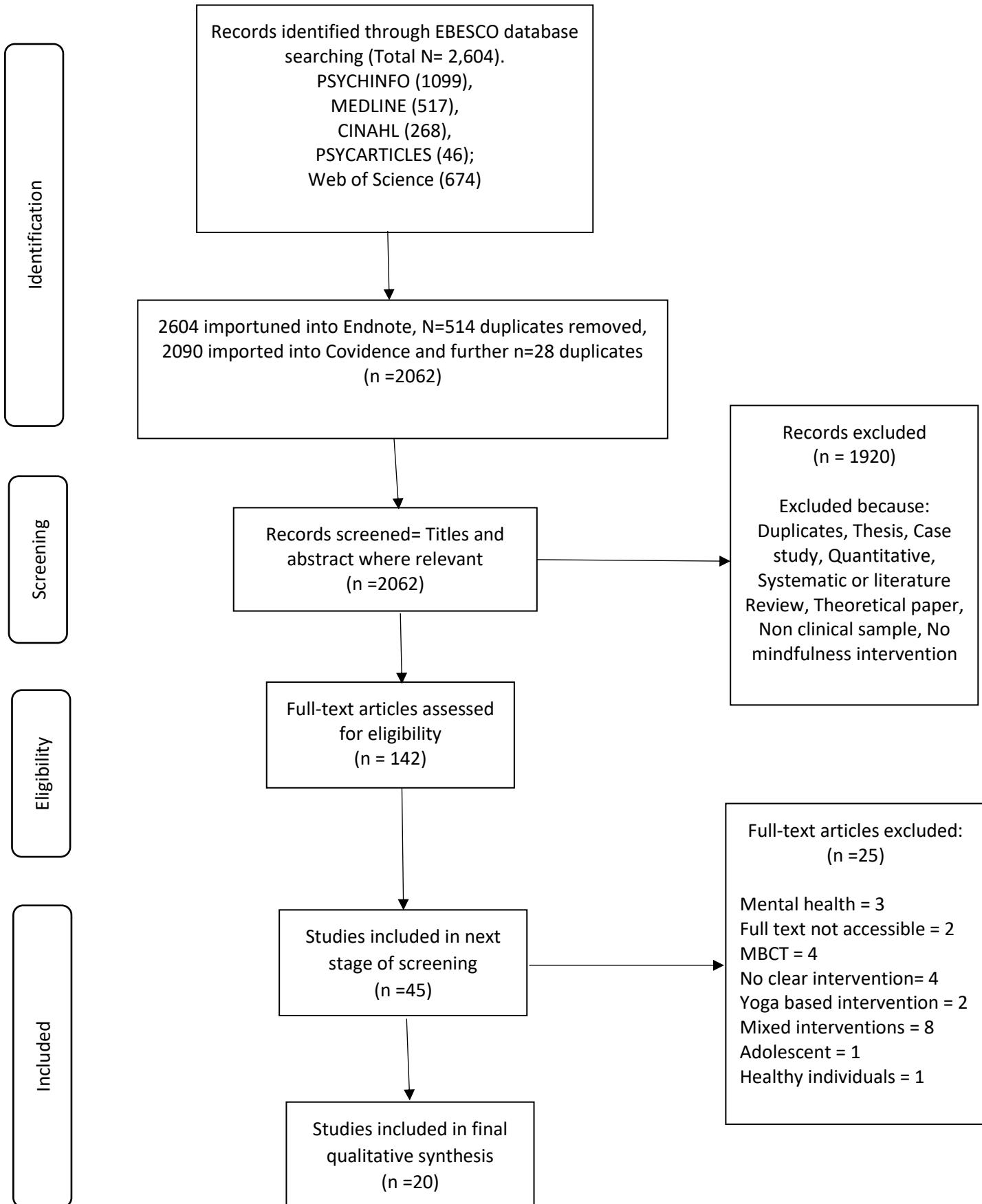


Figure 1. Flow Chart of Systematic Review

## **Appraisal of studies included in the review and quality assessment**

A quality assessment tool was applied, to establish the quality of studies and to help distinguish between studies and their overall contribution. The quality assessment was also used to understand the relative strengths and weaknesses of the studies in order to aid the process of synthesis of the body of evidence (CDC, 2009). There are a number of quality appraisal tools, which can be used for qualitative studies (CDC, 2009). For example, Elliott, Fischer & Rennie (1999) and Yardley (2000) have developed guidelines and recommendations for assessing qualitative research. A number of other published appraisal guidelines also exist (Spencer et al. 2003; Hammersely, 2007; Tong, Sainsbury and Craig, 2007; O'brien et al. 2014).

However, Dixon-Wood (2007) compared three critical appraisal approaches and determined that these may not result in a greater consistency of judgement about whether to include a study within a review. Furthermore, they conveyed that although critical appraisal tools for qualitative studies may indicate that, while one study may be methodologically sound, it may be subjected to poor interpretation. Conversely those with low methodological quality, may generate new insights grounded in the data. In light of this, the current systematic review acknowledges that although the quality appraisal tools used within qualitative research, are subjective and open to interpretation, they support the process of exploration of the current literature, and thereby the implications and contributions to the literature.

For this systematic review, 12 questions were devised from the Critical Appraisal Skills Programme (CASP) (2014) for qualitative research (Appendix C), and from the Consolidated Criteria for Reporting Qualitative Research Checklist (COREQ), (Appendix D). The quality of the studies were assessed by scoring the assessment tool. One point was given when the question was answered with agreement 'yes', and zero points were given for lack of clarity or if the question was answered with a 'no'. This determined the overall Quality Assessment Framework (QAF) score. Please see Appendix E & F for the breakdown of QAF scores, for each of the 20 studies included in this review.

## **Data extraction**

Data was extracted from the final 20 papers into an excel spreadsheet. Table 1. provides an overview of the studies included in the review, organised by study design, as well as their overall QAF score. This process indicated that there is a wide range of physical health conditions for which MBSR or MBI has been implemented and patient experiences explored. There is also a disparity in the quality of these studies.

Table 1.

*Studies included in the review*

<b>Author, Study Design, Country</b>	<b>Aims</b>	<b>Patient group</b>	<b>Intervention</b>	<b>Sample, age, gender</b>	<b>Methods</b>	<b>Theoretical approach/Analysis</b>	<b>Results and Themes</b>	<b>QAF score</b>
Chadwick et al(2008) Qualitative UK	To understand peoples' experience of mindfulness practice and to see what benefit it may have had.	Terminal cancer/ palliative care	Mindfulness Group  (6 weeks, 1 hours each week, 2 x 10 minute exercise, followed by discussion)	N=5, (aged 54 – 77)	Face to face interviews	Interpretative Phenomenological Analysis (IPA) approach	<i>1) Motivation and Hopes;</i> All participants commented on their initial motivation to attend for day care. <i>2) Benefits of Mindfulness;</i> All participants discussed whether mindfulness had been beneficial. <i>3) Relating to the Facilitator;</i> Mindfulness meditation was introduced by a facilitator, whom participants related to in a range of ways, some positive, some negative. <i>4) Relationship with mindfulness;</i> Participants related not only to the facilitator and their illness, but also to mindfulness itself. <i>5) Group process;</i> Mindfulness was the only activity done as a group. Hospice context, Practise outside the group	11
Doran(2014) Qualitative UK	To explore how mindfulness-based techniques, taught at Breathworks, relate to participants' perceptions and management of back pain and to discuss these in relation to embodiment theory.	Back pain	Breathworks Mindfulness Based living well with pain and illness  (8 weeks, 2.5 hours per week, drop in, homework, daily meditation)	N=16  (5 men, 11 women aged 33-66)	Semi structured interviews	Grounded Theory, informed by interpretative. Used constructivist Grounded Theory in analysis.	Themes: 1)Unpacking the pain experience; 2) Changing relationship to pain; 3) Letting go of the label; 4) Self-compassion and acceptance; and 5) Wellness within illness.	7

<b>Author, Study Design</b>	<b>Aims</b>	<b>Patient group</b>	<b>Intervention</b>	<b>Sample, age, gender</b>	<b>Methods</b>	<b>Theoretical approach/Analysis</b>	<b>Results/ Themes</b>	<b>QAF score</b>
Dreger et al (2015) Qualitative Canada	To determine the acceptability, suitability, and perceived value of the MBI through the reported subjective experiences of participants	Type 2 Diabetes Mellitus	MBSR (8 weeks, 2 hours per week, home practice)	N= 11, (average age of 60 years)	Semi structured interviews	Thematic Analysis	1) Factors associated with participation; 2) Consequences of participation (outcome) and; 3) Suggestions for future programs	10
Hawtin et al (2011) Qualitative UK	To explore what are participants' experiences of mindfulness in relation to coping with pain and Psychological wellbeing.	Psoriatic arthritis, Fibromyalgia or Rheumatoid arthritis.	MBSR	N= 5, (aged between 46 and 69 years)	Focus groups	Interpretative Phenomenological Analysis (IPA)	1) Responding to pain; and 2) Psychological wellbeing	11
Howarth et al (2016) Qualitative UK	To assess the views of patients regarding the acceptability of a brief mindfulness-based intervention as a self-management tool.	chronic Obstructive Pulmonary Disease, Chronic Pain and Cardiovascular Disease	Audio mindfulness (10 minute body scan mp3 introduced first at clinic, followed by home practice)	N=14 (aged 21–78 years)	Semi structured interviews & focus groups	Thematic Analysis	1) <i>Perceived benefits of audio</i> ; relaxation, mood improvement, increased coping, reduction in use of medication, increased motivation towards meditation. 2) <i>Acceptability of the audio</i> ; negative experience of the audio, content of the audio (wording, timing, voice), perceived barriers. 3) <i>Improvements to the audio</i> ; timing and pace, presentation	12

<b>Author, Study Design</b>	<b>Aims</b>	<b>Patient group</b>	<b>Intervention</b>	<b>Sample, age, gender</b>	<b>Methods</b>	<b>Theoretical approach/Analysis</b>	<b>Results/ Themes</b>	<b>QAF score</b>
Hoffman et al (2012) Qualitative UK	To explore the acceptability and perceived effects of participating in MBSR using qualitative data nested within an evaluative RCT	Cancer	MBSR (8 weeks)	N= 92 (Mean age of 49.)	Short proforma with semi structured questions and open questions	Content and Thematic Analysis	1) Being calmer, centred, at peace, connected and more confident; 2) The value of mindfulness practice; 3) Being more aware; 4) Coping with stress, anxiety and panic; 5) Accepting things as they are, being less judgemental of myself and others; 6) Improved communication and personal relationships and 7) Making time and creating space for myself	9
Kvillemo et al (2011) Qualitative Sweden	To examine the experiences and perceived effects of mindfulness stress-reduction training as described by the participants in interviews	Cancer; Breast Cancer or Lymphatic Cancer	Mindfulness training programme based on MBSR (8 weeks, 2 hr sessions)	N=18, (17 female, 1 male, mean age 54)	Semi structured telephone interviews	Thematic analysis	Most participants expressed a number of perceived positive effects of participating in the mindfulness program including; increased calm, enhanced sleep quality; more energy; less physical pain; and increased well-being.  However, a few participants experienced no effect.	10
Mackenzie et al (2007) Qualitative Canada	To explore patients' experiences of meditation and impact on subjective well-being, to understand how meditation practice influences patients' lives and mediates	Cancer; Breast cancer, prostate cancer, ovarian cancer, malignant melanoma , multiple cancers	MBSR (8 weeks)	N=9, (7 females, 2 male, between 43- 77, average 60.8yrs)	Semi structure interviews, followed by a focus group	Grounded Theory	Five major themes emerged from the data: 1) Opening to change; 2) Self-control; 3) Shared experience; 4) Personal growth; 5) Spirituality.	12

		their ability to manage their illness.						
Author, Study Design	Aims	Patient group	Intervention	Sample, age, gender	Methods	Theoretical approach/Analysis	Results/ Themes	QAF score
Morone et al (2008)  Qualitative USA	To identify themes that best described or commonly suggested participants' experience of applying mindfulness meditation to pain as well as to their daily lives	Chronic Lower Back Pain	Mindfulness Meditation based on MBSR  (8 week, 1.5 hrs sessions)	N= 27 (65 years and over)	Diary entries	narrative analysis / Based on grounded theory, content analysis of meditation diaries	Themes: 1) experiencing pain reduction from mindfulness meditation, 2) improvement in attention skills, 3) Improved sleep resulting from meditation, 4) Was achieving well-being, 5) was barriers to meditation, 6) Processes of meditation.	10
Van Gordon et al (2016)  Qualitative UK	To explored whether participation in a mindfulness based intervention, patients with Fibromyalgia report experiencing changes in (i) how they experience and relate to their illness and (ii) their attitudes towards societal participation, work and unemployment	Fibromyalgia	Meditation awareness training  (8 weeks, 2 hr sessions)	N=10, (1 male, 9 female aged between 29- 62)	Interviews	Interpretative Phenomenological Analysis (IPA)	Five super-ordinate themes emerged from the dataset: 1) reservations about participating, 2) improvements in psychosomatic well-being, 3) spiritual growth, 4) awareness of impermanence, 5) Increased sense of citizenship.	10

<b>Author, Study Design</b>	<b>Aims</b>	<b>Patient group</b>	<b>Intervention</b>	<b>Sample, age, gender</b>	<b>Methods</b>	<b>Theoretical approach/Analysis</b>	<b>Results/ Themes</b>	<b>QAF score</b>
Bogosian et al (2016) Mixed Method UK	To explore possible treatment mechanisms in the context of a Skype-delivered mindfulness course	Multiple sclerosis	Mindfulness  (8 weeks, 1 hr session, delivered over skype videoconference)	N= 15  interviewed	Semi structured interviews	Deductive and inductive thematic analysis.	1) Acceptance; 2) Decentring; 3) Self-compassion, and self-efficacy; 4) Group dynamics; 5) Prior experience expectations and engagement	11
Chan et al (2016), Mixed Method USA	To examine the experience of learning adoption in persons with COPD as a first step in the process of developing a acceptable and more effective meditation-focused mind/body intervention	COPD	meditation-focused mind/body classes  (8 weeks, 1 hour per week, homework, handouts, audio cd)	N= 32	Reflective journaling & telephone phone exit interview	Grounded Theory	Four themes:  1)Barriers to practice; 2)Learning style; 3) Emotional processing; and 4) Benefits of practice.	10
Dobkin (2008), Mixed Method Canada	To ascertain participant views on the program, mindfulness, and its application to their lives	Breast Cancer	MBSR  (8 weeks)	N= 13  (females aged 37-70 years, average age 54)	Focus group	Thematic Analysis	Themes:  1) Acceptance; 2) Regaining and sustaining mindful control; 3) Taking responsibility for what could change; 4) Spirit of openness and connectedness	8

<b>Author, Study Design</b>	<b>Aims</b>	<b>Patient group</b>	<b>Intervention</b>	<b>Sample, age, gender</b>	<b>Methods</b>	<b>Theoretical approach/Analysis</b>	<b>Results/ Themes</b>	<b>QAF score</b>
Dufour et al (2015) Mixed Method Canada	To gain insight into how and why the program may or may not translate to particular health outcomes	Various Chronic Health Conditions including coronary artery disease, history of myocardial infarction, hypertension, obesity, diabetes, COPD, cancer, arthritis and osteoporosis	Health coaching, including supervised exercise and mindfulness based stress reduction components	N= 16 (8 weeks)	focus groups and narrative reflections	Inductive thematic approach	Six themes were generated: (1) Group dynamic; (2) Learning versus doing; (3) Holism and comprehensive care; (4) Self-efficacy and empowerment; (5) Previous solutions versus new management strategies; and (6) Health care provider support.	8
Eyles et al (2014) Mixed Method UK	To explore participants' views on the acceptability of the MBSR course	Meta static breast cancer	MBSR (8 weeks)	N= 17 (female, aged between 37-65)	Interview & focus group	Thematic analysis	Themes: 1) Barriers to Participation and Recruitment Challenges; 2) Acceptability/Benefits "an Additional Band of Inner Strength; 3) Acceptability/Challenges "Like Having a Full-Time Job!"	10

<b>Author, Study Design</b>	<b>Aims</b>	<b>Patient group</b>	<b>Intervention</b>	<b>Sample, age, gender</b>	<b>Methods</b>	<b>Theoretical approach/Analysis</b>	<b>Results/ Themes</b>	<b>QAF score</b>
Gans et al (2014) Mixed Method USA	To test the feasibility of a novel mind–body intervention, Mindfulness Based Tinnitus Stress Reduction (MBTSR), as a possible tinnitus intervention	Tinnitus	Mindfulness based tinnitus stress reduction (MBTSR)	N=8, (mean age of 58, 6 male, 2 female)	Post intervention feedback from	Not reported	A tinnitus perception shift, a reduction in psychological distress, increased mindfulness, and improvement in general functioning, changes in lifestyle, role of instructor.	5
Keyworth et al (2014) Mixed Method UK	To investigate whether a brief, manualised meditation and mindfulness intervention can reduce worry and thought suppression and improve subjective health and well-being in people with two LTCs	Diabetes and Coronary Heart Disease (CHD)	meditation and mindfulness intervention	N= 27 (6 weeks)	Interview and focus groups	Framework analysis	<p>Participants perceived that meditation represented an opportunity to engage in an integrated activity that bridged mind and body, citing:</p> <p>Relaxation, improved sleep and physical health, and the acquisition of more mindful modes of thinking, such as acceptance and acknowledgment.</p> <p>Participants reported that meditation and the application of mindfulness can feasibly be incorporated into daily self-care routines and potentially reduce reliance on medical management of illness.</p>	11

Author, Study Design	Aims	Patient group	Intervention	Sample, age, gender	Methods	Theoretical approach/Analysis	Results/ Themes	QAF score
Majumadar et al (2002) Mixed Method Germany	To examine effects of an 8-week meditation-based program in mindfulness in a German sample.	Various Chronic diseases including: gastritis, hepatitis C, non-Hodgkin's lymphoma, migraine, chronic, sinus inflammation, asthma, chronic back pain, thyroid disorders, hormonal abnormality, chronic infections, and breast cancer in remission	Meditation-based program in mindfulness (8-week)	N= 21, (17 females, 4 males, aged between 22-62, mean age 39)	semi structured telephone interview	content analysis	Various experiences pertaining to the course format and participation in the intervention group. Beneficial qualitative changes in abilities to live daily life with awareness, mindfulness, calmness, and a less encumbered sense of self (the latter indicating a reduced tendency to attribute personal responsibility to all experiences). Positive experiences with the course format and reported positive qualitative changes in their abilities to live their daily lives in terms of awareness, mindfulness, calmness and a less encumbered sense of self. Successful transfer of course elements into daily life was also usually mentioned.	5
Moss et al (2015) Mixed Method USA	To test the feasibility and effectiveness of an adapted 8-week Mindfulness-Based Stress Reduction (MBSR) program for elders in a continuing care community.	Arthritis, sleep disturbances, hypertension, chronic pain, heart disease	MBSR (8 weeks, weekly 2 hr sessions,)	N= 10	Semi structured interviews	Thematic analysis	Increased present moment awareness, less judgment and greater self-compassion, and increased well-being. Interviewees reported that after mindfulness training, they were more able to pay attention, sustain attention, and bring their minds back when it wandered. More able to be present and the increased present moment awareness allowed them to experience their lives more fully.	7

<b>Author, Study Design</b>	<b>Aims</b>	<b>Patient group</b>	<b>Intervention</b>	<b>Sample, age, gender</b>	<b>Methods</b>	<b>Theoretical approach/Analysis</b>	<b>Results/ Themes</b>	<b>QAF score</b>
Petersen et al (2016) Denmark	To describe and predict the patients who would benefit from a mixed methods study. Mixed Methods Denmark (MBSR) course and those for whom the conditions or timing are not Optimal.	Mixed chronic pain	MBSR (8 weeks)	N=7, (4 women and 3 men)	Focus groups and case stores, evaluation questionnaires	Not specified	Focusing on the issue of what works, four categories of interest were identified from the transcribed interviews: 1)lessons learned; 2)being oneself; 3)permanence; and 4)continuity as a condition for success	8

### **Method of synthesis:**

There is much debate about whether data from qualitative studies can be synthesised for systematic reviews. Unlike quantitative studies such as Randomised Control Trials (RCT), which are standardised, and thus lending themselves to meta-analysis, qualitative research studies are often not generalisable, and are time, context and participant specific, making them difficult to replicate (Dixon-Wood et al, 2006; CDC, 2009). However, there is a line of argument asserting that if qualitative studies can be systematically reviewed like quantitative studies, they have the potential to inform the developments of treatments, intervention, as well as policy and practice (Campbell, 2003). Furthermore, as more qualitative studies become published, a growing number of methods of synthesising qualitative studies have been developed from Meta-ethnography, Grounded Theory, Thematic Synthesis, Textual Narrative Synthesis, Meta-narrative, Critical Interpretive Synthesis, and Ecological Triangulation (Barnett-Page & Thomas, 2009).

In order to make sense of multiple sets of qualitative data, it is helpful to use a systematic approach to reviewing studies. Qualitative methodologies are crucial to gaining an understanding of what people experience and depending on methodology, can help generate theories and understanding of processes. There is debate within the literature about how qualitative data should be synthesized (Page & Thomas, 2009). Both meta-ethnography (Nolbit & Hare, 1988) and thematic synthesis (Thomas & Harden, 2008) were considered as possible methods to conduct the current review. Meta-ethnography aims to interpret the text for inner meaning, seek new meaning, or re-interpret published literature. Additionally, it aims to generate new theoretical explanations and involves multiple stages of synthesis including first, second and third order interpretations; for example, translating the studies within each other, generating theory and interpreting (Page & Thomas, 2009). Thematic synthesis aims to summarise two or more papers in a narrative (Thomas and Harden, 2008). It offers a clear, transparent and replicable method, which has been demonstrated in other qualitative reviews, for example by Scope, Uttley & Sutton (2016). Furthermore, it is a technique that can be used in a variety of reviews to conduct a synthesis in a systematic way, yet is grounded in the studies included in the review. Thomas and Hardens', (2008) narrative synthesis was used for the current review as the aim was to synthesise multiple qualitative studies in a narrative, summarising the most poignant themes emerging from the data.

This systematic review adopts Thomas & Harden's (2008) three stages of Thematic Synthesis, to synthesise the qualitative data from the final studies.

First, all the text labelled as ‘results’ or ‘findings’ in the 20 study’s result section, along with any ‘findings’ from abstracts were imported into NVivo 11 for analysis. The three stages of thematic synthesis (Thomas & Harden, 2008) were then conducted. This included: 1) Line by line coding of results of primary studies: 2) The organisation of these codes into related areas to create descriptive themes: and 3) The generation of analytical themes.



## Results

### Descriptive Overview

The final 20 studies fell into two broad categories; studies that were qualitative and those that used mixed methods. The qualitative studies broadly aimed to explore experiences and perceived effects of participating in a mindfulness intervention (N=6). The remaining qualitative studies explored: participants' perceptions and management of pain in relation to the embodiment theory (n=1), the impact of mindfulness on coping and wellbeing (n=1), identification of themes that describe experiences of applying meditation for pain (n=1), and whether patients with fibromyalgia report changes in relationship to their illness and changes in attitudes to societal participation, work and unemployment (n=1).

The mixed methods studies had a greater variety of qualitative aims. These included: exploring views of participant's experiences (N=2), mixed-method feasibility and acceptability studies (N=4), exploring who would benefit from mindfulness intervention (N=1), exploring whether mindfulness reduced worry, through suppression and improves wellbeing (N=1), exploring why the programme did not relate to health outcomes (N=1), experience of learning adoption to further develop an intervention (N=1), and exploring treatment mechanisms (N=1).

Studies were conducted in various countries including; UK (n=9), USA (n=4), Canada (n=4), Sweden (n=1), Germany (n=1), Denmark (n=1). Mindfulness was the main intervention in all the programmes, as this was an inclusion criterion for this review. Several studies adopted the standardised eight week MBSR course (n=8). Nine of the studies' interventions were based on the traditional eight week MBSR but had alternative names such as 'Meditation based programme in mindfulness' or 'Mindfulness group'. One study was based on Breathworks, one eight-week mindfulness course was delivered via Skype and another through audio. The studies looked at the experience of mindfulness for a number of health conditions including: Cancer (n=6), Pain (n=3), Diabetes (n=2), Fibromyalgia (n=2), COPD (n=2), Multiple Sclerosis (n=1), Tinnitus (n=1), or collectively for a wide range of physical health conditions (n=3). Participants were recruited from a range of settings including: health centre, hospitals, through community advertisements, charities, and cancer patient organizations, GPs, self-help groups, cancer centres, audiology clinic, retirement community, pain centre, oncology unit, NHS Services and rehabilitation programs. Sample sizes varied from five to 92. A variety of methodologies were used including focus groups, semi structured interviews, open-ended questionnaires, diaries, post intervention feedback forms, evaluation questionnaires, journals and case studies. Various analyses were applied including; IPA (3), Grounded Theory (4), Thematic Analysis (9), Framework Analysis (1), Content analysis (1), or analysis

was not specified (2). All the studies used patient's own experience, where a study also reported staff views alongside patient views (N=1) these results were not included in the review.

## Narrative Synthesis

This systematic review generated a range of qualitative themes from both mixed methods and qualitative studies; however, some qualitative findings were not pertinent to the review question. These will briefly be reported at the end of this chapter. Therefore, only data concerning participants' experiences (attitudes, perception, views, impact, experiences) will be discussed. This thematic synthesis reports the most prominent themes that were found to be significant for participants, and each will be considered in turn and supported with patient quotes directly from the studies:

- 1) Perceived barriers to participation and practice
- 2) Positive consequences and benefits of participation
- 3) Group attributes
- 4) Negative experience
- 5) Home practice and application to life

### 1) *Perceived barriers to participation and practice*

Perceived barriers to participation and practice were a common theme across 60% of the studies (12/20). A number of studies described a range of perceived barriers to participating in a mindfulness group and to practising mindfulness. These included circumstantial challenges, internal barriers, learning styles, prior experiences and beliefs, reservations about participation, programme specific challenges, physical pain and social anxiety.

The theme of circumstantial challenges was prevalent in 20% of the studies, and included family demands and obligations, poor weather, health concerns, having busy and stressful lives, various forms of distraction, not having the time, having full-time jobs, and having holidays planned to name a few. Physical health or pain was another barrier; "*What was difficult for me was to find a good position because I am so very rigid in my body. I could not sit down*" (Kvillemo et al, 2011). Internal barriers included such as not wanting to ask others for help, so they could attend (Chan et al, 2016).

One study also noted that individuals may feel socially anxious or uncertain about their practice in front of others; "*I didn't like having to take the shoes off. I had to make sure I had clean socks on 'cause I didn't want people to see holes in my socks*" (Dreger et al, 2015).

Reservation about participation was another common subtheme. One of Bogosians' participants validated this sense of reservation, "*I had a reservation that it might make me unhappy,*

*because not understanding, very much about it, I thought I'm not really sure if I'm quite ready to accept what I'm going to learn about myself.*" Reservations also stemmed from lack of understanding about mindfulness, some individuals had made association between mindfulness and the supernatural (Van Gordon, 2016).

Chan et al (2016) acknowledged the learning styles of 'adapting, accepting, or rejecting' as potential barriers. It could be said that a rejecting learning style could be linked to prior experiences and beliefs. For example, not believing that mindfulness could be beneficial, and that as individuals they did not need to become more mindful as they were already performing activities that attained relaxation (Chan et al, 2016). Another participant quote stood out as describing this sense of reservation, or doubt, as well as the complexity of learning a new skill, whilst recognising the process of change; "*After a while, it was like I looked forward to going. It took a while for me to grasp the concept and, you know, the theory behind or the reasons behind, you know, the exercises and everything. I guess the thing is...maybe I'm just full of doubt or just a little...wary. After a while, it was like...it wasn't so bad. I guess once I got into a routine, you know, knowing I was coming and sort of planning around it. The first few times was like, oh, I don't have time for this type of thing. So it was just having the mindset that okay...it's only going to be for so long and I come to realize that, okay, these exercises are good, she's [the instructor] making me slow down... and uh, take a look at what I do... it was just good exercise and I was thankful for that*" (Dreger et al, 2015). This mirrors Chan et al's (2016) 'learning style', indicating that this could be a process of rejecting, adapting and accepting, as well as a learning style.

## 2) Positive consequences and benefits of participation

Almost all of the studies discussed participant's positive experiences of the mindfulness interventions and the positive consequences as well as impact. The most prevalent positive consequences in the context of having a chronic illness included: improved health and wellbeing, increased awareness and ability to cope, a changing relationship to health, attitudinal and perspective changes, and behavioural changes. Each of these will be considered in turn.

Improved Health and Wellbeing: almost all studies (90%) described that participants reported improved health and wellbeing in some respect. Most commonly, this was in the form of improved psychological distress, aiding sleep, a sense of calmness, feeling relaxed, and improvements in health and/or reduction in pain. Improved psychological distress encompasses reports of reduced worrying, panic, improvement in low mood, feeling less stressed and reports of general emotional changes. This was reported in 50% (10/20) of the studies. For example; "*It*

*definitely made me more cheerful and I, um, improved my outlook . . . and I'm almost certain that I haven't got so down since.*" (Chadwick, 2008). Improvement in sleep was frequently reported by respondents in 35% of the studies (Dreger et al, 2015; Eyles et al, 2014; Gans et al, 2014; Kvillemo et al, 2011; Morone et al, 2008; Moss et al, 2015; Van Gordon et al, 2016); "*when I have trouble sleeping, I use the body-scan and it helps me fall asleep again.*" (Moss et al, 2015). Many respondents described feeling relaxed and being calm as a result of practising mindfulness; "*The biggest revelation from the course has been the relaxation and learning about how my body feels like to relax . . .*"(Doran, 2014). Reduction in pain and improvement in health was reported by many of the participants in various studies (7/20); "*I have arthritis, and I am used to living with pain. Sometimes I think that I can reduce the pain during meditation.*" (Kvillemo et al, 2011) and "*When I feel discomfort or pain my body, doing a practice, like the body scan, that really helps me.*" (Moss et al, 2015).

Increased awareness and ability to cope: The aim of mindfulness is to pay attention on purpose, in the moment, without judgement. As would be expected, increased awareness and attention were therefore two of the most commonly reported outcomes, along with the outcome of acceptance. 65% of study respondents described an increase in awareness. For example, "*I learnt about my posture, regarding how I sat . . . mindfulness has heightened the awareness of the tension in one's body*" (Chadwick et al, 2008). Chan et al, (2016) reported 'increased awareness of both positive and negative emotions', an awareness of loss of control (Dobkin, 2008; Hoffman et al, 2012), an awareness of the world around them (Dreger et al, 2015, Hawtin et al, 2011), and an increased awareness of present moment (40% of studies) was also stated. Being able to pay attention and bring their mind back when it wandered was another positive outcome (Moss et al, 2015).

60% of studies reported acceptance, such as choosing to stay with difficulties when they arose (Bogisian et al, 2016), being more accepting of themselves (Dobkin, 2008), and accepting pain (Doran, 2014). Eyles' (2014) study, described participants becoming 'less reactive to the emotional distress and accepting the disruption to their lives'.

Increased ability to cope was described by 60% of authors. For example, "*Using the focusing techniques and accepting techniques for difficult problems that have been very invaluable. They are the tools that I will use. I see them as tools that you can use the same way you use a knife, a fork to eat your food, you know, use them as tools to help me manage my condition*" (Bogosian et al, 2016) Furthermore, Dobkin's, (2008) participant stated "...because it really taught me good coping skills, and while I was going through the cancer experience, I did not realize at the time that I was not

*coping. I was existing, I was going through the process without really um sitting back to think about my emotional well-being*". Hoffman et al, (2012) stated that 'coping better with stress, anxiety and panic' was one of their key themes that one of their participants stated: '*I now feel that I have a way of understanding and dealing with stress which is available to me every moment of my life*'. Eyles' (2014) described participants becoming 'less reactive to the emotional distress and accepting the disruption to their lives' which could also be seen as a result of increased ability to cope.

Compassion to self and others and improved relationships and communication: Individuals reported a change in relationship to themselves in the form of being more self-compassionate. Self-compassion was reported in 35% of studies; '*the program helped me stabilize myself and enjoy time that I had for myself and not feel guilty*' (Dobkin, 2008), and compassion to others; "*I think about other people more, I guess I don't know how to say it....empathetic I guess is the word*" (Chan et al, 2016). Studies also reported that respondents stated improved relationships and communication with others (Bogosian et al, 2016; Eyles et al, 2014; Hoffman et al, 2012; Mackenzie et al, 2007; Moss et al, 2015).

Attitudinal and perspective changes: Perspective changes were reported in relation to practising mindfulness (Chadwick, 2008). Dobkin (2008) participant reported: "*It's changed my mind-set completely. I'm much more conscious all the time of what I'm doing and why I'm doing it, and even if it's not right, at least I'm conscious*". Similarly, Dufour et al (2015) reports; "*This program actually helped me to change my mind-set*". Gans et al, (2014), reported that attitudes and beliefs about tinnitus shifted; "*Tinnitus doesn't seem like a terrible curse anymore. It's sometimes annoying now but not insurmountable*". Furthermore, Mackenzie et al's (2007) participant described a transformation in the meaning of cancer; "*The way I look at cancer is that once you get through the awfulness it's a very powerful motivator to live your life. I'm grateful I can come up here and be reminded of that.*" These changes in perspective and meaning may have changed illness experiences, perception of illness, and relationship to health, self and others.

Changing relationship to health, illness experience, self and other through attitudinal and perspective shifts: Relating differently to health and illness and perception shift was conveyed in at least 55% of the studies. Chadwick et al (2008), conveyed that the individuals related differently to illness because of mindfulness; "*I'm happier in myself and more accepting I think. He, he taught us to look at our illness in a different way . . . I think, think that is the main thing really he taught us, to look about the illness differently and it made us more able to cope and rise above it*". Likewise, it was also noted in terms of coping and experience of illness by Keyworth et al, (2014); "*adopting a more*

*balance or accepting perspective helped cope and adjust to the uncertainty associated with living with a long-term illness". Mackenzie et al, (2007), also quoted a respondent's change in relationship to health; "The healing has elevated me to a higher level of recognizing this programme as beneficial, no matter what. It's changed my outlook on life, my relationship to other people and, most importantly, my relationship to stress and health".*

Doran (2014) described respondents change in perception of pain and how this alters the illness experience; "*I looked at things in a very absolute way, so my pain was solid, my pain was everlasting. With the perception that I got through the course, I see that everything is always changing, and that includes my pain. That helps me enormously and the way that I live with it. It gives me a life that is liveable!*"

Shifts in perspective also change how some engaged with their illness, for example, Hawtin et al, (2011) describes a participant deliberately engaging with the illness experience; "*finding out where the pain is ... breaking it up ... slowing down into it*". Dreger et al (2015), also described how attitudinal shifts such as having a more positive outlook, acceptance, and more self-compassion, resulted in better relationships with others. Similarly, Eyles et al (2014), describes how these 'shifting perspectives resulted in a changed relationship with themselves, with others, and with their illnesses.'

**Behavioural changes and new strategies:** A number of studies conveyed that participants made behaviour changes, which they benefited from. Dreger et al (2015), reported behaviour changes from 'smoking less, eating less, and making healthier food choices'. Dufor et al (2015) reported increased use of self-management strategies rather than health care driven strategies. Keyworth et al (2014), conveyed that meditation was linked to the ability to cope with negative thoughts and rumination "*I do tend to feel obliged by what other people say ... and now I just, sort of, take a deep breath and go, it doesn't matter... And, this has, sort of, made me reconsider... I tend to be able to think, it doesn't matter what other people say or what other people think, am I happy with what I've done? Yes, fair enough.*" A number of studies also noted reduction in use or reliance on medication (Dufour et al, 2015; Howarth et al, 2016; Keyworth et al, 2014; Majumadar et al, 2002; Petersen et al, 2015) (5/20). Other less reported positive consequences included, making more time for yourself (3/20) and personal and spiritual growth (3/20).

### 3) Group Attributes

Group attributes were discussed as a key theme in nine out of the 20 papers (45%). General positive experiences were reported by group members (Dobkin, 2008). This can be illustrated by

quote from Dufor et al (2015); “*I really liked the group environment, that was an aspect that I really enjoyed I found that part of the program a big help*”. Aside from general positive experience the social aspects of the mindfulness groups, social support, sharing similar experiences and the opportunity to learn from others experiences were discussed by several authors. According to participant interviews, the group dynamic was an important aspect of the experience of the programme (Bogosian et al, 2016). This was both in terms of sharing diagnosis but also in being novices in mindfulness (Bogisian et al, 2016; Kvillermo et al, 2011). Participants appreciated how the group enabled validation and normalization; “*It was helpful knowing others were having the same issues as me...that made me feel better*” (Dreger et al, 2015). Chadwick et al (2008) reported group process factors as important; connecting with others being a reason for attending the course, and as well as learning mindfulness through hearing others comments and experiences. This was also echoed by participants interviewed by Dufour et al (2015); “*it is the different perspectives that come through. What one person might think about a particular situation is different than what another person might come up with.*” In addition, Keyworth’s (2014) participant reported, “*A very significant thing is the socialisation, the fact that you can talk about the conditions and then you can observe others people with similar conditions, and it gives you an idea to get things in perspective*”. The group aspect was also meaningful in that it cultivated awareness in a non-judgemental environment, enabling self-compassion (Moss et al, 2015). Many respondents also commented that the group was a factor supporting their continuing participation in the courses.

In contrast, Howarth et al (2016) conducted a study, in which the intervention did not involve an 8-week group format, but a brief mindfulness based audio intervention, delivered in the clinic requiring home practice. Therefore, group process was not a reported theme. However, Bogosian et al (2016), adopted a mindfulness intervention, which was delivered over skype video conference to three to five individuals. Despite individuals not being present in the same room, ‘group dynamics’ were considered to be one of five important themes.

#### 4) Negative experience

A small number of the overall papers (N=6, 30%) reported that participants experienced negative or unwanted side effects of the programme, negative effect of practising mindfulness, and in particular negative impact on their emotions. Individuals also described difficulties with performance of meditation or mindfulness exercises due to physical pain. In relation to the programme itself, one study reported negative perceptions or ambivalence about the full day of mindfulness. One participant described it as “*I thought the day was a bit too much. I didn’t feel—from my point of view—that the day really added anything that the other sessions hadn’t and didn’t give*

*me. I just thought it was a bit too long, I really wanted to go home. I just didn't really want to be there any longer. . . . I did find it tiring actually . . . oh and the silent eating—I could never get on with the eating”* (Eyles et al, 2014).

Kvillemo et al (2011) found that at least three of their participants did not experience any effect or experienced negative effects of home practice due to ‘the inability to share and deal with emotions that were evoked’: “*It was very hard doing the exercises on our own at home. I also thought that the techniques were somewhat too powerful in one way, if you don't feel emotionally stable. As you are doing a lot of the exercises alone at home, and you cannot process your experiences. It felt like I needed to talk to someone who had the right competence, not just talk to a friend.*” Petersen et al (2015), described four case studies where individuals experienced unwanted side effects from doing meditation including experiencing panic attacks, intense feelings of anger and a ‘strange form of trance’.

Negative impact on emotions was one of the most common negative responses. For example, Chan et al (2016) described that participants reported increased awareness of fear, panic, and worry regarding COPD; “*Being mindful of my body brings up guilt*”. Kvillemo et al (2011) reported that the program led to an emphasis of negative mood; “*It [the program] did not help me to get out of my situation. I have been really down during the summer. I don't know, it might be that I was heading too far down for this to work. I don't know, it felt meaningless, almost like it emphasized the bad situation.*” Many noted that their physical pain made it harder to perform some of the exercise due to pain or stiffness; “*What was difficult for me was to find a good position because I am so very rigid in my body. I could not sit down*” (Kvillemo et al, 2011).

##### 5) Home practice and application to life

50% of the studies reported patient’s experience of practising mindfulness outside of the context of the course. Five of the studies reported continued practice or incorporating it into daily life as one of their overarching themes. Keyworth et al (2016) discussed the feasibility of incorporating mindfulness practice into daily life and the potential to reduce medication. Similarly, Mujumdar’s (2002) participants reported the successful transfer of skills into daily life. Petersen et al’s (2015) participants accounts recognised that continuity of practice was important for success. Furthermore, Howarth et al (2016) reported an increased motivation toward meditation and Dobkin (2008) described individuals taking responsibility for what could change outside of the course.

However, barriers to home practice were also reported. These included: learning a complex practice, disbelief that mind-body practice could be helpful (Chan et al, 2016), distractions whilst meditating, such as interruptions from family (Dreger et al, 2015), feeling like it was a burden to practise (Eyles et

al, 2014), finding it hard to practise when other people were present (Majumdar et al, 2002), and finally, some individuals required prompting by family members (Chadwick et al, 2008).

### Summary of themes

Increased ability to pay attention and increased awareness of thoughts, emotions and bodily sensation and moment-to-moment awareness, seem to lead to the development of the observing self. Respondents reported that this led to an ability to notice symptoms earlier and prevent flare ups by choosing how to respond or by responding differently. This ability to choose how to respond may have given rise to the positive outcomes noticed in their improved wellbeing. This may result in an increased sense of control and in turn, confidence. Acceptance of emotions and physical health difficulties, alongside increased self-compassion and a choice in response, could lead to self-efficacy and empowerment, which could be perceived as personal growth, and in turn provide an increased ability to cope. These new positive experiences may then give rise to changes in attitude and shifts in perspectives in ill health, producing feedback into behavioural changes. The group setting provided social support, and offered a normalising and validating space to learn a new skill with likeminded people. Alongside this, home practice provided a safe place to practise mindfulness and an opportunity to integrate it into everyday life.

### Themes not relevant to review question

There were a number of themes that emerged across the studies that did not fit with the research question, such as factors leading to initial participation, which included health concerns (Dreger et al, 2015; Keyworth et al, 2014; Mackenzie et al, 2007; Petterson et al, 2015), intrinsic motivation, such as curiosity about the programme (Dreger et al, 2015; Keyworth et al, 2014; Petterson et al, 2015), hopes for the course (Bogosian et al, 2016; Chadwick et al, 2008; Eyles et al, 2014; Keyworth et al, 2014), trust in health institute (Dreger et al, 2015; Keyworth et al, 2014, Mackenzie et al, 2007) and other programme attributes (Dreger et al, 2015; Keyworth et al, 2014; Kvillemo et al, 2011). Programme attributes, such as the value of supplementary material, facilitator attributes (Bogosian et al, 2016; Chadwick et al, 2008; Dufour et al, 2015; Gans et al, 2014; Keyworth et al, 2015) location of programme (Chadwick et al, 2008; Dufour et al, 2008), intervention name, and content were also explored, but not pertinent to the review question. Improvements and suggestions to programmes were also recommended by some (Howarth et al, 2015; Dreger et al, 2015).

## Inconsistencies in study findings

Overarching themes were occasionally reported in different ways, for example the ‘benefits of attending’ and ‘group attributes’ were considered to be ‘factors for supporting continued participation’ and have been included in the overarching themes of this systematic review. However, a number of themes identified in the studies did not fit with the majority of other studies such as, ‘increased sense of citizenship’ or ‘spiritual growth’ (Van Gordon et al. 2016; Mackenzie et al, 2007). This could have been due to the range of different research questions, study aims and variations in interventions from traditional MBSR to brief mindfulness audio.

## Conclusion

Mindfulness based interventions are acceptable for many individuals with LTHC and physical health problems. There are a range of barriers throughout an individual’s journey, from initial participation, to ongoing attendance, to home practice. Individuals can experience both positive and negative impacts of mindfulness interventions. The group aspect of these interventions are valued by participants for their social aspect, social support, validation, and normalisation and shared experiences of illness and ill health. Those who have reservations about mindfulness, may go through a process of reservation, adjustment and acceptance. However, a minority of individuals may experience negative side effects of practising mindfulness. Although the overall themes reported in this review, such as; various positive consequences, group process, and negative consequences, were supported by the majority of studies, due to varying research questions, the sub themes were not reported by all of the studies.

## Discussion

A relatively small number of independent qualitative studies have explored and reported patient experience of MBSR or MBI, consequently there have been very few qualitative systematic reviews; notably, exploring patient's experience of MBCT (Cairns & Murray, 2015) or MBCT and MBSR for both mental health and physical health patients (Malpas et al. 2012). The aim of this systematic review was to review participant's experiences with LTHCs and perspectives of MBSR or MBI, not including MBCT. The three-step process of Thematic Synthesis (Thomas & Harden, 2008) identified five major themes; 1) perceived barriers to participation and practice: 2) Positive consequences and benefits, which included a number of sub-themes: 3) Group attributes: 4) Negative experience: and 5) Home practice and application to life. These offer insights into barriers and benefits for service users, and have implications for stakeholders offering mindfulness interventions for LTHC.

### Current review in relation to previous research

Malpas et al's (2012) systematic review describes the therapeutic process involved in mindfulness based approaches for both mental health and LTHC. They describe a process involving three phases; perceived safe certainty, safe uncertainty, and grounded flexibility. Cairns & Murray's (2015) systematic review aimed to understanding how MBCT contributes to positive therapeutic change, and identified five major themes; taking control through understanding, awareness and acceptance, impact of group, taking skills into everyday life, feeling towards self and role of expectations. The current review differs from these reviews in terms of its methodology, as both Malpas (2012) and Cairns & Murray (2015) utilise the meta-ethnography method of synthesising qualitative research. Despite these differing methodologies, similarities can be drawn between their themes and those of the current review. The current study builds on the findings of Cairns and Murray (2015) who identify awareness and acceptance, impact of group, taking skills into everyday life and feeling towards self, as key themes.

**Perceived barriers to participation and practice:** This finding was echoed recently by Lomas, Cramer, Dobos, Langhorst & Schmid (2015). In a study exploring the impact of meditation on male participants, they found a range of psychological challenges associated with practice. These included experiencing meditation as a difficult skill to learn and practise, difficulties with managing thoughts and emotions, exacerbating mental health difficulties such as anxiety and depression, and even associations with psychotic episodes.

**Positive consequences and benefits to participation:** Numerous studies support the evidence for the benefits and positive impact of MBI, as well as reduction in psychological difficulties related to physical illness (Baer, 2003; Grossman et al, 2004; Bohimeijer et al, 2009, Merkes, 2010). This review verifies and supports the findings of existing literature through patient experiences.

**Group attributes:** It has long been acknowledged that group context and dynamics influences process and outcome of group interventions (Yalom & Leszcz, 2005). Furthermore, it is well known that social support is considered important, as it allows patients to cope with the stress often caused by chronic illness (Choen, 2004). Group social identity is also related to coping, and can be seen as a resource (Haslam, Jetten, Pstmes, Haslam, 2009). Therefore, it is not surprising that a key theme in this review was the positive impact of group attributes.

**Negative Experiences:** The theme of negative experiences in this review, although evident in independent studies, highlights the possible negative impact of MBI irrespective of health condition. Research in mindfulness has largely ignored the negative consequences or side effects of mindfulness and psychotherapy research (Dimidjian & Hollon, 2010). However, the studies in the current review have shed light on how wide spread negative side effects might be. Allen et al (2009) also reported that their participants experienced difficulties when they realised that mindfulness was not a cure and expressed further difficulties in 'doing' mindfulness. Being aware of such difficulties for participants has implications for the development of future MBI.

**Home practice and application to life:** The emergence of this theme is not surprising considering that MBI emphasises cultivating and bringing mindfulness to all aspects of everyday life (Kabat-Zinn, 2001). Similarly, Carin & Murray (2015) also discuss the various ways that taught skills are taken and applied into everyday life. Research has shown that time spent on practising mindfulness is related to significant improvements to wellbeing (Carmody and Baer, 2007), which also has clinical implications.

### Links to theoretical concepts and drawing analogies between fields

It is not surprising that the current synthesis reflects the skills that MBSR and MBI aim to teach and deliver (Kabat-Zinn, 2003). The positive impact of an accepting and a non-judging approach, is consistent with the theoretical idea behind MBSR. For example, the attitudinal changes described in the current study are consistent with findings from other studies (Thompson, 2009). Shapiro et al, (2006) describe this as the process of 'reperceiving' as a meta-mechanism, which is primarily, a shift in perspective. These shifts in perspective allow a person to observe themselves differently to the content of their thoughts, thereby changing the nature of their experience. For

example, standing back and observing their personal life rather than being immersed in it. This is similar to cognitive diffusion discussed by Hayes et al (1990).

The perception of being in control is important with regards to health and it is well known that perceived control is associated with, and is considered a protective factor for, psychological and physical health (Glass, Siger and Friedman, 1969). Mindfulness, in particular, enables flexible responses to one's environment, facilitating healthier behaviours and making conscious choices (Pagnini, Bercivitz & Langer, 2016). Baer (2003) also conveys that mindfulness encourages self-management, exposure to emotions, acceptance and results in cognitive changes and relaxation. Additionally, Shapiro et al (2006) explains how intention and attention both improve self-regulation, and in turn, health.

The success of MBSR and MBI for long term health conditions also explains the success of newer third wave therapies, such as ACT, in which acceptance and mindfulness are key processes for psychological flexibility (Hayes, Wilson & Strosahl, 1999). Mindfulness enables the 'observing self' or 'self as context', in which private thoughts, feelings, sensation and memories are observed, as one possible perspective. This observation of what one experiences, without attempting to effect change is considered to be acceptance. The evidence base now shows ACT to be effective in a range of LTHC such as MS, cancer, obesity and diabetes (Montgomery, Kim and Franklin, 2011; Ost, 2014). Recent evidence has demonstrated acceptance to be a crucial part of mindfulness interventions for psychological conditions, such as anxiety (Aisnworth, Bolderston & Garner, 2017).

### Critical review

The literature included in the current review contained studies with a variety of research questions from specific to broad, mostly exploring experiences of mindfulness for individuals with PHCs. All studies came from a variety of Western countries, for a range of health conditions. A variety of methods were used amongst the studies to elicit patient views. Thematic analysis was the most common utilised analysis method, followed by grounded theory and IPA.

### Methodological quality of included studies

All studies provided context and aims of their study (N=20). There were a range of recruitment methods stated (n=18). The methods used to collect data were mostly interview methods (n= 9) and focus group (n=3), or both (n=5), diaries (n=1), open questionnaires (n=1) and a journal (n=1). Almost all studies clearly stated their qualitative methodology (n=19).

The quality assessment process identified scores that ranged from 5 to 12 points (Appendix E & Appendix F), which suggests variability in the quality of studies. However, the majority of the

studies (18 out of 20) scored between 7 and 12 out of 12, with over half the papers (n=12) scoring above 10, 14 papers scoring above nine and only two papers scoring a five. Based solely on the scores of the QAF, the quality of the overall studies under review could be considered as high.

The included studies, utilised a wide range of qualitative analyses, all with varying epistemologies. Difficulties were encountered in scoring the studies due to disparity and lack of clarity in reporting of methodology and transparency of the analysis process adopted by authors. For example, many did not consider the relationship of the interviewer to their participants or report self-reflection (n=4). Furthermore, despite most studies (n=19) stating their method of analysis, only 10 of the studies adequately described the method of analysis. For this reason, some studies scored lower. Furthermore, the sample sizes across the studies varied greatly, from using IPA with five participants to collecting written feedback from 92 participants.

The inclusion criteria accepted qualitative data within mixed method studies. Half of the studies in this review fell within this category. The studies were included as they were all deemed to contain data relevant to the review question, however this then had consequences, in that the qualitative aspect of the studies were not reported to the same effect as a qualitative paper alone. This is reflected in the lower QAF scores for the mixed method papers. It appears that poorer quality studies had less to contribute to the overall thematic synthesis, than those that appeared to have higher QAF scores, possibly due to limitations on word limits imposed by journals.

Although qualitative research implies that researchers aim to explore experiences of a phenomenon or an intervention, this was not always the case in the final studies included in this review. However, the studies were all considered with the focus on participants' experiences of the interventions, regardless of the research question of the study. For example, Van Gordon et al (2016) aimed to understand if participating in a MBI caused Fibromyalgia patients to experience changes in the way they related to their illness, and their attitude towards societal participation, work and unemployment, rather than their direct experience of the mindfulness intervention. Furthermore, within the current set of literature, not all studies had a standardised MBSR intervention, although many studies based their intervention on the typical eight week MBSR, therefore results should be taken in the context of the varied intervention lengths of the MBI.

## Methodological quality of the current review

### *Strengths*

As recommended by Thomas & Harden's (2008), a thematic synthesis was adopted to draw together the findings for this review. Thematic synthesis involves re-coding the results of qualitative papers. Using a systematic methodology specific to qualitative research ensures that not only is this

systematic review replicable, but also provides more credibility to the review. Furthermore, studies were quality assessed using the CASP quality assessment tool, enabling a standardised review of all studies. This tool balances items on method and findings. Similarities could be seen between the reported themes of the studies included in the review, despite varying health conditions and populations, such as adults and older adults. For example, 19/20 of the studies alluded to the positive consequences of mindfulness practice as key theme. Group dynamics were reported as a key theme in nine out of the 20 papers. Furthermore, ten of the studies reported patients' experience of practising mindfulness outside of the context of the course. Five of the studies reported 'continued practice' or 'transfer of course elements' into daily life as one of their key themes. Although it may appear that the similarities in key themes across the papers were low for some themes like home practice, negative experiences and perceived barriers, many of the papers still discussed these concepts without including them as a key theme leading to the overarching themes in this review.

#### *Limitations*

As qualitative studies are not all standardised unlike some quantitative studies, comparisons were therefore difficult. The quality assessment tool used aimed to overcome differences in methodologies, data sources, recruitment and analysis, inherent to qualitative research. However, the final papers were not cross checked by a second reviewer during the quality assessment process which may be a limitation.

None of the studies were discarded after the quality assessment process had been completed, as there is no empirically tested method for excluding qualitative studies as there are in quantitative systematic reviews. All the studies were included in the synthesis; however, one could argue that those with a lower QAF score should have been excluded from the review, as not all the results of the studies were pertinent to the review question.

Although mental health diagnosis was an exclusion criteria for the current literature review, not all studies within the review verified whether they assessed for a mental health diagnosis within their populations. Where some studies did, they usually excluded individuals with severe psychiatric conditions; however, this does not mean that individuals did not meet criteria for mild to moderate mental health conditions. For example, in Chan et al's (2016), study the inclusion criteria for participation in the mindfulness intervention was COPD; however, it became clear that non attending individuals had increased levels of social anxiety.

## **Implications**

### *Clinical and practitioner points*

This review indicates that MBI, notably MSBR are acceptable for individuals with long term and physical health problems. Individuals can experience both positive and negative experiences of mindfulness interventions. The group aspect of these interventions are valued by participants for their social aspect and social support, and those who have doubts or who are unsure about mindfulness may go through a process of reservation, adjustment and acceptance. Clinicians should be mindful that individuals may have different experiences, at different stages throughout their journey. Individuals are able to incorporate mindfulness practice into everyday life and should be encouraged to do so within MBI. Despite the overwhelming positive consequences of mindfulness reported in the literature, negative experiences were also reported. Independent studies are beginning to report negative experience of mindfulness which are important to bear in mind, as these have implications for the development of future MBI, specifically for recruitment into and attrition from studies. Clinicians and researchers should be observant of these negative side effects, and provide adequate support to participants should they occur.

### *Research*

As MBSR was developed for pain and later for cancer, there are a disproportionate number of studies for both these health conditions. More independent qualitative research is needed in the field of mindfulness for a wider range of physical health conditions, which then needs to be replicated to build the qualitative evidence base. There is a small but growing field of research for psychological intervention in relation to respiratory conditions (York et al, 2016), but more is needed to understand the benefits and mechanisms of such interventions. Further qualitative studies exploring mindfulness interventions for specific health conditions will enable understanding of mechanisms, attrition rates in research studies, and barriers.

## **Conclusions**

Due to disparity and inconsistencies in reporting, it can often be difficult to draw conclusions from qualitative studies that varied so much in their methodology, analyses of data, as well as quality of study. Despite varied methodologies and inconsistencies in reporting, clear similarities were observed, namely the positive outcomes in improved wellbeing and increased ability in coping. Individuals can experience both positive and negative experiences of mindfulness interventions. The group aspect of MBI interventions were valued for their social aspect and social support. Those who have doubts about mindfulness may go through a process of reservation, adjustment and acceptance. Individuals are able to incorporate mindfulness practice into everyday life, however a

small minority may experience negative consequences and challenges to participation. These findings have raised implications for clinical delivery of MBI, particularly in relation to the side effects and negative experiences of mindfulness, which would warrant further research and inquiry.



# Chapter 2 – Empirical Paper: Poorly Controlled Asthma patients experience of a brief mindfulness-based intervention: a qualitative approach

## Introduction

### The impact of asthma on wellbeing

Asthma is a long term health condition affecting both young and older people. Asthma affects 334 million people worldwide (Global Asthma Network, 2012) with 1 in 11 children and 1 in 12 adults experiencing asthma (Centre for disease control and prevention (CDC)). In the UK 4.3 million adults currently live with asthma, it is responsible for 1200 deaths each year. Typical symptoms include breathlessness, wheezing, tightness of chest and coughing.

Asthma can affect all aspects of quality of life including social and physical functioning, pain, fatigue, mental health and general health (Bousquet et al. 1994). Asthma can affect an individuals' emotions, concentration and self-management behaviour. The experience of breathlessness or an asthma attack can be frightening and can cause panic, anxiety and low mood (Spinhoven et al. 1997).

It can have indirect costs to society including absence from work and early retirement, as well as a socioeconomic impact on families (Barnes, Jonsson & Klim, 1996). Furthermore, research indicates that severity of asthma is correlated to cost (Serra-Batles, Plaza, Morejon, 1998; Godard, Chanez, Siraudin, Nicoloyannis & Duru, 2002). Asthma symptoms are responsible for a large number of hospital admissions. Most of these are emergencies; however, 70% may have been preventable with appropriate or early intervention. It costs the NHS £1 billion a year, an additional £800 million for pharmaceuticals, and an extra £6 billion due to time off work and loss of productivity (NHS England service specification).

### Difficult Asthma/Poorly Controlled Asthma (PCA)

Patients with severe, difficult and hard to control asthma are considered a separate patient group from the majority of asthmatics with mild to moderate disease. They have an estimated prevalence of 140 patients per million populations (NHS Standard contract, 2013-2014). These patients, also known as having poorly controlled asthma (PCA), tend to have increased symptomatology and more severe asthma in comparison to those with better control over their disease. This is associated with increased anxiety, impaired coping and cognition (Lavoie, Bouthillier, Bacon et al. 2010). Those with PCA require systematic assessment and specialist care in tertiary

respiratory centres. The management of PCA usually involves increasing the use of inhalers. Whilst pharmacological intervention is effective for some with PCA (Abraham & Michie, 2008) fewer than half of these individuals achieve good symptom control (Demoly et al. 2010). PCA is more complex than mild to moderate asthma and one of the reasons for its complexity includes excessive anxiety (Rimington, Davies, Lowe and Pearson, 2001). Psychological distress is up to six time more common in individuals with poorly controlled asthma than the general population (Thomas, Burton, Moffat & Cleland, 2011).

### Comorbidities in asthma

Most long-term health conditions have associated psychological comorbidities. Rates of psychiatric disorder among asthmatics are reported to be double those than in the general population (Goldney, Ruffin, Fisher & Fisher, 2003). Those with asthma are more likely to be diagnosed with depression and anxiety (Hasler et al. 2005; Brumpton et al. 2013). Furthermore, Goodwin (2003) identified that anxiety and depression is up to six times more common in people with asthma, and that this is more commonly associated with poor asthma control, and poor outcomes (Thomas et al, 2011; Rimington et al, 2001). Depressive and anxiety disorders are also associated with worse asthma-related quality of life (Lavoie et al, 2003). Zhang et al. (2016) found that psychological dysfunction significantly increases the risk of asthma exacerbations, hospitalization, and unscheduled visits to emergency departments. They also found that comorbid psychological dysfunction adversely affects asthma exacerbations, with differential effects of anxiety and depression. Psychosocial factors are one of several factors associated with difficult asthma (Scottish Intercollegiate Guideline Network (SIGN), 2016).

Chida, Hamer and Steptoe (2008) express that 'the association of asthma and psychological comorbidity may be bidirectional and mutually detrimental, leading to a self-perpetuating cycle' leading to deteriorating mental and physical health. For example, psychological and emotional factors can affect the behavioural precautions taken by asthma patients (Bender, 2006). Furthermore, those with severe asthma report experiencing more psychological distress, as well as impaired emotional coping (Lavoie et al, 2010). Those who have poor compliance are likely to have higher depression scores (Bosley et al 1995). Thomas and Price (2008) convey that acknowledging and exploring the pathophysiological associations for comorbidities in asthma are important for clinicians treating asthma. Identifying risk of poor outcomes may point to effective treatment options, as well as recognising them as possible confounding factors within research trials.

Stress and psychological factors have clearly been identified as being linked with onset, progression and exacerbation of asthma (Edwards et al. 2017). Psychological state strongly predicts

a range of outcomes including asthma quality of life, increased use of health provision and medication, as well as asthma related cost (Goldney et al, 2003; Brinke et al, 2001; Cluley and Cochrane, 2001). Despite these findings, the evidence base for interventions is still underdeveloped. The need to understand the affective, behavioural and neurocognitive mechanisms that impact outcomes is paramount (Edwards et al, 2017). The Department of Health have identified psychological comorbidity as a key research priority, as it is often unrecognised (DOH, 2011). However, at this point it is not yet clear whether treating anxiety and depression in asthma, would lead to better outcomes in quality of life, as well as reduction of health care utilisation, mediation and related costs.

### **Psychological therapies for asthma**

Asthma is complex, affecting people in diverse ways, including effects on concentration, emotional state, and self-management behaviour. Therefore, there is a greater need for harmonisation between approaches to this disease, in order to reduce differences in diagnostic rates and help individuals achieve better control of their condition. Inter disciplinary working can increase the speed to diagnosis, and put a greater focus on comorbidity and the interaction between mental and physical health. Psychological intervention may help improve quality of life for people with asthma by addressing psychological difficulties, which leads to better asthma control and a reduced risk of exacerbations. For example, psychoeducational interventions may help to reduce hospital admissions and also help improve asthma symptoms (Smith, Mungford, Holland, Noble & Harrison, 2007). Furthermore, psychological therapies can aid adherence to long term asthma treatment (Gamble, Stevenson and Heaney, 2011). Furthermore, psychoeducational interventions are recommended for adults seen in specialist asthma clinics (British SIGN).

The Department of Health has conveyed that identifying studies of psychological treatments in asthma, are a research priority. While there is some evidence for the effectiveness of CBT for improving quality of life, asthma control and anxiety levels in people with asthma, the evidence overall is low and not conclusive (Kew et al, 2016). Yorke et al, (2015) who produced a systematic review of non-pharmacological interventions for adults with asthma found RCTs for five main non-pharmacological interventions including relaxation-based therapies, mindfulness, biofeedback techniques, CBT, and multicomponent interventions. They concluded that due to a variety of outcome measures used, application to clinical practice is limited due to trial heterogeneity and that there is a lack of clear guidelines for non-pharmacological therapies for asthma. As the evidence base for current psychological interventions for asthma is non-conclusive and low (Yorke et al, 2015) researchers have begun to explore the usefulness of mindfulness, as there is a plethora of evidence

for its benefits in other long term health conditions (Baer, 2003; Grossman et al, 2004; Crowe et al, 2016). In comparison, the reviews of the qualitative evidence base of mindfulness for long term health conditions sparse. Malpass et al (2012) has reviewed both MBCT and MBSR for mental health and physical health conditions and Carins & Murry, (2015) has reviewed how MBCT contributed to therapeutic change.

## Mindfulness

Mindfulness has been defined by Kabat-Zinn (1994) as “paying attention in a particular way: on purpose, in the present moment, and non-judgmentally”. Mindfulness in its current form, is inspired by Buddhist tradition but does not have any religious connotations. It is not a structured psychotherapy but rather a concept to be cultivated through one’s life. It involves the willingness to notice where ones attention is, at any given moment, including on thoughts about the past or future, feelings and body sensations. The intention is not to change these experiences but attend to internal experiences and to gain self-regulation of moment to moment attention. Furthermore, it is practiced with an attitude of non-judgemental acceptance (Baer, 2003). The regular practice of mindfulness has the ability, over time, to promote moment to moment awareness, as well as health benefits, to clinical and non-clinical population, such as reduction in pain, stress, anxiety and depression (Grossman et al 2004; Hoffman et al 2010).

Mindfulness Based Stress Reduction (MBSR) in particular was developed for the treatment of chronic pain and stress related disorders in hospital settings. It involves an 8-week course, lasting two hours each, plus a full days training during week six. Participants are taught to non-judgementally observe their emotions, thoughts and external events and consider their states as passing events (Kabat-Zin, 1990). The course also involves group discussions and reflections, as well as home practice, which encourages bringing awareness to daily activities. MBSR has now been implemented worldwide for a range of different chronic health conditions (Shapiro et al, 2006; Dobkin et al, 2011). Most mindfulness based interventions for LTHC are based on MBSR.

In recent years, mindfulness has been combined with a number of other approaches. Several therapy programmes have emerged such as; MBSR, MBCT, DBT and ACT, which consider mindfulness an essential component of their therapy. These programmes have shown positive outcomes at reducing physical health and mental health outcomes. For example, Fellows et al. (2015), have demonstrated the used of ACT with asthma patients. Acceptance based approaches, which challenges the traditional dominance of CBT (Morely et al, 1999), has found to have long term benefit.

## Effectiveness of mindfulness based interventions

Mindfulness interventions have been shown to help a range of mental health difficulties such as anxiety and depression (Khoury, et al 2013), Post-Traumatic Stress Disorder (PTSD) (smith et al. 2011), Stress (Shapiro, Schwartz and Bonner, 1998), and somatization disorders (Fjorback et al, 2013). Furthermore, there is a wealth of evidence for its effectiveness for physical health conditions such as; Fibromyalgia (Schmidt et al. 2011), chronic fatigue (Suraway, Roberts & Silver, 2005), Multiple Sclerosis (Grossman et al. 2010), Psoriasis (Kabat-Zinn 2003) and Pain, (Morone, Greco and Weiner; 2008). The evidence has also pointed to improved quality of life, mood and stress in cancer patients (Carlson et al, 2003; Carlson & Bultz 2004). In a review of MBSR for LTHCs, Crowe et al, (2016) found emerging evidence that MBSR is effective at reducing the daily impact of LTHCs, such as primary insomnia and irritable bowel syndrome and found a small to moderate effect at improving physical health status (functioning and wellbeing) in asthma, pain, tinnitus, fibromyalgia and somatization disorders.

In respect to respiratory conditions specifically, a systematic review by Harrison et al (2016) aimed to describe how mindfulness is delivered for those with a respiratory diagnosis and examined the impact it has on health-related quality of life (HRQOL). They found that adherence to mindfulness was poor, and that no impact was seen on disease specific health related quality of life. Nor were there improvements to mindful awareness or stress levels and therefore were unable to draw conclusions due to varied delivery and outcome monitoring. The literature examining mindfulness and respiratory conditions is limited, and as a result, firm conclusions cannot be drawn, however there are promising signs.

There is only one study to date, which has looked at the effectiveness of mindfulness in comparison to treatment as usual in a randomised control trial (RCT) for asthma in particular. Pberts et al. (2016) study is the first RCT, comparing an eight-week mindfulness course, to a control condition of an educational programme. They measured quality of life via the Asthma Quality of Life Questionnaire (AQLQ), lung function, and asthma control and perceived stress. Participants were followed up at 10 weeks and six and 12 months. They found clinically significant improvements from baselines in QOL but not lung function, as well as clinically significant improvement in perceived stress for the MBSR group. The MBSR group also showed significant decrease in use of rescue medication in comparison to the control group. MBSR produced lasting effects on QOL and perceived stress, with greatest effects in AQOL for emotional function, suggesting coping resources increased in patients in the MBSR group. As this is the first study of its kind, with a clear positive finding, it shows that mindfulness has uniquely supportive features in comparison to other complementary programmes. Other therapies such as CBT have shown to be effective at improving

QOL for asthma patients, but do not demonstrate long term gains at six months (Ross, Davis and Macdonald, 2005).

### Why mindfulness may be helpful for difficult asthma patients - Theoretical possibilities

Asthma impacts QOL in a number of ways. The symptoms of asthma, including wheezing, tightened chest and breathlessness, are distressing and are associated with episodes of bronchoconstriction. Breathlessness can have a strong affective component, causing anxiety and enhancing distress (Sipnoven et al, 1997). There are numerous ways to improve QOL in asthma patients, independent of medication, including reduction in stress and anxiety and improvements in self-management. Those with poorly controlled asthma tend to experience increased levels of anxiety. Mindfulness based interventions have been shown to effectively treat anxiety and mood disorders (Evans, et al 2008; Hoffman et al, 2010; Khouri et al 2013) and to help individuals manage their physical health conditions (Thompson, 2009).

Models of anxiety suggest that individuals may have deficits in cognitive and attentional control and that these may be risk factors for the development of worry and anxiety. Individuals with clinical levels of anxiety demonstrate maladaptive attentional biases towards threatening stimuli that may be modulated by biases in attention (Derryberry & Reed, 2002). Researchers have put forward cognitive models of asthma, such as the cognitive affective framework, which suggests that asthma patients can often have inaccurate perceptions of their respiratory symptoms (Janssens, 2009). Furthermore, others such as Deshmuk et al, (2007) have put forward a cognitive-behavioural perspective suggesting that asthma patients with anxiety and panic can hyperventilate, which can trigger or exacerbate an asthma attack. The associated anxiety can also lead to avoidance or influence preventative treatment affecting asthma control and quality of life.

It is understood that mindfulness effectively treats anxiety and depression via a number of processes, including acceptance, relaxation, exposure, cognitive change, relapse prevention and self-management (Baer, 2003). Furthermore, it is understood that mindfulness is associated with attentional and emotional processing, which has been demonstrated via self-report. For example, Chamber, Cheuen Yee Lo and Allen, (2007) found that after a 10-day intensive mindfulness course for a non-clinical population, novice meditators showed improvements in self-reported mindfulness, working memory and sustained attention compared to a control group who received no mindfulness training. Behavioural change and neurobiological measures of anxiety and attention have also been demonstrated (Ochsner, Bunge, Gross & Gabrieli, 2002). Additionally, a recent systematic review and meta-analysis indicates promising evidence that meditation is beneficial for improving quality of

life in asthma patients (Paudyal, Jones, Grinley, Dawood & Smith, 2017). The reviewers suggest possible mechanisms of how meditation may work including helping with control and feedback of respiratory muscles (Nayak & Shankar, 2004) as well as the impact of relaxation and positive mood, which can help individuals cope with chronic illness (Yang et al, 2016).

There is increasing evidence that mindfulness-based changes in attentional functioning are highly relevant for reducing anxiety symptoms (Brown et al., 2011). Changes in executive attention may lead to better emotion regulation and reduced negative elaborative processing (i.e. worry) in anxious individuals, as well as reducing negative cognitive biases to threat-stimuli (Chiesa et al., 2013). Therefore, mindfulness-related attentional benefits may also benefit and correct biased emotion-processing in anxiety. For those with greater ability of mindfulness, objective, non-judgemental awareness may result in the ability to engage in ‘metacognitive insight’, whereby thoughts are perceived to be transient, insubstantial mental events rather than accurate representations of reality (Bishop et al., 2004). This may in turn reduce worrying thoughts, as there is less opportunity for negative processing, such as worry.

Mindfulness treatments encourage deliberate, non-judgemental attention and have demonstrated a range of effects on several behavioural measures of attention (Josefsson & Broberg, 2011; Moore & Malinowski, 2009). Individuals with asthma and especially PCA, experience anxiety and dysfunctional thinking. Therefore, mindfulness could possibly be an appropriate intervention for patients with difficult asthma.

## Qualitative Methodologies

Although it is imperative to collect outcomes data in order to evaluate new interventions, it is equally important to understand the acceptability, as well as mechanisms by which interventions are working. This therefore necessitates the use of qualitative methods to evaluate patient experience rather than using outcomes measures (such as a QOL measures) although these are useful in their own right. The Department of Health’s ‘Liberating the NHS: Legislation Framework and Next Steps’ (2010) encourages putting patients at the heart of the NHS. Through increased patient collaborations and shared decision making between patient and health care services, services are built that are sensitive to client needs and improve outcome. Kelson et al (2012), convey that evidence based guidelines should consider explicitly the preferences and values of ‘consumers’ such as patients, caregivers and that the public should be involved in the process of integrating those values into the development of guidelines. Equally, Smith and Ross (2007) convey the importance of involving service users in the planned expansion of NHS care and policy.

Research has focused on the quantitative outcomes of psychological interventions for anxiety and depression in asthma however, less is known about how patients experience these interventions. Starks and Trinidad (2007) suggest that qualitative methods are the most suitable to examine institutional and social practices, identify barriers and solutions to change, discover successes and failures of interventions, and is the most suitable way to answer questions of meaning. Additionally, King et al (2005) recognized the role of qualitative evaluations as a first step in understanding the acceptability of new treatments, which is increasingly important due to high attrition rates found in outcome studies, which also impacts the ability to implement therapies. Furthermore, whilst studies show the physical and psychological health benefits of mindfulness via quantitative outcomes, such as symptom reduction, it fails to acknowledge the complex experiences of patient's perspectives. One independent study to date, by Malpass, Kessler and Sharp (2015) has explored COPD patient's experience of 8 week MBCT intervention. They found that patient's experienced greater acceptance, a new relationship to breathing, noticed bodily sensations to detect early warning signs, and linked pulmonary rehabilitation advice to mindfulness and a greater sense of control. This study however, lacked rigour as strategies to minimise bias were not applied, such as bracketing during coding and double coding transcripts.

### Background to research question and aims

Mindfulness interventions have been shown to help in anxiety, depression and chronic pain, but have had little attention in asthma. Qualitative research in adults with poorly controlled asthma and co-morbid anxiety is needed to illuminate patient perspectives on its use and acceptability.

The current study aims give to a voice to service users and to complement a wider study looking at the acceptability and feasibility of delivering a four-week mindfulness course to patients with difficult asthma and comorbid anxiety. It will be adding to the small but growing body of research in mindfulness in asthma (Pbert et al, 2012) and qualitative research for mindfulness based interventions (Malpass et al. 2012, Cairns and Murray 2013; Wyatt, Haper and Weatherhead, 2014).

This study aims to answer the question of what are service user's experiences of a brief mindfulness based intervention for the difficult asthma population, its perceived value and subjective experience, which together intends to inform future applications of the intervention in the form of a larger RCT. It is hoped that attending the brief mindfulness intervention would aim to provide participants with PCA, skills in mindfulness, which would have a positive impact on anxiety, impaired cognitions and coping mechanisms.

Study aims:

- 1) The primary aim of the study is to explore the experiences of patients with difficult asthma of attending a brief mindfulness group to gain insight into how they perceived the impact of the intervention on their asthma, their wellbeing and self-management of the condition.
- 2) The Secondary aims of the study is to develop an understanding of factors that may act as barriers or difficulties to engaging with mindfulness approach.



## **Method**

### **The service**

The Difficult Asthma Service supports individuals who have poorly controlled asthma (PCA) in the south of England. The service consists of a multidisciplinary team made up of doctors, nurse specialists, psychologists and physiotherapists. The service provides assessments and treatment for approximately 679 adults a year.

### **Design**

A qualitative study was conducted, using a focus group and semi structured interviews, with open ended questions. The focus group and semi structured interviews were recorded on audio tape, transcribed, and then coded and analysed using thematic analysis (Braun & Clark, 2006).

### **Procedure**

#### *Recruitment*

This study applied a convenience sample from the parent study of mindfulness for difficult asthma (Please see Appendix G for Information Sheet). All participants who consented to the study were invited to participate in a focus group and later to telephone interviews.

#### *Inclusion criteria*

Participants needed to be adults, over 18 years, with a confirmed diagnosis of asthma. In addition, the participants needed to be under the care of the Difficult Asthma Clinic, with screening scores of six or greater for anxiety, on the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) in order to attend the brief mindfulness course.

#### *Exclusion criteria*

Participants were excluded from the study if they were under 18 years of age or had a previous diagnosis of major or unstable comorbid psychological disorders, other than anxiety or depression. They were also excluded if they were currently participating in another asthma intervention study or had acute exacerbation of asthma requiring a course of oral steroids, within 28 days of the baseline appointment.

### **The mindfulness courses**

The brief mindfulness course comprised of a four-week intervention, utilising elements of both MBSR and MBCT. Each session lasted one and half hours, with 10-20 minutes' recommended home practice a day. Each week covered a different topic area including; training the mind to pay

attention, reconnecting the mind and body, becoming aware that thoughts are not facts, and establishing on going practice. The following is an outline of material covered each week:

**Week 1** –This session aimed to train the mind to pay attention and taking control by exploring thoughts and emotions that we can get caught up in when our minds wander, causing distress.

Participants learnt how to calm a wandering mind with attention training using breath as a focus.

**Week 2** – Reconnecting mind and body, and becoming emotionally aware, by learning to control our emotions rather than them controlling us.

**Week 3** – Mind Games: this included understanding our minds can ‘play tricks’ with us, becoming aware of familiar thought patterns that may be based on false mental models. Appreciating that we often miss the interpretation of experience and that “thoughts are not facts”.

**Week 4** – Establishing practice, learning to taking care of ourselves and integrating mindfulness into our daily routine.

Please see Appendix H for an extended outline of each session. The four-week course was a run by an independent, qualified MCBT and MBSR practitioner, practicing yoga for 38 years, and mindfulness meditation for over six years, with experience running mindfulness groups in a wide range of settings including public, private and research arenas.

### **Data collection**

Seventeen individuals consented to attending one of two, four-week mindfulness courses. Six weeks after the intervention, participants were invited to a focus group to elicit in depth discussions about their experiences of taking part, of mindfulness, and the acceptability of the intervention. After low attendance at focus group (N=3) and three-month follow-up appointments, the protocol was amended to include additional follow-up semi structured interviews by phone to explore their experiences of mindfulness. Nine individuals, eight of whom had completed some part of the mindfulness intervention took part in the semi structured telephone interviews. Please see Appendix I and J for ethics and amendment. Consenting participants (Please see Appendix K for consent form) were contacted by telephone to arrange an appropriate time for a semi structured telephone interview.

### **Focus group**

The purpose of the focus group was to exploit group interaction as part of the method, which often allows more divergent themes to emerge, expose dominant narratives, highlight group norms, as well as allowing a consensus to be reached (Kitzinger, 1995). The focus group interview schedule (Appendix L) included open questions, with prompts to encourage participants to provide

an in-depth responses. The focus group was conducted by a senior research associate, within the research team, who had extensive experience in qualitative methodology and specific experience in research in mindfulness for cancer.

### Semi Structured interviews

The purpose of the semi structured interviews was to explore PCA patient's experiences of attending a brief mindfulness course, whilst also exploring patient's experiences of difficulties taking part and practicing mindfulness. The same interview schedule as the focus group was utilized to enable consistency. The schedule was designed to be used flexibly with patients, to gain more idiosyncratic views and experiences. Following the first few interviews, some adaptations were made to the schedule to ensure depth of responses. The interviewer used an open conversation approach, aiming to get a balance between gaining information about experiences whilst freely offering contributions. Although all participants had previously provided their written consent to take part in the interviews, each telephone interview began with discussing confidentiality and obtaining verbal consent.

Telephone interviews took place from the University of Southampton in a quiet room and lasted between 30 minutes to an hour. To avoid social desirability effects, and bias, the telephone interviews were conducted by a Trainee Clinical Psychologist (AP) who was not associated with the study to start with and did not attend the mindfulness course. The trainee psychologist (AP) was also not directly involved in the formulation of the research question for the parent study, therefore avoiding bias when conducting interviews. The Trainee Psychologist did however, have knowledge of mindfulness and experience of running mindfulness sessions in an inpatient mental health setting, and therefore was familiar with the intervention and its delivery. Furthermore, the trainee psychologist had been involved in, and conducted qualitative research projects prior to this study, both in paediatric and adult settings.

### Participants

Twelve participants, three male and nine female, aged between 24 and 61, from the Difficult Asthma Clinic took part in the current study. See Table 2 for demographic information. Three individuals attended the focus group, and telephone interviews were conducted with the remaining nine patients who had attended any part of two, four-week mindfulness courses run between May 2016 and July 2016. At the time of the focus group and telephone interviews, all participants had a clear diagnosis of asthma and were under the care of the difficult asthma service. The focus group

took place six weeks after the first four-week course, and remaining participants were interviewed five to six months after attendance at the course.

**Table 3.**

*Summary of demographic and clinical information*

Participant	Focus Group or interview	Age	Gender	Age diagnosed between	HAD_A	HAD_D	Number of Mindfulness sessions attended	Previous experience of mindfulness
FG1	Focus group	52.10	F	6 to 11	10	9	4.00	yes
FG2	Focus group	36.13	F	6 to 11	9	5	4.00	No
FG3	Focus group	45.73	F	19 to 40	7	3	3.00	No
P1	Interview	49.57	F	12 to 18	6	3	3.00	no
P2	Interview	52.10	F	-	11	14	0.00	no
P3	Interview	61.10	M	41 to 60	6	4	4.00	no
P4	Interview	46.21	F	12 to 18	7	8	4.00	yes
P5	Interview	41.50	M	Under 6	13	13	1.00	no
P6	Interview	62.99	F	51 to 60	7	2	4.00	yes
P7	Interview	24.00	F	Under 6	14	6	1.00	yes
P8	Interview	33.36	F	Under 6	9	9	3.00	no
P9	Interview	48.00	M	19 to 40	8	2	4.00	yes

Note: HAD\_A = Hospital Anxiety and Depression Scale pre-anxiety scores

HAD\_D = Hospital Anxiety and Depression Scale pre-depression scores

### Ethics

Ethics review for this study was provided by the National Research Authority South Central – Berkshire B Research Ethics Committee and was given a favourable outcome (Ref: 15/SC/0522, Appendix I). A minor amendment was sought and approved (Appendix J) in order to add the trainee psychologist (AP) to conduct telephone interviews for this study. Informed consent was sought from participants at the start of the overall study by members of the research team, and this included informed consent to the focus group and semi-structured telephone interviews. Verbal consent was sought again at the start of the focus group and telephone interviews. Data collected via the focus group and semi structured interviews, in the form of electronic audio files and then later transcripts, were stored on password protected documents on university password protected computers.

### Qualitative analysis

The focus group and the interviews were recorded on a digitally encrypted recording device and transcribed verbatim. The focus group was transcribed by an external agency, whilst the semi structured interviews were transcribed by the trainee clinical psychologist, who conducted the

interviews. Both focus group and interview data were analysed simultaneously, allowing within method triangulation and verification, as well as convergence and divergence of themes (Teddlie, Tashakkori 2008; Yardley, 2008). Furthermore, combining the telephone interviews and focus group data allowed one to achieve greater depth from the interview and greater breadth from the focus group (Crabtree, Yanoshik, Miller, & O'Connor, 1993).

This study uses Thematic Analysis to explore the following research question: What are poorly controlled asthma patient's experiences of a brief mindfulness intervention? Thematic analysis was the chosen analysis and was applied to the transcripts, as it offers an accessible, yet theoretically flexible approach and can provide a rich and detailed, yet complex account of data. Furthermore, thematic analysis is not wed to any pre-existing theoretical framework in comparison to Interpretive Phenomenological Analysis (IPA) (Braun & Clarke, 2006). Thematic analysis also allows for greater flexibility, with sampling and allows identification of themes at a semantic level (Braun & Clarke, 2006). The analysis was inductive, allowing themes to emerge from the data and the researcher took a critical realist stance (Holloway, 1997; Ponterotto, 2005).

The six steps outlined by Braun & Clarke, (2006) were used to analyse the data:

*Step 1: Familiarising yourself with the data* – AP conducted the interviews and transcribed the interviews verbatim. The focus group transcript and semi structured interview transcripts were read and re-read multiple times by AP, in order to gain familiarity to the data. Notes were taken during transcription, noting topics emphasised by the patients and those that reoccurred.

*Step 2: Generating initial codes* – A random sample of the overall interviews (3/9) were independently hand coded by three individuals (AP, BA and GJ) (see Appendix M) to prevent interpretations based on associations in the literature (Corbin & Strauss, 1990) and to account for subjective bias. The cross coding was conducted by AP who had conducted the interview and transcribed them, BA who was part of the research team and GJ who was an experienced qualitative researcher, external to the study and APs academic supervisor. The three individuals met to discuss similarities and differences between their codes and to come to a consensus through discussion on codes.

The first two coders found that they generated similar specific codes. The third coder coded broad areas rather than specific narrow codes. The codes that emerged from all three reviewers: AP, BA and GJ were used and applied to the rest of the interviews and focus group data. Data was imported into NVivo 11 (2015) by AP to support coding and analysis of data, allowing a systematic approach.

NVivo 11 (2015), is a software programme developed to code qualitative data sets, enabling organisation, analysis and development of themes. Nodes, which are the equivalent to codes, can electronically be created for each code or concept. The programme develops a list of codes or nodes (Appendix N), along with a list of reference sections that have been highlighted (Appendix O). These Nodes can then be applied throughout the rest of the transcript and across transcripts and later merged where relevant. Codes from each transcript were noted in Nvivo 11 (2015) by AP and applied to later transcripts, making the analysis an iterative process.

**Step 3: Searching for themes-** Once all transcripts were coded in Nvivo, similar codes were cross referenced by comparing the extracts from the transcripts, and collapsing and merging codes where necessary. This process continued until several key themes emerged. The flexible use of Nvivo allowed codes to be arranged into possible domains.

**Step 4: Reviewing themes -** Emerging themes were discussed with supervisor's BA and GJ, increasing the reliability of the chosen themes.

**Step 5: Defining and naming themes –** AP, BA and GJ met again to clarify and verify the thematic map and names of the themes.

**Step 6: Producing the report-** AP produced a report of the overarching, and subthemes in the form of the current thesis.

The focus group and semi structured interviews provided a rich and detailed account of participant's experiences ranging from impact of the course, the skills they had learnt, group experience, the role of the facilitator, improvements, reasons for taking part in the study, views on non-drug therapies, prior experiences, and the lived experience of asthma. For the purpose of this thesis, the results will report and focus on the primary and secondary research question. For example, during development of themes, a number of subthemes appeared important. These were 'facilitator attributes' including the impact of the facilitators' qualities and character on attendees; 'course materials' such as supplementary handouts and audio recordings and the 'group impact', which included positive and negative attributes about the group such as sharing of health condition, techniques, valuing discussions and multiple viewpoints, as well as worries about attending a group. These subthemes fell under the category of contextual factors. It was decided that contextual factors, such as 'impact of group' would not be included, as they are commonly reported elsewhere in mindfulness literature (Carin & Murray, 2015); however, it is important to acknowledge the role of these contextual factors

in participants' experiences of the brief mindfulness intervention for difficult asthma. More detailed information about contextual factors can be found in Appendix P.

The quotes selected in the results section demonstrate a small quantity of the transcript material from the focus group and interviews data. Only relevant quotes that link to the research question are reported, as they express the essence of themes, or because they provide the most powerful expression of an overarching or sub theme.

### Reflexivity

A reflective diary was kept throughout the research process, and especially during interviewing, transcription and coding. It is important to acknowledge the researcher's impact on the process of research, especially in qualitative research, where reality can be co-constructed in the interaction with the participant and researcher (; Braun & Clark, 2006; Willig, 2012; Willig, 2013). The researcher was aware during transcription of the interviews that several opportunities had been missed to ask follow-up questions, which were noted and kept in mind for future interviews. The researcher's personal context as a female, trainee clinical psychologist, working within a mental health context, was noted. Being aware of this, meant they were able to be aware and mindful of not searching for expressions of difficulties, lack of coping or psychological wellbeing, but instead notice the full range of experiences. It should also be noted that the researcher has an interest in mindfulness, and uses it within a professional context. Throughout the research process, regular conversations with supervisors also took place. This allowed for additional reflective practice alongside the self-reflective process of 'bracketing' (Starks & Trinidad, 2007), which allows qualitative researchers to step back from a phenomenon or research in order to observe and put aside assumptions (Barker, Pistrang and Elliot, 2007).



## Results

Three females participated in the focus group, and nine individuals (three males, six females) partook in the semi-structured telephone interviews. The results below describe the overarching and subthemes, derived from the focus group and interviews. All names have been changed and replaced with a code to protect the confidentiality of participants. The participants in the focus group will be referred to as FG1, FG2, and FG3. The participants in the semi structured interviews will be referred to as 'P1' 'P2', 'P3', 'P4', 'P5', 'P6', 'P7', 'P8', and 'P9'.

Four overarching themes emerged from the data analysis process; (1) Wellbeing, (2) Challenges, (3) Acceptability, and (4) Integration, each with a number of subthemes each, see thematic map in Figure 2. These overarching and subthemes are also represented in Table 3.

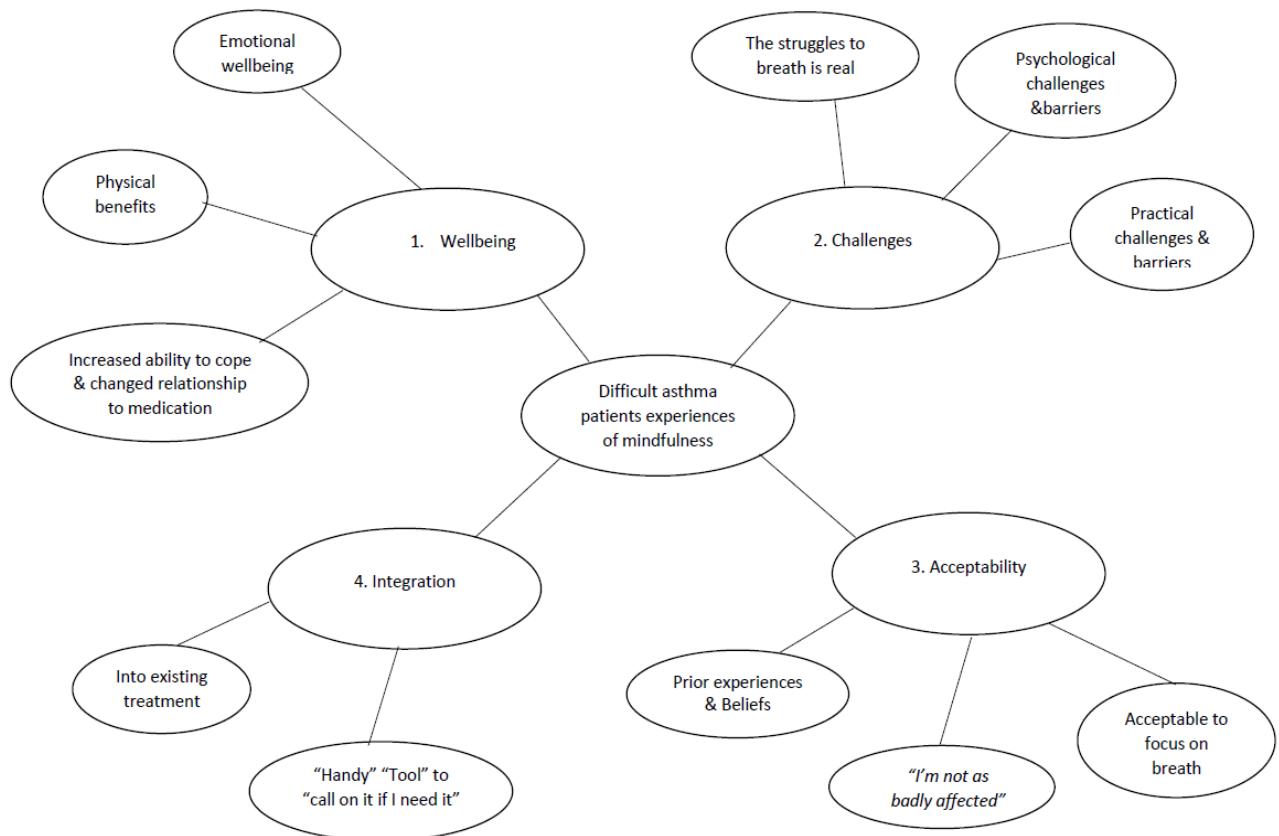


Figure 2: Thematic Map of Overarching and Sub themes

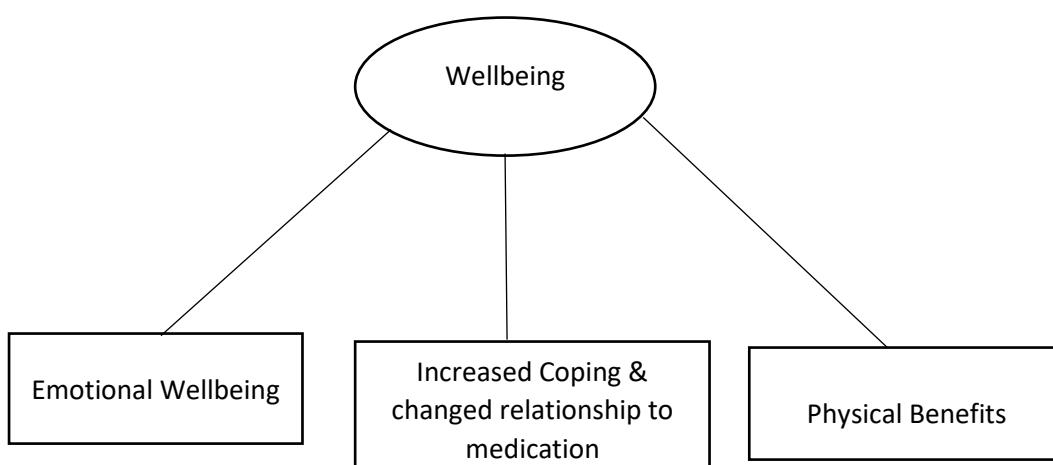
**Table 3**

*Overarching and Subthemes from Thematic Analysis of Interviews and a Focus Group.*

Overarching Theme	Sub-theme
1. Wellbeing	1.1 Physical benefits 1.2 Emotional wellbeing 1.3 Increased ability to cope & changed relationship to medication
2. Challenges	2.1 The struggle for breath is real 2.2 Psychological challenges & barriers 2.3 Practical challenges & barriers
3. Acceptability	3.1 Acceptable to focus on breath 3.2 "I'm not as badly affected" 3.3 Prior experience & beliefs
4. Integration	4.1 Integrating mindfulness into existing treatment 4.2 "It's a handy tool" & "call on it if I need it"

### 1. Overarching Theme – Wellbeing

A key overarching theme of the experiences of mindfulness groups, was the impact on the individual's overall wellbeing. Individuals reported a range of benefits, which included emotional wellbeing, physical wellbeing, and in turn their ability to cope with their asthma and how this interacted with their relationship to medication. See Figure 3 below for a map of this theme.



*Figure 3 – Theme 1 – Wellbeing*

### *1.1 Emotional wellbeing*

A predominant subtheme that emerged from almost all participants, was the impact of mindfulness on their psychological and emotional wellbeing. In particular the words ‘calming’ and ‘relaxing’ were most frequently used to describe the effect of mindfulness. Participants reported benefits to sleep, enhanced ability to help cope with stress, worry, anxiety and a potential to prevent feelings of panic when having an asthma attack.

*“but having that, having the mindfulness, focus on the breath exercises, are quite good at calming that inner voice of stress in your head and allowing you to relax more, and sleep.” (P6, F)*

This next two quotes demonstrate the variety of perceived benefits of mindfulness, experienced by the participants, including helping with anxiety or worry, and aiding sleep. Others spoke of mindfulness helping with stressful life events such as other physical illnesses, work related stress or looking after elderly parents.

*“I don’t do it all the time and, um especially if I’m a little worried or anxious about things, it’s not something I do on a regular basis, but I do use it, I use it as a, well as I said about the sleep, I use it at night, but I have used it in the day, I’ve had a few awkward things happening lately so um injuries and that it helps me with that takes my mind of it (P1, F)*

*“yeah, yeah I’ve found it useful, I’ve had quite a lot of stress um particularly with my parents having ill health um recently and as I mentioned before, I’m, I’m been doing my masters whilst working full time, and in the dissertation period in the last few months that have only just finished its, it’s been useful to have something to make me, um when I’m getting very stressed, to calm me down focus more, on, on not being soo, soo, um caught up in that emotion and I’m sort of, sort of slow that down” (P6,F)*

This quote highlights applying mindfulness practice in relation to sleep, but interestingly elucidates the role of cognitions in the process or reducing anxious negative thoughts. Furthermore another participant explains how mindfulness helps with negative thoughts.

*“I always used to get in a terrible state before I used to go on holiday. I don’t like flying anyway and this year I did feel very much more relaxed and I did my breathing and kept my feet on the ground and I did and I didn’t keep waking up in the morning thinking ‘oh I wonder what’s going on at home’ and all these sorts of things that go through your mind.” (FG2, F)*

*"I don't know about you, you think 'well I'll fall asleep, could this be the night that I don't wake up' when you're feeling that unwell. Those little intrusive thoughts that, okay not often, they don't dominate my life or anything, but I've found that I've had a lot fewer intrusive thoughts. Yes, when I have struggled to get off to sleep I have gone back to the mindfulness practices and I've found that I get into a deep relaxation a lot quicker" (FG3, F)*

The practice of mindfulness seemed to benefit individuals in several ways, including individual's ability to 'refocus' attention and accepting sensations.

*"....how to really breathe and feel your breathing and take note of it, you know, and everything, and the ways that your bodies feels and everything like that during the time and to accept those umm feelings and everything you know, and describing them, and everything, umm but, it was yeah, it was, it was.....that really helped that, umm yeah." (P4,F)*

*"it's really difficult to describe what's happening, but there is, the feeling of focus and relaxation that is brought about by mindfulness ah, that includes breathing in a more sensible way, and I think doing some breathing exercises was definitely making me feel better..." (P9, M)*

## *1.2 Increased coping and changed relationship to medication*

In conjunction with mindfulness' impact on emotional wellbeing, was its ability to increase an individual's ability to cope. Mindfulness was discussed as a proactive approach, using it as a preventive strategy for asthma exacerbations. Individuals were able to be more aware of triggers to prevent an asthma attack, use mindfulness to help control of their existing strategies, or use it to reduce stress and panic linked to an asthma attack. In this sense, mindfulness enabled proactive self-care. This new coping strategy had the possibility to change individual's relationship to medication, by delaying the use of medication, reducing the overuse of medication and in the long run, had the potential to keep individuals out of hospital.

Here, several participants talk about the perceived sense of control that mindfulness gave them, enabling them to cope:

*"...so then I found that [mindfulness] quite helpful really to bring it to in control rather than sort of panicking and it getting out of control." (P5,M)*

*“....I don’t think it’s ever stop the ah medicines umm I can’t see, I can’t see me getting off the inhalers, and such forth but I can see it may be, helping me umm control what it is that I am doing now” (P8,F)*

*“With the mindfulness I was really quite resentful. Every time I had an asthma attack I hated it and it has [mindfulness] helped get the breath and the more you can focus on the breathing you can try and control it and for me it gave me back some of the control and some of my not hating myself so much really.” (FG2, F)*

Using mindfulness as an early intervention, or as a preventative measure, was commonly reported by some of the participants. This preventative measure included the overuse of medication, recognising early symptoms in order to act appropriately, in turn preventing potential hospitalization.

*“oh god I’d love to be able to use mindfulness to cure everything unfortunately umm, you know, I know that I need, I need to take the drugs as well, but it’s to help prevent me from going in and having more drugs pumped into me and that” (P4, F)*

*“...In the, you know, into the intensive care unit again, near me and everything so it hasn’t prevented it fully but when I have had sort of like mild attacks and everything its prevented them from going into bigger attacks because I’ve, I’ve relaxed down and I’ve taken my mind off, of the, the starting to get panicky and just it taking over my mind the asthma, I’ve re focused my mind on something else”*

*(P1,F)*

*“umm it’s helped me be pro-active in stopping problems before they become an issues umm I, breathlessness, tiredness, exhaustion I am able to act upon them, through mindfulness, because I notice and then think I’m going to act upon that rather than sort of, xxxx suddenly have to panic and not know what you’re going to do, so yes I have found it to be really helpful in being proactive.”*

*(P5,M)*

In one instance, although the individual’s views on medication remained unchanged, it prevented hospitalization via the increased ability to cope.

*“...it hasn’t changed the ways with my medication and everything, um what it has changed is, is, is, um I’ve manged um some asthma attacks at home, which could have quite easily um you know led me into hospital...”(P4,F)*

Others described changes in their relationship to their medication, either by taking less of it, or delaying the use of it. For example this quote elucidated the reduction in use of asthma medication.

*“I definitely don’t use the Ventolin so much at all, I was using throughout the day on and off but I hardly use it now, only if I’ve been doing a lot and getting slightly breathless that’s all, it’s very good”*  
*(P1, F)*

*“...but if I’m waking up in the night and having a breathing problem then I’m not using an inhaler, I’m using the technique to help me” (P9,M)*

*“Yeah I haven’t taken the medication yet so um I’m trying to hold off and see whether anything happens, you know, if I get worse, then I’ll take it but at this moment in time its fine” (P3,M)*

*“Yeah I don’t take [other medication], when I’m having an asthma attack I give the inhalers a change to work, more, if that makes sense” (P4,F)*

### *1.3 Physical benefits*

Another important sub theme that emerged was the physiological benefits of practicing mindfulness and improvements to asthma via improved breathing and reduction in asthma exacerbations.

*“In terms of my breathing I have found it helpful at times, not always. I had an infection recently and now I have this residual cough and it’s not always helpful for that, but for general breathlessness I’ve found that I’m able to come out of the breathlessness quicker than perhaps I would have otherwise.*

*I’m a lot more mindful of how I am breathing both at rest and in exertion.” (FG2,F)*

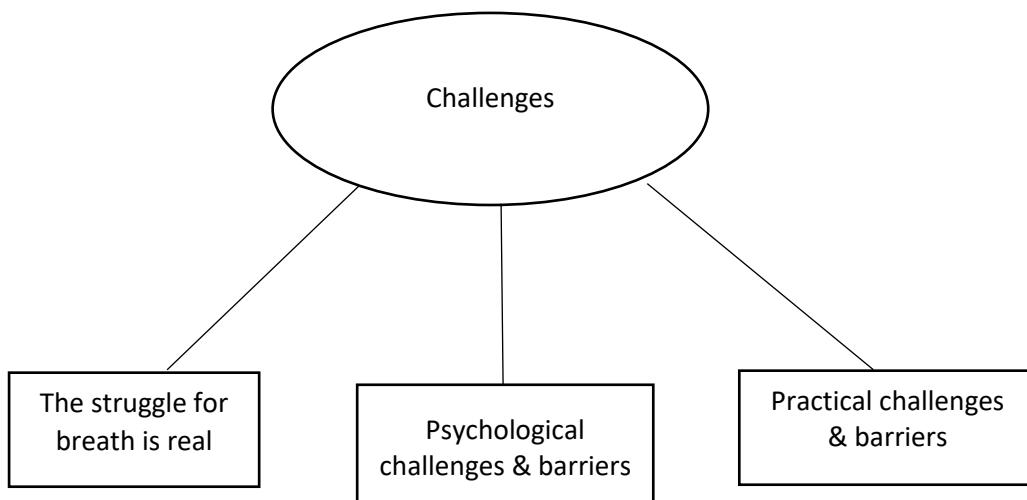
One participant also experienced a marked difference in blood pressure:

*“I have found it extremely useful for my blood pressure, I’ve got high blood pressure and I sit there and I have noticed a difference from when I start it and when I finish it I mean this is meditation really isn’t it,...And it just calms you right down it had dropped my blood pressure right down” (P3,M)*

*"By doing the diaphragmatic breathing that mindfulness teaches, that in itself shifts a lot of the phlegm on your chest, so again you're bringing it up. It's not just sitting there. You're not swallowing it necessarily." (FG3,F)*

## 2 Overarching Theme - Challenges

This superordinate theme denotes the various perceived difficulties that the participants reported with mindfulness. This includes three subthemes including initial difficulties with focusing on their breath, and psychological and practical challenges - which contributed to difficulties in attendance and practicing various mindfulness exercises. See Figure 4 below for a thematic map of this overarching theme.



*Figure 4 – Theme 2 – Challenges*

*2.1 The struggle for breath is real - "[The] One thing you don't want to do"/ "too far gone" to use mindfulness*

Understandably, struggling to breathe for asthmatics is stressful, anxiety provoking and can lead to panic. Many described the difficulties involved in being asked to focus one's attention on their breath. One participant described it as a 'weird sensation'. Some articulated how it was an asthmatics job not to focus on their breathing, as this would then indicate there was a problem. P6 describes this succinctly;

*"if you're focusing on your breath and you're conscious of your breathing, that sort of psychological links to you having bad asthma, so that sort of goal of the asthmatic person is to not be aware of*

*breathing because that means then it's not being problematic and I always found that difficult to get past and I think other people in my group found that particularly difficult." (P6,F)*

*"Being asked to focus my breathing can be quite difficult because it just sort of emphasises the fact that I can't breathe, I feel like I can't breathe. It's the same in a situation like a panic attack as well, sort of like, if you are hyperventilating and you feel like you can't breathe and someone says focus on your breathing, 'well I can't breathe', it's like because, sometimes makes it a bit worse." (P7, F)*

Others described an optimal time to incorporate mindfulness and apply it whilst experiencing asthma. It appeared that when their breathing was severe or they experienced being 'too far gone' into their asthma attack, then mindfulness was not even considered as a possible technique. However, when breathing difficulties were not as severe, it was easier to practice and apply mindfulness.

*"Yeah um, I guess it depends on the situation, so say like if I was to go for a walk in, I would be out of breath, because I'm not so bad, but if I'm having an attack then there's no way, I just wouldn't be able to do it...." (P8,F)*

*"I'm just too far gone, um maybe if I was a bit more mindful of the earlier signs of an attack umm it might not be so bad but um, but when I'm already in the throes of it , no, no, I do panic, but I think everyone does, you can't breathe, you panic, then everyone's around you, and your panicking and then the ambulance gets there and, the then the last thing you're thinking about it focusing on being mindful of your breathing, you're just trying to breath." (P8,F)*

However, despite these initial difficulties, some members of the groups found it acceptable to focus on their breath. Furthermore, those that struggled with the breathing exercises, commented on how learning to focus on external objects and surroundings made it more accessible to do mindfulness of the breath. This then added to their experience of mindfulness being a flexible and adaptable approach and technique. Therefore, focusing on external objects could be a helpful avenue to applying mindfulness for asthmatics.

*"umm I found that [focusing on breathing] a little bit difficult at first but doing it, I soon got it, its ah... well you're trying to bloody breath let alone focusing on your breath, and bring it on and everything like that. It's hard but then when, you know, I got it and everything, you know, yeah it's all second nature with it, and um and, you know, yeah it was, um, it was, found it a weird sensation at first, but you know, I thought I soon got into it soo."* (P4, F)

*"...but I think um, I think the way that it was explained and the different techniques of, as you say of focusing more on the physical not just the breathing but, but having other focuses like having your feet on the ground and things like that did help to take that away and make that more easy to do"*

(P6,F)

## 2.2 Psychological challenges and barriers

Psychological challenges were a key subtheme for this population. Factors such as social anxiety, and feeling self-conscious or embarrassed in a group setting, were commented on as possible barriers to attendance. P5 describes how his social anxiety was so overwhelming that he was no longer able to attend after the first session;

*"I, did obviously only went to one session which, which I then obviously found that I wasn't able to do, carry on, I wasn't able to carry on, because of a few factors that had already mentioned about people, too many people and also the time changed on the day and I turned up late and so that made me feel even more anxious because, obviously I wasn't able to really engage fully because of, or because I was worried 'what are people going to be thinking' and that sort of made it more difficult."*

(P5,M)

This quote points out the issues around social anxiety and self-consciousness for anxious asthmatics, in particular when practicing the physical mindfulness exercises;

*"umm yeah it was really the ones where you were getting up and trying to doing lots of things in front of people, I think that was the worst, that's the worst, when I'm back home I can do it in my own private time, then that's good"* (P3,M)

*"Also I found the movement, particularly the walking one that we did, I found that a bit difficult because you sort of worried you're going to walking into something or someone so I preferred the sort of being like still, and doing the sort of body scan type umm type exercises.* (P6,F)

For some, despite the psychological difficulties such as feeling self-conscious, the benefits appeared greater than their anxieties and therefore enabled the acceptability of mindfulness:

*"I must admit when we were walking around um doing some of the stuff I felt a bit embarrassed but I, I managed to block most of it out, no actually, over all it was very good" (P3,M).*

Additionally, one participant described how despite having anxious thoughts or feeling self-conscious, mindfulness actually helped with the anxiety;

*"I think you think about breathing anyway, but I think mindfulness helps you to do it in a more positive way rather than like we said before, the anxiety of 'I can't breathe, oh God everyone is looking at me'. I think it's more a case of like FG1 said you're able to centre into yourself and get control of the breathing quicker." (FG3,F)*

### *2.3 Practical challenges and barriers*

Another subtheme that emerged, was the practical barriers to attending the course. Those who were unable to attend or attended only one session of the course, reported a number of practical reasons such as ill health or work commitments for withdrawing. Other practical challenges to attending included other life commitments, such as family life, holidays, but also travel and distance. Location and parking were also considered by some as potential barriers to attendance. It is also important to bear in mind that this is a population with poorly controlled asthma, who have co-morbid anxiety, but often also have multiple physical health problems. Here P2, describes how an operation she had been waiting for meant that she could not attend:

*"I would participate, but at that time I was also waiting for an operation, which I had done, which meant that I could not attend, I did one session, umm well I did the paper work, but then I couldn't attend after that because I had had the surgery, umm, and I just I just couldn't do it as I was recovering from that..." (P2,F)*

*"I mean 4 weeks isn't that big a commitment, but if you've got, I suppose, if you've got families or whatever that could be difficult" (P6,F)*

Those that attended the course, described challenges to practicing mindfulness both within the group and externally, at home or in daily life. These practical challenges included physical

disabilities, difficulties finding the time to do mindfulness due to work and family commitments. Some felt that they could only practice under certain conditions, such as when it was quiet, and when they would be free of distractions from their family;

*"The difficulty with this whole thing is finding the time to do it when I'm not going to be disturbed..."*

*(P3,M)*

*"I found that some weeks I had more time than others to do the home practice and I probably didn't, I did always practice but I didn't do it as frequently as perhaps I should have done, um cuz it is that that discipline that you have to do it on your own and find quite time, quite space, to do it, I found, I feel like it's a bit of a lame excuse but I found that a bit difficult." (P6,F)*

### 3. Overarching Theme - Acceptability

This theme relates to how acceptable asthma patients found practicing mindfulness within the course. Several subthemes were identified under this superordinate theme (see figure 5). Although a number of psychological and practical challenges were reported, many participants found it acceptable to focus on their breath. Interviewees also minimised their illness in comparison to others in the group, which could be a way of making mindfulness acceptable to practice. People's prior experiences and beliefs also influenced the acceptability of a non-drug therapy.

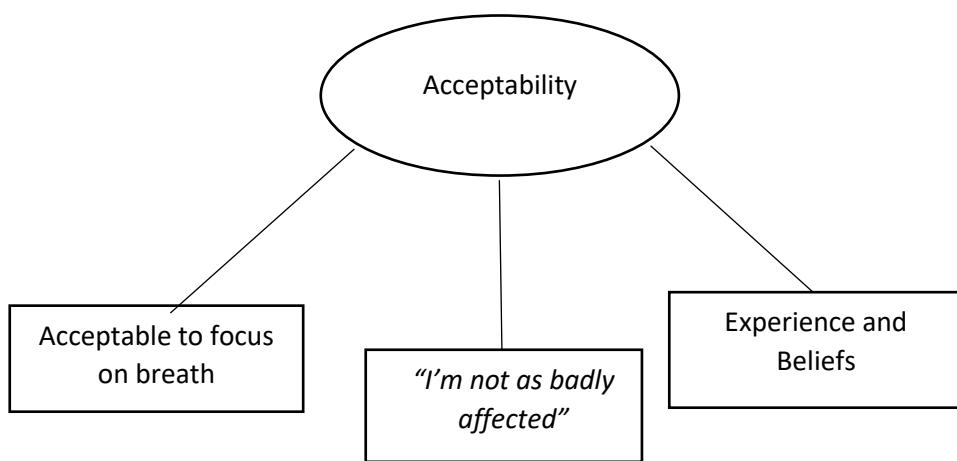


Figure 5 -Theme 3 – Acceptability

### *3.1 Acceptable to focus on breath*

There is little doubt that experiencing breathlessness is difficult and anxiety provoking for asthmatics. However, despite this, focusing on the breath and body sensations were acceptable to most participants and even surprisingly positive and helpful for some.

*"Um I just kind of sort of stop for a second and then sort of focus on my breathing a bit. Sort of make sure I am not over breathing." (P7, F)*

*"Umm I think the thing that most surprised me was the actual, that it was actually helping....If you see what I mean, I was, I thought, how can you actually umm concentrate on what's it is that is hurting you or is injuring you and it helps, but it seems to it does it really does seem to" (P3, M)*

### *3.2 "I'm not as badly affected"*

Bearing in mind that those who were eligible for the mindfulness course, had difficult asthma, many of the individuals who attended the course, experienced other people's asthma as worse than their own. This social comparison, of interpreting and or believing their own health condition as better than others, could be seen as a possible way of coping with their illness. This then consequently assisted in making mindfulness a more acceptable strategy for a physical health condition like asthma, which is dominate by the medical model.

*"I function quite well on a day-to-day basis compared to a lot of other people" (FG1, F)*

*"I mean I'm not as badly affected, I'm not as badly affected, I'm not as quite as, I mean I have been, but with the medication it's quite well controlled, with the medication, umm but I have found the that mindfulness does help you know, it relaxes me more" (P3,F)*

*"...they were a nice friendly group, not sure I had much in common with them, but they were ok people, um I could see that several of them were in a much worse state than I was in. (P9, M)*

### *3.3 Prior Experience and Beliefs*

Participant's prior experiences and views about non drug therapies appeared to influence their how acceptance of and motivation towards mindfulness for difficult asthma. Those who had experienced alternative therapies, such Yoga or Pilates, or other psychological therapies for their mental health difficulties, described greater belief in alternative therapies, and therefore greater openness and willingness towards mindfulness for asthma.

*"I mean some of the people had actually been on mindful...mindfulness courses before so I mean they clearly knew that it was good cause they wouldn't have come back would they? (P3, M)*

*"yeah I've done sort of meditation in the past um I used to go to a reiki group, I've done um sort of group guided visualisation meditation type and things like that, so I'm quite familiar with that." (P6, F)*

Previous experience in mindfulness as a therapy or similar meditation, also aided their ability to do mindfulness, and in particular focus on their breath or body.

*"No because I've done vipassana meditation previously that trains you very well in that respect [focusing on the breath] so I was extremely comfortable with that" (P9, M)*

*"umm I learnt mindfulness a few years back, so it was really good to have a refresher course and to go through ways of you know of mindfully working through an asthma attack you know and everything and that way, you know, it was really, really good" (P4, F)*

Prior and current beliefs about mindfulness were evident in a number of quotes. For example, prior scepticism, doubts and reservation were common for a small minority of individuals, who were then pleasantly surprised about how mindfulness could be useful.

*"I was slightly sceptical to begin with. I thought oh another trial sort of thing. I've been on several, but I must admit it has been most helpful and I would recommend it to anyone." (FG2, F)*

*"yeah it, I must admit I was very sceptical when I went into it um I thought this is going to be a load of rubbish but actually it worked quite well" (P3,M)*

Individual's beliefs and views on non-drug or alternative therapies, as well as the efficacy of mindfulness also contributed to potential barriers to attendance. For a small minority, their views and beliefs about non drug therapies still remained during the post intervention interviews. This could be seen as a possible barrier for attendance for others with similar views.

*"I think you would have to be careful, that perhaps somebody who doesn't mind taking medication or is suspicious of traditional medication, then perhaps they could seek that as an alternative, which clearly it isn't and there are times, say when you have a severe exacerbation or you have an infection when no matter how much mindfulness you do, you're not going to think yourself better. " (FG3, F)*

*"I've gone through all the holistic ways. I've had Reiki, hypnotherapy, hypoallergenic this, hypoallergenic that, the herbal supplements and all that's happened is it's made my exacerbations worse and I've left it too long and I've ended up in resuscitation. That was my drawback with it."*

*(FG1,F)*

*"I trust my doctors, I trust the medicine, umm I know not everyone likes taking lots of medicine, I do take a lot of medicine, I'm on 10 tablets, different tablets a day but, 10 tablets a day, 4 inhalers, nasal sprays you know, but I know that my doctors have got my best interest at heart, so you know I'm very pro science, pro medicine, I wouldn't substitute my medicine for alternatives, no." (P8,F)*

#### 4. Overarching Theme – Integration

Integration was the last predominant theme. Participants spoke of mindfulness as a complementary adjunct to their existing medical treatment, which denotes one subtheme. It was often described as an accessible tool that could be used when needed, this describes the second subtheme. See Figure 6 for graphical map of this overarching and subthemes.

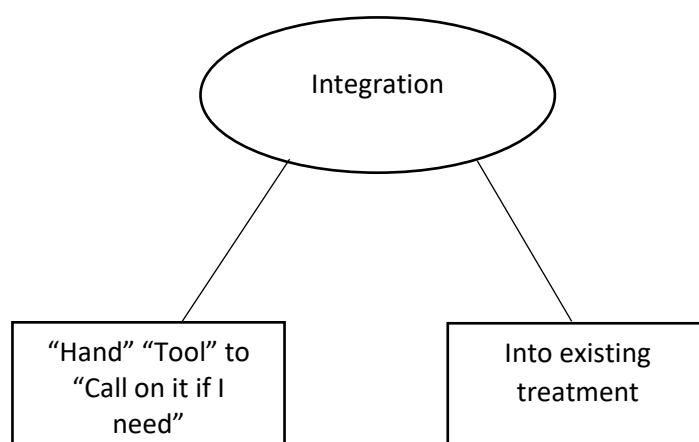


Figure 6 – Theme 4 - Integration

##### 4.1 Integrating mindfulness into existing treatment

For many there was a strong sense that medication had its place, ascribing to the medical model. However, the majority of interviewees conveyed that mindfulness was not a replacement or

alternative way of managing asthma, but instead had a complementary role alongside medication.

For example;

*"I think I would use caution using that as an alternative method for inhalers because on a nursing point of view, you do need the steroids. You do need the nebulisers. You do need the inhalers. I think it would work in conjunction, as long as you know that and it's not going to fix it and you can't leave home without your inhalers and without your nebulisers." (FG1, F)*

*"No not at all, still think they [medications] are the most important part of my, umm, I just think this adds a bit more, it, that's all... But I think it will help at the other end, if it makes a difference um sort of one percent, it's still a good thing to have... You know because it just gives you that little bit extra, that you can go on." (P3,M)*

*"obviously I have my inhalers if I start having an asthma attack and that I go for my Ventolin and that, but I also then to sit quietly you know and just do some mindfulness and try and re focus my mind and relax me down" (P4,F)*

Several individuals described how their medication and mindfulness worked together, interacted or helped control existing strategies or even enhance the use of their medication.

*"I think it definitely has a place alongside it, I don't think, I'm not one to reach for the Ventolin if I'm feeling a bit stressy, unless I've really got, really finding it impactful, symptom wise, umm I think it's, its, complimentary to the medication rather than anything else" (P6,F)*

*"I think it's helped me seeing mindfulness as a type of medication and I think it's like FG1 was saying I think when I am having an exacerbation and I want my nebuliser I'm also doing my breathing and my mindfulness and so it's probably aiding the effect of the nebuliser." (FG3, F)*

In some cases it was hard to tell which was making the difference:

*"...um I spoke to Dr X, my asthma is um, I've just started on a new medicated of xxxx, so um, it's difficult to tell if it's that, or the mindfulness, but my breathing is a lot better than it was." (P1,F)*

4.2 "Handy" "tool" to "call on it if I need it"

Several participants described the various mindfulness skills they had learnt as 'a tool'. Additionally, they reported appreciating the flexibility and accessibility of being able to use the 'tool'

as and when they needed to, as well as, being able to personalise the technique to suit their needs. One individual described mindfulness as 'handy', but many described the convenience and accessibility of the various mindfulness techniques. The ability to integrate mindfulness and 'use it when needed' had a positive impact on individuals.

*"If you don't use the tools you can mix it up how you need it." (FG1, F)*

*"I think it's given me that ability I can just call on it if I need it to relax and settle down" (P1, F)*

*"The one thing I do, is go out to the coffee shop and just sit there, and um just sort of gaze into my coffee and do it from there so it's, it's quite handy it do that..." (P3,M)*

Others explained how they had integrated it into everyday life, and/ or used mindfulness at a specific time and place. For example; to aid sleep, during times of daily stress, at work or coffee shops and to help with other illness, other than asthma. The application to other areas of life was really evident in participant's reports of integration.

*"Yes, it's come in useful in home life. I've also given it to my children who are doing GCSEs and things. That's helped as well in that. It's helped at work and it's helped with my friend, with her Asperger's as well." (FG,1, F)*

*"Well apart from the sleeping, um I've had a few stressful moments um since I've retired, sorting out things, and pensions , private pensions and, it's quite stressy sometimes trying to get information and things so then I get back and I practice the techniques and start again. (P1,F)*

*"To be honest I used, used it more since I've been away from the course, when I'm in a situation when I'm finding it a bit difficult or where I'm about to go into a situation where it could potentially be tricky to prepare myself, so not necessarily using it as a day to day." (P6,F)*

Here, P3, describes how he intended to apply the new skill externally, to other areas of life beyond asthma.

*"when I snapped my Achilles tendon and got unfit then it really got bad um so now I'm trying to get fit again and I think this might help towards that I'm just trying, see when I'm doing exercises I am, I haven't actually brought it in yet, but I've thought of ways of actually when I'm sitting there on the*

*exercise bike of something I could actually bring it into that, I think that's the advantage of this mindfulness is that's you can adapt it to your situation" (P3,M)*

It was also seen as an acceptable alternative to physical exercise;

*"Mindfulness, it came along to tell me something, it came along to tell me, here's a useful technique you're getting older now you may not be able to do physical exercise, do mental exercise instead"*  
*(P9,M)*

### **Summary**

In summary, this study aimed to look at asthmatics, with poorly controlled asthma and comorbid anxieties, experience of a four-session mindfulness group. Four key overarching themes emerged from the rich and broad data including: Wellbeing, Challenges, Acceptability and Integration, which are further organised into 11 subthemes. The following discussion section will discuss these themes in relation to theory and existing literature. It will also consider the implications of the current findings for service delivery and clinical care, and future research in the field of mindfulness for difficult asthma.



## Discussion

The current study aimed to explore PCA patient's experience of a brief mindfulness intervention. The study found four overarching themes: *Wellbeing, Challenges, Acceptability and Integration.*

### Interpretation of results and current findings in light of previous research

**Wellbeing:** Self-reported improvements in psychological wellbeing is a common outcome of mindfulness practice. This is supported by existing literature, that suggest time spent on mindfulness practice correlates with improved mindfulness skills, which in turn mediates the relationship between practicing mindfulness and improvements in psychological wellbeing and stress (Zgierska et al. 2013; Carmody and Baer, 2008). This study found a range of personal benefits of practising mindfulness, including benefits to emotional and psychological wellbeing, as well as physical benefits. The positive impact of mindfulness on wellbeing is supported by previous qualitative research for a range of long term health conditions (Van gorden et al, 2016; Chadwick et al, 2008; Eyles et al 2014; Moss et al 2015; Keyworth et al 2014; Gans et al, 2014; Hawtin et al, 2011). Specifically, similar findings are reported by patients for improvements in mood (Chan et al, 2016; Gans et al 2014; Hoffman et al, 2012; Howarth et al, 2016) and sleep (Morone et al, 2008) as well as for various health conditions. Promising quantitative data to support reduction in perceived stress, improvements in QOL, but not lung function, for asthma patients attending a MBSR group is only just emerging (Pbert et al. 2016).

Although subjective reports from the current study indicate improvements in physical health, which is qualitatively supported by Keyworth et al (2014) for Diabetes and CHD patients, these findings are not yet quantitatively supported in the literature for asthma patients (Pbert et al, 2016). Additionally, despite qualitative support for some of the current findings and those by Malpass et al (2015), Mularski et al (2009) found no measurable improvement to HRQOL or breathlessness after an 8-week mindfulness based breathing therapy group for COPD patients, in comparison to a support group.

Research shows that the experience of breathlessness can negatively impact cognitions and behavioural coping mechanisms (Lavoie et al, 2010). Furthermore, Hamarta, Ozyesil, Deniz & Dilmac, (2013) found that locus of control and mindfulness predicts subjective wellbeing. Considering this, participants in the current study report experiencing an increased sense of coping with stress, anxiety, panic and their asthma symptoms, as well as the possibility of reducing asthma exacerbations via the ability to notice early warning signs and responding accordingly. Kraemer et al

(2015) recently found that mindfulness skills and acting with awareness significantly predicted fewer panic symptoms, and decreased anxiety sensitivity for young adults with asthma. This has the potential to improve self-efficacy, and the ability to cope with anxiety and stress. This ability to cope and encourage positive self-management is increasingly important for this population, as measures of psychological state are more strongly predictive of outcome, than physiological measures of asthma control (Goldney et al, 2003; Brinke et al, 2001; Cluley and Cochrane, 2001).

**Challenges:** Although a range of benefits were reported, it is important to acknowledge the challenges for this population, especially in relation to focusing ones attention on breath. This is understandable considering that breathlessness is a significant symptom of asthma, which causes anxiety and enhances symptom perception, via brain processing pathways (Von Leupoldt et al. 2009).

Lomas et al (2015) notes a number of experiential challenges associated with meditation practice. Similar challenges to attendance and practice were found by Martinez et al, (2015) who explored the challenges to enrolment and participation in a MBSR programme among veterans, such as struggling to find time and aversion to group setting. Similar barriers and challenges are reported in the qualitative literature for Fibromyalgia, MS, COPD and cancer (Kvillemo et al, 2011; Chan et al, 2016; Bogosian et al, 2016; Van Gordon et al, 2016 & Eyles et al, 2016). Furthermore, social anxiety and self-consciousness specifically were reported as barriers by Derger et al (2015) for diabetes patients and Chan et al (2016) for COPD patients.

Expectation of the efficacy of non-drug therapies suggest that mindfulness may not suit those who are overly aligned to the medical model. Expectations as a mediating role in individual's experiences of mindfulness intervention is also acknowledged elsewhere in research (Mason and Hargreaves, 2001). Kabat-Zin (2003) recommends asking patients at the start to let go of any particular expectation or judgements of the course, or any expectation of benefits or goals for improvement but to remain with their lived experience in the moment.

**Acceptability:** It is well established that mindfulness is acceptable and beneficial for a wide range of physical health conditions (Crow et al, 2016; Malpas et al, 2012). However, literature for respiratory conditions is only emerging, yet is already demonstrating mindfulness as an acceptable intervention (Harrison et al, 2016; Chan & Lehto, 2016) which is echoed by the current study. Additionally, those who found it difficult to focus on their breath preferred to bring their attention externally, for example to objects or sounds, making it acceptable for them.

The sub theme of 'I'm not as badly affected' could be interpreted as a way of minimising illness, or a form of denial, both which can be seen as a cognitive coping strategy to buffer distress (Felton, Revenson and Hinrichsen, 1984; Ridder et al, 2008) and therefore making mindfulness an acceptable intervention compared to medication. Furthermore, research with asthma patients has identified that a proportion of patients do not identify as having asthma. For example, Green and Bitten (1998) identified several studies suggesting that despite receiving an asthma diagnosis by health care professionals, asthma patients may not accept the medical interpretation of their condition and associated medical treatment. Additionally, Halam, Mora and Leventhal (2006) found that 53% of patients believe they only had asthma when they were having symptoms. This was also more recently supported by Freedman et al, (2013) who similarly found that 54% of asthma patients in their study believed that they only had asthma when symptoms were present.

**Integration:** There was a clear description of how participants were integrating the skills they had learnt into and with everyday life, but also using it flexibly, when required. For a group who frequently experience stress and anxiety, the convenience and flexibility of mindfulness was seen favourably. Similarly, to Keyworth et al (2014) the current study found that mindfulness can be incorporated into daily life, and has the potential to reduce the reliance on medication. The results from this study suggest that the support given within the course to generalise the skills to other areas of life, contributed to integrating mindfulness skills into everyday life and existing treatment.

## Strengths

There are a number of strengths to this study. Although this study adds to the existing literature considering physical health patient's experience of mindfulness, many such studies focus on multiple health conditions, whereas this study is unique in that it is the first qualitative study to exclusively explore poorly controlled asthmatics experience of mindfulness. Conducting telephone interviews enabled individuals and the researcher to reduce travel cost and burden to their health, as well as having the advantage of participants being in the comfort of their own home and the ability to express their own views. This may have enabled them to feel comfortable enough to share their personal experiences and journeys, despite the interviews not being face-to-face. Secondly, having a researcher external to the initial research team conduct the focus group and telephone interviews, meant that there was no conflict of interest and possible bias was reduced. The interviewees varied between low and high attenders, as well as those that dropped out, enabling a sample which can be seen to be representative of a clinical population. This permitted views and voices of negative and difficult experiences, which enriched understanding of factors influencing

attendance and attrition, enhancing the findings reflected in the themes to be heard. Combining the focus group and telephone interview data provided rich data from the interview, and a breadth of data from the focus group (Yardley, 2004). Several transcripts were also triple coded to avoid analysis conforming to one perspective. Another strength lies in the use of Thematic Analysis, as it allows for greater theoretical flexibility (Braun & Clark, 2006). This study takes the first step in exploring the subjective experiences of mindfulness for asthma patients with PCA.

### Limitations

Although there are a number of strengths to this study, it is important to consider possible limitations. Interviews were not conducted face to face, due to difficulties accessing this hard to reach population, who were spread over a vast geographical area, in order to maximise the sample size and accommodate for ill health. This could have reduced the rapport that develops from face to face interviews and availability of nonverbal feedback. There was also a substantial period of time between participants attending the two mindfulness courses and being interviewed, which could have affected their recall of the group sessions. Furthermore, respondent validation of the themes would have been desirable.

A considerable number of participants had previous experience of alternative therapies such as Meditation, Pilates, or Yoga or previous experience of mindfulness itself through mental health services. Therefore, this could potentially bias the findings, as those who had previous experience may have been more likely to join the study and their responses at interview may have been informed by these previous interventions. Additionally, it is possible that those who had positive expectations, due to previous experience, were more likely to attend and therefore give rise to positive experiences. However, this is also reflective of a naturalist sample in clinical practice.

The results of this study exclude other themes that emerged from the data such as subjective experience of living with co-morbid asthma and anxiety, suggestions for future practice, reasons for taking part in the studies and possible mechanisms of change. Some of these themes were excluded as they did not answer the research question directly, or there is already well-known understanding within the literature around the theme. For example, mechanisms of how mindfulness can be helpful is well known within the literature (Baer, 2003; Shapiro et al, 2006). Furthermore, literature exists around group process and context (Yalom & Lessszcz, 2005) and how social support can aid coping with a chronic illness (Choen, 2004) as well as, group identity acting as a resource when coping with ill health (Haslam et al, 2009).

However, it is important to acknowledge the presence of these data and possible themes, such as the contextual factors (Appendix P) as they are clinically relevant to service delivery and practice.

## Theoretical considerations

The experience of breathlessness can lead to hypervigilance of respiratory symptoms (Harison et al, 2014), which can lead to anxiety and stress and low mood. Mindfulness therefore has the potential to increase awareness of the link between the mind and the body. Reduction in anxiety and catastrophic thinking will have a positive impact on ability to cope and increase self-efficacy. There can often be learned association between experiencing breathlessness and inactivity as a result of anxious thoughts around breathlessness (Asthma UK; Deshmuk et al, 2007). For patients with asthma and comorbid anxiety, who may get stuck in a cycle of fear or avoidance behaviour, mindfulness not only has the potential to increase acceptability of uncomfortable sensations but to also increase coping and increase self-management.

## Implications to clinical practice

For people with difficult asthma who also experience varying degrees of anxiety, a brief mindfulness course is an acceptable, complementary adjunct to pharmacological interventions and can successfully improve psychological wellbeing and assist with improving self-management of PCA. The current study has several implications to clinical practice. Increased coping with stress, anxiety and panic, has the potential for reduction in emergency department attendance and the associated costs. If PCA is managed more effectively by individuals via improved self-management skills, this can have implications both for service user's quality of life and the professionals treating them. Furthermore, this increase in coping may lead to patients using medication more appropriately, rather than overuse or delaying use of medication. This could have a potential long-term impact on the cost of medication and health care utilisation for asthmatics.

Future brief mindfulness courses for this population, should consider the very real difficulties experiences with focusing on the breath and the possibility of introducing mindfulness of objects or external environment, for those who initially find it uncomfortable to bring their attention to their breath. The psychological challenges for anxious asthmatics should be considered when setting up future mindfulness interventions. Social anxiety and self-consciousness should be normalised and acknowledged within the group setting, perhaps incorporating further elements of cognitive challenging (Wells, 2013) at the start of such groups. Participants should also be encouraged to individualise mindful practices, in order to adapt and implement them into everyday life.

## Future research

The acceptability and positive subjective experience of attending a brief mindfulness intervention for difficult asthma indicates promising results. As research in this area is in its infancy,

it would be beneficial to conduct tailored mindfulness interventions for LTHCs including specific respiratory conditions. As part of this, it would be important to qualitatively explore patient's experiences in order to explore if patient views are similar, preferably with a larger sample size. Future research should aim to explore the impact of mindfulness on an asthma population who have not experienced mindfulness or similar interventions before, in order to be able to separate the impact of the intervention. Exploring and identifying for whom mindfulness is suitable, and when it is contraindicated would also be beneficial, by further exploring perspectives from those who have struggled to attend, or struggle to do mindfulness exercises. Research exploring the impact on improved self-management and the long-term impact on health care utilisation would be beneficial, in order to quantitatively verify participant's subjective experiences. Future studies may also want to explore how social anxiety prohibits practicing mind –body exercises and mindfulness.

## Conclusions

There is little current provision of psychological care for those with difficult asthma. Asthma patients with co-morbid anxiety and depression are not routinely screened, nor have access to appropriate or suitable provisions to address their dual mental and physical health needs. Evidence suggests that MBSR has the potential to reduce stress and improve QOL for asthmatics (Pbert et al, 2016). The current study found that PCA patients with mild anxiety, receiving a brief mindfulness intervention, found mindfulness acceptable and beneficial to their physical and emotional wellbeing, despite the challenges. They were also able to successfully integrate mindfulness into their existing treatment and daily life. Therefore, integrating tailored MBIs within the existing treatment for difficult asthma patients, can help reduce anxiety and stress, which can be a trigger and consequence of an asthma attack. This has the potential to increase self-management of PCA and reduce exacerbations, which lead to frequent hospitalisations health care utilisation, which would warrant further empirical inquiry.

## Appendices

## Appendix A- PRISMA Checklist

<b>Section/topic</b>	<b>#</b>	<b>Checklist item</b>	<b>Reported on page #</b>
<b>TITLE</b>			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known.	
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	
<b>METHODS</b>			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	

Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., $I^2$ ) for each meta-analysis.	
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	
<b>RESULTS</b>			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	
<b>DISCUSSION</b>			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	
<b>FUNDING</b>			

Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	
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From: Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., & The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 6(6): e1000097. Retrieved from: <http://www.prisma-statement.org/PRISMAStatement/Checklist.aspx>

## Appendix B - PICOS table

<b>Review question/objectives</b>	Patient experiences of mindfulness based interventions for physical health conditions
<b>Population/Participants</b>	Adults over the age of 18 Diagnosed or self-reported physical health, Long term health conditions, Physical health, chronic illness/disease
<b>Intervention</b>	Mindfulness based intervention, MBSR, mindfulness/meditation interventions
<b>Comparator</b>	None
<b>Outcomes</b>	Patient experiences of mindfulness
<b>Setting</b>	Community, inpatient, primary care, acute
<b>Study design</b>	Qualitative or mixed methods studies only

Appendix C- Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist

Screening Questions	Yes	Can't tell	No
<b>1. Was there a clear statement of the aims of the research?</b>  <i>Consider:</i> <ul style="list-style-type: none"><li>• What the goal of the research was</li><li>• Why is it important</li><li>• Its relevance</li></ul>			
<b>2. Is a qualitative methodology appropriate?</b>  <i>Consider:</i> <ul style="list-style-type: none"><li>• <i>If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants</i></li></ul> <b>Is it worth continuing?</b>			
Detailed Questions			
<b>3. Was the research design appropriate to address the aims of the research?</b>  <i>Consider:</i> <ul style="list-style-type: none"><li>• <i>If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?</i></li></ul>			
<b>4. Was the recruitment strategy appropriate to the aims of the research?</b>  <i>Consider:</i> <ul style="list-style-type: none"><li>• <i>If the researcher has explained how the participants were selected</i></li><li>• <i>If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study</i></li><li>• <i>If there are any discussions around recruitment (e.g. why some people chose not to take part)</i></li></ul>			
<b>5. Were the data collected in a way that addressed the research issue?</b>  <i>Consider:</i> <ul style="list-style-type: none"><li>• <i>If the setting for data collection was justified</i></li><li>• <i>If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)</i></li><li>• <i>If the researcher has justified the methods chosen</i></li><li>• <i>If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?</i></li><li>• <i>If methods were modified during the study. If so, has the researcher explained how and why?</i></li><li>• <i>If the form of data is clear (e.g. tape recordings, video material, notes etc.)</i></li><li>• <i>If the researcher has discussed saturation of data</i></li></ul>			
<b>6. Has the relationship between researcher and participants been adequately considered?</b>  <i>Consider:</i> <ul style="list-style-type: none"><li>• <i>If the researcher critically examined their own role, potential bias and influence during:</i></li><li>• <i>Formulation of the research questions</i></li></ul>			

<ul style="list-style-type: none"> <li>• Data collection, including sample recruitment and choice of location</li> <li>• How the researcher responded to events during the study and whether they considered the implications of any changes in the research design</li> </ul>			
<b>7. Have ethical issues been taken into consideration?</b>  Consider: <ul style="list-style-type: none"> <li>• If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained</li> <li>• If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)</li> <li>• If approval has been sought from the ethics committee</li> </ul>			
<b>8. Was the data analysis sufficiently rigorous?</b>  Consider: <ul style="list-style-type: none"> <li>• If there is an in-depth description of the analysis process</li> <li>• If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?</li> <li>• Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process</li> <li>• If sufficient data are presented to support the findings</li> <li>• To what extent contradictory data are taken into account</li> <li>• Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation</li> </ul>			
<b>9. Is there a clear statement of findings?</b>  Consider: <ul style="list-style-type: none"> <li>• If the findings are explicit</li> <li>• If there is adequate discussion of the evidence both for and against the researcher's arguments</li> <li>• If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)</li> <li>• If the findings are discussed in relation to the original research question</li> </ul>			
<b>10. How valuable is the research?</b>  Consider: <ul style="list-style-type: none"> <li>• If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practise or policy, or relevant research-based literature?</li> <li>• If they identify new areas where research is necessary</li> <li>• If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used</li> </ul>			

Appendix D - Consolidated criteria for reporting qualitative research (COREQ): 32-item checklist

No. Item	Guide questions/description	Reported on Page #
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	
3. Occupation	What was their occupation at the time of the study?	
4. Gender	Was the researcher male or female?	
5. Experience and training	What experience or training did the researcher have?	
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: study design</b>		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	
12. Sample size	How many participants were in the study?	
13. Non-participation	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	

19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	
20. Field notes	Were field notes made during and/or after the interview or focus group?	
21. Duration	What was the duration of the interviews or focus group?	
22. Data saturation	Was data saturation discussed?	
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	
<b>Domain 3: analysis and findings</b>		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	
25. Description of the coding tree	Did authors provide a description of the coding tree?	
26. Derivation of themes	Were themes identified in advance or derived from the data?	
27. Software	What software, if applicable, was used to manage the data?	
28. Participant checking	Did participants provide feedback on the findings?	
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
30. Data and findings consistent	Was there consistency between the data presented and the findings?	
31. Clarity of major themes	Were major themes clearly presented in the findings?	
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

## Appendix E- Quality Assessment Framework Scoring for Qualitative Studies

	<b>Chadwick (2008)</b>	<b>Doran (2014)</b>	<b>Dreger (2015)</b>	<b>Hawtin (2011)</b>	<b>Howarth (2016)</b>	<b>Hoffman (2012)</b>	<b>Kvillemo (2011)</b>	<b>Mackenzie (2007)</b>	<b>Morone (2008)</b>	<b>VanGordon (2016)</b>
1. Was there a clear statement of the aims of the research?	Yes (1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)
2. Is a qualitative methodology appropriate?	Yes (1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Unclear(0)	Yes(1)	Yes(1)	Yes(1)	Yes(1)
3. Was there a research design appropriate to address the aims of the research?	Yes (1)	Unclear(0)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)
4. Was the recruitment strategy appropriate to the aims of the research?	Yes (1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)
5. Was the data collected in a way that addressed the research issue?	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)
6. Has the relationship between researcher participants been adequately considered?	Yes(1)	Unclear(0)	Unclear(0)	Yes(1)	Yes(1)	No(0)	Unclear(0)	Yes(1)	No(0)	No(0)
7. Have ethical issues been taken into consideration?	Yes(1)	Yes(1)	Unclear(0)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Unclear(0)
8. Was the data analysis sufficiently rigorous.	Unclear (0)	No(0)	Yes(1)	Yes(1)	Yes(1)	No(0)	Unclear(0)	Yes(1)	Yes(1)	Yes(1)
9. Is there a clear statement of findings?	Yes(1)	No(0)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)
10. How valuable is the research?	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)
11. Is an interview guide provided, or the topic of questions specified?	Yes(1)	No(0)	Yes(1)	No(0)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	No(0)	Yes(1)
12. Was a theoretical framework specified?	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)	Yes(1)
<b>Quality Assessment Framework Score (Max of 12)</b>	11	7	10	11	12	9	10	12	10	10

Key: Yes= 1, Unclear/unable to determine = 0, No = 0

Appendix F- Quality Assessment Framework Scoring for Qualitative part of Mixed Method Studies

	<b>Bogosian (2016)</b>	<b>Chan (2016)</b>	<b>Dobkin (2008)</b>	<b>Dufour (2015)</b>	<b>Eyles (2014)</b>	<b>Gans (2014)</b>	<b>Keyworth (2014)</b>	<b>Majumdar (2002)</b>	<b>Moss (2015)</b>	<b>Petersen (2016)</b>
1. Was there a clear statement of the aims of the research?	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
2. Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3. Was there a research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Unclear
4. Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
5. Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes
6. Has the relationship between researcher participants been adequately considered?	No	No	No	No	No	No	Unclear	No	No	Unclear
7. Have ethical issues been taken into consideration?	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	No	Yes	Yes
8. Was the data analysis sufficiently rigorous.	Yes	Unclear	Unclear	Yes	Yes	No	Yes	No	No	No
9. Is there a clear statement of findings?	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Yes
10. How valuable is the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
11. Is an interview guide provided, or the topic of questions specified?	Yes	Yes	Yes	No	No	No	Yes	No	No	Yes
12. Was a theoretical framework specified?	Yes	Yes	No	Yes	Yes	No	Yes	No	Unclear	No
<b>Quality Assessment Framework Score (Max of 12)</b>	11	10	8	9	10	5	11	5	7	8

Key: Yes= 1, Unclear/unable to determine = 0, No = 0

## Appendix G – Patient Information Sheet

### **Participant Information Sheet**

**A group mindfulness intervention to help people with asthma**  
**Chief Investigator: Professor Mike Thomas**

#### **What is the aim of the study?**

This study aims to find out about how a course of mindfulness might help people who have difficult-to-manage asthma, and what people think about it.

#### **Why have I been invited?**

You have been invited because you are being treated for asthma at the Southampton Difficult Asthma Clinic that is taking part in this study, and you meet the inclusion criterion of having a score > 6 on the Hospital Anxiety and Depression Scale. About 20 people will take part in this study. If you do not wish to take part in this study, it will not affect your medical care in any way.

#### **What will I have to do in order to take part?**

At the start of the study, you will attend a normal asthma check-up. As well as the usual checks, you will be asked to complete some questionnaires and a couple of brief computer tasks.

You will attend the mindfulness intervention, which involves 4 weekly group sessions and 'homework' (practices that you should do at home) between each session. You will be reimbursed for any travel costs to attend these. Each weekly group session will last about 1.5 hours.

After the intervention, at your next asthma check-up, you will complete the same questionnaires and computer tasks. You may also be asked to take part in a focus group or telephone interview, so you can give your views on the mindfulness and your experience of it.

While taking part in the intervention you will still receive your usual clinical care.

#### **What is Mindfulness?**

Mindfulness is rather like meditation; it involves practising paying attention to yourself, your body and the world around you. The 4-week course this study will be using is based on mindfulness-based stress-reduction (MBSR), which has been shown to help people with a range of conditions and life-issues. MBSR is a group program that uses a combination of mindfulness meditation, body awareness and yoga. Over the 4-weeks you will practice mindfulness in a group, be given an

opportunity to ask your mindfulness teacher any questions you may have, and be given 'homework' practice that you can complete during the week.

### **What are the computer tasks?**

The brief computer tasks will last about 20 minutes. You will be given instructions by the experimenters, who will show you how to complete the tasks, which will involve using a touch-screen computer. The task measure reaction-time, have been often used with young and old participants and do not involve any language or reading. Some of the computer tasks will be administered by medical students, as part of their student research project.

### **What are the possible advantages and disadvantages of taking part?**

Your feedback will help us develop a mindfulness intervention for people with asthma, as well as understand how mindfulness may be able to help people with asthma - you may learn some new ideas to help with your asthma too. The main disadvantage of taking part is that you will have to give up some of your time in order to help us.

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

If you choose to take part in the study you are free to change your mind and withdraw at any time without giving a reason. This will not affect your medical care in any way.

### **Will my taking part in this study be kept confidential?**

With your permission, the focus groups interviews and telephone interviews will be audio-recorded to make an accurate record of what is said. These records will not include any names or other details that can identify you, to ensure confidentiality.

All of the data from the study will be held in a locked cabinet in the University of Southampton which only the research team can access. When the study is complete the recordings will be destroyed.

The findings from this study will be used in research reports and the website, but no names will be included in the report or website – so there will be no way anyone can link a quote to the person who said it.

Some of the data, including that of the computerised tasks, will be used by medical student projects as part of a Medical Science degree.

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

The results will be shared as widely as possible with everyone interested in improving the lives of people who have asthma - including doctors, nurses and the general public. We will send you a summary of the findings if you would like one. As stated above, some of the data, will be used by medical student projects as part of a Medical Science degree.

### **Who has reviewed the study?**

The study has been reviewed and given approval by NHS South Central Berkshire B Ethics Committee, ref 15/SC/0522.

### **What if there is a problem?**

If you have any concerns or feel that you have been placed at risk you can contact the Head of Research Governance at the University of Southampton – Ms. Mikayala King at [m.king@soton.ac.uk](mailto:m.king@soton.ac.uk) or telephone 023 80 598848. If you remain unhappy and wish to complain formally you can do this through the NHS complaints procedure. Details are available from your own practice.

### **How can I find out more?**

For more information about this study or if you would like to take part please either return the reply slip enclosed in the freepost envelope provided, or contact the researcher, Dr. Ben Ainsworth on 02380 591950 or [ben.ainsworth@soton.ac.uk](mailto:ben.ainsworth@soton.ac.uk).

**THANK YOU FOR YOUR TIME IN READING THIS  
INFORMATION SHEET**

## Appendix H– Four Week Mindfulness Intervention Session Outline

### 4-Week Mindfulness Intervention

#### **Week 1: Where is your mind?**

*Coming off automatic pilot and being present. Training the mind to pay attention – taking control.*

In this first session participants are introduced to mindfulness. What it is, what are the benefits of practicing and why specifically it may be able to help with asthma?

Central to mindfulness is self-awareness, understanding what we do and why? As we develop self-awareness through practicing mindfulness we are better able to self-regulate and change behaviours.

Mindfulness is the awareness that comes from paying attention, on purpose, non-judgementally to our experience in the present moment. Effectively, we learn to be with our experience, both internally and externally, as it is, not wishing it to be different. Central to dissatisfaction in life is wanting things to be different to how they are, which means we add a layer of negative psychology to our experience. For example, we of course do not want to be in pain, but by bracing against it, resisting it, we make it worse.

Mindfulness cannot change our experiences but can alter how we relate to them.

We will consider the model of how mindfulness works, through training attention, the attitude or approach we bring to experience and by setting our intention. We will explain how we begin to train mindfulness and we will also look at the impact of stress.

Research has shown that nearly half the time our mind is not on the task intended, it is wandering. The problem with this is that when our mind is wandering it is unhappy. It gets caught up in past events, re-running them or worrying about the future, it has a negative bias and is generally preoccupied with ourselves. This means that our thoughts are emotionally charged and we are more likely to be judgemental and reactive. This leads to misinterpretations and misunderstandings. Mind wandering is increased when we are in a low mood or we are stressed. We will introduce mindfulness practices to train attention, so learning to gather and calm a “scattered” mind.

#### **Practices:**

- Settling “checking in” - A simple technique to release tension and learn to relax
- 5 Senses practice - When stressed/anxious learn to calm by turning to sensory mode of mind
- Breath awareness meditation (breath in abdomen as focus) – Attention training
- Breath counting as a means to train attention

Commitment to practice is important, but should not to be a burden. Cultivate the attitude of kindness and acceptance. If individuals have a problem focusing on the breath they can use breath co-ordinated with simple movement or train attention using an external focus.

#### **Week 2: Reconnecting mind and body**

*Becoming emotionally aware – Learning to control our emotions rather than them controlling us.*

In this session we are deliberately learning to tune into physiological signals from the body. These are often missed and we find ourselves caught up in an emotion, we then become aware of how the body feels and we use that to feedback and amplify our emotion. If allowed to continue this can spiral out of control. With mindfulness we are using the body as a “barometer” an early warning system of emotions arising. We can then take action to interrupt this automatic feedback loop

We will explore distinctive signatures in the body for emotions and discuss how somatic sensations affect decisions (embodied cognition). We will look at how mindfulness can be used to regulate emotions. How acknowledging emotions can effectively “turn down” the volume and we will consider refractory period of emotions and how that colours our behaviours.

*Each session after the first will begin with an enquiry as to how the previous weeks practice has been and address any issues arising. This is an essential element in the programme in terms of learning.*

#### **Practices:**

- Settling “checking in” - to release tension and relax
- Stretch & Breath
  - Aware of physical sensations in the body, playing with limits, edges etc...
  - Connecting to the body can be easier with the simple movement of stretching
  - May be beneficial prior to a seated or formal meditation
- Body scan
  - Play with narrow and broad focus as a means of training attention
  - Learning to sense body sensations rather than think about them

Continue to work with attitudes of kindness and acceptance. Develop curiosity (growth mindset) and work with approach mindset.

#### **Week 3: Mind Games**

*Understanding our minds can “mess” with us, becoming aware of familiar thought patterns that may be based on false mental models. Appreciating that we often miss the interpretation of experience and that “Thoughts are not facts”*

This week explores the games our minds like to play, the familiar stories that come round. We look at exercises to see how our mind makes assumptions and how our thoughts can affect how we feel and influence our actions. We will look at how we often miss the “interpretation” stage and think that an experience itself has led to how we feel and behave.

We consider that our thoughts are not facts and that they can at times get us into trouble.

We will look at how we can use mindfulness to deal with thoughts. We will expand this to look at how mindfulness can be used to explore difficulties both emotional and physical. We will consider how ‘turning towards’ and acceptance of difficulties can prevent the extra layer of negative psychology being added.

A key practice of MBCT, a Breathing Space will be introduced here. This will be used as a means of giving space and changing perspective. A way of taking a pause and stepping back especially when facing difficulties.

#### **Practices:**

- Settling “checking in” - to release tension and relax
- Breathing Space
  - Introduce breathing space as bridge between formal and informal practice
  - Respond not react – take a pause set out of habituated patterns
- Practice Breath, Body, Sounds and Thoughts
  - A prelude to mindfulness practice of sitting with our experience
  - Introduce ways of approaching difficulty e.g. discomfort in body
  - Sounds as an analogy that things come and go
  - Thoughts – learning to be with them, observing them rather than getting caught up into them

- Suggestions of how to observe thoughts e.g. on clouds, buses etc...

Continuing to work with mindsets and attitudes. Aware of the “harsh critic” that sits in our head and berates us. Cultivating compassion for ourselves.

#### **Week 4: Establishing a practice**

*Taking care of ourselves. Integrating mindfulness into our daily routine.*

This final session looks at how to establish and sustain a mindfulness practice. We will explore different options for integrating mindfulness into daily life. As most of the time we are moving we will look at using mindful movement as a formal practice.

We will look at how we can take care of ourselves, what action steps we can introduce to prevent stress and exhaustion and lowering of mood.

We will recap on mindfulness techniques that have been introduced during the course and how we might be able to adapt them. We will look at informal practices that can be used throughout the day, as well as looking at short “emergency” practices that can be used specifically to deal with difficulties.

#### **Practices:**

- Settling “checking in” - to release tension and relax
- Breathing Space
  - Breathing space as bridge between formal and informal practice
  - Respond not react – take a pause set out of habituated patterns
  - Adding an action step
- Mindful movement
- Informal practices e.g. STOP
- “Emergency” practices e.g. RAIN

Participants will be able to take away a personalised plan for integrating mindfulness into their lives and how it might help them. The importance of continued practice and support will be considered, along with how to be “kind” to themselves. We will discuss optional practices such as compassion and gratitude practices. They will receive additional recordings to assist with maintaining their practice, as well as practices such as a sleep meditation

## Appendix I – NHS Health Research Authority NRES committee Ethics approval



### South Central - Berkshire B Research Ethics Committee

Whitefriars  
Level 3, Block B  
Lewins Mead  
Bristol  
BS1 2NT

Tel: 0207 104 8204

28 July 2016

Mr Jonathon Griffiths  
4 Cerberus House  
Castle Lane  
Southampton  
SO14 2BU

Dear Mr Griffiths

Study title:	Investigating the impact of a short-course MBSR-based mindfulness intervention on patients with difficult-to-manage asthma.
REC reference:	15/SC/0522
Protocol number:	RHM MED1276
Amendment number:	3.0
Amendment date:	06 July 2016
IRAS project ID:	173692

The above amendment was reviewed at the meeting of the Sub-Committee held on 28 July 2016 via correspondence.

#### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP) [AmendmentForm_ReadyForSubmission]	3.0	06 July 2016
Participant consent form [MIDAS_Consent_Form_v4 4 July 2016]	4.0	04 July 2016
Participant information sheet (PIS) [MIDAS+-+PIS+v5 4 July 2016 docx]	5.0	04 July 2016
Research protocol or project proposal [MIDAS - Protocol v4 4 July 2016]	4.0	04 July 2016

Research protocol or project proposal [MIDAS - Protocol v4 tracked changes 4 July]	4.0	04 July 2016
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#### Membership of the Committee

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

#### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

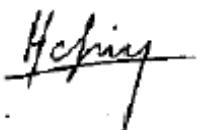
#### Statement of compliance

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

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

15/SC/0522: Please quote this number on all correspondence

Yours sincerely



Ms Helen Sivey  
REC Assistant

pp. Dr John Sheridan  
Chair

E-mail: [nrescommittee.southcentral-berkshireb@nhs.net](mailto:nrescommittee.southcentral-berkshireb@nhs.net)

## Appendix J – Non-substantial/Minor Amendments for NHS studies

### Partner Organisations:

Health Research Authority, England  
NHS Research Scotland  
HSC Research & Development, Public Health Agency, Northern Ireland

NIHR Clinical Research Network, England  
NISCHR Permissions Co-ordinating Unit, Wales

### Notification of Non-Substantial/Minor Amendments(s) for NHS Studies

This template **must only** be used to notify NHS/HSC R&D office(s) of amendments, which are **NOT** categorised as Substantial Amendments.  
**If you need to notify a Substantial Amendment to your study then you MUST use the appropriate Substantial Amendment form in IRAS.**

#### Instructions for using this template

- For guidance on amendments refer to <http://www.hra.nhs.uk/research-community/during-your-research-project/amendments/>
- This template should be completed by the CI and optionally authorised by Sponsor, if required by sponsor guidelines.
- This form should be submitted according to the instructions provided for NHS/HSC R&D at <http://www.hra.nhs.uk/research-community/during-your-research-project/amendments/which-review-bodies-need-to-approve-or-be-notified-of-which-types-of-amendments/>. If you do not submit your notification in accordance with these instructions then processing of your submission may be significantly delayed.

#### 1. Study Information

<b>Full title of study:</b>	Investigating the impact of a short course MSBR- based mindfulness intervention on patients with difficult to manage asthma
<b>IRAS Project ID:</b>	173692
<b>Sponsor Amendment Notification number:</b>	
<b>Sponsor Amendment Notification date:</b>	25/10/2016
<b>Details of Chief Investigator:</b>	
Name [first name and surname]	Dr Ramesh Kurukulaaratchy
Address:	University Hospital Southampton NHS Foundation trust Tremona Road Southampton Hampshire
Postcode:	SO16 6YD
Contact telephone number:	023 8077 7222
Email address:	Ramesh.kurukulaaratchy@uhs.nhs.uk
<b>Details of Lead Sponsor:</b>	

**Partner Organisations:**

Health Research Authority, England  
NHS Research Scotland  
HSC Research & Development, Public Health Agency, Northern Ireland

NIHR Clinical Research Network, England  
NISCHR Permissions Co-ordinating Unit, Wales

Name:	University Hospital Southampton NHS Foundation trust
Contact email address:	Jennifer.peach@uhs.nhs.uk
<b>Details of Lead Nation:</b>	
Name of lead nation <i>delete as appropriate</i>	England
If England led is the study going through CSP? <i>delete as appropriate</i>	Yes
<b>Name of lead R&amp;D office:</b>	R & D office Level E University Hospital Southampton NHS Foundation trust

**Partner Organisations:**

Health Research Authority, England	NIHR Clinical Research Network, England
NHS Research Scotland	NISCHR Permissions Co-ordinating Unit, Wales
HSC Research & Development, Public Health Agency, Northern Ireland	

## 2. Summary of amendment(s)

This template must only be used to notify NHS/HSC R&D office(s) of amendments which are NOT categorised as Substantial Amendments.  
If you need to notify a Substantial Amendment to your study then you **MUST** use the appropriate **Substantial Amendment form in IRAS**.

No.	Brief description of amendment <small>(please enter each separate amendment in a new row)</small>	Amendment applies to <small>(delete/ list as appropriate)</small>		List relevant supporting document(s), including version numbers <small>(please ensure all referenced supporting documents are submitted with this form)</small>	R&D date <small>of amend (category A, For office use)</small>
		Nation	Sites		
1	Extension of study end date- for follow ups and analysis to 1 <sup>st</sup> April 2017. No cost extension due to delays with amendments and study follow up.  Submission Name: Mindfulness for patients with difficult-to-manage asthma (Amendment 1) Submission ID: 18875 Comments: Extension approved providing there are no other changes arising from the extension, such as changes to the protocol, sample size or researcher. If your study has NHS ethics then please ensure the REC are informed and all other parties you have received permissions from for your study.	England	All sites or list affected sites	N/A	N/A
2	For information- Trainee Clinical Psychologist has been added to research team to assist with study follow up/ telephone interviews- Trainee Clinical Psychologist -Aarti Patel- who will be added to the delegation log	England	All sites or list affected sites		
3					
4					
5					

[Add further rows as required]

**Partner Organisations:**

Health Research Authority, England  
NHS Research Scotland  
HSC Research & Development, Public Health Agency, Northern Ireland

NIHR Clinical Research Network, England  
NISCHR Permissions Co-ordinating Unit, Wales

**3. Declaration(s)****Declaration by Chief Investigator**

- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.
- I consider that it would be reasonable for the proposed amendment(s) to be implemented.

Signature of Chief Investigator: ..... 

Print name: Dr Ramesh J Kurukulaaratchy

Date: October 26th 2016

**Optional Declaration by the Sponsor's Representative (as per Sponsor Guidelines)**

*The sponsor of an approved study is responsible for all amendments made during its conduct.*

*The person authorising the declaration should be authorised to do so. There is no requirement for a particular level of seniority; the sponsor's rules on delegated authority should be adhered to.*

- I confirm the sponsor's support for the amendment(s) in this notification.

Signature of sponsor's representative:  .....

Print name: Jennifer Pearce

Post: RESEARCH FACILITATOR

Organisation: UHS FT

Date: 26<sup>th</sup> Oct. 2016

## Appendix K – Consent Form

### **Consent Form**

#### **Mindfulness for patients with difficult-to-manage asthma**

If you are happy to take part in this research then please read all 5 statements below and initial all the boxes if you agree with them.

1. I confirm that I have read and understand the information for this study.
2. I understand that I do not have to take part and that I can withdraw at any time without giving a reason, and this will not affect my medical care or legal rights.
3. I understand that data collected during the study may be looked at by researchers from the University of Southampton and by regulatory authorities, but will not be used for any other purpose
4. If I take part in a focus group or telephone interview, I am happy for a voice recording to be made of the focus group or telephone interview, and that what I say may be used as an anonymous quotation in reports/publications, or in future versions of the site.
5. I agree to take part in the above study.

---

Name of Patient

---

Date

---

Signature

---

Name of Researcher

---

Date

---

Signature

Participant Identification Number:

## Appendix L –Focus Group Topic Guide

### Topic guide

*Below is a list of topics/questions to be discussed in this study. The qualitative work will remain flexible with respect to participants' agendas but we will cover the broad topics/questions noted. It is common in qualitative work to iteratively develop topics and questions as new ideas emerge from early data collection. Therefore, we may add new topics as the focus groups progress and data collection continues. However, the key topics of patient views and experiences will remain the same.*

#### **Introduction:**

- Re-introduce self and purpose of focus group
  - Remind participant what the study is about – that it is to explore their experience of taking part in the mindfulness intervention
- Check **consent** with participant
  - That they are still willing to take part in the focus group and happy for it to be recorded.
- Remind the participant:
  - The focus group will be anonymised when transcribed and any direct quotes will not be used to identify them as an individual.
  - Please try to keep the focus group and everything discussed in this group confidential.
  - They can change their mind about taking part in the study, can stop the focus group at any time or decline to answer a question.
  - Remind them that it will take around 90 minutes.
- Ask the participants if they have any questions.
- Start recording
  - Make sure digital audio recorder is working/test beforehand.

### Experience of taking part in the mindfulness training course

- Please describe you experience of taking part , particularly focussing on anything that was helpful or unhelpful
  - Such as to your breathing or any physical symptoms associated with the asthma
  - Such as with any anxiety, sleep, stress, dealing with hardships, stressful life events
  - What was your experience of having to focus on your body sensations (objective awareness)
  - What are your views on using non drug therapies such as mindfulness to help with difficult asthma
  - Why did you agree to take part
  - How could we have made this easier for people to take part
  - What do you think are the barriers for people to take part

### Views on the techniques taught and home practice

- Please describe your views on the techniques taught during the course and in the home practice
  - Group discussion, Body scan.....,
  - What were your views on using any technique that involved focussing on breath
  - Views on commitment to the sessions – weekly, times, location
  - Views of and commitment to home practice

### Views on the group processes.

- What aspects of the group did you like or not like
  - How did the group get on
  - How did you find being in a group with other people with difficult asthma
  - What difficulties were there in being in a group (not getting on, fear of group speaking, not wanting to share, not wanting to be with others)
  - What benefits were there in being in a group (learning from others, feeling supported from others)
  - Did the intervention need to be delivered in a group
  - How else could it be delivered ie. one/one, forums, telephone, online, apps etc

### Views on the clinical outcomes

- Views of important clinical outcomes, other than those proposed for this study
  - Were the questionnaires relevant – (Asthma quality of life, depression and anxiety, lung function)
  - What other questions do you think we should be asking
  - Please describe whether you think anything has changed as a result of the course – such as your breathing?

### Views on long term use of mindfulness or other meditative practices post intervention

- Please describe whether you have integrated or not integrated any of the techniques into your daily life,
  - If not, why not - what are the barriers for you?
  - Is so - what techniques and how have you managed this and any challenges or barriers to this?

### Views on whether mindfulness has affected experience of taking/adhering to medication

- What is difficult or easy about taking your medicines
- Did it change views on medication
- Were there any changes to the way that you took your medicines

### Views on the relationship between their mood, and their experience of asthma symptoms

- Please describe any instances when asthma has made you stressed or caused a stressful situation?
- Please describe any instances of a stressful situation that may have affected your asthma?
  - any changes to this since taking part in the mindfulness group
- What your thoughts around whether people with asthma might benefit from further help with managing asthma?
  - How about you specifically?
  - Views on non-drug interventions

## Appendix M – Example of independent coding by AP, BA and JG

Sceptical

1 Interview 3

2

3 P – Okay my device is switched on and recording, so xxxx I just wanted to check  
4 that you are happy to take part in this telephone interview today?

5 Z – Yes that's fine

General Exp

6 P – Excellent, so I just wanted to start off by asking just some general questions  
7 about your overall experience of taking part in um in the mindfulness course  
8 what was that like?

9 Z – Actually on the course itself?

10 P - Yeah

11 Z – yeah it I must admit I was very sceptical when I went into it um I thought  
12 this is going to be a load of rubbish but actually it worked quite well there were  
13 a cold of bits that I really felt uncomfortable doing like walking around I mean

Setting

14 the one trouble with the hotel that we were in was that it had a big window  
15 down one side where people could walk backwards and forwards look in and  
16 I must admit when we were walking around um doing some of the stuff I felt  
17 a bit embarrassed but I, I managed to block most of it out, no actually over all  
18 it was very good.

Scepticism  
new  
experience

feeling  
uncomfortable  
windows  
-ve.

Feeling  
embarrassed  
doing exercise

positive  
things about course

19 P – That kind of stuff it really useful for us to know, and you aren't the only  
20 one who's mentioned the window

21 Z - Right

22 P – Okay so can you tell me anymore about that was there anything else that  
23 was good or bad or unhelpful?

24 P - I don't think there was anything bad about it really I mean I can't think of  
25 anything um I, it was, it really opened, it got me thinking about what was going on and that and um I must admit when I sort of applied it outside it, it really made a difference.

28 Z - Okay so tell me a bit more about that?

29 P - Well the one thing I do is the signing in that bit and ah I find that quite handy when I'm having a coffee or something the difficulty with this whole thing is finding the time to do it when I'm not going to be disturbed.

32 Z - okay

33 P - and the one thing I do is go out to the coffee shop and just sit there and um just sort of gaze into my coffee and and do it from there so its it's is quite handy to do that, I haven't done the only other one I've done is the walking one, where you are walking along sort of telling yourself to look at parts of your body as you're walking along and just listening in to everything around you and that I find that quite useful as well.

39 Z - Okay, how is, how has the parts from the course been helpful in any other areas of your life? So having any other impact?

41 P - yes it had I have found it extremely useful for my blood pressure, I've got high blood pressure and I sit there and I have noticed a difference from when I start it and when I finish it I mean this is meditation really isn't it I mean that what. And it just calms you right down it had dropped my blood pressure right down before when I've taken it just before and just after

46 Z - okay

47 P - it's a noticeable difference - Noticeable difference in BP

1 Interview 3

2

3 P – Okay my device is switched on and recording, so xxxx I just wanted to check  
4 that you are happy to take part in this telephone interview today?

5 Z – Yes that's fine

6 P – Excellent, so I just wanted to start off by asking just some general questions  
7 about your overall experience of taking part in um in the mindfulness course  
8 what was that like?

• DIFF (several)  
course /  
CONFIDENTIAL

9 Z – Actually on the course itself?

10 P - Yeah

• sceptical  
• not concerned  
• exposed (unseen)  
• embarrassed  
• v. cool

11 Z – yeah it I must admit I was very sceptical when I went into it um I thought  
12 this is going to be a load of rubbish but actually it worked quite well there were  
13 a cold of bits that I really felt uncomfortable doing like walking around I mean  
14 the one trouble with the hotel that we were in was that it had a big window  
15 down one side where people could walk backwards and forwards look in and  
16 I must admit when we were walking around um doing some of the stuff I felt  
17 a bit embarrassed but I, I managed to block most of it out, no actually over all  
18 it was very good

19 P – That kind of stuff it really useful for us to know, and you aren't the only  
20 one who's mentioned the window

21 Z - Right

22 P – Okay so can you tell me anymore about that was there anything else that  
23 was good or bad or unhelpful?

*Nothing bad (cat)*

*extreme attraction*

- 24 P – I don't think there was anything bad about it really I mean I can't think of  
25 anything um I, it was, it really opened, it got me thinking about what was going  
26 on and that and um I must admit when I sort of applied it outside it, it really  
27 made a difference

- 28 Z – Okay so tell me a bit more about that?

- 29 P – Well the one thing I do is the signing in that bit and ah I find that quite  
30 handy when I'm having a coffee or something the difficulty with this whole  
31 thing is finding the time to do it when I'm not going to be disturbed

*hard to find time*

*not disturbed*

- 32 Z- okay

- 33 P – and the one thing I do is go out to the coffee shop and just sit there and  
34 um just sort of gaze into my coffee and and do it from there so its is quite  
35 handy it do that I, I haven't done the only other one I've done is the walking  
36 one, where you are walking along sort of telling yourself to look at parts of  
37 your body as you're walking along and just listening in to everything around  
38 you and that I find that quite useful as well

*it helps (concentration)*

*listening to sounds*

*calms*

- 39 Z – Okay, how is, how has the parts from the course been helpful in any other  
40 areas of your life? So having any other impact

*your blood pressure*

- 41 P – yes it had I have found it extremely useful for my blood pressure, I've got  
42 high blood pressure and I sit there and I have noticed a difference from when  
43 I start it and when I finish it I mean this is meditation really isn't it I mean that  
44 what. And it just calms you right down it had dropped my blood pressure right  
45 down before when I've taken it just before and just after

- 46 Z- okay

- 47 P – it's a noticeable difference

1    Interview 3

2

3    P – Okay my device is switched on and recording, so xxxx I just wanted to check  
4    that you are happy to take part in this telephone interview today?

5    Z – Yes that's fine

6    P – Excellent, so I just wanted to start off by asking just some general questions  
7    about your overall experience of taking part in um in the mindfulness course  
8    what was that like?

9    Z – Actually on the course itself?

10   P - Yeah

11   Z – yeah it I must admit I was very sceptical when I went into it um I thought  
12   this is going to be a load of rubbish but actually it worked quite well there were  
13   a cold of bits that I really felt uncomfortable doing like walking around I mean  
14   the one trouble with the hotel that we were in was that it had a big window  
15   down one side where people could walk backwards and forwards look in and  
16   I must admit when we were walking around um doing some of the stuff I felt  
17   a bit embarrassed but I, I managed to block most of it out, no actually over all  
18   it was very good

19   P – That kind of stuff it really useful for us to know, and you aren't the only  
20   one who's mentioned the window

21   Z - Right

22   P – Okay so can you tell me anymore about that was there anything else that  
23   was good or bad or unhelpful?

24 P – I don't think there was anything bad about it really I mean I can't think of  
25 anything um I, it was, it really opened, it got me thinking about what was going  
26 on and that and um I must admit when I sort of applied it outside it, it really  
27 made a difference

28 Z – Okay so tell me a bit more about that?

29 P – Well the one thing I do is the signing in that bit and ah I find that quite  
30 handy when I'm having a coffee or something the difficulty with this whole  
31 thing is finding the time to do it when I'm not going to be disturbed

32 Z- okay

33 P – and the one thing I do is go out to the coffee shop and just sit there and  
34 um just sort of gaze into my coffee and and do it from there so its it's is quite  
35 handy it do that I, I haven't done the only other one I've done is the walking  
36 one, where you are walking along sort of telling yourself to look at parts of  
37 your body as you're walking along and juts listening in to everything around  
38 you and that I find that quite useful as well

39 Z – Okay, how is, how has the parts from the course been helpful in any other  
40 areas of your life? So having any other impact

41 P – yes it had I have found it extremely useful for my blood pressure, I've got  
42 high blood pressure and I sit there and I have a noticed a difference from when  
43 I start it and when I finish it I mean this is meditation really isn't it I mean that  
44 what. And it just calms you right down it had dropped my blood pressure right  
45 down before when I've taken it just before and just after

46 Z-okay

47 P – it's a noticeable difference

Chilled effect

## Appendix N – List of codes/nodes developed in NVivo from interviews and focus group

Asthma Patients Experiences of Mindfulness Group.nvp - NVivo Pro

Name	Sources	References	Created On	Created By	Modified On	Modified By
Acceptability	0	0	17/05/2017 18:41	AP	29/04/2017 10:56	AP
acceptable to focus on breath	6	12	17/05/2017 18:41	AP	25/04/2017 16:23	AP
convenience	4	4	17/05/2017 18:41	AP	23/04/2017 13:43	AP
Facilitator	0	0	17/05/2017 18:41	AP	18/04/2017 15:02	AP
focusing on problem helps	4	7	17/05/2017 18:41	AP	25/04/2017 19:07	AP
health care provides legitimacy	2	2	17/05/2017 18:41	AP	23/04/2017 13:34	AP
Health care support required	6	11	17/05/2017 18:41	AP	23/04/2017 22:17	AP
others asthma is worse	5	15	17/05/2017 18:41	AP	25/04/2017 21:06	AP
positive impact of mindfulness	6	21	17/05/2017 18:41	AP	23/04/2017 21:20	AP
positive things about the course	8	18	17/05/2017 18:41	AP	23/04/2017 21:20	AP
Pre-course exp & beliefs influence acceptability	0	0	17/05/2017 18:42	AP	28/04/2017 19:06	AP
relevant to others	6	13	17/05/2017 18:41	AP	25/04/2017 16:21	AP
surprised	2	5	17/05/2017 18:41	AP	23/04/2017 19:45	AP
Integration	0	0	17/05/2017 18:42	AP	29/04/2017 10:56	AP
appreciation of course materials	7	15	17/05/2017 18:42	AP	25/04/2017 16:53	AP
bead makes M accessible	2	5	17/05/2017 18:42	AP	23/04/2017 22:09	AP
Cause of change	0	0	17/05/2017 18:42	AP	23/04/2017 19:56	AP
chosing technique that suit you	3	6	17/05/2017 18:42	AP	23/04/2017 21:24	AP
external application	5	16	17/05/2017 18:42	AP	25/04/2017 16:57	AP
applying mindfulness to attack	2	6	17/05/2017 18:42	AP	23/04/2017 13:13	AP
incorporating it into daily life	6	18	17/05/2017 18:42	AP	23/04/2017 22:15	AP
Home pratice	0	0	17/05/2017 18:42	AP	19/04/2017 22:30	AP
Mindfulness as a technique	0	0	17/05/2017 18:42	AP	18/04/2017 15:40	AP
variety of techniques	6	15	17/05/2017 18:42	AP	23/04/2017 15:22	AP
when to use Mindfulness	0	0	17/05/2017 18:42	AP	18/04/2017 15:24	AP

## Appendix O – List of codes with references from interview and focus group

Asthma Patients Experiences of Mindfulness Group.nvp - NVivo Pro

**Nodes**

- Codes I'm not sure about
- Final Nodes stage 1 - 24.4.17
- Final Nodes Stage 3 29.4.17
- Final themes and sub themes
- Interview Topics
- People
- Cases
- Relationships
- Node Matrices

**Final themes and sub themes**

Name	Sources	References
Acceptability	0	0
acceptable to focus on breath	6	12
convenience	4	4
Facilitator	0	0
focusing on problem helps	4	7
health care provides legitimacy	2	2
Health care support required	6	11
others asthma is worse	5	15
positive impact of mindfulness	6	21
positive things about the cours	8	18
Pre-course exp & beliefs influe	0	0
relevant to others	6	13
surprised	2	5
Intergration	0	0
appreciation of course material	7	15
bead makes M accessible	2	5
Cause of change	0	0
choosing technique that suit yo	3	6
external application	5	16
applying mindfulness to att	2	6
incorporating it into daily li	6	18
Home pratice	0	0
Mindfulness as a technique	0	0
variety of techniques	6	15

**Reference 1 - 0.91% Coverage**

\*: I work up at the general and I work in A&E and this year with my asthma I've been a patient and you've got people coming up to you and you've got them hugging you, 'Oh J\* babe' and I hate that. I'm quite a control freak and that would make things worse and they didn't know if my asthma was getting worse or whether it was driven by them hugging me and touching me and coming over to see me and so it was like catch 22 and it was easier to just blank it out, think of the breath, put my earphones in, close my eyes and then just concentrate on it.

**Reference 2 - 1.27% Coverage**

E\*: Like I said earlier by doing the diaphragmatic breathing that mindfulness teaches, that in itself shifts a lot of the phlegm on your chest, so again you're bringing it up. It's not just sitting there. You're not swallowing it necessarily. I've always had major problems bringing up phlegm because of my tracheal stenosis as well as my asthma and lung damage and I've found now that by doing just a few minutes of the breathing techniques I'm able to bring things up a lot easier. That for me is important and for all of us because, without being gross you have to know what the colour is to know where you're at. Is it yellow? Have I got a virus? Is it green? Have I got a bacterial infection? Is it white? Oh it's just asthma. Is it clear? Oh it's one of those

Asthma Patients Experiences of Mindfulness Group.nvp - NVivo Pro

**Nodes**

- Codes I'm not sure about
- Final Nodes stage 1 - 24.4.17
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**Final themes and sub themes**

Name	Sources	References
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acceptable to focus on breath	6	12
convenience	4	4
Facilitator	0	0
focusing on problem helps	4	7
health care provides legitimacy	2	2
Health care support required	6	11
others asthma is worse	5	15
positive impact of mindfulness	6	21
positive things about the cours	8	18
Pre-course exp & beliefs influe	0	0
relevant to others	6	13
surprised	2	5
Intergration	0	0
appreciation of course material	7	15
bead makes M accessible	2	5
Cause of change	0	0
choosing technique that suit yo	3	6
external application	5	16
applying mindfulness to att	2	6
incorporating it into daily li	6	18
Home pratice	0	0
Mindfulness as a technique	0	0
variety of techniques	6	15

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## Appendix P – Contextual Factors

### Contextual Factors

#### 1. Facilitator Attributes

Participants talked about the facilitator's role in learning about mindfulness and normalising its use. Furthermore, the facilitator's qualities, character and style were also commented on multiple times. Both their role and qualities appeared to influence participants' experiences of learning mindfulness in application to their asthma and it was clear that the instructor was valued by all attendees.

*"so no no it was good all round, and the woman who taught it to us, taught the mindfulness, she had an amazing knowledge of mindfulness and was a really, and was a massive believer in it, which I think was what made it even better for us I think..... yeah it was the teaching, it was, it was, the way, the way with the teaching the, I'd say the woman that delivered the course and that, was absolutely superb on it and I think her, I think the way she you know described how to really breath and feel your breathing and take note of it, you know, and everything" (P4, F)*

*"I thought the teacher was really good, um really good at getting the class to participate um ....she said, she appreciates that people don't always have time in their life to do the full exercises, but to just to be mindful, just to, she said, just to be mindful that you know and to re-focus your mind....the lady was really good at gelling the group if you know what I mean , she made, she made sure everyone participated and that no one was left out, um it was a good little group..." (P8, F)*

Many discussed the flexible and adaptable approach that was used to teach mindfulness;

*"She was great. If you're just given all these exercises and they say, 'You must do one to five exercises' and things that's a turn off for me, but if you say, 'there's the tools, lots of different things what suits you' and then she gives you the confidence to try it out. She encourages you to try it out and to make it your own. That's what was great about her. She was brilliant." (FG J 2, F)*

*"I think also she never once said, 'Oh I know how you've been feeling. You must do this'. It was very much I'm here as a guide." (FG E 3, F)*

One individual discussed how the facilitator or instructor helped to break stigma and normalise the use of mindfulness:

*"people aren't shy about taking the tablets for something but doing something like this, is, its its, people can feel a bit self-conscious um I think normalising it a bit and and xxxx for example or the tutor was talking about her experiences of, of with professional groups and surgeons I think she was*

*talking about, medical students, and I think that sort of thing will make people feel a bit better, saying that this isn't that people who are a bit mental do, it's something that everyone can benefit from, as a sort of healthy life style um option" (P6, F)*

## **2. Course Materials**

This included supplementary handouts and audio recordings that were shared by the facilitator to aid the group sessions. Participants reported appreciating these materials and being able to look back at them in their own time.

*"I've got the ladies downloads, the lady got me to download all her talks she's recorded them and I've just got them on my machines so I can just listen to them any time umm which is very handy once you've done a bit of the course" (P3,M)*

*"Like with the group itself, I only went to one session, but everything was sent by email as well so you, you, still obviously, so even though I didn't attend the last 4 I still received all the information that everyone else was receiving ....yeah because I was able to integrate it into what I was doing myself and then obviously with my 1-1 sessions, yeah, it's just yeah, no it was clear and understandable" (P5,M)*

*"so, so from a practice point of you that was a bit um, bit difficult because it's hard to get comfy enough for it not to be a distraction but um from a positive point of view it was umm it was learning those techniques and different um practice and having been going away with the recordings of, of the different things to try I found really helpful" (P6, F)*

Some reported sharing the handouts and documents they had received with others outside of the group.

*"Yes, it's come in useful in home life. I've also given it to my children who are doing GCSEs and things. That's helped as well in that. It's helped at work and it's helped with my friend with her Asperger's as well. So the lady that we got all the drop boxes from and things said it was okay for me to give the disks to them as well and it's mushroomed out and it's been very helpful." (FG 2, F)*

*"umm I must admit I play the things back now occasionally and she does, she does um bring you into it very well you know, she puts it over very well" (P3,M)*

A number of participants particularly commented on the beaded bracelet that was given out to aid mindful practice:

*"We were given umm ahhh like a bracelet type of thing with a bead thing on it, and um I go, I've worn it ever since the day we were given it, umm I've worn it ever since, and that immediately gets me focused back into the room where we were, umm and to do that practices and do the*

*mindfulness then, so um, very much um, you know, I've got it there, so you know, so as soon as I get that, maybe that feeling I, I go straight to that mindfulness, I mean I've got, I mean I'm fiddling with it now so you know it's, it's, aiding you know to take you straight back that's something so simple this piece of um um cord with um with a bead on it, ah what an impacts it's made, um preventions rather than you know getting myself worked up at all." (P4,F)*

*"sorry I didn't say this before but one thing I really liked was the bracelet that the lady gave us at the end with the bead on it, I thought, she said was like a prayer bead I don't know what it was called umm but I really liked that, that that's kind of having that and focusing on that was like being mindful without knowing you're being mindful does that makes sense? I've completed gone off track I'm so sorry." (P8,F)*

### 3. Group impact

Mindfulness being delivered in a group format was seen positively, with multiple benefits. This included positive attributes about the group such as sharing of health condition and experiences of asthma, sharing feedback and learning from each other, the group being a motivating factor for attendance, preferring to be taught face to face, and generally how group participation and experiences added value to their experience of learning mindfulness.

For example, one individual described preferring to learn face to face;

*"but that fact that I went somewhere you know I went there was taught it, it was better for me then I'm the visual learner so for me it's, better group participation, I probably wouldn't have bothered if it was done any other way" (P8, F)*

*"hmm I found the course really really good and it was also good being around people, umm who you know, had been struggling for years and hear their stories of how they are managing what with the mindfulness and that because they sort of, they had different tips and everything, how they found it and that, so no no it was good all round" (P4, F)*

Individuals talked about valuing group discussions, in which they had the opportunity to hear other group members' experiences of how they practised mindfulness. This also allowed them to hear multiple viewpoints, and share and exchange ideas.

*"Umm well you get the end, others peoples thoughts on how it went, I guess that's all, and sometimes they're very different to what your felt so yeah it's interesting to hear the other views...it's quite good, cuz as I say it gives you the exp...how other people experience it..." (P1, F)*

*"yeah, well if you're talking about what's going on then you will, the longer you can do it, the more likely it is you are to pass something on something that's more, that you know, is interesting to the other person" (P3, M)*

*"I think it's better in a group personally, I've done both obviously when I did me DBT I've done, one to one is very full on, um, very very intense, very full on, I found, um although I found it, you know, good, um, I certainly enjoyed it, is a, is a, you know, it in the group, and I found that I learnt a lot more by session feedback from peoples feedback about how they found it and everything" (P4, F)*

Some talked about the group itself being a motivating factor in their attendance and contributed to their desire to continue attending.

*"...to be honest I would have, I could have carried on with it, um because I find it easier to apply myself when it's in an organised groups it's harder to motivate yourself, even though it doesn't take that long when you are on your own" (P6, F)*

*OR*

*"yeah I, I find that with these sort of things I find that if, I've got something every week I go and do it, with other people, but I'm, that makes me do it, having that structure, I find it easier than imposing it, the structure on myself the discipline because the rest of life gets in the way and the ironic thing is, that the busier you are the more you actually need it anyway so it becomes a bit self-defeating, so for me, having that, structure of physically going somewhere for a certain times, sitting down with other people doing it, um I found better." P6, F*

However, a small minority, who may have been experiencing social anxiety, or other mental health difficulties reported finding the group context overwhelming, and reported how this would potentially make it difficult to attend.

*"Umm how do I feel? Hm I feel it wasn't exactly as accessible, ahh cuz a for myself, my sort of anxiety, panic attacks, and umm depression issues and so the overall was not xxxx group of people made it harder to, be involved and harder to do, yeah" (P5, M)*

*"If people have got anxiety or agoraphobia, it stops them from being able to leave the house, um you know in a normal, I say that with inverted things, yeah sort of you know if they just find it really difficult to leave the house sort of for whatever reason, regarding in terms of anxiety and stuff or even depression, not feeling the motivation to come or just getting out of bed um yeah just things like that I think can really affect someone ability to attend things like that." (P7, F)*

*"I am not very confident about meeting new people. I find it quite anxiety provoking. Um just, it's been a long standing thing, like it's been like that for a really long time so yeah that just personally to me, that what I find difficult " (P7, F)*

*"Yes, I guess that some people that are anxious may not like going to a group situation" (P8,F)*

One individual reported that they would be more likely to attend a group with 'likeminded people' or those with the same health condition;

*"but um I quite like the fact that it was a small group with like, with people with similar situations with asthma umm yeah, so I don't know if I would go to a group on my accord um but say I dunno, it's like if the asthma clinic did one I'd probably go to that, I really did quite like it "(P8, F)*

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