

# **Illness Perceptions and Panic-Fear in Coping with Difficult Asthma**

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## Declaration

I confirm that the literature review, research report and critical appraisal contained within this thesis are my own work and have not been submitted for any other academic award.

## Acknowledgements

Sincere thanks go to the staff at the Difficult Asthma Clinic, Glenfield Hospital for their facilitation of the research process. I express particular gratitude to Professor Andrew Wardlaw for his assistance with development of the proposal and access to the clinic, Anne Prickett and Gail Fretter for administrative assistance and Beverley Hargadon for her help with data collection. Thanks especially to Dr Noelle Robertson for her support and supervision, and to my husband Ben for his faith and encouragement.

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## Thesis Abstract

### Illness Perceptions and Panic-Fear in Coping with Difficult Asthma

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Difficult Asthma is a complex diagnosis relating to poor asthma control, but less related to severe clinical pathology. It is associated with medication non-adherence, poor psychosocial outcomes and high usage of health services. A number of psychological variables have been linked with the diagnosis.

The systematic review examined the qualitative literature concerning patients' experiences of self-managing asthma. A meta-ethnographic approach was used in order to add a layer of interpretive synthesis to the reciprocal translation of studies. A number of overarching themes were identified; *Establishing Normality* explored patients' striving to achieve a balance between asthma symptoms, medication and quality of life. *Beliefs about Medication* identified common distrust of conventional medicine and the strategies used to find alternative ways to cope. *Therapeutic Relationship* gave voice to the frustrations of patients at being expected to self-manage asthma in a context of poor communication, unidirectional consultations and lack of access to quality information. Lack of policy implementation concerning shared models of care are considered.

The empirical study extended the theme of patients managing asthma according to subjective beliefs. The self regulation model was used as a framework to understand the illness perceptions of adults attending a Difficult Asthma Clinic. The intention was to move discussion towards an understanding of illness perceptions as clusters or schemata of beliefs rather than individual dimensions. Four distinct clusters were established in this population based on their illness perceptions; these groups significantly varied on experiences of panic during asthma attacks and the strategies they used to cope with asthma, as well as clinical features such as age at diagnosis. Lung function did not differ between groups, suggesting there may be several potential routes to Difficult Asthma. The potential for tailored psychological interventions, care pathways and future research are discussed within a framework of mutual responsibility for disease management.

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## Whose Lungs Are These Anyway? Achieving Asthma Control Through Self-Management

Kathryn Bradley

### Abstract

*Objective:* This paper reviews findings from a qualitative meta-synthesis regarding the experience of self-managing asthma from the perspective of adult patients.

*Methods:* Systematic review methods for qualitative research were utilised to search, screen and critically appraise data extracted from peer reviewed published papers. The databases PsycINFO, Medline and SCOPUS were searched for papers relevant to the topic, yielding 13 papers suitable for inclusion in the review. The Critical Appraisal Skills Programme (CASP) tool was used to appraise the quality of papers and a meta-ethnographic approach (Noblit & Hare, 1988) underpinned both the synthesis of authors' conclusions about self-management experiences and an interpretative synthesis.

*Results:* The quality of papers was extremely variable; more robust papers were more explicit about their methods, reflexive about their role in the research and more aware of qualitative epistemology. A number of themes were elicited through reciprocal translational analysis and 'line of argument' synthesis using Grounded Theory. Patients strive to achieve balance in order to lead a 'normal life'. With life goals superseding asthma goals, patients may tolerate symptoms or delay seeking help if they prioritise other areas of their lives. Ultimately, patients want to be empowered to self-manage asthma. Access to information and trusting relationships with healthcare professionals are vital for self-management though findings suggest this is sub-optimal. Distrust of medication can present a barrier to achieving life goals with fears about side-effects, tolerance and addiction compromising adherence.

*Conclusions:* Despite extensive research evidence and recommendations to improve health-related quality of life and clinician communication, patient appraisals of asthma care suggest research findings are not routinely implemented in practice. Concordance is likely to be undermined if policies are not translated to practice. Further research is warranted to better understand clinician perspectives of managing chronic illness in meaningful collaboration with patients.

**Key Words:** Asthma, Coping, Communication, Meta-ethnography, Metasynthesis, Qualitative Methods, Quality of Life, Self-management

## Introduction

Asthma is defined by the British Thoracic Society as the presence of wheeze, breathlessness, chest tightness or cough and variable airflow obstruction, particularly in response to environmental triggers (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012). Reversibility of symptoms with pharmacological treatment distinguishes asthma from other respiratory diseases. The WHO estimate approximately 300 million people suffer with asthma worldwide (World Health Organisation, 2008); in the UK, 13% of individuals will have asthma at some point in their lives with around 100,000 hospital admissions per year (Association of Public Health Observatories, 2005). Five million people in the UK currently have a diagnosis of asthma (British Lung Foundation, 2007) and approximately 1500 deaths per year are attributable to the disease (Asthma UK, 2004). Costs to the NHS for asthma are approximately £850 million per year and the wider economy loses 18 million working days annually (Yorke, Fleming, & Shuldham, 2006).

Asthma is a chronic condition with significant adverse impact on quality of life, limitation of activities and restriction of life opportunities (Juniper et al., 1992). Examination of health-related quality of life has been subject to extensive study in asthma (Apfelbacher, Hankins, Stenner, Frew, & Smith, 2011) and significant psychological morbidity predicts asthma outcomes including exacerbations and hospitalization (Wang et al., 2011). The presence of depressive morbidity is estimated globally as 1.6 times more likely in asthmatics than non-asthmatics, with anxiety 1.5 times more likely to be present and alcohol dependence 1.7 times more likely (Scott et al., 2007). Living with asthma is thus particularly amenable to exploration using paradigms developed in clinical and health psychology.

First line therapy for asthma is pharmacological. Physicians use a stepwise approach depending on severity of disease and response of symptoms to management. Inhaled short-acting  $\beta_2$  agonists are initially prescribed with gradual addition of other drugs including inhaled steroids, long-acting  $\beta_2$  agonists and oral steroids (British Thoracic Society, 2008). A range of self-management strategies are advocated in addition to pharmacotherapy. Identifying and avoiding symptom triggers (e.g. dust, pollen), monitoring and recording 'peak expiratory flow' (maximum air flow during forced expiration) and giving up smoking are all associated with better outcomes and advocated by clinicians (British Thoracic Society, & Scottish Intercollegiate Guidelines Network, 2012). Guidelines recommend patients have a written 'Asthma Action Plan' outlining medication, how to identify an exacerbation or asthma attack and what to do in an emergency (Asthma UK, 2004; British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012).

This is predicated on a collaborative management model enabling patients to take control of their condition and suffused with discourse on responsibility and maintaining control. Action plans appear to enhance disease outcomes (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012), though some studies have found a 'knowledge-behaviour gap' that highlights management plans are not always implemented during attacks (Kolbe, Vamos, Fergusson, Elkind, & Garrett, 1996; Ring et al., 2007) if their existence is remembered at all (Sulaiman et al., 2011). Meta-analyses have revealed insufficient evidence to determine the efficacy of action plans (Lefevre et al., 2002) and a qualitative meta-synthesis concluded discrepancies between clinicians' and patients'

explanatory models and beliefs about management decreased the likelihood plans would be used (Ring et al., 2011).

Despite substantial biomedical research increasing understanding of the pathogenesis of asthma and effective pharmaceutical and lifestyle interventions proven to treat asthma in clinical trials, asthma still remains poorly controlled for many individuals. This is largely attributed to poor adherence to medication (Bender, 2002), estimated between 50% (Bosley, Fosbury, & Cochrane, 1995) and 73% of those prescribed preventative and active asthma treatments (Horne & Weinman, 2002). Whilst variously defined, an acceptable definition of adherence is “the extent to which patients follow the instructions they are given for prescribed treatments” (Bissonnette, 2008). Non-adherence involves multiple treatment, clinician and patient-related barriers (predominantly communication, knowledge and psycho-socially based) so clinicians have a vital role in creating an environment which maximises the likelihood of adherence (Bender, 2002). Extensive survey data in primary care shows that despite guidelines highlighting the importance of communication and collaborative doctor-patient relationships, these factors are often ignored in asthma care, with 27.5% of GP’s failing to encourage patients to express doubts and fears, 36.9% unlikely to involve patients in management, and 73% trying to retain control over patients (Braido et al., 2011).

Given the limitations of solely biomedical interventions, and equivocal efficacy of broad psychosocial interventions (Devine, 1996; Fleming, Pagliari, Churchill, Shuldham, & McKean, 2004; Yorke et al., 2006), more detailed scrutiny of intrapersonal variables might enhance how non-adherence is understood. Adherence interventions are often based on the assumption of a deficiency at patient level; such as a need for education or the treatment of psychological morbidity (Haynes, Ackloo, Sahota, McDonald, & Yao, 2008). The modest

results of interventions adopting the ‘patient deficiency’ principle of poor management and the continued existence of poorly controlled asthma despite medical advances highlight the need for a detailed qualitative examination of self-management, to understand more fully patients’ understanding of themselves in relation to asthma and motivations for managing asthma. A summary of published qualitative literature to date can contextualise findings, provide clinicians with a ‘state of evidence’ regarding asthma self-management from the patient perspective and help develop collaborative, patient-centred care. Additionally, it provides a layer of interpretation not evident when considering each study in isolation.

#### Aims

This synthesis aims to integrate qualitative studies which seek to understand the patient experience of self-managing asthma. The aim is to use a meta-ethnographic approach which will summarise narratives on the topic and integrate understanding in a thematic analysis or *line of argument* synthesis.

#### Method

Synthesis of research evidence in healthcare is key to improving outcomes for patients and determining what works for whom (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). The National Institute for Clinical Effectiveness (NICE) and the Cochrane Collaboration emphasise the importance of synthesising evidence, and have made significant progress in reducing morbidity and mortality in health services accordingly. Qualitative research methods have gained credibility in healthcare as an alternative to the paring down of experience to numerical units, which inevitably loses and de-contextualises enriched meanings (Pope & Mays, 2006). Social scientists in medicine use qualitative methods to understand rather than explain, and to hear the voice of the patient. This is not ‘truth’ in the positivist sense of the word, but an acknowledgement that people hold

different 'truths' about health, which are predominantly socially constructed (Pope & Mays, 2006).

Ongoing discussion debates whether qualitative research can be synthesized in the same way as quantitative research (Hannes, 2011). Sensitivity to context in qualitative methods largely prohibits the generalisation of findings from one context to another (though this is not the aim of the approach). However the Cochrane Collaboration recognise the utility of gathering information on a topic to gain broader understanding and have published guidelines for meta-synthesis of qualitative research (Hannes, 2011).

Different approaches to qualitative synthesis have been advanced to develop pooled knowledge, whilst remaining true to epistemological roots (O'Connor, 2009; Barnett-Page & Thomas, 2009). The meta-ethnographic approach synthesises understanding from interpretive studies and involves the translation of studies into one another (Noblit & Hare, 1988). It has been proposed as an alternative to meta-analysis; it is useful for integrating studies in addition to merely comparing them, and can be used for studies which are methodologically diverse (Barnett-Page & Thomas, 2009). Meta-ethnography has usefully been used and comprehensively described in the fields of diabetes (Campbell et al., 2003), depression (Malpass et al., 2009) and medication use (Pound et al., 2005) to understand patient perspectives in healthcare; studies which share the aim of the current review. An This review therefore adopted meta-ethnography to synthesise the experiences of adult patients who self-manage asthma.

After formulating the research question, the databases PsycINFO, Medline and Web of Science were searched for papers to include in the review during August 2011, updated March 2012. Search terms were broad to enable a wide range of papers to be found before filtering relevant titles (see Appendix A) eliciting 120 titles after duplicates were removed.

Two initial questions were devised following the methods of Campbell et al. (2003) for quick screening of titles in database search results; ‘does this paper report on findings from original qualitative research?’ (i.e. excluding literature reviews, editorials and quantitative studies) and ‘is this paper relevant to the synthesis topic?’. Although this synthesis used meta-ethnographic methodology, all qualitative methodologies were included for review rather than solely ethnographic approaches, allowing a more inclusive range of papers (Yardley, 2000). ‘Relevance’ was judged to be 1) about asthma and 2) an adult population. Using this screening method, 89 titles were extracted for review. Abstracts were reviewed for all 89 papers using the same criteria, identifying 57 relevant papers.

The dominant question to guide inclusion was; ‘does this paper focus on the subjective experience of adult patients managing asthma?’. Articles focusing on evaluations of intervention programmes, views of healthcare professionals and studies exploring chronic illness in general (rather than asthma specifically) were excluded, leaving 19 papers for full text review (see Appendix B). These papers were screened for fidelity to qualitative methodology using Lincoln and Guba’s criteria (Lincoln & Guba (1985) see Appendix C) and classified as Key Paper, Satisfactory, Unsure, Fatally Flawed or Irrelevant (Dixon-Woods et al., 2007). Six further papers were excluded on quality grounds as ‘Fatally Flawed’ and deemed insufficiently trustworthy due to poor methodological quality; it was concluded that inclusion would introduce bias (see Appendix C). A total of 13 papers remained for inclusion in the final meta-synthesis (see Table 1).

### *Quality Appraisal*

Quality appraisal of qualitative research is argued to involve a theoretical approach rather than a focus on technical accuracy (Hannes, 2011). Quality and rigour in qualitative

research is problematic; Yardley (2000) notes qualitative methods are deliberately pluralistic, and there is a reluctance to derive core characteristics of methods to preserve richness and diversity. This presents challenges when attempting to evaluate quality in meta-synthesis. Lincoln and Guba (1985) posit four constructs related to qualitative approaches which are roughly equivalent to the aims of realist research, but are more in line with qualitative epistemology (*credibility, transferability, dependability and confirmability*). These four constructs aim to evaluate the ‘trustworthiness’ of a study, rather than determine its ‘truth’ value (See Appendix C).

Debate exists as to whether standardized appraisal tools are appropriate for qualitative research as they impose a homogeneous framework on a pluralistic process. Dixon-Woods (2007) compared methods for appraising qualitative studies, and found little difference between formal appraisal tools and researcher judgement in which papers were selected for review, but using formal tools made researchers more likely to justify their reasons. Therefore the present review utilised an appraisal tool.

The Critical Appraisal Skills Programme (CASP) tool is recommended by the Cochrane Collaboration for use by researchers who are relatively new to qualitative methods of research (Hannes, 2011); this review follows the recommendation that expertise of the research team is considered when selecting an appraisal tool. A study comparing three appraisal tools also found the CASP to be the most user-friendly (Malpass et al, 2009). A data extraction form was designed based on the 10 questions in the CASP tool (Appendix D).

### *Research Design*

The quality of papers was variable with some authors appearing more familiar with the aims and ethos of qualitative approaches, and adhering more rigorously to technical

aspects. All papers clearly stated the aims of their research, with sufficient background knowledge to argue for its importance and relevance. In most cases qualitative methodology was appropriate as authors sought to understand the subjective experience of participants, with the possible exception of Donald, McBurney and Browning (2005) and Poureslami, Rootman, Doyle-Waters, Nimmon and FitzGerald (2011). In few cases was there an attempt to elicit generalisable knowledge, though in these cases a useful narrative of acceptable quality was produced (for example; George, Campbell, & Rand, 2009; Poureslami et al., 2011; Steven, Morrison, & Drummond, 2002). Few papers justified their research design, with many authors failing to articulate which qualitative methodology they utilised or from which theoretical stance they approached their research. It is accepted that qualitative methods are pluralistic with boundaries between different approaches less clearly defined compared to quantitative research; however this argument was not advanced by any authors.

### *Sampling*

All authors described sampling methods adequately, although some papers expressed the rationale more explicitly (such as Jones et al., 2008; Loignon, Bedos, Sevigny, & Leduc, 2009; Steven et al., 2004) Purposive sampling was used in these cases; a method which maximises diversity by choosing participants based on characteristics such as age, gender, ethnicity and social class.

### *Data Collection*

All papers made clear their methods of data collection (for example, semi-structured interviews or focus groups) although few offered a rationale for their choice. Better quality studies included descriptions of topic guide development, or provided a copy in appendices. All studies reported the use of tape recording equipment and transcription to record data,

with a small number of studies using supplemental field notes. Few studies discussed data saturation, and very few studies discussed reflexivity explicitly. The minority of researchers critically examined their own role at any stage of the research from the formulation of questions to the interpretation of data (such as Jones et al. (2008)).

### *Ethics*

The majority of studies stated they had obtained approval from appropriate ethics committees (with the exception of Moffat, Cleland, van der Molen, & Price (2006); Poursalami et al. (2011); Steven et al. (2002); and van Mens-Verhulst, Radtke, & Spence (2004)), though few discussed consent processes. No researchers discussed potential impact of participation on patients.

### *Data Analysis*

Description of the process of data analysis was varied. Some papers did not name their theoretical approach to analysis; though this alone was not sufficient to meet quality criteria (indeed, some who did not name their methodology provided better descriptions of their analysis process; Loignon et al. (2009) being a notable example). All papers used participant quotes to support their findings, but to varying extent. Few papers explicitly used refutational or divergent case analysis, with some papers actively discounting alternative viewpoints (ignoring the perspectives of two men in a predominantly female sample – van Mens-Verhulst, Radtke, & Spence, 2004).

### *Findings*

Most papers included an explicit, concise statement of findings in relation to the original research question, with a discussion of clinical implications. Some researchers considered alternative viewpoints and evidence for and against their conclusions, but most were defensive of their own interpretations. Some researchers provided descriptive rather

than interpretive accounts of their findings, with little attempt to synthesise themes into a coherent narrative, or deeper analysis of themes.

Table 1: Papers selected for inclusion in the review					
Paper	Country/ Setting	Sample N (gender and age)	Ethnicity	Method of Data Collection	Research Question
Baptist et al. (2010)	USA	N=46, 85% female Mean 72.6 +/- 6.9 yrs	20 African American, 23 White, 3 Other	6 focus groups of 6-10 people	To examine age-specific factors influencing asthma management by older adults
Caress et al. (2002)	North West England	N=32, 17 Male, 15 Female, 18-84 (47)yrs	Not stated	Focused one to one interviews	To understand information needs of adult asthma patients
Donald et al. (2005)	Australia	N=5, 2 Male 3 Female, 20-42 yrs	Not stated	Focus group	To explore self-management beliefs of adults requiring an admission to hospital
Doyle et al. (2010)	London, England	N=19, 5 Male, 14 Female Mean 39.5 +/-17.4 years	15 White, 1 Asian, 3 Mixed	Semi-structured one to one interviews	To explore the circumstances and impact of patients having their inhaler switched without consent
George et al. (2009)	East Coast, USA	N=25, 92% Female, 21-52 yrs	76% African American, 24% Caucasian	Semi-structured individual interview	To identify the extent to which urban low-income minority adults have received training in, and implement self- management protocols for acute asthma
Jones et al. (2008)	London, England	N=75, 28 Male, 47 Female, 16-65+ yrs	31 White British, 22 African Caribbean, 8 Asian, 4 Other	Individual interviews	To investigate the relationship between perception of life events, psychosocial factors, coping and asthma admission in patients admitted with an asthma exacerbation and those in general practice
Loignon et al. (2008)	French- speaking	N=24, 10 Male, 14 Female, 27-76(40.2)yrs	Not stated	In-depth, semi- structured	To understand how adults living with asthma deal with illness, perceive self-

	Canada			interviews	management and develop self-care strategies
Moffat et al. (2006)	Grampian, Scotland	N=14, 6 Male, 8 Female, 20-69 yrs	Not stated	Semi-structured interviews	To explore patients' experiences of asthma and primary care asthma consultations in order to identify target areas for intervention
Poureslami et al. (2011)	Vancouver, Canada	N=29, 13 Male, 16 Female, 19-70 yrs	6 Iranian, 6 Chinese, 9 Punjabi, 8 Latino	Focus group	To investigate how asthma patients from new immigrant groups are being informed and educated about asthma and its management, and to identify barriers to knowledge transfer
Ross et al. (2010)	Canada	N=8, 2 Male, 6 Female, 23-53 yrs	Not stated	Semi-structured in-depth interviews	To explore perceptions of self-management amongst people followed up in a severe asthma clinic
Steven et al. (2002)	Glasgow, Scotland	N=23, 12 Male, 11 Female, 20-47 yrs	Not stated	In-depth interviews	To identify factors which motivate patient self-management in asthma & compare to BTS guidelines
Steven et al. (2004)	Dundee, Scotland	N=47, 24 Male, 23 Female, 16-44 yrs	Not stated	Individual interviews	To describe patient goals for life and asthma management to inform asthma concordance
Van Mens Verhulst et al. (2004)	The Netherlands & Canada	N=8, 0 Male, 8 Female, 31-65 (46.8)yrs	Not stated (Nationality 4 Dutch, 4 Canadian)	Individual interviews	To explore how mothers with asthma manage their illness

### *Reciprocal Translational Analysis*

Noblit & Hare's methods of synthesising qualitative studies describe several stages to the synthesis of material (Noblit & Hare, 1988; see Table 2). After selection and quality appraisal, studies are analysed to determine how they relate to each other, how they differ and to determine lines of argument. This stage of the process is *reciprocal translational analysis*, whereby one paper is compared to another to assess common premises, divergent themes and extensions of concepts. Papers are then successively added to the synthesis to compare, explore differences and examine additional context until all papers under review are included. Different results may be obtained depending on which papers are reviewed first and the order of subsequent studies.

Table 2: Definitions of Terms in Meta-Ethnography (Atkins et al., 2008)

<b>Term</b>	<b>Definition</b>
1 <sup>st</sup> Order Construct	Constructs that reflect participants' understandings, as reported in the included studies (usually found in the results section of an article)
2 <sup>nd</sup> Order Construct	Interpretations of participants' understandings made by authors of these studies (and usually found in the discussion and conclusion section of an article)
3 <sup>rd</sup> Order Construct	The synthesis of both first and second order constructs into a new model or theory about a phenomenon
Reciprocal translation	The comparison of themes across papers and an attempt to "match" themes from one paper with themes from another, ensuring that a key theme captures similar themes from different papers
Line of argument synthesis	The development of a new model, theory or understanding by synthesising and interpreting first and second order themes found in the text

The present review ordered studies according to research quality (based on the quality appraisal exercise); the paper judged most rigorous was presented first. Starting with these papers gave more weight to their evidence (Gough, 2007) as it was more

trustworthy and confirmable (Lincoln & Guba, 1985). It is acknowledged the order of studies can not be definitive, although attempts to minimise bias included a second review by another qualitative researcher.

*Balance to achieve a normal life*

*Paper 1: (Steven et al., 2004)*

Steven and colleagues interviewed 47 patients in General Practices in Dundee, UK to understand patient goals for asthma management. They concluded patients improve their condition by balancing several strategies:

a) Living with asthma medication; where medication may improve asthma to aid the pursuit of a normal life, or where medication side-effects may make a normal life difficult

b) Living with environmental triggers; where trigger avoidance may improve quality of life through improved symptoms. At times triggers may be valued activities, so exacerbations are tolerated in favour of these activities, preserving quality of life

c) Living with exercise, where exercise may improve asthma and therefore quality of life, or where exercise prompts the use of reliever medication which interferes with normal life

d) Living with asthma to maximise a normal life; whereby medication, triggers and exercise are balanced to enable patients to live lives consistent with goals and values. Patients with milder disease seemed to make fewer compromises in this regard, whereas those with severe asthma found it was not always possible to pursue a normal life, despite their compromises. Patients utilised these strategies only to live enriched, fuller lives, rather than to control asthma as an end in itself.

*Paper 2: (Loignon et al., 2009)*

Loignon and colleagues interviewed 24 Emergency Department attendees and community patients with asthma to understand how adults deal with illness, perceive self-management and develop self-care strategies. They elicited three methods of self-management amongst participants:

a) Controlling symptoms; medication was perceived the best method to achieve this, despite cost and memory sometimes acting as barriers to successful use. Individuals adopting this strategy tended to be well engaged with the health system.

b) Preventing symptoms; those adopting this as a dominant strategy had little faith in drugs and felt reliance on them indicated illness. They tended to avoid the healthcare system, preferring to adapt lifestyle or consult with complementary and alternative therapy practitioners. Reliever medication was used as a last resort when preventative strategies were unsuccessful.

c) Tolerating symptoms; for those using this as a dominant strategy asthma was an unavoidable reality. Distrust of medications, cost barriers, and poor relationships with healthcare professionals meant they tended to tolerate symptoms or to control them using relaxation and avoiding exertion.

Similar to the patients interviewed by Steven et al. (2004), participants balanced medication with lifestyle choices and symptoms depending on priorities. At times symptoms were preferable to using medications perceived as harmful, or interactions with an untrustworthy healthcare system. Similarly to Steven et al. (2004), this choice was sometimes beyond patients' control; in this case due to financial barriers rather than disease severity.

*Paper 3: (Jones et al., 2008)*

For participants in this study, the relationship between asthma control and ‘*a normal life*’ was explored from a different perspective. As in Steven et al. (2004) and Loignon et al. (2009) control was synonymous with a normal life, yet “chaotic lives, social disorder and perceptions of stress” were prevalent. However, interviewees often did not link stress with exacerbations. Some delayed help-seeking because of previous negative experiences with primary care health professionals, apparently engaging in a trade off between these two aversive experiences.

*Paper 4: (Moffat et al., 2006)*

Moffat and colleagues interviewed 14 patients with severe and difficult asthma from GP practices in the Grampian region of North East Scotland. Patients identified controlling asthma through medication, activity levels and trigger avoidance (including psychosocial triggers). Judgements of control were made based on social comparisons (“am I normal?”). Similar to previous studies, there was a group of patients with an “acceptance of sub-optimal control”; attributed to poor relationships and communication with health professionals. Lifestyle and stress were involved in the ‘balance’ of asthma control in this study, although reluctance to discuss these issues in health consultations was articulated .

*Paper 5: (Caress, Luker, Woodcock, & Beaver, 2002)*

Caress and colleagues interviewed 32 patients with asthma from North West England to gauge preferences for asthma-related information. Patients related increased information to an increased ability to self-manage. Similar to the previous studies, patients engaged in a balancing act between medication, triggers and lifestyle factors, weighing up pros and cons in each case. Trigger avoidance was linked with reduced medication use, which could be preferable for individuals who felt side-effects interfered with self-

management. Those with severe disease felt their lifestyles suffered the greatest impact from asthma, whilst those with milder asthma felt able to live a normal life.

*Paper 6: (Ross, Williams, Low, & Vethanayagam, 2010)*

Ross and colleagues interviewed eight adult outpatients with severe asthma regarding perceptions of self-management. Amongst this population, control appeared synonymous with the use of medication; with trigger avoidance and exercise balanced to a lesser extent. Patients described the need to 'balance the good with the bad'. Asthma control to them meant engaging in valued activities. As observed in other studies, they did not spontaneously report gauging 'control' through clinical observation methods such as Peak Flow monitoring, preferring subjective quality of life judgements. Establishing balance was described as a process of trial and error.

*Paper 7: (Doyle et al., 2010)*

This paper was considered carefully for inclusion in the review, as its subject, patients' feelings about non-consented switches in medication, appeared to deviate significantly from the topic under consideration. However, it is considered good practice with qualitative methods to look for differences as well as similarities, with divergent or discrepant case analyses encouraged. Therefore the paper was considered to add breadth to the understanding of patient perceptions of self-management, i.e.; what happens when management decisions are made without the patient?

The authors of this paper did not elicit themes concerning balance or achieving normality, but shared many common themes with other papers in this review, to be discussed later in the analysis.

*Paper 8: (Baptist, Deol, Reddy, Nelson, & Clark, 2010)*

Baptist and colleagues interviewed older adults about asthma management. Balancing appeared valued due to high prevalence of co-morbidities and polypharmacy, with associated side-effects to avoid or tolerate. Patients sometimes tried medications prescribed for other conditions to control asthma if inhalers were insufficient. The ageing process complicated perception of symptoms; particularly fatigue and lethargy. Appraisals of 'normality' shifted with the ageing process as individuals accepted activity limitation; one participant described how little time they had for anything except eating and taking medication.

*Paper 9: (Steven et al., 2002)*

In this earlier paper by Steven and colleagues, the authors elicited the theme "the value of life experience affected"; patients were only motivated to manage asthma if it interfered with life experiences and values.

*Paper 10: (Poureslami et al., 2011)*

Poureslami and colleagues held focus groups with Iranian, Latino, Punjabi and Chinese immigrants to British Columbia in Canada, to discuss barriers to healthcare access. These patients also discussed wanting to self-manage to improve quality of life. Participants expressed concerns about the ability of medication to achieve this, and shared concerns of those in previous studies about medication; side-effects, perceived addictive nature and possible diminishing effectiveness.

*Paper 11: (Donald et al., 2005)*

Donald and colleagues interviewed patients regarding self-management decisions prior to hospitalisation. Participants reported making decisions to attend hospital based on subjective evaluations of symptoms and severity, rather than asthma action plans or peak flow. The concept of 'leading a normal life' was not explicit in themes elicited, however

some discussed adjusting lifestyles and medication use to control asthma. It is difficult to draw conclusions about this study due to value judgements inherent in some authors' statements (for example "unwilling" to manage asthma, or "suffering no delusions" about asthma being related to lifestyle).

*Paper 12: (George et al., 2009)*

This study focussed on complimentary and alternative therapy (CAM) use amongst African-American asthma patients. Participants talked of 'juggling' conventional medicine with traditional remedies to achieve symptom control. Concerns about side-effects often affected decisions to use CAM, believing it to be safe and natural. However, several participants acknowledged CAM's limitations, after which conventional Western medicine would be needed .

*Paper 13: (van Mens-Verhulst et al., 2004)*

This paper discussed the experiences of mothers managing asthma in the context of family life. These mothers made compromises; sometimes sacrificing asthma control for a normal family life, and sometimes asking the family to compromise so asthma could be controlled. The women emphasised need for substantial flexibility to maintain equilibrium. Mothers at the lower end of the socio-economic spectrum found choice over trigger avoidance constrained, perhaps needing to work long hours or in asthmagenic conditions to support their family financially.

*Interactions with Health Professionals*

Relationships and communication with health professionals was a prominent theme amongst these studies. Loignon et al. (2009) reported poor relationships with healthcare professionals amongst patients who tended to use the strategy 'tolerating symptoms'. Participants who focussed on 'preventing symptoms' tended to avoid healthcare

professionals, preferring to interact with CAM practitioners, perceiving them as more open and supportive. Jones et al. (2008) found mixed views of healthcare professionals depending on setting; staff working in hospitals tended to be valorised, with more negative views held about primary care practitioners. Participants delayed help seeking to avoid negative interactions with primary care staff. Moffat et al. (2006) also considered patient-professional relationships, concluding they were poor with clinicians tending towards authoritarian approaches not appreciated by patients. Participants felt they would be judged for 'non-compliant' behaviour and desired information to enable self-management, but poor communication from practitioners created a barrier to accessing this information. Similar to Jones et al. (2008), these patients had an "acceptance of sub-optimal control" partly due to poor interactions with the healthcare system. The authors concluded those with more severe asthma felt that help from trusted professionals was of fundamental importance.

Ross et al. (2010) also found that patients expressed difficulties obtaining appropriate information which would help them self-manage; they described dissatisfaction with written information from healthcare professionals rather than verbal. Some found written information was insufficient, preferring face-to-face discussions to learn about managing asthma. Others found written information was not sufficiently tailored to their situation, subsequently internalising the fault and feeling there was something wrong with them for not 'fitting in'.

Doyle et al. (2010) added depth to the theme of relationships with professionals, by exploring what can happen when a decision is made without patient involvement. Those who had their inhaler switched without consent experienced anger, upset and shock. Regardless of the quality of the relationship before the switch, patients perceived a decline

following this management decision being made without them. The “surreptitious nature of the switch” was identified as responsible for relationship deterioration. Patients wanted to be involved in decision making and empowered to self-manage asthma.

The focus groups in the study by Poureslami et al. (2011) identified a number of difficulties with communication (indeed, the topic under study was language barriers to healthcare). Patients identified communication difficulties beyond the language barrier, and perceived clinicians to be too busy, not open in communication style and closed to questions. Interestingly the authors attribute most communication difficulties to the language barrier, yet communication issues are clearly identified in other studies where participants and clinicians were colingual.

Donald et al. (2005) seem to refute the narratives voicing dissatisfaction with relationships with health professionals. Similar to Jones et al. (2008), they acknowledge patients prefer to be treated in hospital and appear very satisfied with care there. Patients highlighted the importance of trust in their GP for asthma management and talk of ‘doctor shopping’ when dissatisfied. However, the lack of reflexivity and authoritarian tone of some of the authors’ statements in this paper make it difficult to consider this a truly refutational paper. George et al. (2009) take a particularly critical approach to the theme, describing a wariness of the healthcare system amongst participants who at times felt they were experimented on with toxic drugs. Some patients felt they were in receipt of “cookie cutter care”, with little tailoring to individual needs.

#### *Stress, Lifestyle and Appropriate Topics for the Consultation*

Many studies concluded that stress was a precipitant of symptoms or complicated the process of self-management, yet many patients declined to discuss this with health professionals. Loignon et al. (2009) concluded patients who used the strategy of tolerating

symptoms used relaxation to achieve this, and those who prevented symptoms used lifestyle changes to avert symptom onset. In Jones et al. (2008), the theme ‘chaotic lives, social disorder and perceptions of stress’ concluded that stress was prevalent amongst participants, but often inexplicitly linked to exacerbations or causal models. Poor socio-economic status and lifestyle factors inhibited patients’ capacity for self-management. Moffat et al. (2006) echoed the concept of psychosocial factors having an ‘absent presence’ in Jones et al. (2008), as several individuals described psychosocial triggers but were unlikely to discuss them with health professionals.

Patients felt non-medical factors were relevant to management but not suitable topics for medical consultations. Ross et al. (2010) similarly found that taking medication was prioritised by professionals over exercise and trigger avoidance in narratives about management and control. Participants in the study by Baptist et al. (2010) often used CAM as a supplementary way to manage asthma, but did not discuss this with doctors. Donald et al. (2005) highlight the importance of lifestyle changes, and classify participants as those “unwilling” to change and those who change management strategies as a response to severe asthma attack (however, the authors conclusions do not reflect on the motivations of these two groups). The theme “non-medical prevention” in van Mens-Verhulst et al (2004) highlights the importance some patients place on going beyond medical strategies for managing asthma; whether this is supported by health professionals is not discussed. The focus of Doyle et al.(2010) on medication in their research question precludes it from inclusion in this theme, as it is biased towards discussions of medication.

### *Interpretive Synthesis*

The next stage in the synthesis was to progress beyond a narrative summary of relationships between papers to offer an interpretive analysis of themes, or *Line of*

*Argument* synthesis using Grounded Theory (Noblit & Hare, 1988). Titles for the themes generated are named using participant quotes from the reviewed papers. The presence or absence of the themes in each paper can be seen in Appendix E.

### *Establishing Normality*

#### *“As long as it doesn’t interfere in my life”: Living a Normal Life*

Patients aimed to integrate asthma within their lives to achieve a sense of ‘normality’. They accomplished this in a number of ways; through taking medication, trigger recognition and avoidance, or at times denial of symptoms. For some, previous conceptions of ‘normal life’ were not achievable requiring a redefinition of ‘normality’.

#### *“I don’t think I am such a rare case” : Social Comparisons*

One way patients judged whether they had achieved normality was via social comparison. This took two forms; comparison to others with asthma where patients were concerned with ensuring their symptoms were no more severe than others, and comparison to those without asthma where the main concern appeared to be comparative activity levels.

#### *“I walk that line every day”: Achieving Balance*

Achieving normality with asthma was a perpetual balancing act, with some issues helping patients achieve balance and others upsetting balance. Achieving balance involved trade offs between different management strategies and life goals.

#### *“I often wait, I wait until the last minute”: Delaying Help Seeking*

Many patients put off using medication, delayed contact with services and postponed management plans for as long as possible.

#### *“Mommy needs help”: Family Support vs. Responsibility*

Some patients felt tension between support they relied on from families versus perceived responsibilities as parents, spouses or carers. Some older participants had dual identities as patients and carers for spouses, complicating the ‘balancing act’.

*“It’s a great tablet but it’s dear”*: Financial Implications

For a subset of patients, monetary cost played a role in asthma care. Cost was mostly significant in countries with paid and insurance-led healthcare. However, finances were also affected in countries with universal free healthcare through activity limitation, which affected employment opportunities. Lack of choice over work opportunities for financial reasons compromised trigger avoidance for some (for example, working in dusty or chemical environments).

*Medication Beliefs*

*“If I can go without the Ventolin then I don’t need this Ventolin anymore, I’m not asthmatic”*: Medication Signifying Illness

For some, medication signified illness and heightened their sense of being ‘unwell’ and not coping. They sometimes avoided interactions with health professionals for the same reason; engaging with the system was synonymous with not coping.

*“I just feel like the natural is really less risky”*: CAM as Safe and Natural

Some people preferred to use CAM, believing it to be safer and more natural. However among these people, some acknowledged complementary therapies had limited use when symptoms became very severe.

*“All drugs prescribed are toxic”*: Distrust of Conventional Medicine

Many expressed distrust for conventional medicines and held negative beliefs about medication. Some felt with sustained use they would become immune to the benefits of

medication; others felt medicines were harmful, and some even felt medicines were used to experiment on patients or exploit them financially. Recurrent concerns were raised about side-effects by participants throughout the studies reviewed.

### *Therapeutic Relationship*

*“He is just wanting you out of there, he just wants on to the next one”:*

### *Relationships with Health Professionals*

People expressed ambivalent beliefs about healthcare professionals and sometimes felt judged by them. Several studies discussed participants’ feelings that clinicians did not treat them as individuals. There seemed to be dissatisfaction with General Practitioners and a valorisation of hospital staff; however some felt supported by health professionals and had trusting relationships with them.

*“They give you a row, give you your inhaler and send you on your way”:*

### *Communication Issues and Didacticism of Healthcare Interactions*

The reported quality of communication with health professionals was variable; some reported very positive interactions, whilst others were less than satisfied. Participants highlighted what they considered suitable and unsuitable topics for discussion during consultation; psychosocial issues were often not discussed unless clinicians raised them.

*“Not just to be told it, but I need to know why”:* *Information Needs*

Participants in almost all studies discussed their need for information, seen as key to effective self-management. Rather than be passive recipients of instruction, patients wanted to actively understand and discuss their condition in order to manage it.

*“It’s a case of finding out every day”:* *Trial and Error*

People engaged in a process of trial and error in order to find balance and normality in their lives. This was sometimes true when there was a failure in the therapeutic relationship. At times, patients felt they were in receipt of ‘trial and error’ approaches from clinicians.

### Discussion

This systematic review synthesised findings from several qualitative papers on the subjective experience of managing asthma, using a meta-ethnographic approach. In covering a range of ages, disease severities and settings it gave the synthesis a broader scope when identifying themes pertinent to self-management. Themes elicited in the Line of Argument synthesis were present in many of the studies, although no paper incorporated all the themes, corroborating the meta-ethnographic approach and the value of synthesising qualitative research. One limitation of the synthesis is that none of the studies reviewed took a longitudinal approach to understanding self-management, which could not be extrapolated through diversity of patient samples. What is missing from this review is an understanding of whether coping strategies or attempts at achieving balance or ‘normal lives’ were successful, or how this develops across the lifespan of asthma. Future studies could address this longitudinal element to determine efficacy of self-management strategies.

It was found that patients strive to lead ‘a normal life’ which takes precedence over asthma management. To achieve a normal life, patients emphasise a need to balance the use of medication, selective trigger avoidance and lifestyle alterations to manage symptoms. With life goals superseding asthma goals, patients may tolerate symptoms or delay seeking help if and when they prioritise other areas of their lives. Delay in help seeking has been observed in a number of illnesses, including breast cancer (Facione, 1993), myocardial

infarction (Caldwell & Miaskowski, 2002), infertility (White, McQuillan, & Greil, 2006) and coronary heart disease (Harralson, 2007) with lifestyle demands, guilt and misattribution of symptoms being common reasons for delay and evident in narratives studied in this synthesis.

Financial constraints or asthma severity may make compromises unfeasible for patients. The concept of 'quality of life' in chronic illness has been extensively researched (Strauss, 1975) using both qualitative and quantitative approaches (Anderson, Aaronson, Bullinger, & McBee, 1996) and its measurement is now recommended in holistic approaches to healthcare internationally (Aaronson et al., 1992). However, this synthesis reveals that despite the widespread measurement of this principle, quality of life is still lacking discussion in asthma consultations. What is not clear is whether responsibility for this lies with clinicians or patients (or a more subtle combination of both). This synthesis elucidates that for patients, disease control is a means to achieve improved quality of life. Disease control may be a priority at the population level (Peters, Ferguson, Deniz, & Reisner, 2006) but this is perhaps of less relevance to the individual patient if it does not improve quality of life. For clinicians working with asthma there is a difficult balance to be achieved between individual and population needs (Peters et al., 2006).

The synthesis also revealed patients' experiences with health professionals can lead them to feel negatively judged and that they are burdensome, especially where quality of communication is poor. In keeping with healthcare professionals' aspirations for them, ultimately patients want to be empowered to self-manage asthma, seeing access to information as vital for self-management. Quality of communication affects these information needs; if communication is poor and information needs are not met, patients engage in a process of trial and error to re-establish balance in the pursuit of a normal life.

Trial and error may not always result from unmet information needs; it may signify patients are engaged with management and finding individual, yet non-sanctioned, ways to cope (Greaves, 2012; Kishita & Shimada, 2011).

Effective communication between clinicians and patients has been extensively researched in chronic illness and is increasingly advocated as central to good quality care. Effective communication can improve understanding and clinical outcomes (Stewart, 1995; Thorne, Harris, Mahoney, Con, & McGuinness, 2004) as well as increasing satisfaction (Williams, Weinman, & Dale, 1998) and patient-centred focus (Lewin, Skea, Entwistle, Zwarenstein, & Dick, 2001). In recognition of these outcomes, communication skills inform substantial parts of training curriculae for health professionals. However the findings of this meta-synthesis highlight this policy does not always translate into practice. This is a well-recognised issue, with researchers acknowledging implementation of clinical guidelines is poor overall (Curry, 2000; Solberg, 2000) and lack of guideline implementation regarding collaborative care directly attributed to asthma management failure (Braido et al., 2011). Research agendas in the UK are focussing on improving implementation of evidence-based guidelines in the NHS to increase clinical success (Eccles et al., 2009).

These issues were present despite health professionals' discussion of patient-centred care for decades, from the seminal "Doctors talking to patients" (Byrne & Long, 1976) to more recent concordance models of healthcare, which advocate shared understandings of health and mutually agreed goals for care (Bissell, May, & Noyce, 2004). Rates of chronic illness are rising and there is a pressing onus on GP's to manage these illnesses in primary care (Harris & Zwar, 2007; Kane, Priester, & Totten, 2005). Combined with increasing pressure on GP's to shorten consultations and see more complex patients (Kmietowicz,

2011) there are pressures within the healthcare system which do not facilitate doctors' use of collaborative methods. This may also explain the observed disparity between patients' views of primary and secondary care professionals, where the latter, as specialists can offer longer and therefore more containing consultations.

Some patients in reviewed studies distrusted conventional medicine, fearing side-effects, tolerance and addiction or believing use of medication signifies illness. Some believed it was best to do without medication, or that CAM was more safe and natural. Medication beliefs have been strongly linked with adherence to treatment regimes in chronic illness (Horne, Weinman, Barber, Elliott, & Morgan, 2005) with tools to measure patient attitudes freely available (Horne, Weinman, & Hankins, 1999). Both doctors and patients can be reluctant to discuss medication concerns (Makoul, Arntson, & Schofield, 1995) despite 99.6% of patients wanting information about side-effects (Ziegler, Mosier, Buenaver, & Okuyemi, 2001); perhaps because doctors fear corroborating those concerns (Schofield, Diggins, Charleson, Marigliani, & Jefford, 2010). Some GP's assume patients will raise issues of concern, or curtail discussion to prioritise information giving, with some not believing patients have the desire or ability to share decision making (Stevenson, Barry, Britten, Barber, & Bradley, 2000). These studies may also explain why psychosocial issues are not discussed in consultations by either party; in addition, GP's are rewarded financially for clinical but not psychosocial approaches in asthma (NHS Information Centre, 2010).

In keeping with broader political philosophy, there is a focus on active self-management of health conditions (Gulland, 2011); yet this synthesis suggests self-management can not be achieved without support and access to sufficient information. Despite asthma management guidelines stipulating "non-concordance describes an inability of both parties to come to an understanding, not merely a failure of the patient to follow the

health professional's instructions" (British Thoracic Society, 2008) outward shifts in terminology (i.e. from "compliance" to "concordance") do not necessarily reflect attitude change.

A review of interventions to improve adherence concluded that intervention studies repeatedly do not address patients' health beliefs, and focus narrowly on "one size fits all" information giving rather than understanding motivation (Horne et al., 2005; Horne et al., 2007). This is highlighted by patient narratives synthesized in this review; echoing dissatisfaction with "cookie-cutter care", and emphasising reciprocal understanding. Some social scientists view the shift in terminology but not attitude as a covert power struggle (Adams, Pill, & Jones, 1997), with authors acknowledging that removing the 'expert' position can leave health professionals feeling vulnerable and de-skilled (Wilson, Kendall, & Brooks, 2006). In line with the bi-directional understanding of disease management, further research aimed at understanding clinician perspectives on managing chronic illness collaboratively with patients would be invaluable in furthering attitudinal change towards person-centred care.

In line with numerous studies, this review found that poor communication, uni-directional relationships with health professionals and failure to explore patient beliefs and priorities results in poor patient experience and difficulties self-managing disease. Despite the ubiquity of communication and patient-centred agendas in policy, research and education for health professionals, this review highlights that evidence may not be translated to practice. Meta-syntheses such as the current study are important in allowing patient narratives to challenge practitioners to reflect on whether they implement these values in practice. Concordance models of healthcare are multi-factorial and complex; this

study highlights that there is still significant improvement required to shift attitudes as well as behaviour in healthcare practice.

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## Illness Perceptions and Panic-Fear in Coping with Difficult Asthma

### Abstract

*Background:* Difficult Asthma is a heterogeneous diagnosis for those with poorly controlled asthma with no definitive link to severe lung pathology. Several psychological variables predict clinical outcomes in this population. Illness perceptions as measured by the Illness Perceptions Questionnaire – Revised (IPQ-R) are increasingly used to understand beliefs about chronic illness. Sophisticated use of this tool has evolved beyond interpretation of individual dimensions to consider illness belief schemata using cluster analysis.

*Aims:* To understand how illness beliefs schemata of individuals with Difficult Asthma vary in relation to panic-fear, coping and clinical variables.

*Method:* 119 adults with a diagnosis of Difficult Asthma were recruited from a specialist clinic during November 2011 to April 2012. They completed the IPQ-R for asthma, Asthma Symptom Checklist and Asthma Specific Coping Scale. Clinical and demographic information was obtained, including spirometry values (Forced Expiratory Volume in one second, Forced Vital Capacity and FEV1/FVC ratio).

*Results:* Cluster analysis yielded a four cluster solution based on IPQ-R dimensions. MANOVA comparisons revealed differences in panic-fear and strategies used to cope with asthma. Groups did not differ in lung function. *Compliers* were least likely to experience panic-fear, least likely to have a passive coping style and least likely to seek information or restrict their lifestyle in response to asthma. *Reactive Strivers* experienced high amounts of panic-fear, and the highest degree of lifestyle restriction and information seeking. *Survivors* reported the highest levels of panic-fear, high passive coping and high amounts of personal control. *Ambivalent* patients were more likely to have adult-onset asthma, moderate panic-fear and moderate use of all coping strategies.

*Conclusions & Implications:* It is feasible to understand a Difficult Asthma population using illness perception schemas. The differences in experienced panic-fear and coping strategies between these groups suggest clinical utility in tailoring psychological interventions or care pathways for these groups.

## Introduction

### *Difficult Asthma Characteristics and Disease Burden*

Asthma is defined by the British Thoracic Society as “the presence of symptoms (more than one of wheeze, breathlessness, chest tightness, cough) and of variable airflow obstruction” though there is no gold standard for diagnosis (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012). The definition of ‘Difficult Asthma’ is yet more complex. The British Thoracic Society has suggested that when “a prior diagnosis of asthma exists, and asthma-like symptoms and exacerbations persist, despite prescription of high-dose asthma therapy” or “persistent symptoms and/or frequent exacerbations despite treatment at step 4 or step 5 of the BTS guidelines” (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012) that Difficult Asthma may be indicated. This implies poor control on a moderate dose of three drugs or use of oral rather than inhaled steroids, though the BTS acknowledge that no specific prescription or frequency of exacerbations can definitively diagnose Difficult Asthma.

The exact prevalence of Difficult Asthma is thus unknown, however estimates suggest 5-10% of asthmatic adults are likely to have the diagnosis (Barnes & Woolcock, 1998; Currie, Douglas, & Heaney, 2009). This equates to between 250,000 and 500,000 adults in the UK, based on recent estimates of asthma prevalence (British Lung Foundation, 2007). Difficult Asthma may be the result of inappropriate diagnosis, severe pathology, complex co-morbidity or non-adherence with prescribed treatment (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012; Prys-Picard, Campbell, Ayres, Miles, & Niven, 2006; Robinson et al., 2003). It is related to but not necessarily synonymous with severe asthma, with some studies showing that only half of those with ‘difficult-to-treat asthma’ have severe disease (Dolan et al., 2004). Those diagnosed with

‘Difficult Asthma’ are therefore a heterogeneous group with a definition that relies on treatment practices; the term is utilised by professionals for ease of management and reflects common clinical practice.

The most effective treatment for asthma is usually a combination of an inhaled preventative medication (corticosteroid), taken every day, with a beta agonist inhaler for the relief of acute symptoms as needed. By definition, individuals with Difficult Asthma will be prescribed this treatment regime, probably in high dosage, with additional pharmacological therapies (for example long acting beta-agonists, anti-leukotrienes, theophylline or steroid tablets (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012; Currie et al., 2009). The most up to date guidelines for the management of asthma conclude that evidence for trigger avoidance (such as avoiding allergens, dust and pollen) is equivocal, but that giving up smoking is favourable and maintaining overall health may be beneficial (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012). An assessment of psychological wellbeing is considered “absolutely necessary” in all patients being investigated for Difficult Asthma (Prys-Picard et al., 2006)

Though the exact prevalence of Difficult Asthma is not known, data exist on the complications of managing the disease and its associated outcomes. An expert panel of Difficult Asthma physicians in the UK concluded that high medical resource usage and management complexity makes this patient group in need of improved and targeted care (Prys-Picard et al., 2006). Recent measures of non-adherence to prescribed treatment in Difficult Asthma (using prescription records and blood plasma levels) estimate 88% of patients are non-adherent to inhaled therapies, 45% non-adherent to oral steroids, 35% fill

fewer than half of their prescriptions and 45% fill between half and all of their prescriptions (Gamble, Stevenson, McClean, & Heaney, 2009). A review of international studies conducted in six Western countries estimated that under-use of medication was the most significant contributor to uncontrolled asthma, and linked with increased morbidity, mortality and health care expenditure (Barnes, Jonsson, & Klim, 1996). If uncontrolled asthma is to improve, researchers have emphasised the need for focus on understanding the perspective of the patient and collaborative decision making between patient and clinician, rather than the development of new drug therapies (Heaney & Horne, 2012; Horne et al., 2007; Horne, 2006).

Individuals diagnosed with Difficult Asthma are more likely to utilise health services, to be hospitalised with exacerbations and to experience impaired quality of life (Gamble et al., 2009; Vollmer et al., 1999), and uncontrolled asthma is also a risk factor for increased mortality (Peters, Ferguson, Deniz, & Reisner, 2006). The cost of asthma to the National Health Service is estimated at £850 million per year, with an additional economic burden of 18 million lost working days (Yorke, Fleming, & Shuldham, 2006). The weight of economic burden appears to be due to the cost of uncontrolled disease, including both direct costs (medication, hospitalisations, unscheduled health visits) and indirect costs (days lost in school and work due to asthma and early retirement) (Barnes et al., 1996).

Acute admissions for severe asthma are not merely a reflection of self-management knowledge deficit (Kolbe, Vamos, Fergusson, Elkind, & Garrett, 1996) but are more correctly ascribed to psychosocial factors such as panic, worry over time out of work and adverse life events (Kolbe, Vamos, Fergusson, & Elkind, 1998). Prevalence of psychiatric morbidity for those with asthma is elevated above community norms (Scott et al., 2007) and adverse psychosocial factors are a significant risk factor for asthma deaths (Innes, Reid,

Halstead, Watkin, & Harrison, 1998). Though psychological co-morbidity in Difficult Asthma is common, it is hard to distinguish cause and effect (Barnes & Woolcock, 1998) and the relationship may be one of a 'feedback loop' whereby asthma and psychological problems serve to exacerbate each other (Opolski & Wilson, 2005). However, psychological factors in Difficult Asthma appear to extend beyond psychopathology, with co-morbid psychiatric history considered of uncertain relevance by an asthma consensus panel (Prys-Picard et al., 2006). Psychiatric morbidity and psychiatric diagnosis are less helpful in understanding the nuances of beliefs, attitudes and attributions that are increasingly understood as determining health behaviours.

Psychosocial interventions for Difficult Asthma have offered equivocal results in terms of improving psychological or asthma morbidity, due to the complexity of contributing factors (Smith, Mugford, Holland, Noble, & Harrison, 2007; Yorke et al., 2006). An in-depth exploration of psychological constructs in Difficult Asthma may provide a more comprehensive framework for understanding the psychological complexity of the diagnosis.

### *Panic-fear*

Early research exploring psychological aspects of asthma has focussed on the role of anxiety and panic (Dahlem, Kinsman, & Horton, 1977; Dirks, Kinsman, Horton, Fross, & Jones, 1978; Kinsman, Dirks, Dahlem, & Heller, 1980). Panic-fear is a significant psychological phenomenon associated with asthma given the sensation of breathlessness commonly featuring in both asthma and panic attacks (Smoller & Otto, 1998). Misinterpretation of breathlessness during either attack may lead to inappropriate care, if the patient either ignores their symptoms or seeks inappropriate and excessive medication or treatment. Co-morbid asthma and panic disorder appears to be associated with higher use

of asthma reliever medication and oral steroids, more intensive prescribing, and longer and more frequent hospital admissions, independent of objective clinical measures of asthma severity (Carr, 1999). Clinical consultations that rely on self report may be biased by patient reports of respiratory symptoms; individuals with panic disorder who show normal pulmonary function report symptoms as severe as those persons with asthma (Carr, Lehrer, & Hochron, 1992). Panic-fear also accounts for 25% of the variance in physician prescribing of asthma medication (Hyland, Kenyon, Taylor, & Morice, 1993), partially explained by the finding that those with panic disorder perceive themselves to be more ill (Katon, 1996). Although the research evidence suggests that panic-fear is associated with poor outcomes in asthma, there is a paucity of explanatory research.

Inappropriate use of reliever medication for asthma seems predicted by both low and high panic-fear; those who rate highly on panic-fear tend to overuse PRN (reliever) medication, whereas those who rate low tend to under-use irrespective of pulmonary function (Dahlem et al., 1977). Similar to these findings, patients with high or low panic-fear are more likely to be hospitalised for asthma compared to those with moderate panic-fear (Kinsman, Dahlem, Spector, & Staudenmayer, 1977). This relationship is independent of lung function and oral corticosteroid use and is argued to relate to inappropriate coping strategies, whereby those with high panic-fear are hyper-vigilant and those with low panic fear are avoidant. Generalised panic fear is associated with activity restricted coping and use of as-needed medication and asthma-specific panic-fear is associated with more primary care visits and greater irritability during asthma attacks. It also mediates the relationship between panic disorder and health related quality of life (Feldman, Siddique, Thompson, & Lehrer, 2009)

More recent research into the role of panic in asthma has tended to focus on a dichotomous classification of presence or absence of ‘panic disorder’ as opposed to distribution of panic across a population. These studies have found that a diagnosis of asthma can predict diagnosis of panic-disorder and vice-versa (Hasler et al., 2005), that those with panic disorder and asthma have greater healthcare use and impaired quality of life (Feldman, Lehrer, Borson, Hallstrand, & Siddique, 2005) and that low panic predicts future asthma attacks in those who have recently had asthma attacks (Greaves, Eiser, Seamark, & Halpin, 2002). Despite these useful findings, they focus on a sub-set of patients with a diagnosed psychiatric condition, and do not advance the understanding of the role of panic-fear in the wider asthma population.

### *Coping*

Understanding outcomes for asthma has not only been shaped by constructions around panic-fear; for example a review of ‘emotionally triggered asthma’ found that a repressive and avoidant coping style is a risk factor for asthma morbidity when panic is present (Lehrer, 1998). As with other chronic conditions, coping has figured as an important explanatory variable (Felton, Revenson, & Hinrichsen, 1984). Development of appropriate coping strategies has been a prominent focus of interventions for chronic illness, though reviews highlight modest efficacy, and tend to privilege problem-solving strategies (de Ridder & Schreurs, 2001). The authors conclude that more understanding of how the coping concept relates to chronic illness is needed and that future studies should incorporate the role of beliefs and illness cognitions in our understanding of coping with chronic illness (de Ridder & Schreurs, 1996).

In the field of asthma research, coping has been found to mediate self-management of the disease. Passive and emotion-focused coping appears related to poor medication

adherence, unscheduled health visits, clinic appointment non-attendance and emergency admissions (Baiardini et al., 2006; Barton, Clarke, Sulaiman, & Abramson, 2003; González-Freire, Vázquez-Rodríguez, Marcos-Velázquez, & de la Cuesta, 2010; Lehrer, 1998); denial has been linked to life-threatening asthma attacks, whilst positive reappraisal is linked with appropriate attention to deterioration in symptoms (Barton et al., 2003). A systematic review of relationships between coping style and outcomes for those with asthma debates how different coping strategies may be useful in different situations (for example, problem solving may be inappropriate if asthma is so severe as to limit personal control) (Barton et al., 2003). The authors also acknowledge that further research examining links between coping, psychological distress and asthma is needed; most particularly for those with severe asthma.

#### *Illness appraisals*

More detailed conceptualisation of coping has argued its mediation by cognitive and emotional appraisal, and that the fullest explication of coping should ensure appraisal processes are examined (Lazarus & Folkman, 1984). The Self Regulation Model (SRM), perhaps the dominant appraisal-focused model of health behaviour applied to understanding of chronic illness (Leventhal, Lambert, Diefenbach, & Leventhal, 1997), incorporates theories of illness perception (Weinman, Petrie, Moss-Morris, & Horne, 1996). Illness perceptions in asthma can be broken down into the following components: *illness identity*, (the extent to which one recognises symptoms and labels them as asthma); perceptions of the *cause* of the illness; the perception of the illness as *short or long-term* or as *cyclical*; perceptions of the *consequences* and *coherence* of the illness; beliefs about *personal* and *treatment control* and *emotional representations* of the disease. This model argues subjective experience and beliefs of patients with asthma affects their subsequent

understanding and management of their disease, and is a robust predictor of clinical outcomes and health care usage (Hagger & Orbell, 2003; Petrie & Weinman, 1997).

Since the inclusion of an asthma population in the initial validation sample for the Illness Perceptions Questionnaire-Revised (Moss-Morris et al., 2002), the illness perceptions model has been used to understand and examine different facets of asthma management. In adolescents, illness perceptions mediate the role of anxiety in asthma, with *emotional representations* and *control/cure* explaining the link between anxiety and asthma symptoms (McGrady et al., 2010). Extensions of the SRM/illness perceptions model that incorporate medication beliefs have been used to understand medication non-adherence in asthma (Heaney & Horne, 2012; Horne, Weinman, & Hankins, 1999; Menckeberg et al., 2008; Ohm & Aaronson, 2006). To date there has been scant attention paid to Difficult Asthma in adult populations, with Consultant Physicians and Health Psychologists both calling for more research (Heaney & Horne, 2012).

For patients with related chronic respiratory conditions such as Chronic Obstructive Pulmonary Disease (COPD) illness perceptions have been found to change over time and to be sensitive to change following rehabilitation (Fischer et al., 2010). Within the same disease population illness representations appear important in discriminating between those with and without panic disorder (Howard, Hallas, Wray, & Carby, 2009). Specifically, the *identity*, *timeline*, *consequences* and *emotional representation* constructs helped to distinguish between those with COPD who had panic attacks and those who did not.

Illness representation research is moving towards examinations of relationships between the dimensions rather than analysing the dimensions in isolation. Through cluster analysis, profiles or sets of beliefs can be explored, minimising the risk that associations between variables will be missed due to heterogeneity (Clatworthy, Hankins, Buick,

Weinman, & Horne, 2007). This method moves beyond beliefs held by the individual to explore patterns of beliefs commonly held by sub-groups.

Clusters of illness representations have been used to identify those at risk for poor psychological adjustment to diagnosis and treatment of breast cancer (Buick, 1997); can predict mood and functioning in pain patients (Hobro, Weinman, & Hankins, 2004); coping style, impairment and adaptive outcome in Addison's Disease (Heijmans, 1999); coping and awareness in brain injury (Medley, Powell, Worthington, Chohan, & Jones, 2010) and may be associated with better health outcomes (Petrie & Weinman, 1997). Cluster analysis has been employed to examine perceptions of those with Type II diabetes as part of research to identify effective adherence interventions (Skinner et al., 2010). The study identifies profiles of illness representations: 'resisters accepting' (those who do not fully accept their diagnosis but accede to treatment); 'resisters' (those who reject diagnosis and treatment); 'accepters' (those who accept diagnosis and adhere to treatment), and 'accepters resisting' (those who accept their diagnosis but do not adhere to treatment). Clusters of representations were better at predicting illness outcomes than the standard dimensions in isolation. Identifying these 'profiles' of illness representations within different disease populations may aid better understanding of disease management. It is argued that these cluster profiles may have potential to design tailored interventions and can also be used in cluster analysis of coping strategies (Pimm, 1997) but that more research is needed.

It is clear from the literature that an understanding of psychosocial aspects of Difficult Asthma is vital in managing the disease and limiting its impact both for the individual and in terms of economic burden, and that this understanding should extend beyond dichotomous classifications of psychiatric morbidity. Specifically, the roles of

panic-fear, illness perception and coping have much to contribute to the understanding of Difficult Asthma. The present study attempted to broaden this understanding by studying these elements in combination, within a specific Difficult Asthma population, using newer and more sophisticated models for interpreting illness perceptions.

#### *Research Aims*

1. To understand how the illness beliefs of individuals with Difficult Asthma vary in relation to illness-specific panic-fear symptoms
2. To investigate how illness perceptions and illness-specific panic-fear influence how people cope with Difficult Asthma
3. To investigate whether these outcomes relate to measures of clinical severity
4. To investigate whether clusters of illness perceptions are more useful than individual dimensions in understanding a Difficult Asthma population

## Method

### *Study Design*

The study used a cross-sectional, self-report questionnaire design. It sought to examine illness perceptions of asthma and panic-fear symptoms in people attending a clinic for Difficult Asthma, and the relationship of these domains to coping with asthma. Analyses were planned using linear regression models. Cluster analysis was used to identify separate ‘profiles’ of illness perceptions; K-means clustering was adopted given it has been established as the most appropriate method for clustering illness representations measured with the IPQ-R (Clatworthy, Hankins, Buick, Weinman, & Horne, 2007). Multivariate ANOVA was used to compare differences between clusters.

### *Intended Sample*

The intended sample comprised adult outpatients diagnosed with asthma and attending a specialist Difficult Asthma clinic within an acute teaching hospital in the East Midlands, UK. For a regression model with eight variables, at alpha level  $p=0.05$  with an expected medium effect size, a sample of 107 participants was needed to achieve power for statistical analysis (Cohen, 1992). No power calculation was necessary for cluster analysis given it is an exploratory method not an inferential statistic. Although some authors argue power should be calculated to determine sample size for cluster analysis (Formann, 1984 in Mooi & Sarstedt, 2011), other authors argue there is no specific rule for minimum sample size (Mooi & Sarstedt, 2011). Power and sample size is not considered essential to reporting quality in cluster analysis (Clatworthy, Buick, Hankins, Weinman, & Horne, 2005).

### *Inclusion/Exclusion Criteria*

Those with co-morbid diagnoses were included to keep the sample representative of the clinical population. Participants were excluded if they were unable to understand written English since translations to other languages or accessible formats would compromise the validity of the psychometrically validated questionnaires. Although the Illness Perceptions Questionnaire-Revised and Asthma Symptom Checklist have been translated in to a limited number of other (mostly European) languages, those available were not coterminous with languages most frequently spoken in Leicester. It was beyond the scope of this project to validate the questionnaires in other languages in addition to the main research questions.

#### *Inclusion Criteria*

Over 18 years of age

Diagnosis of asthma

Attending Difficult Asthma Clinic at the Acute Hospital

Able to understand written English

Capacity to consent

#### *Exclusion Criteria*

Under 18 years old

Does not have capacity to consent to participate

No diagnosis of difficult asthma

Not attending Difficult Asthma Clinic at the Acute Hospital

Unable to understand written English

### *Procedure*

Patients received an invitation to take part in the study from the supervising Consultant Physician in the week prior to their routine clinic appointment to inform them the research project was being conducted (see Appendix H). This ensured the required minimum 24 hour period between patients being approached and consent to participate being obtained was observed. At the weekly clinic the Researcher was available when the patient checked in to discuss the study and answer questions. If patients wanted to take part the Researcher discussed consent with them and asked them to read and sign the consent form. They then filled in the questionnaires alone (or with help if requested) and returned completed questionnaires to the Researcher. Lung function data were obtained from clinical notes following the participant's appointment with their doctor.

### *Materials and Measures* (See Appendices I-N)

Patient Information Sheet

Consent Form

Questionnaire Battery:

Demographics and Health Care Details (self reported)

Illness Perceptions Questionnaire-Revised for Asthma

Asthma Symptom Checklist

Asthma Specific Coping Scale

### *Demographics*

Demographic information was collected via patient self report. Patients were asked about age, gender and ethnicity in order to explore potential variations in the data, and to be able to set statistical results within context. Data were collected regarding asthma

medications, co-morbid health problems, time elapsed since asthma diagnosis and number of unscheduled health visits for asthma in the last 12 months (i.e. walk-in clinics, emergency GP appointments and hospital visits). It is acknowledged that there are limitations with patients self-reporting this information, which may not always be accurate (for example, Corser et al., 2008) Information about medication and co-morbidities was corroborated with a case note review (permission for this was obtained during the initial consent process).

### *Illness Perceptions*

Illness perceptions were measured using the Illness Perception Questionnaire-Revised (IPQ-R) (Moss-Morris et al., 2002), a widely used tool in health psychology literature for examining a range of chronic health problems; an asthma-specific version has been created. Items are rated on a five point Likert scale from Strongly Disagree (scored 1) to Strongly Agree (scored 5). Scores for the items in each subscale are summed to produce the subscale total. In the original validation study Cronbach's  $\alpha$  for the subscales *identity*, *timeline*, *cause*, *control/cure* and *consequences* range between 0.79 and 0.89, Pearson correlations for test-retest reliability at three weeks and six months range from 0.49 to 0.88. In the same validation study tests of known group validity between acute and chronic pain patients found significant differences between groups on all dimensions at  $p < .01$  or higher, suggesting good discriminant validity (Moss-Morris et al., 2002).

### *Asthma Specific Coping*

This was measured by the Asthma Specific Coping Scale (ASCS) (Aalto, Härkäpää, Aro, & Rissanen, 2002). The scale has a six factor structure, with subscales covering; restricting lifestyle, hiding asthma, positive reappraisal, information seeking, ignoring

asthma and asthma worry. Items are rated on a 4-point Likert scale according to how often each strategy is used (Hardly Ever, Sometimes, Often, Always), with higher scores reflecting more frequent use. Items of each subscale are summed to provide subscale totals. There is no overall score for coping as the six styles are different, however the authors subcategorise the styles into 'active coping' (*positive reappraisal, information seeking*) and 'passive coping' (*restricting lifestyle, hiding asthma, ignoring asthma and asthma worry*). Active coping is presumed to be a more adaptive way of coping with asthma. Initial validation of the scale with 3,464 participants found the six coping styles measured Cronbach's  $\alpha$  between 0.63 and 0.84. The scale correlates with general coping as measured by the COPE, and health related quality of life (Aalto et al., 2002).

#### *Asthma Symptoms & Panic-Fear*

Panic-fear was measured with a linear scale rather than a dichotomous classification as psychiatric classification is deemed to be of uncertain relevance by a Difficult Asthma consensus panel (Prys-Picard et al., 2006). The Asthma Symptom Checklist (ASC) (Kinsman, Luparello, O'Banion, & Spector, 1973) is widely utilised and has been translated into other languages for use internationally. An asthma-specific scale for panic-fear was used as previous studies have revealed that more general measures (such as the Hospital Anxiety and Depression Scale) have variable sensitivity in detecting asthma-specific anxiety (Bosley, Fosbury, & Cochrane, 1995; Feldman, Siddique, Thompson, & Lehrer, 2009). *Panic-fear* is a subscale of the ASC, in addition to *irritability, fatigue* and two somatic clusters (*hyperventilation-hypocapnia* and *bronchoconstriction*). Items are self-rated on a five point Likert scale according to how often symptoms are experienced (Never, Rarely, Sometimes, Often or Always)

with higher scores reflecting higher frequency. Items from each subscale are summed to provide five scores. There is no overall score for asthma symptoms. Seven of the 36 items make up the *panic-fear* subscale (see Appendix M and Appendix O for further details). In the original validation study, the subscales were derived through principal component factor analysis. *Panic-fear* had a mean of 2.28, a standard deviation of 1.08 and an  $\alpha$  of 0.93. Other subscales' reliability ranged between  $\alpha = 0.84 - 0.91$ .

### *Spirometry*

As well as measuring asthma severity subjectively using self-report, disease severity was measured objectively with clinical data held about the participant by the Difficult Asthma Clinic. Lung function data obtained from spirometry is a standard way to assess asthma pathology (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012; Ferguson, Enright, Buist, & Higgins, 2000). Lung function data collected where available were FEV1 (Forced Expiratory Volume in one second), FVC (Forced Vital Capacity; total amount of breath that can be exhaled) and PEF (Peak Expiratory Flow; air exhaled in one breath). Peak Expiratory Flow is usually monitored in those with an exacerbation or newly diagnosed with asthma; it is not routinely measured (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012).

### *Ethical Considerations*

Following university approval, ethical approval for the project was sought from the local NHS Research Ethics Committee, as well as the Acute Trust's Research Management & Governance (RM&G) department (See Appendix G).

Each person approached was given a Participant Information Sheet to enable them to give informed consent (see Appendix I and J). All participants were free to choose not to take part without any adverse effect on the care they received, and had a minimum of 24 hours to consider the information in the Participant Information Sheet. Provision was made for the unlikely event that the participant became distressed in response to the content of the questionnaires, the Researcher would use their experience as a Trainee Clinical Psychologist for immediate support (whilst maintaining appropriate boundaries within the Researcher role). The Researcher would also discuss with the participant whether it would be appropriate for their health care professional at the clinic to be informed and provide further support. Fortunately this was not necessary throughout the data collection period as no individuals became distressed by the questionnaires.

Participants were reassured that their clinical care would not be affected by their participation or non-participation in the research. This was particularly important to highlight, as some patients were also enrolled in clinical trials, which involved changes in medication in addition to blood and sputum tests. The final choice to participate was kept confidential between the patient and the Researcher after the patient had had a chance to discuss the study and ask questions

Lung function test results were available from previous clinic visits, such that participants had no need to undergo further spirometry. Data were linked to the participant's name by a participant ID number to ensure that data could be withdrawn if the participant no longer wished to take part and requested removal from the study. No participants chose to withdraw after returning their questionnaires.

## Results

### *Data Preparation*

Questionnaires were coded and data entered on to an electronic database using SPSS for Windows Version 20. Subscale scores were calculated using SPSS syntax following scoring criteria in the original studies (Aalto, Härkäpää, Aro, & Rissanen, 2002; Kinsman, Luparello, O'Banion, & Spector, 1973; Moss-Morris et al., 2002). Missing data on the IPQ-R were calculated using methods recommended by the authors (Moss-Morris (2012)). A similar approach was used for the ASC and ASCS; subscales were calculated as the mean score multiplied by the number of subscale items, except where an entire questionnaire was missing (see Appendix O). Statistical analysis was carried out using the functions built in to SPSS.

### *Achieved Sample*

Participants were recruited consecutively over the period November 2011 to April 2012, until the calculated sample size had been achieved; eleven clinics were attended overall. Each clinic is attended by 22 patients on average, meaning just over half the attendees over the sampling frame were recruited to take part in the study. The total sample size was 119 people; additional participants were recruited to allow for missing data.

### *Demographics*

The sample was 60% female and 87% White British (8% Asian Indian, 4% any other ethnic group). The mean age of participants was 48.4 years (range =18-77,  $SD = 14.7$ ) though this was significantly different between men ( $M=54.5$  yrs) and women ( $M= 44.3$  yrs) using an independent samples t-test ( $t(101) = -3.66, p<0.001$ ). Demographics were

similar to baseline characteristics in recent studies of phenotypic clusters of asthma (Haldar et al., 2008).

### *Clinical Characteristics*

The mean time since diagnosis with asthma was 24.2 years (range = 0.2-72 years,  $SD = 16.3$ ) and the mean age at diagnosis 23.1 years (range = 0-71,  $SD = 20.9$  years). Mean Forced Expiratory Volume in 1 second (FEV1) as a percentage of the predicted value for the patient's age, height and gender was 73.8% (range = 29-117%,  $SD = 20.5\%$ ). The mean ratio between FEV1 and Forced Vital Capacity (FEV1/FVC) was 68.2% (range = 33.7 – 92.5,  $SD = 12.9$ ). Peak Expiratory Flow as a percentage of predicted values for age, height and gender was available for 59% of the sample, with a mean value of 83.6% (range = 15-155,  $SD = 28.9$ ). As previously discussed, PEF is not routinely collected for all patients due to its limited clinical utility outside of exacerbations of asthma, (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012) so this value should be interpreted with caution. Medication characteristics of the sample can be seen in Table 3. Approximately half the sample were prescribed oral steroids, suggesting the disease severity and management was commensurate with British guidelines for difficult asthma (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012). Unscheduled health visits for asthma in the last 12 months ranged from none to fifteen, with the mean number of unscheduled visits being 1.9 ( $SD = 2.6$ , median=1, mode=0). Independent sample t-tests revealed that women had more unscheduled health visits on average in the previous 12 months ( $t(102)=2.51$ ,  $p=0.008$ ) with women averaging 2.4 visits and men 1.2 visits. Women also tended to have been diagnosed with asthma at a younger age; a mean of 19.2 year compared to men with a mean age at diagnosis of 28.9 years ( $t(93)=-2.27$ ,

$p < 0.04$ ). Independent samples t-tests did not reveal any significant differences between men and women for other clinical characteristics.

Table 3. Prescribed Medication for Asthma (percentage of sample)

Medication	N (%)
Short Acting Beta Agonist	102 (85.7)
Inhaled steroid	113 (94.9%)
Long Acting Beta Agonist	105 (88.2)
Leukotrine Receptor Antagonists	31 (26.1)
Theophylline	40 (33.6)
Oral steroids	57 (47.9)
Anti-cholinergics	32 (26.9)
Antibiotics	17 (14.3)

#### *Illness Perceptions Questionnaire Revised (IPQ-R)*

For the *identity* subscale of the IPQ-R, questionnaires were generally poorly filled in with many participants neglecting to fill in the second column that determines the *identity* score. This information was only available for 43 participants (36% of the sample). This subscale was therefore not considered a reliable reflection of the *identity* subscale, and reliability analysis of these 43 respondents was borderline (Cronbach's  $\alpha = 0.67$ ). *Identity* was therefore not included in further analyses. Descriptive and reliability statistics for the other subscales of the IPQ-R are reported in Table 4. Cronbach's  $\alpha$  for the remaining IPQ-R constructs suggested the subscales were stable (all  $\alpha > 0.7$ ) except for *Treatment Control* and *Timeline Cyclical*; though an  $\alpha > 0.6$  may be considered acceptable by some sources (Streiner & Norman, 2008), analyses using this scale are interpreted with caution.

Table 4. Descriptive Statistics and Reliability Analysis for IPQ-R

Illness Perceptions (possible score range)	Minimum	Maximum	Mean	Standard Deviation	Cronbach's $\alpha$
Timeline (6-30)	11	30	25.23	3.92	0.71
Consequences (6-30)	9	30	21.71	5.15	0.85
Personal Control (6-30)	10	30	21.12	4.08	0.71
Treatment Control (5-25)	4	25	16.55	3.40	0.63
Illness Coherence (5-25)	7	25	18.16	5.02	0.87
Timeline Cyclical (4-20)	6	20	14.88	3.13	0.69
Emotional Representation (6-30)	6	30	18.08	5.55	0.84

### *Causes of Asthma*

As part of the IPQ-R participants were asked to rate factors according to how much they believed each one had caused their asthma. They were also asked to rank the top three believed causes of their asthma, including any other causes not supplied in the questionnaires (see Appendix L). Results of the top-ranked causes (supplied in the questionnaire) are shown in Table 5.

Table 5. Perceived Top Causes of Asthma

Cause	Ranked 1 <sup>st</sup> N (%)	Ranked 2 <sup>nd</sup> N (%)	Ranked 3 <sup>rd</sup> N (%)	Any N (%)
Stress or worry	9 (7.6)	9 (7.6)	8 (6.7)	26 (21.9)
Hereditary	24 (20.2)	7 (5.9)	3 (2.5)	34 (28.6)
A germ or virus	8 (6.7)	7 (5.9)	3 (2.5)	18 (15.1)
Diet or eating habits	1 (0.8)	2 (1.7)	1 (0.8)	4 (3.4)
Chance or bad luck	1 (0.8)	3 (2.5)	2 (1.7)	6 (5.0)
Poor medical care in my past	2 (1.7)	2 (1.7)	1 (0.8)	5 (4.2)
Pollution in the environment	10 (8.4)	11 (9.2)	11 (9.2)	32 (26.9)
My own behaviour	0 (0)	1 (0.8)	0 (0)	1 (0.8)

Family problems or worries	0 (0)	1 (0.8)	1 (0.8)	2(1.7)
Overwork	1 (0.8)	1 (0.8)	2 (1.7)	4 (3.4)
My emotional state	0 (0)	2 (1.7)	2 (1.7)	4 (3.4)
Ageing	0 (0)	1 (0.8)	4 (3.4)	5 (4.2)
Smoking	3 (2.5)	8 (6.7)	1 (0.8)	12 (10.1)
Accident or injury	0 (0)	1 (0.8)	0 (0)	1 (0.8)
Altered immunity	1 (0.8)	1 (0.8)	7 (5.9)	9 (7.6)
Other	34 (28.6)	23 (19.2)	27 (22.7)	84

Respondents often had unique beliefs about the causes of their asthma, with most people ranking a non-supplied factor as the top cause of their asthma. These are explored further in Table 6. Many participants distinguished secondary smoke from the supplied items ‘smoking’ and ‘pollution in the environment’. Fifteen participants named idiosyncratic causes that could not be subsumed in a broader category and would potentially make participants identifiable; therefore these results have not been reported individually.

Table 6. Non-supplied Perceived Causes of Asthma, N (%)

Cause	Ranked 1 <sup>st</sup> N (%)	Ranked 2 <sup>nd</sup> N (%)	Ranked 3 <sup>rd</sup> N (%)	Any N (%)
Passive/second hand smoke	4 (3.4)	4 (3.4)	2 (1.7)	10 (8.4)
Infection	5 (4.2)	2 (1.7)	2 (1.7)	9 (7.6)
Allergy	5 (4.2)	2 (1.7)	2 (1.7)	9 (7.6)
Environment	2 (1.7)	1 (0.8)	5 (4.2)	8 (6.7)
Other illness	3 (2.5)	3 (2.5)	1 (0.8)	7 (5.9)
Work conditions/occupational	4 (3.4)	(0)	2 (1.7)	6 (5.0)
Weather	2 (1.7)	3 (2.5)	1 (0.8)	6 5.0)
Exercise/exertion	1 (0.8)	2 (1.7)	1 (0.8)	4 (3.4)
Dust/dust mites	1 (0.8)	1 (0.8)	2 (1.7)	4 (3.4)
Chemical exposure	2 (1.7)	1 (0.8)	0 (0)	3 (2.5)
Mother smoked in pregnancy	2 (1.7)	0 (0)	0 (0)	2 (1.7)
Mould	1 (0.8)	1 (0.8)	0 (0)	2 (1.7)
Pets	1 (0.8)	1 (0.8)	0 (0)	2 (1.7)
Other (anonymised)	4 (3.4)	2 (1.7)	9 (7.6)	15 (12.6)

*Asthma Symptom Checklist (ASC)*

The panic-fear subscale of the ASC was the focus of interest in the present study. A histogram showed this subscale to be normally distributed (see Appendix P); combined with a high Cronbach's  $\alpha$  value this suggests the scale could be reliably used in further analysis. However, some authors warn that  $\alpha < 0.9$  suggests item redundancy; i.e. the items of the scale are too similar (Streiner & Norman, 2008). Analyses using panic-fear should therefore be interpreted cautiously.

Table 7. Descriptive Statistics and Reliability Analysis for the ASC

Asthma Symptoms During Attack (possible score range)	Minimum	Maximum	Mean	Standard Deviation	Cronbach's $\alpha$
Hyperventilation-Hypocapnia (9-45)	9	39	20.6	7.3	0.86
Bronchoconstriction (10-50)	20	50	37.8	5.6	0.79
Irritability (6-30)	6	30	18.0	5.4	0.86
Panic-fear (7-35)	7	35	20.3	7.2	0.95
Fatigue (4-20)	4	20	15.1	3.6	0.89

#### *Asthma Specific Coping Style (ASCS)*

The coping style *information seeking* was rated highest on average, and *hiding asthma* the lowest. The coping styles can be grouped in to active coping (*positive reappraisal plus information seeking*) and passive coping (*restricting lifestyle, hiding asthma, ignoring asthma and worrying about asthma*). Active coping is seen as more adaptive by authors of the Asthma Specific Coping Scale, with some caveats concerning short-term compared to long-term coping (Aalto et al., 2002). Active coping was rated more highly than passive coping in this sample, indicating this strategy was used more frequently. Active Coping and Passive Coping were not significantly correlated ( $r=0.03$ ,  $N=114$ ,  $p=0.78$ ).

Table 8: Descriptive Statistics and Reliability Analysis for the ASCS

Coping style (possible score range)	Minimum	Maximum	Mean	Standard Deviation	Mean as % of Subscale	Cronbach's $\alpha$
Restricting lifestyle (4-16)	4	16	10.4	3.3	65.2	0.86
Hiding asthma (4-16)	4	16	8.4	3.2	52.5	0.85
Positive reappraisal (4-16)	4	16	10.3	3.0	64.4	0.75
Seeking information (4-16)	4	16	10.9	2.9	68.1	0.75
Ignoring asthma (4- 16)	4	15	9.0	2.8	56.3	0.71
Worrying about asthma (3-12)	3	12	7.7	2.6	64.2	0.82
Active Coping (8-32)	11	31	21.2	4.7	66.3	0.76
Passive Coping (17- 60)	18	51	35.6	7.9	59.3	0.83

#### *Relationship between Illness Perceptions and Panic-Fear*

Using Pearson's  $r$ , Panic-fear was significantly correlated with belief in the *consequences* of asthma ( $r=0.30$ ,  $N=112$ ,  $p<0.001$ ), belief in a *cyclical* timeline ( $r=0.21$ ,  $N=112$ ,  $p=0.03$ ) and *emotional representations* of asthma ( $r=0.61$ ,  $N=112$ ,  $p<0.001$ ). It was inversely correlated with *illness coherence* ( $r=-0.21$ ,  $N=112$ ,  $p=0.03$ ); i.e. the less understanding of their asthma people felt they had, the more panic-fear they were likely to experience.

#### *Regression Analysis*

The relationship between IPQ-R scores, *panic-fear* and *active coping* was explored using linear regression, with active coping as the dependent variable. The overall model was not statistically significant ( $R^2 = 0.08$ ,  $F(8, 109) = 1.09$ ,  $p=0.37$ ) though *consequences* on the IPQ-R contributed significantly to variance in *active coping* ( $\beta = 0.28$ ,  $t(109) = 2.80$ ,  $p=0.02$ ).

The relationship between IPQ-R scores, *panic-fear* and *passive coping* was also explored with passive coping as the dependent variable. This model was statistically significant ( $R^2 = 0.352$ ,  $F(8, 109) = 6.87$ ,  $p < 0.001$ ). *Panic-fear* ( $\beta = 0.34$ ,  $t(109) = 3.24$ ,  $p = 0.002$ ) and *consequences* ( $\beta = 0.20$ ,  $t(109) = 1.99$ ,  $p = 0.049$ ) contributed statistically significant variance to *passive coping*; higher panic-fear and higher perceived consequences related to higher passive coping.

Finally, the relationship between IPQ-R scores, *panic-fear* and lung function (measured by FEV<sub>1</sub>) was explored, with lung function as the dependent variable. This regression model was also not statistically significant ( $R^2 = 0.12$ ,  $F(8, 104) = 1.56$ ,  $p = 0.15$ ) though *consequences* contributed statistically significantly to the variance in FEV<sub>1</sub> ( $\beta = -0.24$ ,  $t(8, 104) = -1.98$ ,  $p = 0.05$ ). This relationship was inverse; higher perceived *consequences* were associated with lower lung function.

#### *Cluster Analysis*

K-means cluster analysis of IPQ-R scores revealed little variance in the subscale *timeline cyclical*, a solution of nine clusters would be needed for this variable to reach statistical significance (see Appendix Q) whilst the other subscales reach significance with far fewer clusters (see Appendix R). This suggests clusters could not usefully be distinguished on *the timeline cyclical* variable, therefore it was excluded from the analysis. After running the cluster analysis without this variable, convergence was achieved using the fewest iterations when 4 clusters were entered in to the model, suggesting the best fit. Cluster membership for each participant was assigned using the in-built function in SPSS; this was in calculable for five participants due to missing data. Final cluster centres are visualised in Figure 1.

### *Cluster 1*

Cluster 1 consists of 33 individuals who believe their asthma will last a fairly long time but with few consequences. They feel a high degree of personal control over their asthma and the strongest belief of all groups that their treatment will control their asthma. They feel that they understand their asthma well and experience low amounts of emotion about it.

### *Cluster 2*

This cluster consists of 15 individuals who believe their asthma will last the longest of the four groups, but believe the consequences are severe. They feel little sense of personal control over their asthma and do not have much faith that their treatment will control their disease. They have an understanding of their asthma, though less than Cluster 1, and experience a fairly high degree of emotion about it.

### *Cluster 3*

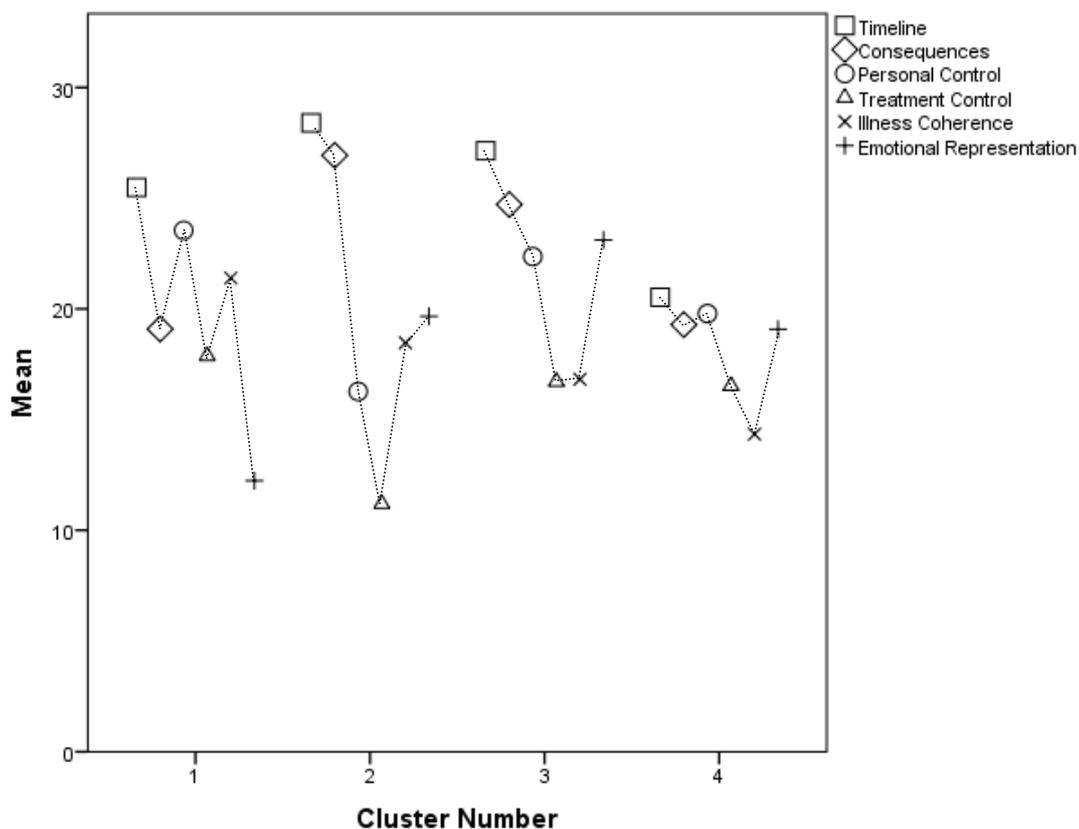
This group of 28 individuals perceive their asthma to be long-term in nature. They believe the consequences of their illness to be severe, though they do feel a lot of personal control over it. They trust their treatment to control their disease, though not quite as much as cluster one. They feel a moderate amount of understanding of their asthma but experience the highest degree of emotion about their disease.

### *Cluster 4*

Thirty eight people make up the final cluster. They perceive their asthma to be comparatively short term compared to the other three groups. They also do not believe there will be many serious consequences as a result of having asthma. They have a moderate sense of personal control but do trust in the efficacy of their treatment. They have

the lowest understanding of their asthma and experience a moderate degree of emotion about it.

Figure 1. Dimensions of the IPQ-R for the Final 4 Cluster Solution



### *Differences Between Clusters*

Additional analyses elucidated further differences between the four clusters (see Table 9). Differences between the clusters on the Asthma Symptom Checklist suggest that asthma attacks are experienced differently by each cluster and coping styles are different for each group. Levene's test for homogeneity of variances was not significant for all variables included at  $p=0.05$  suggesting variances were equal between groups. Therefore parametric tests were used for scale data (multivariate ANOVA). Categorical data were analysed using Chi square, or Fisher's Exact test where cell counts were less than five (tests

for prescription of antibiotics and leukotrine receptor antagonists). Power and effect size for multivariate ANOVA was calculated using SPSS and power for Chi Square and Fisher's Exact was calculated using G\*Power (Faul, Erdfelder, Lang, & Buchner, 2007)

#### *Cluster 1*

This group tended to be diagnosed with asthma in early adulthood and had been living with the disease for nearly thirty years. They had the least amount of unscheduled health visits (though this difference was not statistically significant). They were the least likely group to experience panic during asthma attacks. They were least likely to seek information about asthma or to restrict their lifestyles, and had the highest rated levels of positive reappraisal (though this latter result was not statistically significant). Overall they had the lowest levels of passive coping.

#### *Cluster 2*

These individuals tended to have been diagnosed in their mid-teens. Their lung function was the lowest (though not statistically significantly) and they had the highest amount of unscheduled health visits in the previous 12 months (again, not statistically significant). They were statistically more likely to be prescribed Theophylline. They experienced high levels of panic-fear and fatigue during attacks, and are the group most likely to cope with asthma by restricting their lifestyle and seeking information. Overall they reported the highest levels of active coping (non significant) and passive coping.

Table 9: Differences Between Clusters							
	Cluster 1 Mean	Cluster 2 Mean	Cluster 3 Mean	Cluster 4 Mean	Statistic	Power (p=0.05)	Effect Size
Clinical Features							
Oral steroids	48.5% prescribed	53.3% prescribed	55.6%	41.7% prescribed	$\chi^2 (3, N=111) = 1.35, p=0.72$	0.14	V=0.11
***Theophylline	36.4% prescribed	60.0% prescribed	51.9% prescribed	11.1% prescribed	$\chi^2 (3, N=111) = 16.52, p<0.001$	0.95	V=0.39
Leukotrine Receptor Antagonists	27.3% prescribed	33.3% prescribed	18.5% prescribed	33.3% prescribed	$\chi^2 (3, N=111) = 2.01, p=0.56$	0.19	V=0.13
Antibiotics	3.0% prescribed	20.0% prescribed	26.0% prescribed	13.9% prescribed	$\chi^2 (3, N=111) = 6.75, p=0.58$	0.60	V=0.25
FEV <sub>1</sub> % predicted	74.6	70.1	76.8	77.2	$F(3,90)=0.47, p=0.71$	0.14	$\eta^2=0.02$
FVC % predicted	91.5	89.0	88.2	92.8	$F(3,90)=0.35, p=0.79$	0.12	$\eta^2=0.01$
FEV <sub>1</sub> /FVC % predicted	80.6	78.6	88.1	83.4	$F(3,90)=1.37, p=0.26$	0.35	$\eta^2=0.04$
Unscheduled Health Visits	1.6	2.9	2.2	1.7	$F(3,90)=0.98, p=0.40$	0.26	$\eta^2=0.03$
Personal Characteristics							
Gender	60.6% Female	80.0% Female	71.4% Female	52.6% Female	$(\chi^2 (3, N = 114) = 4.55, p = 0.21).$	0.29	V=0.20
Age	47.9	42.4	43.7	52.2	$F(3,87)=0.220, p=0.09$	0.54	$\eta^2=0.07$
*Age at diagnosis	19.6	15.4	16.1	31.4	$F(3,87)=3.71, p=0.02$	0.79	$\eta^2=0.11$
Years since diagnosis	28.3	27.0	27.6	20.9	$F(3,87)=1.20, p=0.31$	0.31	$\eta^2=0.04$

Symptoms During an Asthma Attack							
Hyperventilation-hypocapnia	19.1	23.5	22.5	20.4	$F(3,106)=1.76,$ $p=0.16$	0.45	$\eta^2=0.05$
Broncho-constriction	36.2	39.1	40.0	37.2	$F(3,106)=2.81,$ $p=0.43$	0.66	$\eta^2=0.74$
**Irritability	15.5	19.1	20.5	18.5	$F(3,106)=5.01,$ $p<0.01$	0.91	$\eta^2=0.12$
***Panic-fear	15.7	23.8	24.4	20.7	$F(3,106)=10.86,$ $p<0.001$	0.24	$\eta^2=1.00$
*Fatigue	13.9	16.8	16.1	14.4	$F(3,106)=3.61,$ $p=0.02$	0.78	$\eta^2=0.09$
Coping Style							
***Restricting lifestyle	8.8	12.8	11.4	10.2	$F(3,106)=7.21,$ $p<0.001$	0.98	$\eta^2=0.17$
Hiding asthma	8.4	7.5	8.5	8.8	$F(3,106)=0.57,$ $p=0.63$	0.17	$\eta^2=0.16$
Positive reappraisal of asthma	11.03	9.7	9.7	10.3	$F(3,106)=1.15,$ $p=0.33$	0.30	$\eta^2=0.03$
*Information seeking	9.9	12.7	11.1	10.8	$F(3,106)=3.42,$ $p=0.02$	0.76	$\eta^2=0.09$
Ignoring asthma	8.2	9.3	9.5	9.2	$F(3,106)=1.50,$ $p=0.22$	0.39	$\eta^2=0.04$
Worrying about asthma	6.1	9.0	9.0	7.9	$F(3,106)=9.34,$ $p=0.21$	1.00	$\eta^2=0.21$
Active Coping	21.0	22.5	20.8	21.1	$F(3,106)=0.43,$ $p=0.73$	0.13	$\eta^2=0.01$
***Passive Coping	31.2	38.5	38.4	36.1	$F(3,106)=,$ $p<0.001$	0.95	$\eta^2=0.14$
* p<0.05      **p<0.01      ***p<0.001							

### *Cluster 3*

This group tended to have been diagnosed with asthma in their mid teens and to have been living with asthma for an average of 27 years. They were statistically more likely to be prescribed Theophylline and reported the highest amount of panic-fear during attacks, as well as the highest amount of irritability . They were highly likely to restrict their lifestyle to cope with asthma, but also to seek information. They used a high degree of passive coping overall. .

### *Cluster 4*

Individuals in this cluster were typically diagnosed in middle adulthood and were relatively newly diagnosed compared to the other three groups. They reported low levels of any symptom during an asthma attack . They did not restrict their lifestyles much but reported the highest levels of hiding asthma (though this latter subscale was non significant between groups).

## Discussion

This study adds to the growing literature utilising clusters or schemas of illness perceptions to understand variations in psychosocial factors in chronic illness. This was particularly useful in a Difficult Asthma sample due to the heterogeneous nature of the diagnosis (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012) and the call for more explanatory psychological research in this population (Heaney & Horne, 2012). The main focus of the study was to establish whether the IPQ-R for asthma could usefully discriminate groups of patients with different beliefs about their asthma, and to investigate the relationship between these schemata, illness-specific panic-fear and ways of coping with difficult asthma.

### *Sample Characteristics*

The mean lung function values in the sample studied indicated mild disease (Kinnear, 2002), though the standard deviation indicated wide variation from this mean, perhaps corroborating the assertion that Difficult Asthma does not always result from severe pathology (Dolan et al., 2004). It is possible that mean lung function scores were higher than expected due to patients' asthma being well controlled on current treatment regimens, given they were cared for in a specialist clinic. The population sampled is arguably engaged with their care given they were attending their specialist appointments.

Levels of panic-fear in the sample were high in accordance with previous research which has concluded higher levels of panic disorder in adults with asthma (Doyle et al., 2010; Scott et al., 2007). The present study extends previous findings by measuring levels of panic fear on a scale rather than as a dichotomous psychiatric classification; a consensus panel of Difficult Asthma experts have concluded that psychiatric diagnosis is less useful

(Prys-Picard, Campbell, Ayres, Miles, & Niven, 2006) and consideration of panic as a continuous phenomenon may have more clinical utility (Brooks et al., 1989)..

#### *Beliefs about Causes of Asthma*

The list of potential causes in the IPQ-R for asthma contains both causes of asthma and triggers for attacks or exacerbations. The cause of asthma is complex and multifactorial, but is broadly an interaction between genetic predisposition and environmental factors, for example allergens, chemicals or smoking (Murphy & O'Byrne, 2010; Pietinalho, Pelkonen, & Ryttilä, 2009). It is not clear whether participants in the present study answered the questionnaire in terms of perceived causes of asthma or perceived triggers, so it is difficult to conclude their level of asthma knowledge with respect to causes. It is known that cardiac patients have been found to struggle to differentiate causes and triggers of myocardial infarction (French, Maissi, & Marteau, 2005), and perhaps the respondents in this sample had the same difficulty.

It is interesting to note that 70% of respondents cited at least one main cause for their asthma that was not supplied in the IPQ-R questionnaire, with 29% of respondents ranking a non-supplied cause as the highest perceived cause of their asthma. This further corroborates the notion that people hold idiosyncratic beliefs about their illnesses that do not always fit with the constructions of health professionals (Ogden et al., 1999; Ogden & Flanagan, 2008). It further highlights the need for care to be tailored to individuals rather than based on whole population means (Department of Health, 2009; Suhonen, Valimaki, & Leino-Kilpi, 2002): permitting patients to set the agenda and specify their priorities, with clinicians providing a framework that allows patients to express these individual beliefs (Middleton, McKinley, & Gillies, 2006).

It is acknowledged that with time-pressured consultations, tailoring care provides a significant challenge to clinicians. The current study may be a useful step in bridging the gap between the one-size-fits-all approach of “cookie cutter care” (George, Campbell, & Rand, 2009) and the challenge of accommodating the needs of each individual patient.

It is also worthy of note that amongst those causes supplied in the questionnaire, ‘stress or worry’ ranked third after ‘hereditary’ and ‘pollution’ as a perceived cause of asthma. This clearly indicates that psychosocial stressors are of high importance to this population of patients with Difficult Asthma, regardless of the accuracy of this belief in terms of medical research on the causes of asthma (Murphy & O’Byrne, 2010). It suggests that approaches to managing asthma should emphasise psychosocial issues as well as biomedical factors; progress in this area may be limited until psychosocial outcomes are given equal weighting with biomedical factors in the discourse on clinical effectiveness (NHS Information Centre, 2010)

*Research Aim 1: How do the illness beliefs of individuals with Difficult Asthma vary in relation to illness-specific panic-fear symptoms?*

Illness specific panic-fear correlated positively with the IPQ-R scales *consequences*, *emotional representation* and *timeline cyclical*, and negatively correlated with *illness coherence*. These results have face validity; those who believe the consequences of their illness are severe, feel emotional about their illness and feel they do not understand their illness might understandably respond with fear and panic. It is also possible the relationship indicates that those prone to anxiety may catastrophise and process information about their disease less effectively. With regards to *timeline cyclical*, panic-fear is increased if

people feel their asthma is unpredictable (rather than believing it is always present).

*Timeline* and *consequences* have been found to predict panic in COPD (Howard, Hallas, Wray, & Carby, 2009) and *emotional representations* have been found to predict anxiety in adolescents with asthma (McGrady et al., 2010) although this study did not replicate the finding that *control* is related to anxiety in asthma. This is perhaps because of the different age and severity of asthma of participants and the differences in outcomes between generalised anxiety and illness-specific panic-fear (Feldman, Siddique, Thompson, & Lehrer, 2009). The high levels of reported panic-fear in this sample add weight to the assertion that psychological assessment is “absolutely necessary” in difficult asthma (Pryspicard et al., 2006).

*Research Aims 2 and 3: How do illness perceptions and illness-specific panic-fear relate to how people cope with difficult asthma? Do illness perceptions and panic-fear relate to measures of clinical severity?*

Previous research has highlighted the need for studies that investigate coping and psychological distress in asthma (Barton, Clarke, Sulaiman, & Abramson, 2003) with a need for the perspective of the patient to be understood in poorly controlled asthma in order to empower self-management (Heaney & Horne, 2012). The hypothesis that illness perceptions and panic-fear influence coping was tested using regression analysis; the association being significant for passive styles of coping but not active coping. The effect of illness perceptions and panic-fear on passive coping was significant, with a large effect size and robust power. The largest predictors of variance in passive coping were higher perceived *consequences* and higher amounts of panic-fear. Direction of the relationship could not be established through these methods, so it is uncertain whether passive coping

leads to higher perceived consequences and higher panic fear, or vice versa, or whether the relationship functions as a 'feedback loop' (Opolski & Wilson, 2005).

These results suggests that passive coping and active coping may reflect different strategies and it is appropriate to address them separately (Aalto, Härkäpää, Aro, & Rissanen, 2002). It is particularly interesting to note that active coping and passive coping were not inversely correlated in this study (indeed they were not significantly correlated at all), which further corroborates the assertion that they are different entities; high use of active coping (often seen as more adaptive by clinicians) does not preclude the use of additional passive coping strategies.

The use of passive coping strategies linked with high amounts of panic (i.e. worrying about asthma but ignoring and hiding it) in participants in this study has interesting implications for clinical consultations; it suggests that patients may not be forthcoming with their concerns about asthma. Clinicians may need to actively raise psychosocial issues with patients to address this.

Lung function may be seen as a proxy measure of coping with asthma (Cooke, Myers, & Derakshan, 2003); if lung function is poor (low) it could be assumed that asthma is being coped with less effectively. Illness perceptions, when studied in the whole sample and not in individual clusters, did not have a statistically significant relationship with lung function (FEV1) when analysed using linear regression. Post-hoc power analysis suggested that the regression did not have sufficient power to reject the hypothesis that FEV1 could be predicted by illness perceptions and panic-fear, despite the sample size calculated from *a priori* power analysis being achieved.

Acute admissions for asthma exacerbations are known to be predicted by levels of panic (Kolbe, Vamos, Fergusson, Elkind, & Garrett, 1996) and the lack of observed fit between illness representations, panic-fear and a common clinical measure of lung function suggests that panic may not be related to severity of symptoms; i.e. that there is an incongruence between what patients and doctors base their management decisions on respectively. However, the lack of an observed association should be interpreted cautiously due to the analysis being underpowered; meta-analysis of illness perceptions research has concluded that the dimensions of the SRM (which the IPQ-R measures) are robust predictors of clinical outcomes in a range of illnesses (Hagger & Orbell, 2003).

The results of the regression analyses suggest that considering illness perceptions in a broad population may be useful in predicting those who use passive coping styles but this does not necessarily translate to changes in lung function. The relationship of psychosocial variables to biomedical outcomes is likely to be complex and a finer grained analysis may have more utility. It has been acknowledged in previous studies that coping is a complex phenomenon, which transcends individual personality characteristics and encompasses situational and environmental factors (Martz & Livneh, 2007); different coping strategies are likely to be useful in different situations (Barton et al., 2003).

*Research Aim 4: Are clusters of illness perceptions more useful than individual dimensions in understanding Difficult Asthma?*

Illness perceptions are increasingly understood as schemata or patterns of beliefs, rather than individual beliefs held in isolation, and predict clinical and psychosocial

outcomes in a number of chronic illnesses (Clatworthy, Hankins, Buick, Weinman, & Horne, 2007); the current study was able to add to this body of knowledge.

K-means cluster analysis of the sample based on illness perceptions (measured using the IPQ-R for asthma) yielded a four cluster solution with all dimensions being statistically significantly different across clusters. Not only did individuals in different clusters vary in their scores on the IPQ-R for asthma, they also varied on age at diagnosis, prescribed medication, symptoms during an asthma attack and coping styles. The existence of different groups of people in the total sample supports the UK asthma guidelines which state that patients with Difficult Asthma are a heterogeneous group (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012). It therefore makes sense to address these groups of people differently rather than treating them as a homogeneous 'Difficult Asthma' diagnostic category. The results suggest that people with different clusters of beliefs have different ways of coping with their disease, in line with suggestions from previous research in rheumatic disease (Pimm, 1997) and calls for illness cognitions to be incorporated in the understanding of coping strategies in chronic illness (de Ridder & Schreurs, 2001). The clusters were useful in detecting differences in *information seeking*, an active coping strategy, as well as passive coping styles overall and the use of *restricting lifestyle*. This coping style is complex as restricting certain aspects of lifestyle (such as smoking) may be adaptive, though evidence for avoidance of other triggers in asthma is equivocal (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012). Due to the complexity of this issue, people who restrict their lifestyles to cope would perhaps be more likely than others to need an individualised approach that took account of their unique circumstances. If future research replicates the findings regarding clusters and coping strategies and finds them to be stable, this could be useful in tailoring patient

pathways and interventions; perhaps by maximising patients' preferred coping style or working to increase clinicians' understanding. The presence of different clusters of illness perceptions may go part way to explaining the equivocal results of psychological interventions for asthma (Smith, Mugford, Holland, Noble, & Harrison, 2007; Yorke, Fleming, & Shuldham, 2006), as the variance in beliefs, coping strategies and levels of negative affect between clusters suggests different approaches would be needed for each group. Further research elucidating which interventions are most effective for each cluster would have potential to significantly reduce the disease burden of Difficult Asthma. However, this argument can be extended beyond the development of interventions for individuals, which assumes the burden of responsibility is solely on the patient. The 2011 president of the Royal College of General Practitioners commented that the belief that patients are rational and reasonable consumers of health care is a "politically correct pretense" (Heath, 2011; p1). She emphasises that quality care occurs within the context of dependable, trusting relationships with clinicians who are sensitive to individual needs and circumstances, not as a result of the individual agency of the patient (Heath, 2011). It is intended that the results of the present study be interpreted within this philosophy, and that the potential development of interventions be as focused on the clinician as on the patient.

There was statistically significant variance between the clusters in reported levels of panic-fear during an asthma attack with clusters that reported the highest levels of panic also using more passive coping strategies. This association has previously been linked with higher asthma morbidity (Lehrer, 1998). As the clusters in the current study did not significantly differ on lung function, this contradicts Lehrer's findings, though the analysis lacked the statistical power to be conclusive.

The relationship of psychosocial outcomes to biomedical markers of disease severity is clearly a complex one (Ritz, Simon, & Trueba, 2011; Wang et al., 2011). Cluster analysis allowed for a more detailed exploration of these issues than linear regression. By comparing clusters, it was concluded that there are significant variations in prescribing, illness beliefs, coping strategies and levels of negative affect, but no statistically significant variation in lung function. This suggests that if psychosocial variables are linked with lung function in asthma, there may be multiple routes to poor disease outcome. Again, the underpowered analysis precludes many conclusions being drawn about this result.

#### *Interpreting the Clusters*

##### *Cluster 1: Compliers*

The first cluster appeared to be compliant with medical models of illness; they accepted their illness would be around for a long time, perceived few consequences as a result of asthma, but had high perceived personal control and trust that their treatment would control their condition. They felt they understood their disease and did not experience high levels of emotion about it. Yet it is interesting to note that these patients were no more likely to use active coping strategies, were the least likely to seek information about their disease and did not have significantly better lung function than other clusters. It could tentatively be concluded that these patients have internalised the messages of health professionals, but that this does not necessarily translate to better lung function. They could therefore be termed *compliers*; useful future research could assess whether they are indeed more adherent with medication. They seem better able to contain their distress during attacks, scoring lowest on the negative affective subscales.

##### *Cluster 2: Reactive Strivers*

Individuals in cluster two were particularly marked by their high degree of emotional representation of asthma combined with their low perceived control over extremely serious perceived consequences; either by their own means or through treatment. They experienced a high degree of negative affect during attacks and coped through a high degree of information seeking and restricting their lifestyles; in fact they rated all coping strategies the highest of all four clusters. This suggests they are striving to find ways to cope with asthma. It is particularly noteworthy that their lung function was not significantly worse than other groups'. It is unclear from this study whether this is because their medication is controlling their asthma symptoms. This group were more likely to be prescribed Theophylline despite equivocal lung function; previous research has found that panic can explain variances in physicians' prescribing choices (controlling for lung function) (Carr, Lehrer, & Hochron, 1992) though it is unclear in the present study whether this explains differences in prescribing.

#### *Cluster3: Survivors*

This group of patients were similar to *reactive strivers* in many ways, with high emotion and low perceived understanding, but a higher degree of perceived ability to control their asthma through their own sense of personal control and through using treatment. They too reported using high levels of coping strategies and reported high amounts of symptoms experienced during attacks (both affective and somatic).

#### *Cluster 4: Ambivalent*

These individuals with adult onset asthma felt they understood their asthma the least (accompanied by a fairly low degree of information seeking) and did not believe their condition would be as long term as other groups, also perceiving fewer consequences. Considering this, their degree of emotional representation was surprisingly high, though

this was not reflected in the amount of negative affect reported during attacks. It is possible that being diagnosed later in life means these patients have not yet organised their beliefs about their illness into a coherent structure. However, illness perceptions research claims that these beliefs are established quite soon after diagnosis (Petrie & Weinman, 2006) and this group did not significantly differ from others on years since diagnosis.

Previous research into asthma has aimed at establishing clusters of asthma based on biomedical information, or 'asthma phenotypes' (Haldar et al., 2008). One way the authors conceptualised the clusters was in terms of the extent of reporting of asthma symptoms correlated with biomedical markers of asthma severity. Where the two measures were congruent (i.e. high symptom reporting and clinical markers indicating high severity, or low reporting and low severity), they named this 'concordant asthma'. This study did not find variation in lung function between groups but did find differences in reported levels of symptoms (measured by the Asthma Symptom Checklist) though the non significant results did not have sufficient power to determine that there was no difference between groups. Additionally, Haldar and colleagues' study (2008) included participants at lower steps of the BTS asthma treatment ladder; presumably resulting in wider variation in lung function and other clinical measures of severity in the sample, whereas the current study only looked at poorly controlled asthma. Future research could aim to integrate these two cluster studies to establish whether clinical asthma phenotypes are related to clusters of illness beliefs and psychosocial outcomes.

#### *Limitations and Future Research*

Although the study develops the understanding of psychosocial issues in difficult asthma, a number of limitations mean the results should be interpreted with caution. This

cluster analysis study is an initial step in re-conceptualising illness perceptions in asthma; though future research would need to replicate the findings in other Difficult Asthma populations to exclude any potential bias (for example, there may be factors within the clinic from which participants were recruited that contribute to some of these outcomes).

The results may not reflect those with difficult asthma that are managed in primary care; although a coherent cluster solution was found, cluster analysis techniques are designed to always find a significant result, so this can not be taken as conclusive evidence of the existence of the four clusters. Additionally, the dimensions that distinguish the four clusters are measured on a continuous scale, so cluster membership may not be as discrete as the cluster solution suggests; it merely estimates the 'best fit' for each individual.

Results from one-way ANOVAs demonstrated statistically significant differences between clusters on several psychological, demographic and clinical variables. However, some results were not statistically significant but lacked statistical power to conclude there was truly no difference between groups. It was not possible to calculate a sufficient sample size using *a priori* power analysis during the planning stage of the study, as it was not known how many groups would emerge from the cluster analysis (this information is needed to perform a power analysis for a one-way ANOVA). Now that this early stage research has suggested the existence of four clusters in a Difficult Asthma population, future research will be able to use these findings to calculate sample sizes large enough for statistical power in ANOVA results.

The instability of some of the illness perceptions subscales may call in to question the final cluster solution. In particular, the *identity* subscale was not entered in to the final cluster analysis due to the amount of missing data. Future studies should incorporate this

data to establish whether this affects the cluster structure. The *timeline cyclical* scale of the IPQ-R did not vary sufficiently amongst participants to be useful in distinguishing clusters, suggesting that patients with difficult asthma tend to have quite high belief that their illness is cyclical (unpredictable) in nature, and this does not vary between clusters. This will be an important finding to replicate in other Difficult Asthma populations as the only scale of the IPQ-R not varying between clusters.

The cross-sectional design of the study only provides a representation of around half of the attendees at one Difficult Asthma Clinic over a four month period. To give more weight to the findings, participants could be recruited from several clinics in addition to recruiting participants with Difficult Asthma who are managed in primary care. A longitudinal approach could be taken whereby illness perceptions were assessed at different time points along the asthma trajectory to assess whether clusters are fixed, stable entities or whether cluster membership changes. It would be particularly interesting to see whether clusters change over time if asthma severity becomes worse, or in response to interventions.

The research is limited to the extent that no information was collected concerning smoking history; this could usefully be included in future studies considering the strong links between smoking, asthma and exacerbations (Pietinalho et al., 2009; Vozoris & Stanbrook, 2011). Smoking is relevant to the topic of illness perceptions, as it is a patient behaviour related to beliefs about personal susceptibility, personal control and causes of illness (Bjarnason, Mikkelsen, & Tønnesen, 2010; Eiser, Eiser, Gammage, & Morgan, 1989; Ogden, 2007) and is routinely investigated in asthma consultations (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2012). Future studies could assess whether rates of smoking differ across clusters.

Measures of lung function used in this study did not differ across groups and hypotheses have been postulated to explain this finding. A limitation of using spirometry measures (FEV1, FVC and FEV1/FVC) is that they are dependent on effort and measure confounding factors in addition to lung function (for example co-ordination, technical proficiency and verbal encouragement from the clinician (den Otter et al., 1997; Townsend, 2011). A wide range of clinical measures of asthma severity can be used if researchers have the knowledge to interpret them (Prys-Picard et al., 2006). Additional clinical variables were not measured in the current study due to lack of medical expertise in the research team and due to the measures being less readily available for all patients. A useful extension of the spirometry markers used in the current study would be their improvement in response to bronchodilators; a marker of asthma control (Kinnear, 2002).

Panic-fear appeared to be robustly associated with a number of variables, though as previously discussed the scale validity may indicate the items are rather highly correlated with each other (Streiner & Norman, 2008). These results should perhaps be interpreted with caution until future studies can replicate the findings. As a caveat to this many of the panic-fear results were in accordance with previous research on anxiety and panic in asthma, suggesting the results are robust.

The four clusters did not differ significantly on their use of active coping overall (information seeking and positive reappraisal), or positive reappraisal, but did differ on their use of information seeking. This suggests that interventions which seek to increase positive reappraisal (such as cognitive behavioural approaches) could perhaps be targeted for all patients with Difficult Asthma; further research is needed to corroborate this deduction and the four clusters established in this research could be used to test this assertion. If the four clusters are used to tailor care or compare intervention outcomes, an

intermediary step is needed whereby IPQ-R thresholds are established for cluster membership.

It is important to acknowledge that using illness perceptions as a framework for understanding the beliefs of those with chronic illness enables understanding of some facets of patient experiences. The forced-choice format of the questionnaire does limit this to an extent, and should be complimented by more qualitative explorations of the experience of managing asthma (such as the work of Jones et al. (2008); Loignon, Bedos, Sevigny, & Leduc (2009); Steven et al. (2004). A useful supplement to this research would be a qualitative exploration of the challenges and frustrations of clinicians working with Difficult Asthma populations to more fully contextualise the current study's findings and underpin truly dyadic and collaborative care

### *Conclusions*

This cluster study adds to the understanding of illness perceptions, panic-fear and coping in Difficult Asthma. It established the existence of four clusters; *compliers*, *reactive strivers*, *survivors* and an *ambivalent*, late-onset asthma group. The results suggest that the different groups experience significantly different levels of negative affect and cope with their asthma using different strategies, despite having similar levels of lung function. This may explain the equivocal results previously found in psychological interventions for asthma. A useful direction for future research would be to corroborate the existence of the clusters in broader Difficult Asthma populations and to investigate differences between other asthma groups, across the illness trajectory and in response to interventions. This study is a useful first step in tailoring psychological interventions for patients with the heterogeneous diagnosis of 'Difficult Asthma' and increasing clinicians' understanding of the psychological aspects of the diagnosis.

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## Critical Appraisal

### *Developing the Research Idea*

I first became interested in the psychological aspects of asthma when working as an assistant psychologist in an IAPT primary care mental health service. The dominant model for low intensity interventions was Cognitive Behavioural Therapy using guided self help. With a focus on mild to moderate anxiety and depression, I would often receive referrals to guide people through a self-help programme for panic disorder. This would teach people to reappraise the ‘faulty negative automatic thoughts’ they were having, and to rebalance their blood gases by a technique known as re-breathing (breathing in to a bag, or your hands, so that blood carbon dioxide and oxygen levels returned to normal after hyperventilation). Very close together, I received two such ‘panic disorder’ referrals for people with asthma. Two things became clear very quickly; firstly, that re-breathing during panic was not an option, due to the risk of death, and secondly, that “I could die if this doesn’t stop soon” was a very real possibility for these two individuals rather than being a ‘faulty cognition’ in need of reappraisal. Perhaps just as importantly, both people had difficulty distinguishing between a panic attack and an asthma attack, due to the similarity of symptoms (and even cognitions). A search of the literature did not yield a CBT protocol for panic disorder in asthma, despite there being recognition of the high prevalence of anxiety in people with asthma.

I kept this interest in the interplay between physiological, emotional and cognitive factors in chronic illness through to starting my Doctorate in Clinical Psychology. After approaching my research supervisor in the first year I was pleased to discover that a local Consultant in Respiratory Medicine was keen to develop a project involving psychological

dimensions in a specific asthma population – those with severe or poorly managed asthma ('difficult' asthma). I also discovered a paradigm for understanding the relationship between cognitions and chronic illness – illness perceptions research.

Negotiating a topic area to focus on was a careful balance between my own interests, what would be useful to the local respiratory team and what would be feasible for a doctoral thesis. Initially, there was greater focus on the concept of adherence to medication, as this was thought to be a large explanatory factor in difficult asthma. This was also the topic of the first year systematic review, which indicated some overlap with anxiety in asthma. However, after developing a project proposal that involved pharmacy checks for adherence (number of prescription written vs. number of prescriptions collected) as well as self-reporting, it was felt that this was too complex and time consuming for a doctoral thesis. It could also have presented a significant challenge in getting the project through NHS Research Ethics (for example, the possibility of a mismatch in self-reported and pharmacy-reported adherence, consent to check up on people in this way). It would have also required considerably more input from the Difficult Asthma team and there were insufficient funds available to reimburse them for this contribution. After discussing the pros and cons with the consultant physician and my supervisor, it was decided that it was more practicable for adherence not to be measured and the focus would be on the other psychological variables suggested – illness perceptions, panic-fear and coping. This was a satisfactory compromise between my own interests, utility to the clinical team and feasibility for a doctoral thesis.

This also required reconsideration of a topic for the literature review. In terms of my development as a researcher, I developed a qualitative review of the literature as these were methods in which I lacked experience. This part of the thesis required considerable

development of my knowledge as I had previously worked mainly with quantitative methods. Choosing a topic for the literature review was difficult, as many initial searches proved topics to be either too broad or too narrow to yield sufficient papers for a review.

Ideally the research project would have explored illness perceptions from a longitudinal perspective. The clinical aspects of my training had taught me to look at things from a broad lifespan perspective; from the origin of difficulties, to the maintenance of those problems and the importance of considering the reciprocal roles that powerful others played in maintaining health. It was frustrating to have to limit myself to a cross-sectional design but this was necessary so that the project could be feasible within the time and resource constraints. I was able to reflect that research happens gradually, building on previous studies and improving upon limitations. Although it is tempting to measure large sets of variables and run multiple analyses, this is not a manageable or rigorous way to conduct quantitative research; it is preferable to focus on a specific research aim and consider the results before moving on to other questions. I was thus able to conclude that all research has constraints and limitations, yet this does not prevent it being a valuable contribution to the knowledge base.

#### *Obstacles, Barriers and Facilitators*

I initially had some difficulties obtaining approval for the study, as I was advised by the Local Research Ethics Committee to submit the project for proportional review – a level of scrutiny appropriate for research which is non-invasive and unlikely to raise too many ethical controversies. I was pleased about this, having had previous experiences of submitting small scale non-invasive questionnaire studies to the same level of scrutiny as clinical trials of investigational medicinal products and been frustrated with the length of time and justification that this took. However, the project did not pass through at the

proportional review stage and needed to be reviewed by a full committee, adding additional delays to the process rather than making it smoother. The committee cited uncertainties about time given to decide on participation, lung function data, data storage and the right of participants to withdraw as necessitating a full review. I learnt from this that clarity is essential in writing research protocols and ethical applications, as I had believed this information was clear in the application.

In addition to requesting NHS Ethical Review I was also required to obtain permission to proceed from the Research Management and Governance department of the Acute Trust from which I was recruiting. I understood that this was necessary to safeguard the patients of the Acute Trust and to ensure there would be no adverse clinical or financial implications for the Trust. However, this involved obtaining signatures from a number of different managers, all of whom I needed to meet with to explain the project.

This caused a delay I had not anticipated, even with my previous experience of being a research assistant both within the NHS and within a University setting. Due to this experience I was able to see the importance of developing relationships with these managers in order to engage them in the research, yet I had to balance this with the desire to start data collection as soon as possible and to stick to my deadlines. Unfortunately this delay meant that when I was ready to start recruitment, the functioning of the clinic had changed so that it no longer matched my protocol. There had initially been an agreement that the clinic nurses would introduce the study and distribute Participant Information Sheets when patients attended for a pre-clinic assessment, thus meeting the ethical requirement for 24 hours to pass between patients being introduced to the study and deciding to take part. However, the clinical team had decided that they would reduce the number of pre-clinic assessments, so it was no longer viable for all patients to be contacted

this way. It was necessary to submit a notice of amendment to the Research Ethics Committee so that patients could be contacted by letter prior to their clinic appointment, resulting in further delays.

Once clearance was granted I was grateful for the help I received from administrators, clinicians and research nurses who worked in the clinic for helping the recruitment phase of the study to be as efficient and speedy as was practicable. The department was very research active and patients were used to being approached to take part in studies. Many were keen to take part and often said they were pleased that psychological aspects of asthma were being studied, though some voiced frustration at the 'forced choice' format of the questionnaires and would have preferred more qualitative style interviews. This meant that despite my initial anxieties about administrative delays, recruitment of participants was quite straightforward and was completed well within time limits. This was with the exception of one extra clinic I recruited from in mid April to increase the numbers needed for statistical power for the linear regression, after realising I did not have enough participants for this particular analysis. Thankfully the effort I had put in early on in setting up a system with the clinic and developing relationships with clinic staff meant that this extra data collection went smoothly.

It was challenging to work within the constraints of an NHS that is continually subject to enhancing clinical and financial efficiency. Despite their willingness to support me, staff were limited in their capacity to assist with research tasks. For example, there was limited administrative support available to help with posting information sheets to patients and obtaining lung function results from medical notes. I became aware of the importance of developing relationships with teams in ensuring the success of research in the NHS, as any help I received was largely due to good will. I was able to reflect on how well clinical

psychology training had prepared me for these more subtle aspects of conducting research in the health service by developing my interpersonal skills and proficiency in multidisciplinary team working.

### *Limitations of the Research*

Throughout the course of the project I learnt to keep in mind my tendency to become very enthusiastic about results, so that I did not over-interpret the meaning of them. It was necessary for me to acknowledge a number of limitations with the study in order to keep this tendency in check. The study was conducted in a single centre. This was partly because I was fortunate enough to make links with an interested consultant early on, which meant I did not have to search for alternative centres. In addition to this, 'Difficult Asthma' is a highly specialist field, and there are a limited number of dedicated clinics in the UK. It is important to acknowledge that there are many more people with Difficult Asthma seen in other clinics, in primary care or not engaged with services, who may not be represented by these results. This issue is also pertinent when considering the exclusion of individuals who were not fluent readers of English. Anecdotally, a number of people from ethnic minority backgrounds declined to take part in the research. Some stated that they would not be able to understand the questionnaire, though of course it is not clear whether they would have participated if the questionnaire was translated in to their first language. Difficulty in recruiting participants from ethnic minorities in health research is a recognised phenomenon (Yancey, Ortega, & Kumanyika, 2006), and awareness of this made me feel less like this was a personal failing of my research and curious about what could be done to improve participation.

One weakness of the study is that some analyses did not have sufficient statistical power. Particularly where this concerned non-significant results, this was a gap in my

knowledge about statistics and required a lot of extra reading to understand the implications of this properly; I also enlisted the help of colleagues and statisticians to understand this complex topic.

A further limitation of the research project was the fact that data were not collected concerning smoking history. Through talking to staff in the respiratory team as well as personal friends who work in medicine, I now realise this may be quite a significant omission from the research as smoking is understandably a very important issue in respiratory disease. This perhaps reflects the difficulty of doing psychological research in clinical areas that are less familiar, as there is a considerable amount of clinical experience that can inform research.

The inclusion of patients with co-morbidities in the sample was a difficult decision to make from a methodological and practical point of view. Excluding those with co-morbidities may have made the project more rigorous in terms of controlling for extraneous variables; however Difficult Asthma is such a complex diagnosis that few individuals would have had no co-existing conditions. This would not only have made the research less clinically applicable but would have resulted in very low participant numbers. After consideration, clinical utility and project completion (as well as sufficient statistical power) were judged as more important. Additionally, illness perceptions research is beginning to focus on multi-morbidity as a significant area of study (Arputharaj, 2012)

During the data collection phase of the study a number of participants expressed a desire to talk in more depth about psychological aspects of asthma, with some voicing dissatisfaction with the limited response format offered by the questionnaires. My natural response would be to help people talk through their experiences; I was also interested in the subjective experience of the patient; information gained through clinical encounters that

adds vital context to the results of quantitative scale research. I therefore had to be quite mindful of boundaries as I was there as a researcher and not a clinician. The SRM may be a useful framework for understanding illness perceptions from an empiricist, quantitative paradigm but it must be balanced with more subjective methods and contextual understanding.

I too acknowledged the limitations of the questionnaires in elucidating the experience of coping with difficult asthma. The asthma symptom checklist did not allow participants to specify coping strategies they used outside of those suggested on the questionnaire. As discussed in the research report, the *identity* subscale of the IPQ-R was poorly filled in many participants seemed not to understand the instructions for these items (the second column was often not filled in). This taught me a valuable lesson about giving clear administration instructions, checking understanding and checking the questionnaires thoroughly when they were completed and returned.

### *Personal Reflections, Lessons Learnt & Personal Development*

Having worked in research environments before starting training, it was interesting to reflect how the DCLinPsy thesis was different to the work I had done before, and how I have evolved as a researcher. My previous experiences of the NHS Research Ethics system prepared me to an extent for the amount of work required, though I felt that I was better able to contain my frustrations about the process this time as I knew what to expect. From working with clinical teams to recruit participants in my role as a research assistant (RA), I was aware just how crucial it was to engage staff to ensure success at the recruitment stage. I developed this knowledge by liaising with previous trainees who had conducted projects in medical settings about the best way to engage teams. I therefore made sure that I

involved the team as early on as possible and developed a project that would be useful to them in order to keep them interested in the research, even changing my research protocol at a late stage (before submission of the proposal in the second year) to bring the project in line with departmental research.

As I learned more about systemic theories during University lectures, I began to reflect on the place of the research project in the health system. I became aware of the dangers of individualising distress and the tendency for medical patients to be referred to psychology to solve problems through interventions with individuals, rather than to reflect on systemic causes of problems. I strived to keep this in mind when interpreting the results; I did not want the results to appear to indicate personal pathology and wanted to highlight questions around how patients develop illness perceptions and whether they are supported to self-manage chronic illnesses. I believe that the literature review helps to maintain this balance within the thesis.

The clinical experience I gained from my first and second year placements meant I was much more confident with recruiting patients than I was when I was an RA, which I believe contributed to successful recruitment of the desired sample. I recalled the difficulty I had as an RA relying on busy clinicians to recruit participants and return questionnaires, therefore as far as possible I designed a project where I could do the majority of the work myself. This made recruitment more straightforward as I could organise my own schedule, however it did place a large burden on me at a time when I was also writing my third year literature review and starting a new clinical placement. I learnt the importance of self care and being organised, as well as prioritising. This was something I had previously found difficult; I had always given priority to my clinical placements and been reluctant to take time off or to turn down clinical opportunities, however negotiating my workload was

essential if I was to prevent burnout and stay on target with my thesis. This was something I had to adjust to early on, as even in the proposal development stage of the project there were many other assignments to be completed in tandem.

During the third year I had a placement working with children with physical health conditions, which really helped me to grapple with the issues of health psychology I was working with in my research, especially when interpreting the themes in my literature review. It was not until I had gained experience on this placement that I was able to make the link between the literature review topic (subjective experiences of managing asthma) and the research project variables measured. I learnt the important relationship between research and clinical practice, as my clinical work was invaluable in setting my research within a psychological practice context. Similarly, the reading and literature reviewing I did in the course of my thesis helped me to understand a number of the concepts that came up in therapy and when working with clinicians on placement. For example, when working with a teenager who was struggling to come to terms with her diagnosis of diabetes, she talked of her confusion at being expected to follow a treatment regimen when she had not been involved in the decision making process; this fit almost exactly with the theme '*not just to be told it, but I need to know why*' from the literature review. She also expressed panic at finding herself in hospital and upset at realising she would have diabetes forever, which she had not previously known; this put the IPQ-R *timeline* scale in to a real clinical context for me. Knowledge of the literature helped me normalise many of the experiences of clients with physical health problems and chronic illnesses. Working on this placement alongside conducting the research cemented my interest in working in the field of health psychology after qualification.

During the write up stage of the project a number of anxieties emerged for me about the design of the project and whether my project was good enough to pass the Doctorate. It was comforting during this time to read a study guide, 'authoring a PhD' which reassured that this was a common experience during the write up phase, and was in fact positive as it signified that a student's learning had come to the point where they were able to critically reflect on their work.

### *Epistemology*

Conducting the literature review was particularly challenging for me in terms of epistemology. My experience in research has always been from a positivist or post-positivist paradigm, so it was a steep learning curve for me to understand more constructionist perspectives. These were concepts I struggled to learn during research methods lectures and required quite a shift in thinking for me. However, I believe the extra effort I put in to understanding these concepts was an invaluable part of developing a rounded research experience.

There are certain assumptions inherent in quantitative methods that do not make them suitable for all kinds of research. Modern healthcare is grounded in positivist science, which takes the epistemological view that there are singular truths that can be observed or measured in order to determine cause and effect relationships. This works well in the natural sciences where subject matter tends to behave in ways that are roughly predictable and objectively observable. There is little argument that this approach has brought about advances in healthcare that have improved and saved many lives (Gray, 2009). However, when human beings are considered beyond their biology and within their social contexts, behaviour becomes less logical and predictable and less objectively measurable (Goldenberg, 2006). I learned that qualitative research seeks to explore subjective

experience, rather than observe cause and effect. Inherent in this approach is the understanding that all experiences are unique due to an infinite number of differences in context (including historical context). Therefore, the aim is not replicability (an impossibility), but dependability; being open and transparent about methods used to obtain results so that others may evaluate the process and being aware of potential sources of bias. There is an acknowledgement that the effect of the researcher on the research process prohibits identical results from being obtainable, rather than striving for objectivity, in which a 'perfect' experimental design excludes all external sources of influence on a cause-effect relationship. After learning about the different quality criteria for qualitative research (Lincoln & Guba, 1985) I became aware of the highly rigorous nature of qualitative methods due to the sensitivity to context and researcher bias; this was quite different to my previous views on qualitative research.

With regard to my literature review, I was particularly concerned that the qualitative methodology may make the project less acceptable to the medical team, whom I presumed would come from more of an empiricist stance. This was particularly challenging as the findings of the literature review were quite negative about the attitudes and skills of health professionals. This has made me reflect on my skills as a future psychologist in engaging with teams that may come from a different theoretical perspective, and how to engage them with psychological ideas. Although I was able to reflect on my learning about quality in these methods, it is a challenge I am yet to face fully, as much of the feedback of the thesis will happen after submission.

As I developed more of an understanding of the limits of the empiricist paradigm, it became difficult for me to maintain belief in the worth of my research and its validity as 'science', and even my role as a 'scientist practitioner'. I was initially anxious about the

literature review and the empirical project coming from different epistemological positions, but after completion of the project I felt that they were not so much juxtaposed, but complemented each other as different aspects of the topic which each made a valid contribution to the field.

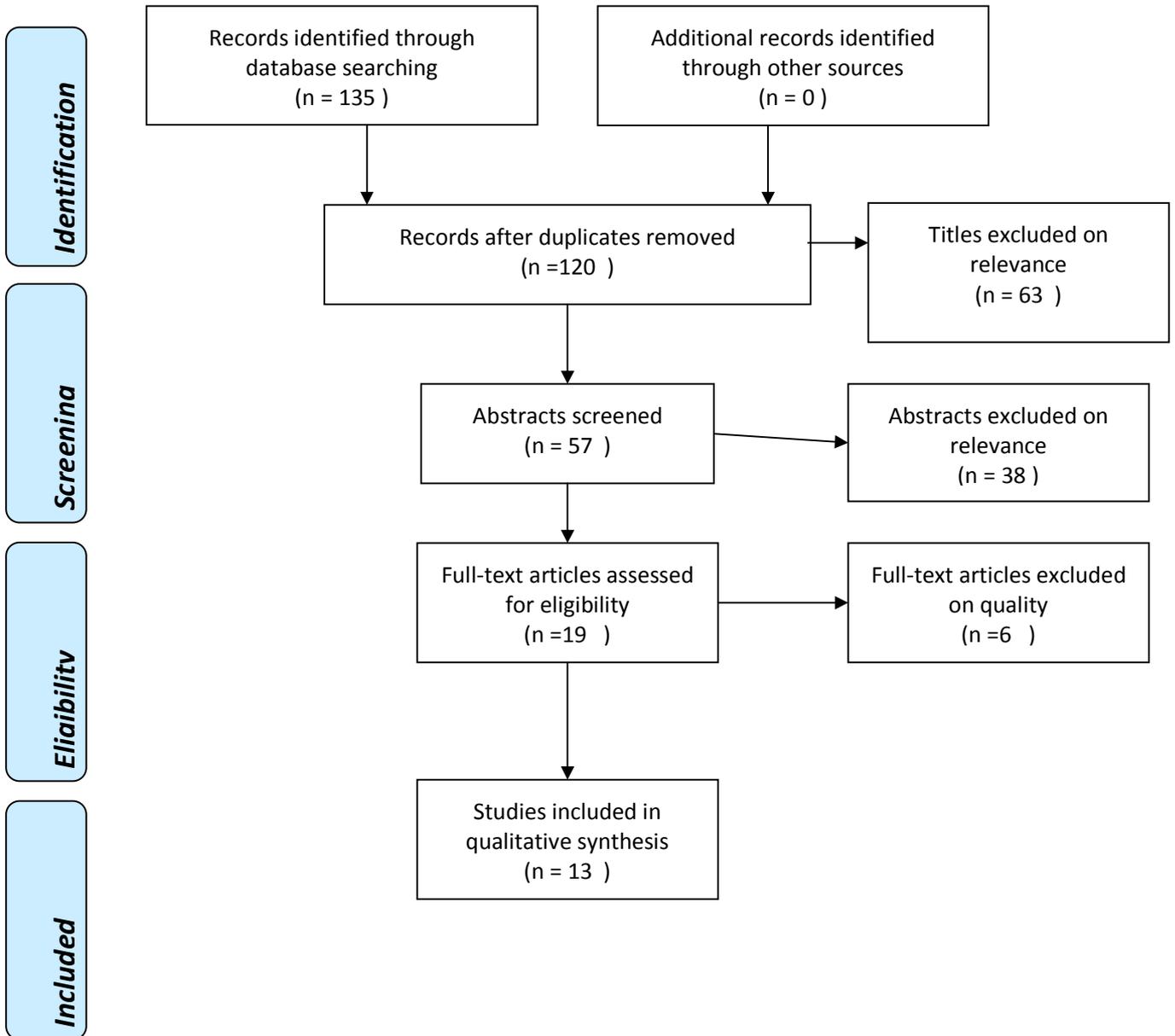
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Appendix A: Search Terms and Databases Used

<b>Database</b>	<b>Search Terms</b>	<b>Search Years</b>	<b>Number of Results</b>
PsycINFO	asthma AND (manag* OR cope* OR coping) - Refine by "adult" - Refine by qualitative study - Refine by peer reviewed journals	1967 -	31
Medline	asthma AND qualitative methodology AND (manag* OR cope* OR coping) - Refine by "adult"	1966 -	27
Web of Science	Topic=(asthma) AND Topic=(qualitative) AND Topic=(manag* OR cope* OR coping) - Refine by "adult"	1970 -	77

Appendix B: Flow Chart of Paper Selection



## Appendix C: Discussion of Quality Criteria

According to Dixon-Woods (Dixon-Woods, Shaw, Agarwal, & Smith, 2004), what constitutes a ‘fatal flaw’ is not fixed. In quantitative systematic reviews, studies are appraised differently depending on methodology; for example a cross-sectional questionnaire study would not be penalised for failing to randomise participants. Dixon-Woods argues that there is no single ‘qualitative method’ like there is no single ‘quantitative method’, so appraisal tools should be broad enough to account for differences in methodology. Hannes (2011) clarifies that “a study may be flawed in terms of transparency of methodological procedures and yet offer a compelling, vivid and insightful narrative, grounded in the data”, i.e. study quality is not just assessed on methodological grounds, but on quality of interpretation and insight too.

‘Truth’ in qualitative research is more about faithfulness to the participant’s narrative (*credibility*) than objective ‘truth’. With sufficient attention to the personal and social context in which the person exists and thick descriptions which ensure a sufficient level of detail, tentative comparisons may be drawn between similar contexts (*transferability*). *Dependability* involves being open and transparent about methods used to obtain results so that others may evaluate the process, acknowledging the effect of the researcher on the research process. To achieve *confirmability* the researcher aims to demonstrate how they used the data to arrive at their interpretations, paying attention to potential sources of bias. They are reflexive about their own influence in collecting and interpreting data.

Appendix D: Literature Review Data Extraction Form

**Eligibility**

Question	If yes	If no
1	Continue	Exclude
2	Continue	Exclude
3	Continue	Exclude

**Study Characteristics**

Study details	Research question	
	Location/setting	
	Theoretical framework	
Participants	Population	
	Age (range, mean)	
	Gender	
	Ethnicity	
	Socio-economic status	
	Disease severity	
	Recruitment method/sampling	
Data collection	Method	
	Who collected the data?	
	Was the data translated or interpreted?	
	How was the data prepared for analysis?	
Analysis	Method	
Validity	What validation methods were used?	
Reflexivity	Did the study report engaging in reflexivity?	
	Saturation mentioned?	
Findings	How are the results presented?	
	DESCRIPTION	
Category 1	Title:	

(Title, description, quotes from participants, authors commentary)		
Category 2		
Category 3		
Category 4		
Category 5		
Category 6		
Category 7		
	Main significant findings	
Authors conclusions	Conclusion (key findings, author remarks)	
	Limitations as identified by authors	
	Implications as identified by authors	
	Key references (not identified by search strategy)	
Comments		

Appendix E: Presence of Themes in Each Paper													
	Baptist	Loignon	Moffat	Steven 04	Caress	Donald	Doyle	George	Jones	Pouresl ami	Ross	Steven 02	Van Mens Verhulst
<i>Establishing Normality :</i>													
"A Normal Life"	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y
Social Comparison	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y	Y	Y
Balance	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y
Delaying Help Seeking	Y	Y	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y
Family Support vs Responsibility	Y	Y	N	Y	N	N	N	N	Y	N	N	Y	Y
Financial Implications	Y	Y	N	N	N	Y	Y	N	Y	Y	N	Y	Y
<i>Medication Beliefs :</i>													
Medication = Illness	N	Y	N	Y	N	Y	N	N	Y	Y	N	Y	N
CAM as safe and natural	Y	Y	N	N	N	N	N	Y	N	N	N	N	N
Distrust of Conventional Medicine	Y	Y	N	Y	Y	Y	Y	Y	N	Y	Y	Y	N
<i>Therapeutic Relationship</i>													
Relationships with Health Professionals	Y	Y	Y	N	Y	Y	Y	N	Y	Y	Y	Y	N
Communication	Y	Y	Y	N	Y	Y	Y	N	Y	Y	Y	Y	Y
Need for Info	Y	N	N	N	Y	N	Y	N	Y	Y	Y	N	N
Trial & Error	Y	Y	N	N	Y	Y	Y	Y	N	N	Y	N	N

## Appendix F: Instructions to Authors for the Journal 'Health Psychology'

### *Manuscripts*

The manuscript title should be accurate, fully explanatory, and no longer than 12 words. The title should reflect the content and population studied. If the paper reports a randomized clinical trial, this should be indicated in the title. The title of brief reports should start with the words "Brief Report".

The title page should include the names of all authors and their affiliations at the time the research was done. This information will be masked to ensure a blind peer review process by the editorial office. Authors should make sure that all other identifying information in the text of the paper is masked/removed prior to submission. All manuscripts must include a structured abstract containing a maximum of 250 words with the following sections: [*this has been exceeded to fit with thesis guidelines*]

- Objective (brief statement of the purpose of the study);
- Methods (summary of the participants, design, measures, procedure);
- Results (primary findings); and
- Conclusions (specific statement of the implications of the data).

Please supply up to five keywords or brief phrases after the abstract. The Introduction should typically not exceed 3-4 pages in length. The paper should be referenced appropriately but excessive citations should be avoided.

All research involving human participants must describe oversight of the research process by the relevant Institutional Review Boards and should describe consent and assent procedures briefly in the Methods section. All statistical tests should include effect size whenever possible.

First person language ("I", "we") should be avoided. Terminology should be sensitive to the individual who has a disease or disability. The journal endorses the concept of "people first, not their disability." Terminology should reflect the "person with a disability" (e.g., children with diabetes, persons with HIV infection, families of people with cancer) rather than the condition as an adjective (e.g., diabetic children, HIV patients, cancer families). Nonsexist language should be used.

It is important to highlight the significance and novel contribution of the work. The translation of research into practice must be evidenced in all manuscripts. Authors should incorporate a meaningful discussion of the clinical and/or policy implications of their work throughout the manuscript, rather than simply providing a separate section for this material.

*Health Psychology* publishes a broad array of types of papers. Authors of qualitative and measure development papers should read the guidelines for these types of papers, noted below.

### *Qualitative Research*

Research papers that utilize qualitative methods should follow the general instructions to authors for style and format. We ask that authors of qualitative papers review the additional guidance below to assure that papers meet the following criteria utilized by *Health Psychology*.

The introduction should make a compelling case for the significance of the study and clearly identify if the study is a stand-alone study or if it fits into a larger study. For example, qualitative manuscripts may inform the development of a survey, use small-incident samples, or establish feasibility. The specific qualitative paradigm should be specified (e.g., grounded theory, qualitative descriptive approach, interpretive phenomenology) with a rationale as to why it was selected to address the research question.

At the same time, authors are encouraged to avoid methodological tutorials and cite appropriate references for the methodology. Describe your sampling frame clearly and how the sample was selected, justifying the type and size of your sample using appropriate language for qualitative studies.

While many qualitative studies may not use a conceptual model, if you have done so, explain how the model may have shaped the design, data collection, analysis and interpretation. Explain carefully how you strengthened and insured rigor in your study e.g., data analysis protocols (including how coders were trained), audit procedures, and demonstration of data saturation. Describe the data analysis and how it relates to your overall approach or paradigm. Present rich and compelling results with data that have been analyzed and interpreted appropriately for your method (e.g., discourse analytic results would be presented differently than those of a grounded theory).

The paper should convey how this research fills an important gap in the science and promises to change the way we approach future studies.

## Appendix G: Correspondence with Research Ethics Committees



### National Research Ethics Service

#### Derbyshire Research Ethics Committee

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 8839436  
Facsimile: 0115 8839294

16 February 2011

Miss Kathryn Davies  
Trainee Clinical Psychologist  
Leicestershire Partnership Trust  
104 Regent Road  
Leicester  
LE1 7LT

Dear Miss Davies

**Study title:** **Illness Representations and Panic-Fear in Coping with Difficult Asthma**  
**REC reference:** **11/EM/0015**

The Proportionate Review Sub-Committee of the Research Ethics Committee reviewed the above application on 15 February 2011.

#### Ethical issues

The Committee felt that this application had material ethical issues and that a review at a full REC meeting is required in order to give an opinion on the study.

- The committee were happy with the approach to patients coming from the clinician, however they were concerned the patient does not have long to consider consenting. A suggestion was put in the application that the PIS could be given at the first appointment, consent could then be taken at a second appointment, and the committee felt this would be more appropriate consent process.
- It was noted there is no initials box on the consent form and it refers to the incorrect date of the PIS
- The committee had concerns about the storage of some data, please clarify how the consent forms and questionnaires are to be stored separately and how long you intend on keeping these. Please also clarify if you plan to store manual X-Ray files and why this is needed
- It was unclear to the committee what information you are extracting from the lung function tests and where this is going to be stored
- In the application a pilot study for the usability of the questionnaire is mentioned. It was unclear if this stage had already taken place, and if the documents submitted in this application are the updated versions
- In the PIS under section 'What will happen...' you mention that it will not be possible to withdraw their data if they are withdrawn, however as you will still have the consent forms, that link the names with the patient ID, you can remove their data. Could you clarify why patients do not have this option.

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority  
*The National Research Ethics Service (NRES) represents the NRES Directorate within the  
National Patient Safety Agency and Research Ethics Committees in England*

WPH 1370

**Arrangements for further review**

We have referred your application back to the local allocation service for review by a full REC.

The REC now appointed to review your application is:

Nottingham Research Ethics Committee 1 on 8 March 2011

The co-ordinator from the above REC will write to you with further details of the meeting at which your application is to be reviewed. We will send on copies of all paperwork relating to this application to the above REC on your behalf.

An ethical opinion on the application will be given within 60 days of receipt of a valid application by this Committee.

**Membership of the Proportionate Review Sub-Committee**

The members of the sub-committee who took part in the review are listed on the attached sheet.

**Documents reviewed**

The documents reviewed were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
REC application	68007/18312 3/1/348	24 January 2011
Questionnaire: Your Views About Asthma		
Questionnaire: Causes of My Asthma		
Questionnaire: Asthma Symptom Checklist		
Questionnaire: Psychological Factors in Coping with Difficult Asthma	7	26 January 2011
Participant Information Sheet	7	26 January 2011
Protocol	7	26 January 2011
Referees or other scientific critique report		23 November 2010
Investigator CV		26 January 2011
Investigator CV		26 January 2011
Participant Consent Form	7	26 January 2011
Covering Letter		26 January 2011
Questionnaire: Asthma Specific Coping Scale	1	26 January 2011

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/EM/0015	Please quote this number on all correspondence
------------	--

Yours sincerely



**Mr Phil Hopkinson**  
**Chair**

Email: [carol.marten@nottspct.nhs.uk](mailto:carol.marten@nottspct.nhs.uk)

Enclosures: List of names and professions of members who took part in the review

Copy to: Dr David Clarke, Leicester Partnership



## National Research Ethics Service

### Nottingham Research Ethics Committee 1

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 8839390 (Direct Line)  
Facsimile: 0115 9123300

16 March 2011

Miss Kathryn Davies  
Trainee Clinical Psychologist  
Leicestershire Partnership Trust  
104 Regent Road  
Leicester  
LE1 7LT

Dear Miss Davies

**Study Title:** Illness Representations and Panic-Fear in Coping with  
Difficult Asthma  
**REC reference number:** 11/EM/0015

The Research Ethics Committee reviewed the above application at the meeting held on 8 March 2011. Thank you for attending to discuss the study.

#### Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Investigator CV		26 January 2011
Investigator CV		26 January 2011
Participant Information Sheet	7	26 January 2011
REC application	68007/183123/1/348	24 January 2011
Participant Consent Form	7	26 January 2011
Covering Letter		26 January 2011
Referees or other scientific critique report		23 November 2010
Questionnaire: Asthma Specific Coping Scale	1	26 January 2011
Questionnaire: Your Views About Asthma		
Questionnaire: Causes of My Asthma		
Questionnaire: Asthma Symptom Checklist		
Questionnaire: Psychological Factors in Coping with Difficult Asthma	7	26 January 2011
Protocol	7	26 January 2011
Email correspondence from Researcher/Statistician		16 February 2011
No Opinion letter from Derbyshire REC		16 February 2011

This Research Ethics Committee is an advisory committee to the East Midlands Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

### Discussion

- The Committee informed you that the main ethical concern was over the time taken to consider taking part i.e. 1 hour. You stated that since you have received feedback from the Derbyshire Research Ethics Committee you have discussed this issue with Professor Wardlaw at the University Hospitals Leicester, and you have agreed that those who will be attending a clinic appointment a week before potentially entering into the study, will receive information regarding the study that can be taken home. You were aware however, that this will 'miss' some potential participants. You stated that you had thought about sending information out by post, but there is no manpower available for sending letters etc.
- The Committee asked whether you have considered sending the questionnaires out by post to enable participants to complete them at home and bring them back when they have their clinic appointment. You stated that there are insufficient funds to do this.
- You were asked to give further information regarding the storage of data. You stated that participant names will not be stored with the data. Data will be anonymised following completion of the questionnaires.
- The Committee asked you if you will be looking at X-Rays in the study. You confirmed that you will not be accessing X-Rays – this is a mistake in the application. You did state, however, that you will collect information from lung function tests. You confirmed that this data is already available; you will be asking the Clinician/clinic staff for this data on the day when questionnaires are completed.
- The Committee asked why the Protocol had not been changed following peer review to reflect any comments. You confirmed that this is an oversight on your part.
- You were asked regarding the ethnicity of participants i.e. will you or will you not be including those who cannot understand written English? You confirmed that those who cannot understand written English will be excluded from the study.
- The Committee informed you that they had noted that COPD is mentioned in the Protocol and asked what its relevance was with this study. You stated that it is used in a general sense as some patients may relate to this terminology rather than having asthma.
- The Committee asked you whether potential participants will be aware that they have asthma even though they are attending an asthma clinic, and why you chose this condition. You stated that looking at literature relating to this, some do not acknowledge that they have asthma i.e. they are in denial. However, in this study they are attending the severe asthma clinic so they should be aware. You stated that you decided to go with asthma as the wording in the questionnaires refer to this condition.
- You were asked regarding the demographics of the study. You confirmed that you will not be including those who cannot speak or understand English. However, most will be acculturated.
- The Committee asked you what access you have to the data that is required for the study. You stated that all data will be accessed via the Clinicians/clinic staff

etc. The Committee mentioned that this would create a time burden on clinic staff. You stated that this has already been agreed by Professor Wardlaw.

- The Committee informed you that the wording in the Asthma Specific Coping Scale is rather confusing and asked whether any of the questions could be changed. You stated that this is a validated questionnaire and therefore would not want to change any questions. You stated that in fact all questionnaires used in the study are validated except for the demographics questionnaire which was devised by you.
- You were informed that the Consent Form will require a section to enable participants to consent for you to access medical data.

#### **Provisional opinion**

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

The Committee delegated authority to confirm its final opinion on the application to the Chair.

#### **Further information or clarification required**

- The Protocol requires updating to incorporate any changes to the research e.g. methodology, consent etc.
- The Participant Information Sheet will require revision to take into consideration the revised recruitment method i.e. information being given out at an earlier clinic appointment. The Committee suggested that the questionnaires be given out with the Participant Information Sheet and that participants bring them back at their following clinic session, and you are asked to consider this.
- The Participant Information Sheet states that participants can withdraw from the study should they wish to. However, it states that data cannot be withdrawn. The Committee agreed that there should be a link to the data from the Consent Forms. Therefore, data could be withdrawn. It should be made explicit in the Participant Information up to what point a person can withdraw and what data will and will not be used etc.
- The questionnaires should be presented to participants in a way that it is clear what sequence they should be completed in, otherwise it is rather confusing.
- The name of the Research Ethics Committee detailed in the Participant Information Sheet as having reviewed the study should be changed to the 'Nottingham 1 Research Ethics Committee'.
- The Consent Form has no 'initial' boxes to enable the participant to consent to each point. These should be inserted.
- The Consent Form should include a numbered point to state that 'I give consent to the Researcher to access my medical data'.

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 14 July 2011.

#### **Membership of the Committee**

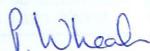
The members of the Committee who were present at the meeting are listed on the attached sheet.

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

<b>11/EM/0015</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

Yours sincerely



PP **Mr Robert Johnson**  
**Chair**

Email: trish.wheat@nottspct.nhs.uk

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.*

*Copy to: R&D Department for NHS care organisation at lead site - Dr David Clarke*

**Nottingham Research Ethics Committee 1**

**Attendance at Committee meeting on 08 March 2011**

**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Walter P Bouman	Consultant Psychiatrist	No	
Dr Glenys Caswell	Research Fellow	Yes	
Professor Cris S Constantinescu	Professor of Neurology	Yes	
Ms Helen Crow	Research Midwife	No	
Mr Robert Johnson	Research Coordinator	Yes	
Reverend Keith Lackenby	Lay member	No	
Mr Jon Merrills	Barrister / Pharmacist	Yes	
Mr Robert Oldroyd	Lay member	Yes	
Dr Noble Philips	General Practitioner	Yes	
Mr Ian Thompson	Lay member	Yes	
Mrs Shirley E White	Lay member	Yes	
Ms Fran Willis	Teacher	Yes	

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Ms Trish Wheat	REC Committee Co-ordinator

Mail Reply Reply to All Forward Move Delete Junk Close

- Deleted Items (1)
  - Drafts [7]
  - Inbox (17)
  - Junk E-Mail [4]
  - Sent Items
- Click to view all folders
- thesis
- Manage Folders...

### ethics amendments

Davies, Kathryn M.

You forwarded this message on 9/26/2011 12:30 PM.

**Sent:** Monday, May 09, 2011 10:46 AM  
**To:** trish.wheat@nottspct.nhs.uk  
**Attachments:** [protocol v8 .doc \(103 KB\)](#) (Open as Web Page); [Participant Information Sh~1.doc \(35 KB\)](#) (Open as Web Page); [Consent Form v3.doc \(24 KB\)](#) (Open as Web Page)

Hi Trish,

I called a moment ago to ask about the process for submitting my amendments - thank you for your help. I enclose my amended documents for the project 'Psychological Factors in Coping with Difficult Asthma'. Changes are underlined and highlighted. Please let me know if you need anything else from me. I look forward to hearing from you.

Kind Regards  
Kat Davies

-----  
Kat Davies  
Trainee Clinical Psychologist  
University of Leicester



## National Research Ethics Service

### NRES Committee East Midlands - Nottingham 1

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 8839390 (Direct Line)  
Facsimile: 0115 9123300

26 May 2011

Miss Kathryn Davies  
Trainee Clinical Psychologist  
Leicestershire Partnership Trust  
104 Regent Road  
Leicester  
LE1 7LT

Dear Miss Davies

**Study title:** **Illness Representations and Panic-Fear in Coping with  
Difficult Asthma**  
**REC reference:** **11/EM/0015**

Thank you for your letter of 09 May 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

#### Confirmation of ethical opinion

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

#### Ethical review of research sites

##### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

##### Non-NHS sites

#### Conditions of the favourable opinion

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

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

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority  
*The National Research Ethics Service (NRES) represents the NRES Directorate within the  
National Patient Safety Agency and Research Ethics Committees in England*

WPH 1370

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

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

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

*Sponsors are not required to notify the Committee of approvals from host organisations*

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

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		26 January 2011
Investigator CV		26 January 2011
Investigator CV		26 January 2011
Other: No opinion letter form Derbyshire REC		16 February 2011
Other: Email from Researcher/Statistician		16 February 2011
Participant Consent Form	8	17 April 2011
Participant Information Sheet	8	17 April 2011
Protocol	7	26 January 2011
Protocol	8	17 April 2011
Questionnaire: Asthma Specific Coping Scale	1	26 January 2011
Questionnaire: Your Views About Asthma		
Questionnaire: Causes of My Asthma		
Questionnaire: Asthma Symptom Checklist		
Questionnaire: Psychological Factors in Coping with Difficult Asthma	7	26 January 2011
REC application	68007/183123/1/348	24 January 2011
Referees or other scientific critique report		23 November 2010
Response to Request for Further Information		09 May 2011

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### **After ethical review**

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views

known please use the feedback form available on the website.

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

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

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

**11/EM/0015**

**Please quote this number on all correspondence**

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

Yours sincerely



PP **Mr Robert Johnson**  
**Chair**

Email: [trish.wheat@nottspct.nhs.uk](mailto:trish.wheat@nottspct.nhs.uk)

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Dr David Clarke, Leicestershire Partnership NHS Trust*

*documentation for the study*

Yes  No

*If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.*

Participant Information Sheet and Consent Form remain unchanged from the versions approved by Nottingham 1 REC. Submitted for consideration is a cover letter from the clinic consultant to be posted to patients a week before their appointment.

**Is this a modified version of an amendment previously notified and not approved?**

Yes  No

**Summary of changes**

*Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.*

*If this is a modified amendment, please explain how the modifications address the concerns raised previously by the ethics committee.*

*If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.*

During the panel review of the study's REC application, suggestions were made as to how to enable patients to access a Patient Information Sheet 24 hours before consent is sought. Several suggestions from the panel were noted and the option given favourable ethical opinion was to give patients an Information Sheet at their pre-clinic assessment appointment, which happens a week before the full clinic.

It is now apparent that a relatively small proportion of patients attend the pre-clinic assessment and another method is required to get Information Sheets to patients in time for the full clinic, where consent will be sought.

It is proposed that patients be posted a Patient Information Sheet and a cover letter (enclosed) from the clinic consultant, Professor Andrew Wardlaw, a week before the full clinic. Administrators from the Department of Respiratory Medicine have agreed to provide addresses should this amendment be approved, so that the researcher (Kathryn Davies) does not need to access the patient database. The Patient Information Sheet remains unchanged from the version approved by Nottingham 1 REC.

Changes are on page 9 of the revised protocol, underlined and highlighted.

**Any other relevant information**

*Applicants may indicate any specific issues relating to the amendment, on which the opinion of a reviewing body is sought.*

**List of enclosed documents**

<i>Document</i>	<i>Version</i>	<i>Date</i>
Updated Protocol	Version 9	29/11/2011
Letter to Patients	Version 1	29/11/2011

**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 to be implemented.*



## Health Research Authority

### NRES Committee East Midlands - Nottingham 1

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Tel:  
Fax:

14 December 2011

Miss Kathryn Davies  
Trainee Clinical Psychologist  
Leicestershire Partnership Trust  
104 Regent Road  
Leicester  
LE1 7LT

Dear Miss Davies

**Study title:** **Illness Representations and Panic-Fear in Coping with Difficult Asthma**  
**REC reference:** **11/EM/0015**  
**Amendment number:** **1**  
**Amendment date:** **29 November 2011**

The above amendment was reviewed at the meeting of the Sub-Committee held on 13 December 2011.

#### 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
Letter of invitation to participant	1	29 November 2011
Protocol	9	29 November 2011
Notice of Substantial Amendment (non-CTIMPs)	1	29 November 2011
Covering Letter	Email	02 December 2011

#### 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 (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

<b>11/EM/0015:</b>	<b>Please quote this number on all correspondence</b>
--------------------	---

Yours sincerely



pp

**Reverend Keith Lackenby**  
**Vice Chair**

E-mail: [stephen.briggs@nnotts.nhs.uk](mailto:stephen.briggs@nnotts.nhs.uk)

*Enclosures: List of names and professions of members who took part in the review*

*Copy to: Chief Investigator – Professor Andrew Wardlaw, Professor of Allergy and Respiratory Medicine, University of Leicester, Glenfield Road, Groby Road, Leicester. LE3 9QP*

*Sponsor/R & D - Dr David Clarke, Leicestershire Partnership NHS Trust, George Hine towers, Towers Hospital, Gipsy Lane, Leicester. LE5 0TD*

**NRES Committee East Midlands - Nottingham 1**

**Attendance at Sub-Committee of the REC meeting on 13 December 2011**

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Reverend Keith Lackenby	Lay member	Lay Plus
Dr Ian Ross	Consultant Physician	Expert

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Mr Stephen Briggs	Assistant Coordinator
Ms Trish Wheat	REC Committee Co-ordinator

Appendix H: Letter of Invitation to Participate (Printed on Trust Headed Paper)

**Department of Respiratory Medicine,  
Allergy and Thoracic Surgery**

**Consultant: (Anonymised)**  
**Telephone: (Anonymised)**  
**Fax: (Anonymised)**  
**Email: (Anonymised)**

Our Ref:

[DATE]

**Psychological Factors in Coping with Difficult Asthma**

Dear

We are undertaking a research study looking at the psychological factors involved in coping with difficult asthma. This involves completing some questionnaires. Please find enclosed a patient information leaflet which describes the study which may be discussed with you if you are agreeable when you next attend the difficult asthma clinic. Please do not hesitate to contact me if you require any further information.

Kind regards

**(Consultant – Anonymised)**

## Appendix I: Participant Information Sheet

### **‘Psychological Factors in Coping with Difficult Asthma’.**

#### **Invitation to take part**

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Our researcher will go through the information sheet with you and answer any questions you have. This should take about 5 minutes. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

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

We would like to find out what helps people with difficult chest problems to cope. In particular we are looking at two psychological factors. The first is how much anxiety people feel about their chest problems. The second is the beliefs people have about their chest problems. These psychological factors have been studied in chest problems before. However, no-one has researched what effect they have when combined together.

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

We are inviting people who attend the Difficult Asthma Clinic at XXX Hospital. It does not matter whether you experience anxiety or not, you can still take part. We would like to get views from a range of people. 108 people will be recruited in total.

#### **Do I have to take part?**

It is up to you to decide to join the study or not. If you agree to take part, we will ask you to sign a consent form. You are free to withdraw at any time without giving a reason. The standard of care you receive will not be affected.

#### **What will happen to me if I decide to take part?**

We will ask you to fill in a questionnaire. This will take about 15-30 minutes to complete. The questions are about your chest problems, your beliefs, feelings and emotions you experience and how you cope with your chest problems. This questionnaire is a one-off and no follow-up is required. With your permission, the study will involve a researcher looking at your recent medical records held by the Difficult Asthma Clinic. This is so that we can take the results of clinical tests in to account when we look at everybody's answers. You do not need to do anything for this part of the study as we will use results from your most recent tests.

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

The questionnaire will take 15-30 minutes of your time. A minority of people may find it a little upsetting to answer questions about how they are coping with a difficult illness, though the questionnaires have been used before and do not usually cause distress.

#### **What are the possible benefits of taking part?**

We cannot promise the study will help you personally but the information we get from this research will help our understanding of how to help people cope with their asthma.

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

You have the right to withdraw at any time, just let us know using the contact details below and we will not include your questionnaire or clinical data in the results.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers on **(removed)**, who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting University Hospitals Leicester Research & Development on **(removed)** .

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

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. An administrator from the Difficult Asthma Clinic will need to know you have taken part in the study so that we can obtain your clinical data from their database. However, nobody will get to see what answers you gave to the questionnaire and no-one else will be told that you took part. After we collect your clinical data, no identifying information about you will be kept with your answers. Your questionnaire will be linked to your name by a participant ID number; this is so that we can withdraw your data if you decide you no longer wish to take part. The data we collect from you will be stored on a password-protected computer at the University of Leicester. There will be no identifying information in the write up of the study and no individual answers will be picked out. The data will be stored in a locked archive for 7 years in accordance with University policy. Staff from NHS Research & Development may need to access the data for quality assurance purposes.

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

The broad scientific results of the study will be written up as a thesis for the award of Doctorate in Clinical Psychology. They will also be submitted for publication in scientific journals. The XXX Hospital Difficult Asthma Clinic will see summarised reports of the research, but no individual participants or answers will be identified.

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

The University of Leicester is sponsoring the research as part of an academic qualification. There is no monetary gain for this organisation as a result of your participation.

**Who has reviewed the study?**

All research conducted in the NHS is reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. The study has been reviewed and given favourable opinion by Nottingham 1 Research Ethics Committee

**Further information and contact details**

You may want further information. For general information about research and research ethics, [www.nres.org.uk](http://www.nres.org.uk) is a useful source of information. If you would like further specific information about this study, you can contact the lead researcher, Kathryn Davies by contacting the Department of Clinical Psychology on **(removed)**. If you would like advice as to whether you should participate, you could talk to a member of staff in the Difficult Asthma Clinic or a trusted friend or relative.

Appendix J: Consent Form

**Consent Form**

Centre Number:

Study Number:

Patient Identification Number:

Title of Project: Psychological Factors in Coping with Difficult Asthma

Name of Researcher: Kathryn Davies

**Please initial**

1. I confirm that I have read and understood the information sheet dated 17<sup>th</sup> April 2011 (version 8) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I give consent for the Researcher to access my medical data
4. I understand that relevant sections of my medical notes and/or study data may be looked at by responsible individuals from the study team, sponsor, NHS trust or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
5. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of person taking consent	Date	Signature

Appendix K: Additional Demographic Information Questionnaire

**Psychological Factors in Coping with difficult Asthma**

1. What is your age?

2. Are you:

Male

Female

3. Which do you feel best describes your ethnic background? (Please circle)

**White**

A British

B Irish

C Any other White background

**Mixed**

D White and Black Caribbean

E White and Black African

F White and Asian

G Any other mixed background

**Asian or Asian British**

H Indian

J Pakistani

K Bangladeshi

L Any other Asian background

**Black or Black British**

M Caribbean

N African

P Any other Black background

**Other Ethnic Groups**

R Chinese

S Any other ethnic group

Z Prefer not to say

4. Which medications are you taking for your asthma/chest problems? (Please list all)

5. Do you have any other health problems? If so, please list them here

6. How long ago were you diagnosed with asthma?

7. Have you had any unscheduled health visits due to your asthma/chest problems in the last 12 months (i.e. emergency appointments, walk-in clinics, A&E)? If so, how many?

Please now fill in the other questionnaires in this booklet.

---

For Researcher Use:

FEV1:

PEF:

FVC:

Appendix L: Illness Perceptions Questionnaire Revised for Asthma

## YOUR VIEWS ABOUT YOUR ASTHMA

Listed below are a number of symptoms that you may or may not have experienced since your asthma. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your asthma, and whether you believe that these symptoms are related to your asthma.

	I have experienced this symptom <i>since my asthma</i>		This symptom is <i>related to my</i> <i>asthma</i>		
	Yes	No	Yes	No	
Pain	Yes	No	_____	Yes	No
Sore Throat	Yes	No	_____	Yes	No
Nausea	Yes	No	_____	Yes	No
Breathlessness	Yes	No	_____	Yes	No
Weight Loss	Yes	No	_____	Yes	No
Fatigue	Yes	No	_____	Yes	No
Stiff Joints	Yes	No	_____	Yes	No
Sore Eyes	Yes	No	_____	Yes	No
Wheeziness	Yes	No	_____	Yes	No
Headaches	Yes	No	_____	Yes	No
Upset Stomach	Yes	No	_____	Yes	No
Sleep Difficulties	Yes	No	_____	Yes	No
Dizziness	Yes	No	_____	Yes	No
Loss of Strength	Yes	No	_____	Yes	No

We are interested in your own personal views of how you now see your current asthma.

Please indicate how much you agree or disagree with the following statements about your asthma by ticking the appropriate box.

VIEWS ABOUT YOUR ASTHMA		STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	My asthma will last a short time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IP2	My asthma is likely to be permanent rather than temporary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IP3	My asthma will last for a long time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	<b>VIEWS ABOUT YOUR ASTHMA</b>	<b>STRONGLY DISAGREE</b>	<b>DISAGREE</b>	<b>NEITHER AGREE NOR DISAGREE</b>	<b>AGREE</b>	<b>STRONGLY AGREE</b>
IP4*	<b>This asthma will pass quickly</b>					
IP5*	<b>I expect to have this asthma for the rest of my life</b>					
IP6	<b>My asthma is a serious condition</b>					
IP7	<b>My asthma has major consequences on my life</b>					
IP8*	<b>My asthma does not have much effect on my life</b>					
IP9	<b>My asthma strongly affects the way others see me</b>					
IP10	<b>My asthma has serious financial consequences</b>					
IP11	<b>My asthma causes difficulties for those who are close to me</b>					
IP12	<b>There is a lot which I can do to control my symptoms</b>					
IP13	<b>What I do can determine whether my asthma gets better or worse</b>					
IP14	<b>The course of my asthma depends on me</b>					
IP15*	<b>Nothing I do will affect my asthma</b>					
IP16	<b>I have the power to influence my asthma</b>					
IP17*	<b>My actions will have no affect on the outcome of my asthma</b>					
IP18*	<b>My asthma will improve in time</b>					
IP19*	<b>There is very little that can be done to improve my asthma</b>					
IP20	<b>My treatment will be effective in curing my asthma</b>					
IP21	<b>The negative effects of my asthma can be prevented (avoided) by my treatment</b>					
IP22	<b>My treatment can control my asthma</b>					
IP23*	<b>There is nothing which can help my condition</b>					
IP24	<b>The symptoms of my condition are puzzling to me</b>					
IP25	<b>My asthma is a mystery to me</b>					
IP26	<b>I don't understand my asthma</b>					

IP27	<b>My asthma doesn't make any sense to me</b>					
IP28*	<b>I have a clear picture or understanding of my condition</b>					
IP29	<b>The symptoms of my asthma change a great deal from day to day</b>					
IP30	<b>My symptoms come and go in cycles</b>					
IP31	<b>My asthma is very unpredictable</b>					
IP32	<b>I go through cycles in which my asthma gets better and worse.</b>					
IP33	<b>I get depressed when I think about my asthma</b>					
IP34	<b>When I think about my asthma I get upset</b>					
IP35	<b>My asthma makes me feel angry</b>					
IP36*	<b>My asthma does not worry me</b>					
IP37	<b>Having this asthma makes me feel anxious</b>					
IP38	<b>My asthma makes me feel afraid</b>					

## CAUSES OF MY ASTHMA

We are interested in what you consider may have been the cause of your asthma. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your asthma rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your asthma. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries					
C11*	Overwork					
C12*	My emotional state e.g. feeling down, lonely, anxious, empty					
C13*	Ageing					
C14*	Alcohol					
C15*	Smoking					
C16*	Accident or injury					
C17*	My personality					
C18*	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR asthma. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

## Appendix M: Asthma Symptoms Checklist

How often do you experience each of the following symptoms **during an asthma attack**? Please show how often you experience each symptom during an attack by circling 'Never', 'Rarely', 'Sometimes', 'Often', or 'Always' for each item.

<b>Numb</b>	Never	Rarely	Sometimes	Often	Always
<b>Mucous congestion</b>	Never	Rarely	Sometimes	Often	Always
<b>Cranky</b>	Never	Rarely	Sometimes	Often	Always
<b>Irritable</b>	Never	Rarely	Sometimes	Often	Always
<b>Hard to breathe</b>	Never	Rarely	Sometimes	Often	Always
<b>Headache</b>	Never	Rarely	Sometimes	Often	Always
<b>Edgy</b>	Never	Rarely	Sometimes	Often	Always
<b>Frightened</b>	Never	Rarely	Sometimes	Often	Always
<b>Short of breath</b>	Never	Rarely	Sometimes	Often	Always
<b>Chest congestion</b>	Never	Rarely	Sometimes	Often	Always
<b>Itchy lungs</b>	Never	Rarely	Sometimes	Often	Always
<b>Afraid of dying</b>	Never	Rarely	Sometimes	Often	Always
<b>Frustrated with things</b>	Never	Rarely	Sometimes	Often	Always
<b>Dizzy</b>	Never	Rarely	Sometimes	Often	Always
<b>Rapid breathing</b>	Never	Rarely	Sometimes	Often	Always
<b>Worn out</b>	Never	Rarely	Sometimes	Often	Always
<b>Panicky</b>	Never	Rarely	Sometimes	Often	Always
<b>Weak</b>	Never	Rarely	Sometimes	Often	Always
<b>Pins and needles feelings</b>	Never	Rarely	Sometimes	Often	Always
<b>Itchy throat</b>	Never	Rarely	Sometimes	Often	Always
<b>Worried about the attack</b>	Never	Rarely	Sometimes	Often	Always
<b>Tingly in spots</b>	Never	Rarely	Sometimes	Often	Always
<b>Chest tightening</b>	Never	Rarely	Sometimes	Often	Always

<b>Scared</b>	Never	Rarely	Sometimes	Often	Always
<b>Shallow breathing</b>	Never	Rarely	Sometimes	Often	Always
<b>Choking</b>	Never	Rarely	Sometimes	Often	Always
<b>Fatigued</b>	Never	Rarely	Sometimes	Often	Always
<b>Chest filling up</b>	Never	Rarely	Sometimes	Often	Always
<b>Short tempered</b>	Never	Rarely	Sometimes	Often	Always
<b>Worried</b>	Never	Rarely	Sometimes	Often	Always
<b>Anxious</b>	Never	Rarely	Sometimes	Often	Always
<b>Itchy skin</b>	Never	Rarely	Sometimes	Often	Always
<b>Nauseated</b>	Never	Rarely	Sometimes	Often	Always
<b>Coughing</b>	Never	Rarely	Sometimes	Often	Always
<b>No energy</b>	Never	Rarely	Sometimes	Often	Always
<b>Worried about myself</b>	Never	Rarely	Sometimes	Often	Always

### Appendix N: Asthma Specific Coping Scale

Please read the following statements. Decide for each one how often you do the things described to cope with your asthma. Please show your answer by circling 'Hardly Ever', 'Sometimes', 'Often' or 'Always'.

I avoid strenuous activities	Hardly Ever	Sometimes	Often	Always
I avoid exertion	Hardly Ever	Sometimes	Often	Always
I try to live cautiously to avoid attack of shortness of breath	Hardly Ever	Sometimes	Often	Always
I avoid situations that could bring on an attack	Hardly Ever	Sometimes	Often	Always
I avoid telling people about respiratory disease	Hardly Ever	Sometimes	Often	Always
I avoid talking about my respiratory disease	Hardly Ever	Sometimes	Often	Always
I try to hide my respiratory disease	Hardly Ever	Sometimes	Often	Always
I tell others about my respiratory disease	Hardly Ever	Sometimes	Often	Always
I try to learn something positive about my falling ill	Hardly Ever	Sometimes	Often	Always
I try to think about my illness in a positive light	Hardly Ever	Sometimes	Often	Always
I have found new important things in my life	Hardly Ever	Sometimes	Often	Always
I try to mature as a person through illness-related experiences	Hardly Ever	Sometimes	Often	Always
I try to find out more about my respiratory disease	Hardly Ever	Sometimes	Often	Always
I follow what is said and written about respiratory diseases in the media	Hardly Ever	Sometimes	Often	Always
I ask health care personnel about my respiratory disease	Hardly Ever	Sometimes	Often	Always
I try to find out what causes my shortness of breath	Hardly Ever	Sometimes	Often	Always
I try to forget that I have a respiratory disease	Hardly Ever	Sometimes	Often	Always
I pretend that my disease does not bother me at all	Hardly Ever	Sometimes	Often	Always
I avoid thinking about my respiratory disease	Hardly Ever	Sometimes	Often	Always
I tell people that my disease troubles me less than it really does	Hardly Ever	Sometimes	Often	Always
I am afraid that my respiratory disease will get worse	Hardly Ever	Sometimes	Often	Always
I worry about my respiratory disease	Hardly Ever	Sometimes	Often	Always
I watch my night's sleep	Hardly Ever	Sometimes	Often	Always

## Appendix O: SPSS Scoring Syntax

Following the advice of Moss-Morris (2012) Missing data for the IPQ-R were calculated for subscale totals by using the mean score for the subscale multiplied by the number of subscale items. This was calculated if there were a minimum number of responses for each subscale (a maximum of two missing responses for subscales of 6 items, a maximum of one missing response for other subscales). The syntax in SPSS was as follows:

```
COMPUTE IPQ_timeline = 6*MEAN.4(IPQ1,IPQ2,IPQ3,IPQ4,IPQ5,IPQ18).
COMPUTE IPQ_consequences = 6*MEAN.4(IPQ6,IPQ7,IPQ8,IPQ9,IPQ10,IPQ11).
COMPUTE IPQ_personalcontrol=6*MEAN.4(IPQ12,IPQ13,IPQ14,IPQ15,IPQ16,IPQ17)
COMPUTE IPQ_tmtcontrol = 5*MEAN.4(IPQ19,IPQ20,IPQ21,IPQ22,IPQ23).
COMPUTE IPQ_illnesscoherence = 5*MEAN.4(IPQ24,IPQ25,IPQ26,IPQ27,IPQ28).
COMPUTE IPQ_timeline_cyclical = 4*MEAN.3(IPQ29,IPQ30,IPQ31,IPQ32).
COMPUTE IPQ_emotional_rep=6*MEAN.4(IPQ33,IPQ34,IPQ35,IPQ36,IPQ37,IPQ38).
EXECUTE.
```

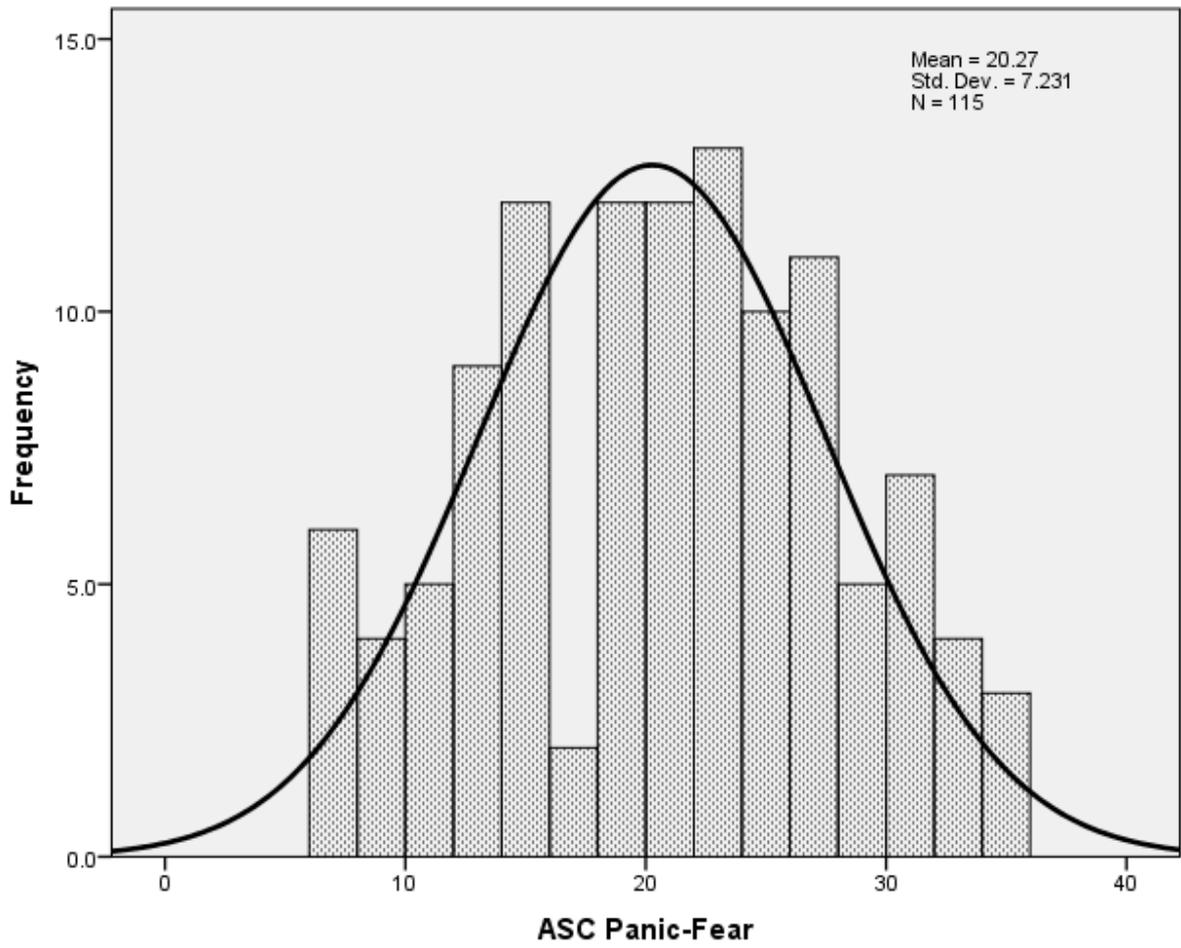
The same criteria were used to calculate subscales with missing responses for the Asthma Symptom Checklist (ASC):

```
COMPUTE ASC_hh=
9*MEAN(ASC1,ASC6,ASC11,ASC14,ASC19,ASC20,ASC22,ASC32,ASC33).
COMPUTE ASC_broncho=
10*MEAN(ASC2,ASC5,ASC9,ASC10,ASC15,ASC23,ASC25,ASC26,ASC28,ASC34).
COMPUTE ASC_irritability= 6*MEAN(ASC3,ASC4,ASC7,ASC13,ASC29,ASC31).
COMPUTE ASC_panicfear=
7*MEAN(ASC8,ASC12,ASC17,ASC21,ASC24,ASC30,ASC36).
COMPUTE ASC_fatigue= 4*MEAN(ASC16,ASC18,ASC27,ASC35).
EXECUTE.
```

The same criteria were used to calculate subscales with missing responses for the Asthma Specific Coping Scale (ASCS):

```
COMPUTE COPE_restrict=4*MEAN(COPE1,COPE2,COPE3,COPE4).
COMPUTE COPE_hide=4*MEAN(COPE5,COPE6,COPE7,COPE8).
COMPUTE COPE_positive=4*MEAN(COPE9,COPE10,COPE11,COPE12).
COMPUTE COPE_info=4*MEAN(COPE13,COPE14,COPE15,COPE16).
COMPUTE COPE_ignore=4*MEAN(COPE17,COPE18,COPE19,COPE20).
COMPUTE COPE_worry=3*MEAN(COPE21,COPE22,COPE23).
EXECUTE.
```

Appendix P: Histogram of Panic-Fear Scale



Appendix Q: Nine Cluster Solution SPSS Output

Nine cluster solution:

**Iteration History<sup>a</sup>**

Iteration	Change in Cluster Centers								
	1	2	3	4	5	6	7	8	9
1	8.077	7.516	7.610	7.638	7.879	10.098	8.224	8.470	5.686
2	2.063	1.463	1.755	2.005	2.526	1.890	.485	2.289	2.566
3	1.246	.969	.913	2.321	.000	1.858	.722	.000	1.786
4	1.763	.443	.000	1.358	.000	.771	.946	.000	.000
5	1.672	.372	.696	1.624	.000	.638	1.035	.000	.000
6	.000	.827	.000	1.356	1.355	.485	.000	.000	.000
7	.000	.546	.624	.600	.000	.302	.000	.000	.000
8	.000	.000	.000	.000	.000	.000	.000	.000	.000

a. Convergence achieved due to no or small change in cluster centers. The maximum absolute coordinate change for any center is .000. The current iteration is 8. The minimum distance between initial centers is 17.234.

**ANOVA**

	Cluster		Error		F	Sig.
	Mean Square	df	Mean Square	df		
IPQ_timeline	192.336	8	7.144	105	26.924	.000
IPQ_consequences	239.191	8	10.766	105	22.218	.000
IPQ_personalcontrol	112.936	8	9.231	105	12.234	.000
IPQ_tmtcontrol	70.436	8	7.930	105	8.883	.000
IPQ_illnesscoherence	216.973	8	11.110	105	19.529	.000
IPQ_timeline_cyclical	24.601	8	8.940	105	2.752	.008
IPQ_emotional_rep	278.789	8	11.729	105	23.770	.000

**Final Cluster Centers**

	Cluster								
	1	2	3	4	5	6	7	8	9
IPQ_timeline	17	27	25	28	29	24	28	19	17
IPQ_consequences	22	22	14	25	28	22	27	18	20
IPQ_personalcontrol	23	25	23	24	15	19	19	19	22
IPQ_tmtcontrol	17	18	18	17	10	16	14	17	19
IPQ_illnesscoherence	22	22	19	20	22	17	12	11	19
IPQ_timeline_cyclical	18	15	14	15	15	13	17	15	15
IPQ_emotional_rep	13	14	12	25	18	19	23	18	26

Appendix R: Four Cluster Solution SPSS Output

**Iteration History<sup>a</sup>**

Iteration	Change in Cluster Centers			
	1	2	3	4
1	11.279	12.062	11.752	11.674
2	.693	1.108	.255	.437
3	.483	.000	.000	.398
4	.281	.000	.000	.248
5	.000	.000	.000	.000

a. Convergence achieved due to no or small change in cluster centers. The maximum absolute coordinate change for any center is .000. The current iteration is 5. The minimum distance between initial centers is 25.219.

**Final Cluster Centers**

	Cluster			
	1	2	3	4
IPQ_timeline	25	28	27	21
IPQ_consequences	19	27	25	19
IPQ_personalcontrol	24	16	22	20
IPQ_tmtcontrol	18	11	17	17
IPQ_illnesscoherence	21	18	17	14
IPQ_emotional_rep	12	20	23	19

**ANOVA**

	Cluster		Error		F	Sig.
	Mean Square	df	Mean Square	df		
IPQ_timeline	351.345	3	11.225	110	31.300	.000
IPQ_consequences	369.583	3	17.593	110	21.008	.000
IPQ_personalcontrol	218.974	3	11.053	110	19.811	.000
IPQ_tmtcontrol	159.667	3	8.337	110	19.151	.000
IPQ_illnesscoherence	302.029	3	18.148	110	16.643	.000
IPQ_emotional_rep	635.666	3	14.135	110	44.971	.000

## Appendix S: Chronology of Research Process

Submission of Proposal to University and Panel Attended	June 2010
Submission to NHS Ethics Proportionate Review	January 2011
Submission to NHS Local Research Ethics Committee	February –March 2011
Approval by LREC (After Amendments)	May 2011
Submission of Proposal to Acute Trust RM &G	June 2011
Amendments Required by RM&G	August 2011
Approval by RM&G	November 2011
Notice of Substantial Amendment	December 2012
Data Collection	November 2011 – April 2012
Data Inputting	November 2011 – April 2012
Statistical Analysis	February – April 2012
Writing of Thesis	November 2011– April 2012
Submission of Thesis	April 2012

## Appendix T: Statement of Epistemological Position

The approach taken to the research project came from a stance of post-positivism. There was acknowledgement that knowledge is based on human constructs but is largely still observable through the process of scientific discovery, with sensitivity to the limitations of the empirical approach in understanding human experiences. This was seen as an appropriate stance, as illness perceptions research focuses on the subjective beliefs of individuals but measures them in an empirical fashion through the use of psychometrically validated scales.