Considering the role of culture on asthma self-management behaviour: Using the Bangladeshi and Pakistani exemplar populations

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A thesis submitted in partial fulfilment of the requirements of the Degree of Doctor of Philosophy

Barts and the London

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Queen Mary, University of London

August 2018

Statement of originality

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Date: 14th August 2018

Details of collaboration and publications:

Ahmed, S., Salim, H., Steed, L., & Pinnock, H. (2017). Blue inhalers: blowing hot and cold. *NPJ primary care respiratory medicine*, *27*(1), 6.

Ahmed, S., Steed, L., Harris, K., Taylor, S. J. C., & Pinnock, H. (2018). Interventions to enhance the adoption of asthma self-management behaviour in the South Asian and African American population: a systematic review. *NPJ primary care respiratory medicine*, *28*(1), 5.

Acknowledgements

Abstract

Background: Self-management improves asthma outcomes and has been widely recommended in guidelines, though interventions are less effective in UK South Asian communities. Asthma, self-management and South Asian sociocultural contexts are all dynamic, therefore making sense of these factors is necessary. This thesis aimed to understand the role of two UK South Asian subcultures (Bangladeshi and Pakistani) on asthma self-management, which can help set the foundations for developing holistic bottom-up interventions.

Method: Using the MRC guidance on developing complex interventions, this thesis: i) narratively synthesises 16 RCTs (17 papers) in South Asian and Black populations to explore the extent to which variance in self-management is due to ethnicity and/or various sociocultural contexts, ii) semi-structured interviews with 27 Bangladeshis and Pakistanis with asthma to understand the role of culture in self-management, and iii) semi-structured interviews with nine healthcare professionals to understand their perspective on providing supported self-management to these communities.

Result: i) Sociocultural contexts (including whether individuals were from a minority or indigenous population) was important for developing interventions targeted at different cultures, but bottom-up interventions were rare. Ethnic minority interventions (South Asian and African-American) were less effective than interventions delivered in indigenous Indian populations, ii) The perspectives of individuals with asthma showed understanding the Bangladeshi and Pakistani self (the person) in self-management was helpful to understand various forms of self-management around the body, context, and distribution of knowledge/discourses, iii) The perspective of healthcare professionals showed that they mostly made universal assumptions about culture and adapted supported self-management accordingly (in the absence of adequate cultural training).

Conclusion: A holistic approach to developing bottom-up interventions, considering the perspective of Bangladeshi and Pakistani individuals and healthcare professionals are needed. Some intervention ideas that can be explored further are: medicine adherence during Ramadhan, psychological interventions (e.g. religious coping and dealing with emotions), raising physical/symbolic self-consciousness (e.g. beliefs), better service/language provisions and cultural training/information for healthcare professionals.

Definition of terms

Term	Definition
Acculturation	Cultural changes influenced by encountering another mainstream culture.
Acculturative stress	The reaction and experience of daily stress and degree of psychological/sociocultural adaptation challenges resulting from encountering a larger mainstream society.
Culture	*"A socially transmitted or socially constructed constellation consisting of such things as practices, competencies, ideas, schemas, symbols, values, norms, institutions, goals, constitutive rules, artifacts, and modifications of the physical environment"* (as cited in Fiske, 2002, pg.85).
Cultural hybridity	Bi-cultural competence and negotiations of being a part of two or more cultures with a new sense of belonging.
Culturally modified	Interventions developed for a majority population but modified to apply to other ethnic groups using various strategies e.g. language translation.
Cultural relativism	The belief that culture should be judged by its own merits rather than the culturally bounded values and standards of another, and cultural diversity should be recognised and respected.
Culturally tailored	Bottom-up interventions that considered cultural dimensions unique to individuals within a group e.g. level of spirituality in religion.
Culturally targeted	Bottom-up interventions that accounted for the shared characteristics of a cultural group during development e.g. religion.
Emic-etic perspective	The outsider-insider cultural perspective to data interpretation.
Ethnocentrism	The practice of judging a culture compared to standards of another culture where the better society is often judged as keeping up with the progression of time.
'Majority' South Asians	Interventions from South Asian countries where the South Asian population forms a majority e.g. India.
'Minority' South Asians/African Americans	Interventions from countries where the South Asian/African American population forms a minority e.g. UK.
Habitus	Internalised dispositions of second nature social rules and categorisations on perceptions, thoughts and behaviours predicted by past experiences, and social, cultural and economic capital.
Institutional racism	Public institutions response of ignorance to the needs of ethnic minorities that is not directly obvious.
Conflictual power (power 'over')	The capability of individuals/groups/institutions to prevail over another in doing something that a person is resistant to, would not normally do and is not in their interest. This form of power is based on social relations.
Consensual power (power 'to')	The general ability of individuals/groups/institutions to allow something to occur. This form of power is based on material and/or social action; often entailing finite power that is not produced but acquired from another who loses power.
Self-management	*"The tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their conditions"* (The US Institute of Medicine as cited in Adams et al., 2004, pg. 57).

Definition of terms (continued)	
Subcultural groups	Smaller and homogenous groups bounded by similarities of life experiences and historical ties in their country of origin which produce a mutual sense of identity, creating customs and traditions that enhance a sense of belonging that can be sustained even in a new environment with another mainstream culture.
The self	Direct or indirect statements that comprise of the self referring to *'I', 'me', 'mine', 'myself'* in social motivations, attitudes, beliefs, intentions, norms, roles and values.
Universalism	The belief that there are fixed universal cultural realities regardless of time.

List of abbreviations

1G	First Generation
2G	Second Generation
3G	Third Generation
4G	Fourth Generation
ATS	American Thoracic Society
CAM	Complementary and Alternative Medicine
CDSMP	Chronic Disease Self-Management Program
COPD	Chronic Obstructive Pulmonary Disease
CRN	Clinical Research Network
ECRHS	European Community Respiratory Health Survey
ERS	European Respiratory Society
GP	General Practitioner
GINA	Global Initiative for Asthma
HCP/s	Healthcare Professional/s
HEMS	Helicopter Emergency Medical Service
ICS	Inhaled corticosteroids
ISAAC	International Study of Asthma and Allergies in Children
LABA	Long-Acting Beta-Agonist
LMICs	Low or Middle Income Countries
MRC	Medical Research Council
NICE	National Institute of Clinical Excellence
NIH	National Institute of Health
PAAPs	Personalised Asthma Action Plans
PACE	Physician Asthma Clinical Education
PAL	Practical Approach to Lung health
PAPA	Perceptions and Practicalities Approach
PEFR	Peak Expiratory Flow Rate
PIS	Patient Information Sheet
PPI	Patient and Public Involvement
QOL	Quality of Life
RCT/s	Randomised Controlled Trial/s
SABA	Short-Acting Beta-Agonist

List of abbreviations (continued)

SES	Socio-Economic Status
SIGN/BTS	Scottish Intercollegiate Guidelines Network/British Thoracic Society
SL-ASIA	Suinn-Lew Asian Self-Identity Scale
TCS	Theory Coding Scheme
TDFs	Theoretical Domains Framework
WHO	World Health Organisation
UK	United Kingdom

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Chapter 1. Introduction

1.1 Rationale for the thesis

Asthma is a variable, heterogeneous and chronic respiratory condition, with significant burdens. Due to this, individuals with asthma need to adjust their self-management accordingly over a period of time (GINA, 2016; Pavord et al., 2017; SIGN, 2016). Asthma prevalence is higher in developed countries rather than South Asia. South Asians in the United Kingdom (UK) have poorer asthma outcomes and higher unscheduled care, compared to the mainstream White population and other ethnic minorities (Beasley, 1998; ECRHS, 2002; Netuveli et al., 2005; Sheikh et al., 2016). In support of this, growing evidence on the migrant paradox suggests that individuals from developing countries have better health outcomes before migrating to developed countries (Holmboe-Ottesen & Wandel, 2012; Lesser, Gasevic, & Lear, 2014). In addition to this, South Asian culture has heterogeneous features (e.g. subcultural group similarities and differences, acculturation[1], generational status and cultural hybridity[2]), suggesting that asthma self-management for each South Asian community in the UK context may be distinct and their perspective need further exploration for intervention development. Sometimes, users of the biomedical approach can exclusively focus on promoting the disease management of asthma (e.g. medicine adherence), however holistic asthma self-management (which considers the perspective and expertise of those living with asthma) means that self-management should not be segmented into fragments and pieces, therefore the perspective of healthcare professionals (HCPs) who provide supported self-management to these communities need to be considered (Schulman-Green et al., 2012; Trappenburg et al., 2013).

Asthma, self-management and South Asian culture all have dynamic characteristics that change over time and need to be conceptualised, interpreted and implemented adequately (Castro et al., 2010; Pavord et al., 2017; Schulman-Green et al., 2012). Holistic intervention development is an approach which can effectively incorporate and optimise all these factors by recognising the perspective and expertise of the individual with asthma and HCPs who

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[1] Acculturation is the cultural changes influenced by encountering another mainstream culture (Berry, 1997; 2005; Sam & Berry, 2010)

[2] Cultural hybridity is the bi-cultural competence and negotiations of being a part of two or more cultures with a new sense of belonging (Hall, 1990, 2014)

provide support them, therefore a review of interventions in this area for South Asians was necessary (Schulman-Green et al., 2012; Trappenburg et al., 2013; Udlis, 2011). Although, holistic self-management is widely recognised in literature, its practical implementation in interventions has been scarce and the robustness of interventions are questionable (Holland, 2017; Sinha, 2014; Triandis, 2018; Udlis, 2011). Due to interventions not sufficiently taking the complexity of culture into account, there was a need to look at new interventions that develop a comprehensive picture of the field (Barrera et al., 2013; Castro, Barrera, & Steiker, 2010).

Throughout the thesis, underlying power dynamics in health research and services have been highlighted. Power is intangible (Paradies, 2006); constantly constructed, deconstructed and negotiated, hence it can increase or decrease (Anyan, 2013; Paradies, 2006). Power can also be situational (e.g. social policies), relational (e.g. way of thinking, acting and interacting with others), or subtle e.g. the use of cultural terms (Holmes, Hughes, & Morrison, 2014). There can be three strategies in conceptualising power in health (Haugaard, 2002):

- Power 'over' (conflictual power) - consists of the capability of individuals/groups/institutions to prevail over another in doing something that a person is resistant to, would not normally do and is not in their interest. This form of power is based on social relations e.g. doctor-patient relationship.

- Power 'to' (consensual power) - consists of the general ability of individuals/groups/institutions to allow something to occur. This form of power is based on material and/or social action; often entailing finite power that is not produced but acquired from another who loses power e.g. mutual consent in an activity.

- Power as constitutive reality - this is power that determines who the individual/group/institution is that has power, their agendas/interests and what is influenced e.g. the employment of doctors in the position of power in healthcare settings (Haugaard, 2002).

Typically, power can be central and entangled with cultural health research (Storey, 2010). In a sense, cultural research in health psychology can be framed as a political activity engaging in critical thinking; recognising the political nature of human existence, freedom of thought and respect for others (Freire, 2018; Garthwaite et al., 2016). Critical health psychology and other disciplines recognise that hierarchical entities (dominant elites/classes who have access to resources e.g. specialist knowledge) can have the power to define the

world (Storey, 2010; Zoller & Dutta, 2009), create boundaries and regulate knowledge or meaning through authority and legitimate channels, and this transforms over time. Power struggles in cultural research has generally been around what can be defined as 'normal' (Storey, 2010). For instance, presenting meaning of health and illness as a universal truth beyond question can support the interests of the powerful (McHoul, McHoul, & Grace, 2015; Zoller & Dutta, 2009). This can be a form of narrative control to define social reality through the use of language throughout history e.g. meaning of cultural words and terms (Ahmad & Bradby, 2008; Burke et al., 2009a; Storey, 2010). There is a wealth of literature on the theoretical and evidence based understanding of power dynamics (Garthwaite et al., 2016). Most notably, work from Foucault (an influential philosopher) who suggested power is an inescapable dimension of social reality (McHoul, McHoul, & Grace, 2015). But, the mere existence of power inevitably indicates that there is a resistance to power (McHoul, McHoul, & Grace, 2015), e.g. exploring the true and essential meaning of something (Storey, 2010). This strand of research has been underexplored in preventable asthma inequalities (Doron & Broom, 2013; Garthwaite et al., 2016). Evidence to support the existence of power has been explored in many areas of health research, for instance doctor-patient relationship (Helman, 2014; Joseph-Williams, Elwyn, & Edwards, 2014), institutional racism[3] (Ramaswamy & Kelly, 2015), gender (Connell, 2012), technology and surveillance (Poland et al., 2005), and power distribution in the research process between the researcher and the researched or vice versa (Anyan, 2013).

1.2 Structure of the thesis

The thesis focusses on the earliest phase of the Medical Research Council (MRC) guidance to ensure practical effectiveness of considering culture before intervention development (that an intervention can work in everyday practice), consisting of:

- Identifying the evidence base - evaluation of existing evidence base e.g. conducting literature reviews and a systematic review.

- Identifying and developing theory - developing a theoretical understanding of behaviour changes e.g. reviewing existing evidence, theory and primary research such as the qualitative interviews (Craig et al., 2008).

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[3] Institutional racism is the public institutions response of ignorance to the needs of ethnic minorities that is not directly obvious (Ramaswamy & Kelly, 2015)

Table 1 shows the structure of this thesis which consists of nine chapters including three literature reviews (chapter 2, 3, 6), and three research chapters: a systematic review (chapter 5), a qualitative study with Bangladeshi and Pakistani individuals with asthma (chapter 7), and a qualitative study with HCPs who support Bangladeshi and Pakistani patients (chapter 6). To simplify concepts that have been used, most definition of terms is provided in footnotes. The findings of the thesis will aid the understanding of the role of UK Bangladeshi and Pakistani culture on asthma self-management behaviour, which can help set the foundations for developing holistic bottom-up interventions. The two subcultural groups Bangladeshi and Pakistani populations (two of the major South Asian communities in the UK) were included due to the complexity and dynamic nature of culture. South Asians are not a homogenous group, therefore specific features of diversity and commonality needed consideration.

Table 1. Structure of the thesis

Objectives	Key finding	Chapter
To understand the dynamic nature of asthma, self-management and the general South Asian sociocultural context to examine the importance of diversity and commonality.	The perspective of individuals with asthma and HCPs can help inform cultural influences that need to be considered before developing holistic asthma self-management interventions, since it allows the dynamic features of asthma, self-management and South Asian sociocultural context to be incorporated.	Background literature was reviewed (see chapter 2).
To understand what can inform/optimise holistic asthma self-management interventions for the general South Asian population.	A comprehensive picture of what cultural factors have been considered/implemented to enhance the development of holistic asthma self-management interventions for South Asians was reviewed, and this has not been reflected or researched well.	Background literature was reviewed (see chapter 3).
To understand theory underpinning the qualitative studies in chapter 7 and 8; the acculturation model (Berry, 1997; 2005; Sam & Berry, 2010) and cultural hybridity theory (Hall, 1990, 2014).	Cross-cultural psychology theories were reviewed to help understand the dynamic nature of Bangladeshi and Pakistani culture and any interactions with the healthcare system.	Background literature was reviewed (see chapter 6).
To identify the gaps and limitations of previous research (from chapter 2 and 3) with a view of adding to the literature, through the aims and objectives of the thesis.	Key findings of the aims and objectives have been answered in chapter 9.	Aims and objectives were described (see chapter 4).
To analyse interventions for South Asians (and as a comparator the Black population) to explore the extent to which variance in self-management may be due to ethnicity and/or various sociocultural contexts: *Analysis one -* • Describe features of culturally relevant asthma self-management interventions. • Synthesise the evidence for the effectiveness of asthma self-management interventions. • Identify barriers and facilitators of implementing asthma self-management behaviour.	The influence of sociocultural contexts (including whether individuals are from a minority or indigenous population) are important for adequately developing, delivering and evaluating self-management interventions targeted at different cultures, however bottom-up interventions were rare.	A systematic review was reported and narratively synthesised randomised controlled trials. The review analysis was separated into two analyses (see chapter 5).

Table 1 continued		
Analysis two – • Establish the extent to which theory has been used in interventions. • Identify and describe theoretical intervention components. • Examine the relationship between reported barriers and facilitators and theoretical intervention components. • Synthesise the relationship between theory use and intervention components to asthma outcomes.		
To interview Bangladeshis and Pakistanis with asthma: • To understand the role of culture in self-management by exploring perspectives of the first, second, third and fourth generations in the UK. • To identify the categories of HCP/s that were most significant for participant's asthma care (not necessarily the individual's own HCP). • To describe what type of asthma self-management interventions Bangladeshi and Pakistani individuals feel would be useful for themselves and/or their community.	The perspective of Bangladeshi and Pakistani participants with asthma showed that the importance of understanding who the person is (the self) and how this influences asthma self-management. The Bangladeshi and Pakistani self in self-management was tied to the body (e.g. balancing emotions in the body), society (e.g. cultural stress), and social discourses e.g. knowledge from HCPs shaped understanding of self-management (sometimes as disease management).	Semi-structured interviews were conducted (see chapter 7). Categories of HCPs identified by participants were interviewed and presented in chapter 8.
To interview HCPs who provide supported self-management to Bangladeshi and Pakistani individuals with asthma: • To understand HCP perspective on Bangladeshi and Pakistani culture and asthma self-management behaviour (i.e. cultural realities) and how they provide supported self-management to these communities. • To explore the type of asthma self-management intervention/s HCPs feel would be useful for Bangladeshi and Pakistani individuals with asthma. • To explore the type of asthma self-management intervention/s HCPs feel would be useful for their future practice needs.	The perspective of HCPs showed that there was a gap in cultural training/information to provide adequate supported self-management that was in line with holistic representations of self-management for patients. Therefore, HCPs made universal assumptions about their perception of culture and what needs to be adapted for supported self-management. Although, sometimes HCPs also considered individual differences in Bangladeshi and Pakistani culture.	Semi-structured interviews were conducted (see chapter 8).

Table 1 continued		
To discuss the findings of the thesis, recommend suggestions for developing future asthma self-management interventions, discuss methodologies used in this thesis and implications of findings.	The perspectives of individuals with asthma and HCPs have been examined and implications have been suggested to help highlight holistic cultural features and for future intervention developers to ensure practical effectiveness and cultural relevance in self-management.	Discussion of findings, recommendations, methodology and implications (see chapter 9).

Chapter 2. Literature review: The dynamic nature of asthma, self-management and the general South Asian sociocultural context

This chapter introduces the dynamic nature of asthma, self-management and South Asian sociocultural context; which all need to be appropriately conceptualised and further understood to avoid homogenous implementation in interventions.

2.1 Asthma

This section summarises the heterogeneity of asthma (in the way that it has been conceptualised, its treatment and consideration of geographical diversity in guidelines), and the significant asthma burden.

2.1.1 Defining asthma

There is no standard definition of asthma. Asthma guidelines have used slightly different definitions, but there are common features (GINA, 2016; SIGN, 2016). The Global Initiative for Asthma (GINA) (GINA, 2016), and the Scottish Intercollegiate Guidelines Network/British Thoracic Society British Guideline on the management of asthma (SIGN/BTS) (SIGN, 2016), agree that asthma is a variable chronic respiratory illness, which is increasingly understood to be due to chronic airway inflammation in individuals (GINA, 2016; NRAD, 2014; SIGN, 2016). Its diagnosis usually relies upon the history of an individual's respiratory symptoms, including:

- Wheeze (which is an abnormal high-pitched respiratory noise that originates from the chest).
- Chest tightness.
- Cough (which can vary over time and severity) and may be productive of sputum (GINA, 2016; SIGN, 2016).

The variability of asthma means symptoms appear and disappear over time and vary in severity. Symptoms may naturally fade or need medication/treatment to resolve (GINA, 2016; SIGN, 2016). Individuals are also faced with asthma attacks (episodic worsening of

symptoms which are outside the person's normal daily asthma variation), that can vary in severity (mild, moderate or severe) (GINA, 2016; NRAD, 2014; Reddel et al., 2009). Due to the variability of asthma, tests are often negative (where results from measurements such as peak flow and spirometry appear normal), even if someone has asthma (NRAD, 2014; SIGN, 2016), and medication prescribed to people varies (NICE, 2013).

What triggers asthma (environmental factors that worsen symptoms) can also differ for individuals, including:

- Exercise/physical activity (NRAD, 2014; SIGN, 2016).

- Exposure to allergens/irritants or early life exposures e.g. house dust mites and food allergies (NRAD, 2014; SIGN, 2016).

- Occupational asthma in work environments that can have various environmental triggers (SIGN, 2016).

- Weather changes, cold air or viral respiratory infections e.g. cold and flu (NRAD, 2014; SIGN, 2016).

- Climatic variations e.g. air pollution and fumes (NRAD, 2014; SIGN, 2016).

- Psychological conditions (e.g. depression and anxiety), that can affect motivation for adhering to medicine and aggravate stress (which can itself trigger asthma) (NRAD, 2014; SIGN, 2016).

- Behavioural factors that can reduce effectiveness of medication e.g. active and passive smoking, alcohol, drugs, obesity and being overweight (NRAD, 2014; SIGN, 2016).

- Gender e.g. female hormones (SIGN, 2016).

In the face of guidelines trying to reflect the variability of asthma, the recent Lancet Commission proposes that physiological, pathological and clinical feature-based characteristics of asthma are outdated, since they suggest a universal and measurable definition which does not reflect or do justice to describing asthma and its heterogeneous nature. Little progress has been made on this in the last ten years especially in guidelines (Lancet, 2006; Pavord et al., 2017). For instance, airway inflammation is heterogeneous. Raised blood eosinophil counts[4] are, i) easy to measure and ii) help to tailor treatment. For example, individuals with eosinophilic asthma are likely to benefit from and respond to inhaled corticosteroids (ICS). This can potentially be used to target ICS treatment, rather than

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[4] Blood eosinophils are white blood cells that increase with the allergic inflammation responsible for asthma symptoms in some individuals (Pavord et al., 2017)

indiscriminate prescribing ICS to all individuals with asthma as a 'one size fits all' approach. Assessment of biomarkers for asthma may potentially be the way forward in providing precision medicine (Pavord et al., 2017).

2.1.2 Treatment of asthma

Achieving good asthma control

Tailored treatment can improve, control and reduce asthma symptoms allowing individuals to live a normal life. Early and good asthma control can be attained and sustained by increasing or decreasing medication and by individuals familiarising themselves with what aggravates their symptoms and triggers attacks (NICE, 2013; SIGN, 2016). The ideal clinical maintenance of asthma control is defined as (SIGN, 2016):

- No daytime symptoms.
- No nocturnal asthma awakenings.
- No rescue medication use.
- No asthma attacks.
- No limitations on activity.
- Normal lung function.
- Lack of medication side-effects.

Individual motivation to maintain good asthma control using medication may differ depending on whether there are side-effects, the inconvenience of taking daily treatment or the severity of asthma. It is also important to monitor medication adherence by tracking whether treatment needs to change over time, checking whether proper inhaler technique is being used to ensure medication reaches its destination, and minimising asthma triggers (NICE, 2013; SIGN, 2016). Evidence suggests that one method of helping individuals monitor their asthma is by using written personalised asthma action plans (PAAPs), which can help identify symptom deterioration and triggers, and provide information on when to use medication and access medical care (GINA, 2016; NICE, 2013; NRAD, 2014; SIGN, 2016).

Effective and safe asthma medication strategies

The recent Lancet Commission on asthma (Pavord et al., 2017), has noted that the progress in understanding and developing better individualised medication has been little in the last

ten years (Lancet, 2006; Pavord et al., 2017). There are two core groups of medications which can be delivered in a range of inhalers (Pavord et al., 2017; SIGN, 2016). These medications are important to use alongside each other. Individuals with asthma are expected to try and test different inhaler devices to see which suits them best (SIGN, 2016). At the same time, there are some devices that are recommended due to safety and effectiveness concerns (SIGN, 2016):

- Reliever inhalers - reliever medication (usually coloured blue) is a short-term treatment used to relieve symptoms particularly during asthma attacks. It immediately reaches the lungs to help relax and open up the airway allowing better breathing. People with asthma are always expected to carry a reliever inhaler with them (Asthma UK, 2016a; SIGN, 2016). Commonly, reliever bronchodilators are inhaled short-acting beta-agonist (SABA) (SIGN, 2016). Infrequent reliever use suggests good asthma control, as rare asthma symptoms mean that very little medication is needed (Asthma UK, 2016a; SIGN, 2016).

- Preventer inhalers - preventer medication are treatment that should be used daily and work over time (e.g. ICS). Preventer medication treat long-term airway inflammation and sensitivities in the lungs, reduce the likelihood of experiencing symptoms or reacting to triggers. They also improve lung function and quality of life (QOL), and prevent asthma attacks (Asthma UK, 2016b; SIGN, 2016).

There are also combination inhalers consisting of preventer medication with the addition of a long-acting reliever (e.g. ICS/long-acting beta-agonist; LABA), that can be used to treat poorly controlled asthma or in situations where there is a risk that individuals who are given a LABA may decide to stop using the ICS (that can have an increased risk of severe/fatal asthma). The Lancet Commission recommended that going forward, asthma treatment needs to recognise that individuals respond differently to medication and therefore treatment needs to be matched according to the person e.g. what type of asthma they have, co-morbidities, lifestyle and environmental factors (Pavord et al., 2017).

2.1.3 Diversity in asthma guidelines

Asthma guidelines are vehicles that synthesise research evidence into recommendations for best practice, which are likely to lead to improved asthma outcomes (for both professionals and people with asthma). HCP's comprehension and interpretation of, and organisational support for implementing guidelines may also vary (Gagliardi & Brouwers, 2015; Loudon et

al., 2014; Vernooij, Willson, & Gagliardi, 2016). There are various asthma guidelines, including:

- Those that are relevant to the UK e.g. SIGN/BTS (SIGN, 2016), and National Institute of Clinical Excellence (NICE) guidelines (NICE, 2013).
- Global guidelines e.g. GINA (GINA, 2016), and the World Health Organisation (WHO) Practical Approach to Lung Health (PAL) (WHO, 2007).
- Those specifically targeted at a particularly audience e.g. International European Respiratory Society/American Thoracic Society (ERS/ATS) guidelines on definition, evaluation and treatment of severe asthma (Chung et al., 2013).

In relation to global guidelines that are applied to low or middle-income countries (LMICs), the Lancet Commission highlights that they often implicitly assume asthma is the same across countries and that standard asthma care should match developed countries, albeit recognising contextual factors such as affordability, availability of medication and basic tools for testing diagnosis (Pavord et al., 2017), though the latter is recognised to some extent in global guidelines (GINA, 2016; WHO, 2007). To appreciate asthma in terms of geographical diversity means to work towards conceptualising and treating asthma as a heterogeneous condition e.g. what works and what does not work in one country such as differences in healthcare systems and medication effectiveness may be dependent on the climate in various countries (Pavord et al., 2017).

2.1.4 The burden of asthma

There has been little epidemiological research on the burden and cost of asthma, particularly for South Asians in the UK (accounting for diagnosis not restricted to ethnicity) (Mukherjee et al., 2016; NRAD, 2014). In between 2011 and 2012, 240,000 people in the UK were diagnosed with asthma (Mukherjee et al., 2016). Evidence suggests that asthma accounts for a high level of mortality and unscheduled care e.g. accident and emergency visits, hospital admissions, out of hours care and consultations (NICE, 2013; NRAD, 2014; Sheikh et al., 2016). During 2011 to 2012, there were over 65,000 hospital admissions in the UK, of which the majority were from England (54,789) and aged 15 or over (33,470). Mukherjee et al. (2016) found that the burden of annual cost on the UK healthcare system each year included:

- £1.1 billion primary care costs, leading to inpatient asthma episodes and deaths. On average, there were 5,600 weekly incidents of asthma episodes in primary care, an

estimated 2.7 million cost for General Practitioner (GP) consultations, 3.7 million cost for nurse consultations and 54,000 out of hour asthma calls.

- There were 113,000 ambulance visits for asthma, 121,000 accident and emergency visits, 93,900 patient episodes, 6,100 day-case episodes and 1,800 intensive care unit episodes.

The wider societal impact included:

- School absenteeism (2.8 million absences).

- Work absenteeism (4.1 million work days lost).

- Disability living allowance was claimed for 36,980 individuals, accounting for 24,100 in England, 5,980 in Northern Ireland, 3,600 in Scotland and 3,300 in Wales (Mukherjee et al., 2016).

Despite increased investment in asthma medication (Pavord et al., 2017), death rates for severe, moderate and mild asthma are still increasing. Moderate and mild asthma accounted for above 50% of deaths (NRAD, 2014). Most asthma deaths were avoidable (NRAD, 2014). The implementation of self-management has been one widely recommended strategy to reduce asthma burdens (NICE, 2013; NRAD, 2014; Sheikh et al., 2016; SIGN, 2016).

2.2 Self-management of asthma

Asthma is heterogeneous (Pavord et al., 2017). To develop an foundation and understanding of South Asian culture that may influence asthma self-management, there is a need to also examine the heterogeneity of the term self-management, in the way it has been conceptualised, evolved and implemented as an approach for managing the variable nature of asthma (GINA, 2016; SIGN, 2016).

2.2.1 Historical understanding of self-management

Self-management was initially used to describe information provided in education (Creer, 2000). It was recognised that information provision was not enough to produce behaviour change, henceforth psychological concepts were integrated in understanding self-management (Newman, Steed, & Mulligan, 2004), e.g. self-efficacy (the belief that one has the ability to complete a task) through activities such as problem-solving and goal setting (Bandura, 1977), coping with stress (Folkman, 1984; Lazarus, 1992), or readiness to change from the transtheoretical model (which is how prepared people are to change their behaviours e.g. motivations to change) (Prochaska & Velicer, 1997). Similarly, cognitive

behaviour therapy was considered as part of self-management (a talking therapy where thinking and behaviour towards an illness are identified and challenged) (Newman, Steed, & Mulligan, 2004).

The evolution of understanding self-management over time (from providing education to applying psychological concepts), has allowed self-management to move away from a field that suggested HCPs were the experts compared to people with asthma, to a more participatory approach, where both parties work together and expertise on each side are recognised (Morris, Kennedy, & Sanders, 2016; Schulman-Green et al., 2012; Trappenburg et al., 2013). This demonstrates that the term self-management is continually evolving (a dynamic attribute), and needs to be looked at holistically; from the perspective and experience of the person with asthma and HCPs who support them (Schulman-Green et al., 2012; Trappenburg et al., 2013; Udlis, 2011). As an example, PAAPs have evolved since the 1980s from the use of different terminologies (e.g. 'treatment plans', 'self-management plans' or 'action plan'), and whether plans were basic or complex (e.g. general plans that involve medical management to more holistic plans that incorporate lifestyle and health promotion factors), or those aimed at individuals or organisations to promote implementation of their use (Ring et al., 2011).

2.2.2 Defining holistic self-management

This thesis uses the US Institute of Medicine's definition of self-management widely used in clinical guidelines (e.g. SIGN, 2016) as, *"The tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their conditions"* (as cited in Adams et al., 2004, pg. 57). The purpose of self-management is to enable people to monitor and manage living with their chronic illness with self-confidence, typically adjusting physically, emotionally and psychosocially (Adams et al., 2004; SIGN, 2016). This definition of self-management may be characterised as holistic, as it recognises the inclusion of different biopsychosocial dimensions (Carnes et al., 2012).

Supported self-management which is widely recommended in asthma guidelines (e.g. GINA, 2016; SIGN, 2016) can be defined as, *"The assistance caregivers give patients with chronic disease in order to encourage daily decisions that improve health related behaviours and*

clinical outcomes. Self-management support can be viewed in two ways: as a portfolio of techniques and tools that help patients choose healthy behaviours; and a fundamental transformation of the patient-caregiver relationship into a collaborative partnership" (as cited in Bodenheimer, MacGregor, & Sharifi, 2005, pg.4). A meta-review of systematic reviews on randomised controlled trials (RCTs) by Taylor et al. (2014), revealed supported self-management in asthma helped reduce unscheduled secondary care (e.g. hospitalisations and accident and emergency attendance/consultations), and improved QOL and asthma control for people from a range of backgrounds. A taxonomy derived by Pearce et al. (2016) from workshops with asthma experts found that the most effective support in interventions (what works, for who and in which context) for enhancing asthma self-management behaviour were those that had multi-components (Pearce et al., 2016).

Common core components in self-management support interventions that were specific to the variability and individual differences of asthma, included:

- Structured education about asthma and self-management repeated over time. The strongest evidence for reducing unscheduled healthcare (for asthma attacks in emergency departments and hospitalisations), was attributed to education that acknowledged an individual's pre-existing knowledge and asthma beliefs (Pearce et al., 2016; Taylor et al., 2014). Some evidence suggested that interactive learning was better than dictated education (or education provided in isolation) (Taylor et al., 2014), and education should also be culturally sensitive e.g. considering contextual environment for ethnic minorities (Pearce et al., 2016; Taylor et al., 2014).

- Regular clinical reviews e.g. access to care during worsening of asthma and managing acute episodes and psychological response to daily life with asthma adjustment. Patient-provider relationship and involvement was important to provide an atmosphere of open communication, trust, encourage participation and medication adherence (Pearce et al., 2016). Additionally, provision of PAAPs, in particular recognising and responding to signs of deterioration (with varying duration, intensity and delivery formats) (Pearce et al., 2016). This was supported by the National Review of Asthma Deaths (NRAD) report, which revealed that of the people with asthma who died, 23% owned a PAAP and 22% failed to attend asthma reviews a year before their death (NRAD, 2014).

Other factors that were important for asthma and also other long term conditions included trigger avoidance, teaching how to monitor asthma symptoms, optimal treatment strategies, promotion of adherence and using behaviour change theories (Pearce et al., 2016). Little is

known about the demographic characteristic of a person that can help enhance self-management (Touwen, 2016). Systematic reviews have shown that there needs to be a whole systems approach to implementing self-management (patient, HCP and organisational level) (Pinnock et al., 2015; Taylor et al., 2014).

2.2.3 Understanding the implementation of holistic self-management

The Lancet Commission emphasised that self-management is a core aspect of asthma management that helps deal with its variable nature (Pavord et al., 2017). However, self-management itself is also heterogeneous according to the person (Dwarswaard, et al., 2016; McCorkle et al., 2011). Therefore, the person (the self) in self-management needs exploration (Sinha, 2014; Triandis, 2018). The overall experience of living with an illness is a dynamic shifting process. Different illnesses necessitate a variety of self-management behaviours or supported self-management (De Silva, 2011; Torsi, 2012). A qualitative meta-analysis by Schulman-Green et al. (2012) found that the type of self-management behaviour can differ according to the condition that is being managed, for instance diet alterations may be more important for irritable bowel syndrome than asthma. Additionally, individuals do not necessarily self-manage optimally and attention to self-management can vary over time, involving differential focus (Schulman-Green et al., 2012). For example, circumstances where self-management routine changes, individuals learn other skills, new diagnosis or development of illness complications, access to ongoing HCP support, changes to family health and support including breakdown of relationships (Dwarswaard et al., 2016; McCorkle et al., 2011; Schulman-Green et al., 2012).

In terms of holistic asthma self-management, it identifies the individual as the expert of living with asthma, a process where people are actively involved in planning and learning, and therefore they are best placed to assess their own self-management and what support is needed over time, suggesting that they have a unique perspective of self-management (Schulman-Green et al., 2012; Trappenburg et al., 2013; Udlis, 2011). From this viewpoint, the heterogeneity of holistic self-management may mean it is not universal but individually and socially constructed (e.g. the meaning given to self-management), and this may vary around identity such as culture. Therefore, this may mean that the actual term self-management does not necessarily need to be widely known to individuals (Udlis, 2011).

Some studies have identified that the perspective and lived expertise of both individuals with asthma and HCPs need consideration (e.g. Kritikos et al., 2010; Mammen & Rhee, 2012).

Understanding the segmented approach to self-management

There may be a theoretical recognition that self-management needs to be holistic, but at times its implementation by HCPs and researchers may not be widely considered (Schulman-Green et al., 2012; Trappenburg et al., 2013; Udlis, 2011). For instance, asthma is a good example where users of the biomedical model can predominantly focus on disease management and monitoring of asthma (e.g. medicine adherence), therefore prioritising medical self-management while overlooking psychosocial and other factors (Sadler, Wolfe, & McKevitt, 2014; Schulman-Green et al., 2012). A systematic review by Sadler, Wolfe and McKevitt found HCPs commonly focussed on disease management of various long-term conditions including asthma that emphasised on individual responsibility for self-management. However, individuals with asthma perceived self-management to be broader incorporating medical, psychological and social factors, managing responsibly alongside and in partnership with HCPs. This mismatch of perception suggests that self-management needs to be contextually relevant to the lives of individuals with asthma (Sadler, Wolfe, & McKevitt, 2014).

A person may also be influenced by multiple core relationships (not just HCPs), including family, peers and organisations/institutes (who are able to provide resources) (Udlis, 2011). Evidence for the role of others in self-management is growing, providing a deeper understanding of a person's approach to self-management e.g. exercising in peer or familial context (Morris, Kennedy, & Sanders, 2016; Udlis, 2011). A qualitative study by Morris, Kennedy & Sanders (2016) on diabetes, chronic obstructive pulmonary disease (COPD) and irritable bowel syndrome in North West England showed that a person's social network is complex and changes over time:

- The main social supporters for participants were family members and friends. Daily practical support from the former group consisted of reminders to take medication, assistance during appointments, cooking appropriate food and performing activities together e.g. exercise. In terms of peer support, participants referred to them if they were perceived to have available resources e.g. ability to collect medication from the pharmacist.

- HCPs were the least utilised, but clinicians were the central point of reference for completing specific tasks and concerns (e.g. prescriptions), though information from clinicians were valued over other sources.
- If participants had conflict with any sources of support such as negative influences (e.g. special occasions/events that do not cater for dietary requirements or disengagement in a relationship), alternative support was sought elsewhere e.g. re-establishing relationships with others (Morris, Kennedy, & Sanders, 2016).

2.2.4 Understanding the 'self' in self-management

If individuals are treated as experts of their own condition, the individual persona; 'the self' in their context should be central to holistic self-management e.g. the meaning given to self-management (Dwarswaard et al., 2016; McCorkle et al., 2011; Triandis, 2018). The self can be broadly defined as direct or indirect statements that comprise of the self referring to *'I', 'me', 'mine', 'myself'* (Triandis, 2018), in social motivations, attitudes, beliefs, intentions, norms, roles and values (Cooley, 2017; Triandis, 2018). The self; who a person is with/without asthma or individually/collectively, their lived sociocultural and contextual experiences or expertise, and how the self changes/redefines itself over time can help to understand self-management behaviour (Ahmed et al., 2018; Fortun et al., 2014). The self has been applied to health research but not specifically in health psychology (Kralik et al., 2004; Kralik, Paterson, & Coates, 2010). Although, it can be argued that the self has been explored in terms of cognitions and emotions e.g. illness representations (Leventhal, Benyamini, & Shafer, 2007). In contrast, the self has been commonly used in social psychology; looking at structures and processes that an individual knows by which they can assess themselves, present themselves to others and maintain control. The social psychology discipline can help inform the area alongside health psychology. This is of particular relevance when exploring self-management in a specific cultural group (Baumeister, 2006, 2012). For instance, self-evident information consistent with the definition of the cultural self is more likely to be positively processed, assessed and translated into behaviour (a principal known as cultural relevance) (Castro et al., 2010; Castro, Barrera, & Martinez, 2004).

The social identity theory (a behaviour change theory from social psychology) can help define self-identity (which mainly emphasises on collective identity largely informing cultural/ethnic identity in one's sociocultural context) defined as, *"Part of the individual's self-concept which*

derives from his (or her) knowledge of his (her) membership in a social group (or groups) together with the values and emotional significance attached to that membership" (as cited in Tajfel & Turner, 2004, pg. 63). Identity in this context is defined by relationships e.g. familial and role identities (Tajfel & Turner, 2004; Triandis, 2018). This is underpinned by two processes of social identity theory; social comparisons and self-categorisation, which are important parts of formulating social identity (Michie et al., 2014; Tajfel & Turner, 2004):

- Self-categorisation is reflexive, that treats the self as an object that can be categorised and labelled (e.g. in response to the social world) (Michie et al., 2014; Tajfel & Turner, 2004).

- Social comparisons enable individuals to categorise the self with those who are similar, as part of the in-group (the group that is positively differentiated and evaluated from other groups hence increasing a sense of perceived belonging), in comparison to outgroups (those who are differentiated and evaluated as different e.g. differences in language. Perceived belongingness can be at an individual and group level (Tajfel & Turner, 2004).

The formulation of individual identity is largely vague; described as a process where self-definition relies on the individual person e.g. individual possessions, experiences and accomplishments. This is due to the social identity theory assuming that social identity is the primary foundation for self-definition, which is particularly applicable to understanding the self in self-management when cultural groups are at play (Jaspal, 2010; Michie et al., 2014).

The cultural self can be subjective (shared by members of a culture) and dependent on various cultural characteristics -

- Cultures can be individual and/or collective - each culture can have a combination of different selves shaped by varying situations (explained below). One may be more common than the other in a group (Triandis, 2018), and it is likely people in a group can vary on individual and collective dimensions depending on contextual factors such as migration (Cohen, Wu, & Miller, 2016):
  → The individual self - those raised in individualistic cultures tend to cognitively convert situations using individual settings e.g. social relationships and interactions are treated as separate and individuals are mostly independent of others.
  → The collective self - those raised in collective cultures tend to cognitively convert situations using collective settings (e.g. family or religion), because they lean towards the perception of closeness between group members (Triandis, 2018).

- Cultures can be complex or simple. Complex cultures tend to be individualistic (e.g. comprising of more choices), as opposed to simple food gathering cultures e.g. nomads.

- Cultures can be loose and/or tight – this depends on the extent norms are reinforced by the cultural group. In loose cultures, geographical mobility allows norms to be flexible (e.g. the West). In contrast, tight cultures are more homogenous collective cultures (e.g. Japan), therefore deviations from cultural norms are less tolerable, punishable or considered as improper behaviour e.g. social criticisms of eating Western food. In between are cultures that are tight and loose (e.g. China), depending on the sociocultural context e.g. rural areas of a country and smaller families tend to be tight as norms are clearer and better reinforced compared to urban areas of a country and bigger families (Triandis, 2018).

Most empirical evidence on the South Asian self are either outdated (Sinha, 2014), or focus mainly on Indians as opposed to other South Asian subcultures (Marsella, De Vos, & Hsu, 1985; Roland, 1991; Sinha & Tripathi, 1994; Sinha, 1988). This suggests that there is a need to understand self-management for different South Asian communities in detail over time, especially in new environments (Davidson, Liu, & Sheikh, 2010; Liu et al., 2012). Existing literature has shown that the Indian self can be flexible with a range of loose/tight and individual/collective traits (Sinha, 2014; Triandis, 2018):

- The Indian self was part of the body (bounded by the body) which was perceived to be a common part of the western self, and the self was also a collective part of a group e.g. the family, tribe, religion or caste (perceived to be common in the African/Asian self) (Marsella et al., 1985).

- Individualism in religious and ethical values were consistent with the peace of mind and freedom from stress e.g. teachings of Hinduism and Buddhism such as meditation (Roland, 1991; Sinha & Tripathi, 1994; Sinha, 1988).

- Greater collective connectedness with others e.g. response to the needs of others was seen as a moral obligation (Miller et al., 2015). The individual/private self was systematised collectively as 'we', 'our' and 'us'. For instance, the family were a part of the self sustained despite migration, hence the good health of the self also incorporated the health of the family (Gupta, 1999; Roland, 1991; Sinha, 1988). Therefore, this definition of the self was dictated by cultural values and the place a person has in the community e.g. individual responsibility/role in the family and family social status (Gupta, 1999).

2.3 Considering the general South Asian sociocultural context

Asthma and self-management are heterogeneous, which need to be adequately considered in interventions (Pavord et al., 2017; Schulman-Green et al., 2012). To develop interventions within a specific cultural group however there is also a need to understand the heterogeneous nature of South Asian culture and their sociocultural context (Schulman-Green et al., 2012; Trappenburg et al., 2013; Udlis, 2011). This section defines culture and describes some distinct features of South Asian sociocultural context in the UK.

2.3.1 Defining and conceptualising culture

There is no single definition of culture. Often, consideration of the theoretical understanding of culture is missing in health research (Bhopal & Sheikh, 2009; Castro, Barrera, & Steiker, 2010). A minimum of 164 definitions of culture have been documented. Fragmented by numerous disciplines and their standard approach to defining culture, leaving abundant room for interpretation (Liu et al., 2016). There have been various attempts to reach a consensus on the definition of culture. This thesis uses the following consensus/definition of culture that considers both individualistic and collectivist aspects that may be meaningful to South Asian culture (Sinha, 2014; Triandis, 2018); *"A socially transmitted or socially constructed constellation consisting of such things as practices, competencies, ideas, schemas, symbols, values, norms, institutions, goals, constitutive rules, artifacts, and modifications of the physical environment"* (as cited in Fiske, 2002, pg.85).

In this respect, culture becomes a subjective reality to the individual who experiences it and others who observe it (Triandis, 2018). Culture can be learnt or transmitted across generations; through cultural knowledge that are observable (e.g. symbols), or cognitive (e.g. beliefs), allowing individuals to meaningfully define society including identity, relationships and boundaries with others (Liu et al., 2016; Yadav & Yadav, 2015). To make sense of the complexity of culture, culture can be thought of as a mosaic; a structural framework of a collage of factors that contribute to an individual's sociocultural identity. Each identity of an individual can consist of a combination of cultural tiles e.g. age, gender and ethnicity or shared communal factors such as common heritage, religion and family. The mosaic can

provide an identifiable structure of culture as a collection of cultural elements and reflect the complexity of culture in its sociocultural context (Chao & Moon, 2005).

2.3.2 South Asian intergroup subcultural heterogeneities

Figure 1. Map of South Asia (Wasay, Khatri, & Kaul, 2014)

The expression 'South Asians' is a broad term that is widely used to describe individuals whose family have originated from the Indian subcontinent (known as South Asia), which comprise of the following main countries: India, Pakistan, Bangladesh, Sri Lanka, Nepal, Maldives, Bhutan and Afghanistan (see Figure 1) (Hasnain, Parikh, & Nagaraj, 2017).
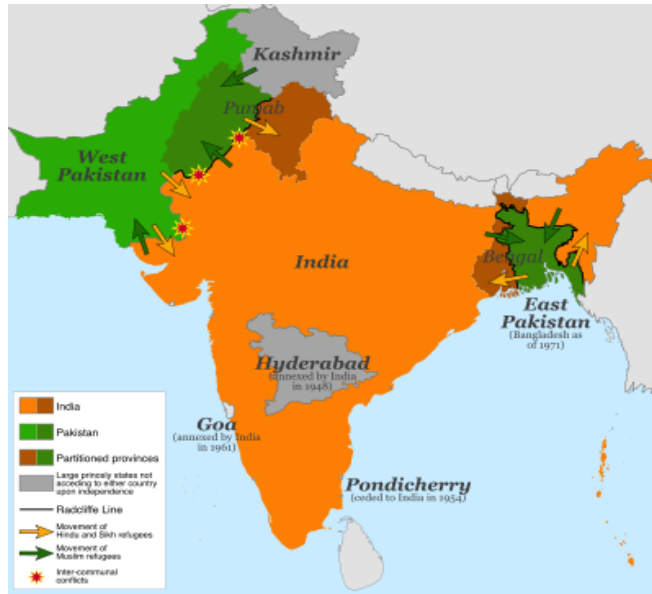
Figure 2. Map of the Indian partition 1947 (Work, 2017)

South Asians from different South Asian countries can be similar in many cultural respects e.g. perception of asthma, health and illness (Liu et al., 2016; Sharif, 2012), but the term does not recognise the widespread differences amongst each subcultural group at a local and national level (Sharif, 2012). Similarities and differences in smaller and homogenous subcultural groups who live alongside each other, are bounded by similarities of life experiences and historical ties in their country of origin which can create a mutual sense of identity/belonging, but can also be fluid (Barrera et al., 2013; Fernando, 2010). Subcultural diversity becomes even more complex when considering South Asians who migrate and/or have settled in non-South Asian countries, and the cultural changes that occur from being in a new environment and encountering a mainstream culture e.g. acculturation[5] (see section 2.3.5), which shapes a broader sense of belongingness (Chatterji & Washbrook, 2014; Sam & Berry, 2010; Sharif, 2012).

There are various examples of cultural diversity amongst South Asians which can be seen in the history, geographical locations and languages of these countries, reflecting that all South Asians are not homogenous and that they should not be treated as such (Chatterji & Washbrook, 2014; Sharif, 2012). For instance:

- Historical diversity - India, Pakistan and Bangladesh were formerly one country known as 'India' during British colonisation, which went through the process of partition causing

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[5] Acculturation is the cultural changes influenced by encountering another mainstream culture (Berry, 1997; 2005; Sam & Berry, 2010)

the displacement of many individuals. For example, the provenance of Punjab and Bengal were divided into two, based on the majority population's religion in those areas; the state of Punjab was separated into India and Pakistan, and Bengal was separated into West Bengal/Tripura India and East Pakistan. The latter gained independence in 1971 and is now known as Bangladesh (see Figure 2). Individuals from these localities either describe themselves as Punjabi Indians, Punjabi Pakistanis, Bengali Indians or Bengali Bangladeshis (Chatterji & Washbrook, 2014; Van Schendel & Abraham, 2005).

- Geographical diversity - the distance between the West Indian district of Gujarat and Bangladesh is over 2,000 kilometres which is equivalent to the distance between London and Athens (Henley & Schott, 1999).

- Language diversity - there are over 800 South Asian languages (including various dialects), English learnt due to colonisation and languages learnt from countries of migration e.g. the African language Swahili. Some of these South Asian languages include: Punjabi (including the Mirpuri dialect), Urdu, Hindi, Tamil, Gujrati (including the Kutchi dialect), Pashto, Bengali (including the Sylheti dialect), Marathi and so forth. In addition, there are also oral languages with no written form e.g. Sylheti and Mirpuri. This can complicate healthcare service delivery and intervention e.g. problems in choosing the right interpreter and translated written information may not align with oral languages. These discrepancies may influence a person's understanding and response to information (Sharif, 2012; Subbārāo, 2012).

2.3.3 The cultural diversity and commonality of two South Asian subcultures: the Bangladeshi and Pakistani populations

To understand the complexity of Bangladeshi and Pakistani cultures, there is a need to comprehend historical, geographical, ecological, religious and other factors. The cultural factors below illustrate that South Asian culture is not homogenous, rather there are multifaceted cultural similarities and differences, which is complicated by additional factors such as migration and acculturation (detailed in section 2.3.6) (Haleem & Smart, 2013; Liu et al., 2016; Rahman & Smart, 2014; Sharif, 2012).

Historical and geographical factors

Evidence suggests ancient native settlers in Northern parts of Bangladesh and Pakistan were Indo-Aryans, who were nomad tribes with fair skinned and Indo-European speakers (dating back to 1500 BCE) (Haleem & Smart, 2013; Rahman & Smart, 2014). A minority of Dravidians (from Southeast Asia such as Cambodia), who were dark skinned settled in the Southern parts of Bangladesh (Rahman & Smart, 2014), and Pakistan (Haleem & Smart, 2013). The culture of Pakistan is diverse because of the historical movement of people from neighbouring countries: Central Asia, South Asia and Middle-East, including refugees from Afghanistan. In addition, the Indus river in Pakistan attracted both Persian and Greek people over centuries (Haleem & Smart, 2013). This has shaped Pakistani individuals to have unique characteristics that are culturally and linguistically distinct, though religion, geography, history and genetic factors may unify them (Haleem & Smart, 2013; Malik, 2006; Rahman & Smart, 2014). For instance, upper Pakistan Pashtuns are more likely to have similar cultural similarities with Afghan Pashtuns in Afghanistan, whereas in the Northern mountains of Pakistan there are smaller populations who are descendants of people from Central Asia such as Tibet and Persian tribes. In comparison, Southern Pakistan the Baloch tribes claim their ancestors were non-Arab Kurds, Punjabis have roots to ancient India and West Asia tribes, and some people from Karachi and Balochistan may have African descendants (Malik, 2006).

Over time, both cultures have also been ruled over by Mongolians (the Mughals), leaving behind remnants of infused culture such as mixed marriages and conversions to Islam (Haleem & Smart, 2013; Malik, 2006; Rahman & Smart, 2014). Today, South Asia is a big continent comprising of numerous countries (Hasnain, Parikh, & Nagaraj, 2017). The Indian partition caused a major cultural shift. The displacement of people mean that they hold different affiliations. For instance, individuals from West and East Bengal may identify with each other as 'Bengalis' (Ahmed, 2004). Some Bangladeshis may still want Pakistan to rule over Bangladesh identifying themselves with Pakistanis and others may not. Inevitably, there may still be hostility between both cultures, especially amongst people who lived through the civil war (Ahmed, 2004; Chatterji & Washbrook, 2014; Henley & Schott, 1999; Van Schendel & Abraham, 2005).

Religious factors

Religion can play a significant role in the lives of some individuals forming a part of their culture (Mishra et al., 2017). There is no universal definitions of religion due to its complex

nature (Cragun et al., 2016). However, the criteria for religiosity can be classed as the orientated worldview expressed using beliefs, stories, symbols, values and worship, whether it is organised or private (Peterson, 2001). Religious identity can shape attitude towards health, illness and treatment e.g. the practice of circumcision (Mishra et al., 2017; Perera & Chang, 2018). The degree of internalising religion differs according to one's identity (Graafland, 2017). For instance, a person may believe and actively practice religion, another person may belong to a religion as a member passively, and/or other individuals may become more religiously orientated during stressful situations such as searching for answers, meaning, fulfilment and relationship with a higher being, and for adopting positive coping behaviours (Cragun et al., 2016; Graafland, 2017; Mishra et al., 2017). There may be many individual expressions of religion e.g. attending ceremonies/events, study groups, donating financially and other practices (Cragun et al., 2016).

Today, Islam is the religion of majority of people in Pakistan and Bangladesh (Haleem & Smart, 2013; Rahman & Smart, 2014). Pakistan has a small minority of Christians and Hindus (Haleem & Smart, 2013). Whereas, in Bangladesh the biggest religious minority population are the Hindus and small proportions of Christians, Buddhists and Bahais (Rahman & Smart, 2014). Both Bangladeshi and Pakistani cultures can practice cultural versions of Islam due to the lack of education in religion or may believe in its ideology without practicing it. Culture may trump religion in certain parts of the country (Haleem & Smart, 2013). Therefore, Muslim and Hindu Bangladeshis may identify with each other through nationalistic values e.g. celebrating independence day (Ahmed, 2004). Additionally, there are some common religious health beliefs amongst Muslims and Hindus e.g. predestination of illness from God (Haleem & Smart, 2013). To add to this, all Muslims are not the same due to differences in interpretations and meanings of the religion (Rassool, 2015). For instance, there are different methods of praying. To highlight one of many examples, Sunni Muslims are supposed to pray five times a day however most Shia Muslims are required to pray three times a day due to combining two prayers and they usually prostrate themselves upon a clay tablet from Karbala (their holy place) (Abbas, 2010; Koenig & Shohaib, 2014; Rassool, 2015; Tarlo, 2010). Most South Asians are Sunni Muslims (Rassool, 2015).

Prayer can be a form of physical and mental relaxation as it can involve a conversation with a higher entity, in addition to meditation and mindfulness which can act as a deeply focussed process on the breath, muscles, heart rate and enhances awareness of an individual's

emotions, thoughts and experiences in various religions (Mishra et al., 2017; Perera & Chang, 2018). For instance, in Hinduism it is believed that liberation can be achieved through becoming one with higher divinity physically and mentally (the higher self). Breathing is believed to be a delicate form of this process that comprises of biological energy that is sustained known as 'prana' in Indian medicine, which was practiced through exercises such as yoga, meditative techniques and prayer. Maintaining prana is an essential preventative and healing method for avoiding aging and death. Similarly, Islam teaches the combination of the mind and body can help attain good health using movements/exercises in prayer and mindfulness and meditation (Mishra et al., 2017).

Ecological factors

The Bangladeshi population is known for their rich diet consisting of fish (including prawns and shrimp), eaten with rice (aligned with the culture of farming and fishing) (Belton et al., 2011; Rahman & Smart, 2014). Ilish/Ilisha fish consisting of many fragile bones is a signature Bengali fish (Rahman & Smart, 2014). This is not surprising since the ecological environment of Bangladesh is positioned in one of the world's largest riverine delta: numerous rivers and rivulets flowing through the land and the Bay of Bengal (Ahmed, 2004; Van Schendel, 2009). The cultural attachment to fish and rice can be maintained after migration (Belton et al., 2011). In the Pakistani culture, roti (flat round bread) is more common due to the ecological desert environment (including arctic upper mountain regions) (Ahmed, 2004; Belton et al., 2011).

Other cultural factors

Sometimes health may be dealt with collectively such as within the family or male elders (Perera & Chang, 2018; Triandis, 2018). Elders in a family are respected in both Bangladeshi and Pakistani culture. Non-blood related peers, acquittances and so forth are referred to as a close relative such as uncle or aunt rather than by name. Less autonomy and respect may be given to independent decisions, since all choices affect the family, and everyone should look after each other (Harry, 2012; Hawthorne et al., 2007; Rahman & Smart, 2014). The obligation of men to financially support their families is a major part of Bangladeshi and Pakistani culture (a form of masculinity). Responsibilities of females often revolve around domestic duties (Harry, 2012). On the same note, marriages within the family is a social norm

in Pakistani culture, whereas marriages within the Bangladeshi family are uncommon unless there are circumstances that encourage it e.g. due to preference or in most cases to bring a relative to another country for a better life (Harry, 2012; Rahman & Smart, 2014). These cultural values may overlap with other South Asian cultures e.g. some Indians prefer to marry within family and some do not (Harry, 2012).

2.3.4 The general UK South Asian population

Ethnic minority population in the UK has been growing, particularly in England and Wales (Davidson, Liu, & Sheikh, 2010; Office for National Statistics, 2011). The UK Census (2011) showed that:

- In England and Wales, the South Asian population increased from 4.4% in 2001 to 6.8% in 2011, representing the largest ethnic minority group (agreeing with the growth of South Asians in Scotland) (Office for National Statistics, 2011; The Scottish Government, 2011). In England and Wales -
  - → The Indian population were the biggest ethnic minority group (0.5% in 2001 to 2.5% in 2011).
  - → The Pakistani population were the next largest (0.6% to 2.0% from 2001 to 2011).
  - → Thereafter the Bangladeshi population (undefined value that was not reported).
- Following this, the second largest ethnic minority group were the Black population (2.2% in 2001 increased to 3.4% in 2011), then the Chinese population (0.4% in 2001 to 0.7% in 2011) (The Guardian, 2012). Thereafter, new ethnic groups were added to the Census 2011 checklist (the latest Census), who had a small growth (2%), comprising of Arabs (0.4%) and the Gypsy or Irish community (the smallest ethnic group 0.1%) (Office for National Statistics, 2011).

The proportion of White ethnic group has been declining over the years in England and Wales, from 94.1% in 1991, 91.3% in 2001 to 86% in 2011, although they remain the majority population in the UK. Within this population, the largest group were the 'White British' (80.5%), who have been declining since 2001 (87.5%), and the 'Other White' ethnic group category consisting of Europeans (e.g. the Polish) (Office for National Statistics, 2011).

Most South Asians from Bangladesh and Pakistan are Muslims, whereas Indians can have a diverse range of religions (Doron & Broom, 2013). In 2011, the main religions amongst South Asians in the UK were as follows:

- UK Muslims were the second largest religious group -
  → 5% in England and Wales (Census, 2015).
  → Less than 3% in Scotland (The Scottish Government, 2011).
- Other religions (e.g. Buddhist, Hindu, Jewish and Sikh) represented -
  → In England and Wales - 0.4% (Census, 2015).
  → Less than 3% In Scotland (The Scottish Government, 2011).
  → 0.8% in Northern Ireland (including Muslims) (Sedghi, 2012).

2.3.5 Historical perspective of South Asians in the UK (a generational viewpoint)

Individuals from South Asia have always been a community of migrants (Chatterji & Washbrook, 2014). The UK has been a host to South Asians dating back to the 17th century but increasing rapidly during the past half century. In part this was due to labour shortage after World War II when there was a mass migration from South Asian countries (commonly from the Bangladeshi district Sylhet, Indian and Pakistani districts Punjab, Gujarat and Mirpur), which peaked during the 1970s/1980s (Chatterji & Washbrook, 2014; Hsueh et al., 2015; Jaspal, 2010). After the African independence in 1968, British citizenship was also given for displaced 'Indians' (mainly in East African countries such as Kenya, Tanzania, Malawi, Zambia and Uganda), who faced hostility from Black Africans in the 1980s, as Indians were often considered as allies of the unpopular British colonisers due to their gatekeeper roles during the African colonisation. Additionally, at the same time Sri Lankan refugees were given British refuge due to civil war (Chatterji & Washbrook, 2014).

Early migration measures attempted to prevent migrants from leaving the UK which meant many became residents e.g. the Commonwealth Immigrants Act 1962/1968 (Chatterji & Washbrook, 2014). But, widespread discriminative/racist attitudes and violent behaviour from some British individuals/groups has been argued to have restricted South Asian integration or adaptation into the mainstream culture e.g. retaining South Asian language as the dominant form of speech (Jaspal, 2010), and settlement areas that reflect South Asian cultural values such as establishing halal food shops and media outlets. This may have helped maintain and protect traditional South Asian culture from the perceived hostile UK environment (Alam, 2007).

Arguably, second generations (those born or raised as a child in the UK) have readily shown more adaptation e.g. studies have found they are more likely to be 'balanced bilinguals' (i.e. individuals competent in both languages) due to an early age from school and/or home settings (Jaspal, 2010, 2015; Jaspal & Coyle, 2010a). Code switching describes a form of language crossing (the switching between two languages in a sentence, phrase, conversation and so forth), that depend on the situation in question and perceived identity of one self (Rampton, 2014; Traugott, 2008). Today, some South Asians may not speak any South Asian languages or they may be 'passive bilinguals'; who can comprehend South Asian language/s but are not accustomed to speaking it (Jaspal, 2010). Hence, generational status may be an important dimension of South Asian culture. The generational perspective on language adoption demonstrates why sole reliance on language modifications in interventions may be inappropriate for the needs of all South Asians, yet most interventions readily use this approach (Sharif, 2012; SIGN, 2016).

2.3.6 Acculturation

The process of *acculturation* can be widely understood as changes influenced by encountering another culture in a new mainstream environment (Berry, 1997; 2005; Sam & Berry, 2010). Acculturation can be generally defined as, *''Those phenomena which result when groups of individuals having different cultures come into continuous first-hand contact, with subsequent changes in the original culture patterns of either or both groups, under this definition acculturation is to be distinguished from assimilation, which is at times a phase of acculturation''* (as cited in Redfield, Linton, & Herskovits, 1936, pg.149-152). Hence, acculturation can be the consequence of a phenomenon when individuals/groups who settle in a new sociocultural environment come in contact with mainstream individuals or groups, causing a two-way reciprocal transformation of cultural and psychological changes (see chapter 6 for an in depth understanding of acculturation) (Berry, 2005; Sam & Berry, 2010). In this respect, *'Everyone is involved, and everyone is doing it'* (as cited in Berry, 2005, pg.700). Although, more cultural changes occur in the minority group than the mainstream society, as acculturation produces actions and reactions in the situational frame of a dominant and a submissive group (Berry, 2005; Sam & Berry, 2010).

Adaptations can be an ongoing upon cultural contact over time and dependent upon the situation, which can be direct (e.g. language, beliefs, values, social institution and

technology), and/or indirect (e.g. changes in ecological environment), and/or delayed (e.g. internal cultural and psychological adjustments) (Berry, 2005). After the first generation of South Asians mass migrated to the UK, societal conditions slowly transformed in areas of settlements e.g. cultural needs were integrated into the society (e.g. building mosques and restaurants serving South Asian food), which also influenced the mainstream culture (Hsueh et al., 2015). Equally, some South Asians may have also adapted to aspects of the mainstream culture; observable modifications in health behaviours (e.g. changes in cultural knowledge and symbols), and cognitive modifications e.g. common beliefs, schemas and norms which explain body functions and disease processes passed on throughout generations (Barrera et al., 2013; Kao, Hsu, & Clark, 2004). These behaviours and cognitions are continuously evaluated and revised in a new environment depending on the available resources (Barrera et al., 2013). This reflects the notion of culture as a dynamic body which can be modified to include fresh ideas and perceptions, as people cultivate new strategies of reacting to the environment around them (Singer, 2012). Today, most UK born/raised South Asians have better education, employment and socio-economic status (SES) compared to the first generation who migrated to the UK, indicating that they may have different health needs due to lifestyle differences such as minimal language barriers (Griffiths et al., 2001; McManus & Savage, 2010).

2.3.7 Cultural hybridity

A gap in thinking around acculturation (see section 2.3.5) (Berry, 1997; 2005; Sam & Berry, 2010), is that it does not fully account for people who are creating hybrid cultures by interacting with their traditional culture and other cultures, rather than just acculturating between two cultures (Ali, 2008), e.g. traditional South Asian and British culture may be less important compared to an identity related to one's career (Tarlo, 2010). Hall coined *cultural hybridity* as individuals who are compressed between two or more cultures, not in a state of conflict, but they have become bi-culturally competent allowing them to utilise different cultural collections, switch codes and blend cultural symbols in hybrid ways. This occurs in a state of constant negotiation between main identities (Hall, 1990, 2014), e.g. language/code switching[6] (Rampton, 2014). Individuals develop identities that merge across national and local levels with a new sense of belonging (Hall, 1990, 2014). Hybridity involves a certain level

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[6] Code switching is the switching between two languages in a sentence, phrase, conversation and so forth (Rampton, 2014)

of experimentation, negotiation, learning and articulation between the combinations of cultural identities to seek out which aspect of culture are the most important to an individual (Chatterji & Washbrook, 2014; Tarlo, 2010). For instance, some young South Asians consciously educate themselves in religion (Islam) e.g. choosing to dress according to Islamic identity (in absence of or in combination with traditional clothing), hence creating a new wave of South Asians with orthodox views, reforming and filtering the practice of Islam that has been merged with oral hearsays, cultural customs and traditions, hence the Islamic identity may be prioritised over all other sense of belonging (Werbner, 2004), e.g. learning the Arabic language (Jaspal & Coyle, 2010b).

2.3.8 The complexity of culture

Culture is heterogeneous (including subcultural differences, religiosity, generational status, acculturation and cultural hybridity), and its complexity needs to be adequately considered before conducting research (Bhopal & Sheikh, 2009; Castro, Barrera, & Steiker, 2010; Schulman-Green et al., 2012; Trappenburg et al., 2013; Udlis, 2011). In this respect, individuals may identify with multiple different factors as part of their cultural mosaic[7] (Chao & Moon, 2005). This means that it may be difficult to define/recruit a homogenous group of people in research and problematic to define an intervention tailored to a specific group (Castro, Barrera, & Steiker, 2010; Perera & Chang, 2018). Researchers and HCPs need to be aware of this implication and use a biopsychosocial lens (a holistic perspective) (Perera & Chang, 2018). For example, an intervention with religious messages may not create an impact for every individual, particularly if patients do not resonate with a religious identity (Koenig & Shohaib, 2014; Perera & Chang, 2018). The dynamic nature of a person's culture may also suggest that the use of the term 'South Asians' may not be correct when indiscriminately referring to selected groups of the population, as each community have similar but sometimes different patterns of behaviour e.g. migration patterns (Chatterji & Washbrook, 2014; Hall, 2014; Jaspal, 2015). Therefore, focussing on specific populations may be a way forward to understand cultural complexities and how it influences health, and tailoring interventions so that these complexities do not get overlooked (Castro, Barrera, & Steiker, 2010).

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[7] Cultural mosaic consists of tiles and a structural framework of a collage of factors that contribute to an individual's sociocultural identity (Chao & Moon, 2005)

2.4 Chapter summary

This literature review has shown that to develop asthma self-management interventions for South Asians, the following needs to be considered:

- Asthma, self-management and South Asian sociocultural context are heterogeneous and change over time (Pavord et al., 2017; Schulman-Green et al., 2012; Sinha, 2014).

- The perspective and expertise of an individual with asthma on self-management is important to account for the heterogeneous nature of asthma and culture (Schulman-Green et al., 2012; Trappenburg et al., 2013; Udlis, 2011). Therefore, holistic self-management interventions are needed that may benefit from exploring the self[8] in self-management within sociocultural contexts (Sinha, 2014; Triandis, 2018).

- Supported self-management from HCPs over time is important, but they may be promoting the disease management of asthma rather than holistic self-management (Sadler, Wolfe, & McKevitt, 2014; Schulman-Green et al., 2012). Self-management support can also originate from social networks such as family, peers or community organisations/institutions. Therefore, the perspective of HCPs (or significant others) on providing supported self-management to South Asians is also needed (Morris, Kennedy, & Sanders, 2016).

- South Asian culture is multifaceted and dynamic. Its complexity illustrates that the culture should not be treated as homogenous in research (Bhopal & Sheikh, 2009; Castro, Barrera, & Steiker, 2010).

- There are various distinct and shifting dimensions of the South Asian sociocultural contexts in the UK compared to South Asia, further illustrating the complexity of the culture (Castro, Barrera, & Steiker, 2010), e.g. subcultural differences, religiosity, generational status (Fernando, 2010), acculturation[9] (Berry, 1997; 2005; Sam & Berry, 2010), and cultural hybridity[10], that need to be explored further (Hall, 1990, 2014).

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[8] The self can be broadly defined as direct or indirect statements that comprise of the self referring to *'I', 'me', 'mine', 'myself'* (Triandis, 2018), in social motivations, attitudes, beliefs, intentions, norms, roles and values (Cooley, 2017; Triandis, 2018)

[9] Acculturation is the cultural changes influenced by encountering another mainstream culture (Berry, 1997; 2005; Sam & Berry, 2010)

[10] Cultural hybridity is the bi-cultural competence and negotiations of being a part of two or more cultures with a new sense of belonging (Hall, 1990, 2014)

- Concentrating on specific South Asian subcultures may provide a more holistic understanding of the role of culture on asthma self-management behaviour (Castro, Barrera, & Steiker, 2010).

This chapter discussed the dynamic features of asthma, self-management and South Asian sociocultural context that can change over time. Holistic asthma self-management interventions for different South Asian populations can capture and optimise these heterogeneities by considering the perspective and expertise of the person with asthma and HCPs (or significant others) (Schulman-Green et al., 2012; Trappenburg et al., 2013; Udlis, 2011). Therefore, there needs to be an understanding of what needs to be considered to optimise asthma self-management in the general South Asian population by reviewing existing evidence base in detail (which is described in the next chapter).

Chapter 3. Literature review: Research informing the development of holistic asthma self-management interventions for the general South Asian population

The last chapter described the dynamic nature of asthma, self-management and South Asian sociocultural context that can be reflected and optimised in holistic asthma self-management interventions. This chapter describes the relevant research that can help narrow down what needs to be considered to develop an holistic understanding of asthma self-management behaviour in different South Asian subgroups (Schulman-Green et al., 2012; Trappenburg et al., 2013; Udlis, 2011), including asthma prevalence, the application and relevance of cultural concepts and behaviour change theories, consideration of cultural health beliefs/practices and cultural competence in healthcare services.

3.1 Asthma prevalence research

This section describes epidemiological research on asthma prevalence in South Asians that may be useful for defining what needs to be addressed to understand asthma self-management behaviour in these populations. Research described in this section mainly focusses on young people/adults and older adults who are the target participants for the research in this thesis.

3.1.1 International variations in asthma prevalence

Two international asthma prevalence studies were conducted at the turn of the 21st century; the European Community Respiratory Health Survey 2 (ECRHS) (ECRHS, 2002; Janson et al., 2001), and the International Study of Asthma and Allergies in Children survey (ISAAC) (Beasley, 1998). Both surveys used standardised measurements and definitions, allowing reliable worldwide comparisons to be made (Beasley, 1998; ECRHS, 2002; Janson et al., 2001). Surveys found globally that there was a lower prevalence of asthma in South Asian countries (e.g. India), than in developed countries (e.g. Australia, New Zealand, America, Ireland and the UK), suggesting that asthma in South Asians was most likely influenced by environmental risk factors in these countries e.g. migration (Beasley, 1998; ECRHS, 2002; Janson et al., 2001). It is worth noting that in both surveys there may have been small

discrepancies in international comparisons due to cross-cultural and linguistic differences (Beasley, 1998; ECRHS, 2002), e.g. the ISAAC survey translated their validated questionnaires into 39 languages where equivalent terms for symptoms such as wheezing were at times non-existent, but video questionnaires were used to illustrate symptoms and draw reliable comparisons between different cultures and languages (Beasley, 1998).

Migration is an example of one environmental risk factor that can be explained by well-studied migrant paradoxes (Roura, 2017), e.g. the healthy immigrant effect (Kennedy et al., 2015), that suggests South Asian migrants are more likely to be healthy in South Asia compared to when they migrate to developed countries. The deterioration in health may possibly be due to difficulties in adapting to the UK environment (Kennedy et al., 2015; Roura, 2017), such as negative health stressors or loss in sociocultural capital and assets (e.g. social support) (Falicov, 2009). Studies of acculturation for different South Asian populations have shown dietary changes (e.g. increased red meat and convenience food intake), had implications for developing health conditions (e.g. obesity, type 2 diabetes and cardiovascular disease), though there were some positive dietary changes e.g. fruit intake (Holmboe-Ottesen & Wandel, 2012; Lesser, Gasevic, & Lear, 2014). This may explain findings from qualitative studies that found many older individuals from different South Asian backgrounds favour travelling back to their home country for a long duration to reduce their symptoms and improve asthma control, which they complain increases on their return to the UK (Griffiths et al., 2001; Hussein & Partridge, 2002).

Another mixed research study found that there was a strong preference amongst Indian, Bangladeshi, Pakistani and Nepalese individuals with diabetes for hot climates and the belief that lifestyle in South Asia was healthier (Patel et al., 2015). Certain hot geographical places have been described as therapeutic (Culley et al., 2013). A literature review by Culley et al. (2013) found that one of the purposes of visiting South Asia for health issues was to explore diagnosis for children, suggesting that there may be better standard of care in some services which may be less financially draining (Culley et al., 2013). The most recent study on migration and asthma incidence in UK Indian, Pakistani and Bangladeshi individuals found that migration during early life as a child (below the age of five), increased the risk of asthma (Kuehni et al., 2007).

3.1.2 Asthma prevalence in the UK

A nine-year (2001 to 2010) retrospective cohort study by Sheikh et al. (2016) found Pakistani men and women had the worst asthma outcomes followed by Indian men, in comparison to other ethnicities e.g. White Scottish and Chinese. For instance, hospitalisation rates for Pakistani, Indian and 'Other South Asians', increased from 20% to 50% compared to other ethnicities e.g. the Chinese population had decreased hospitalisations from 30% to 40% over the nine years of the study. Findings from this study suggests that other ethnic minorities (e.g. the Chinese population) in Scotland have better asthma outcomes and unscheduled care rates compared to South Asians (Sheikh et al., 2016). Another study analysed primary care data and found that there was higher risk of adult and child hospitalisation in various Black and South Asian subgroups due to inappropriate overprescribing of SABA (this risk was higher for adults), compared to the White population. This finding could not be attributed to asthma severity or primary care prescribing/management differences, suggesting that perhaps the role of culture in health-seeking or self-management may be important (Hull et al., 2016). A systematic review meta-analysis of thirteen studies conducted from 1981 to 2002 by Netuveli et al. (2005) found that:

- South Asians in the UK have poorer asthma outcomes compared to the majority White and Black population, resulting in high accident and emergency visits and hospitalisations, even though asthma related symptoms were found to be lower in South Asians compared to Black and White children (9.6% compared to 16.2% and 14.6%).

- The prevalence of clinician diagnosed asthma was lowest for South Asian (7.6%), compared to Black (15.0%) or White children (10.6%).

However, the review had poor quality reporting of its definition of ethnicity and did not consider subcultural differences (Netuveli et al., 2005).

A concern of epidemiological research is that it typically simplifies the definition and measurement of asthma confining it to clinical symptom descriptions and biological determinants that vary geographically (e.g. asthma genes) (Pavord et al., 2017), which culture is condensed to fixed static features e.g. language spoken at home (Singer, 2012). As there is no standard recommendation on how to conceptualise asthma or culture, studies use a variation of measures, which make comparisons across time and studies/populations difficult (Pavord et al., 2017; Singer, 2012). For instance, the Census has changed the way it measures ethnicity over time (Office for National Statistics, 2011). Often, research based on the Census does not differentiate between the different ways ethnicity was measured across

each Census (Liu et al., 2012; Singer, 2012), e.g. categorisations have changed; Bangladeshis were originally included in the 'Other South Asian' group and new ethnic group tick boxes were added over time (Office for National Statistics, 2011).

3.2. Applying culturally relevant terms

There is a paucity of recent epidemiological research on asthma prevalence in different South Asian subgroups (Beasley, 1998; ECRHS, 2002; Janson et al., 2001), and the prevalence research does not effectively conceptualise or reflect the dynamic characteristics of asthma, self-management and South Asian culture (Ahmad & Bradby, 2008; 2007). This section describes adequate definition, interpretation and application of culturally relevant terms has implications for cultural research (Castro, Barrera, & Steiker, 2010; Storey, 2010).

3.2.1 Treating culture as static versus dynamic in research

The perspective of culture as static

Most research treat culture as a static entity (Bhopal & Sheikh, 2009; Castro et al., 2010). The static perspective views culture as something external to a person, existing independently with its own laws and privileges. Individuals are presumed to be passive carriers of cultural guides who do not have any power to control it, which suggests culture can be measured and predicted by a system of rules (Castro, Barrera, & Steiker, 2010). It could be argued that this view indirectly suggests that since culture guides behaviour, it can also act as a barrier towards the adoption of preferable health behaviours that improve outcomes (Ahmad & Bradby, 2008; 2007; Castro, Barrera, & Steiker, 2010). Subsequently, interventions can be developed with the aim of rectifying cultural norms that are perceived to be flaws leading to poor health. However, since the static definition of culture assumes independence from human influences (the view that people are passive carriers of culture), it be considered to be a paradox; since behaviour change cannot be targeted in interventions if people are passive to cultural norms and beliefs (Castro et al., 2010).

Approaching culture from a static viewpoint

Hierarchical entities[11] who have conflictual power 'over'[12] defining cultural terms can use concepts as a strategy to exercise socio-political power and dominance over other groups by treating culture as static (Ahmad & Bradby, 2008; 2007; Castro, Barrera, & Steiker, 2010). For example, the authority to define cultural terms can create abstract boundaries that has the ability to render disputable terms widely acceptable in society (Davidson, Liu, & Sheikh, 2010; Singer, 2012). People generally take on static labels placed on them by hierarchical groups because it provides them with a sense of community (Ahmad & Bradby, 2008; 2007). One method of implementing the static view of culture in research is the use of proxy terms for and instead of culture e.g. race and ethnicity (Liu et al., 2016). It has been argued that race has no definition or scientific validity and therefore today it has been less extensively used to define culture in research (Afshari & Bhopal, 2010; Hughey, Embrick, & Doane, 2015). But, it is claimed that the term race was defined by hierarchical groups who used the concept to differentiate themselves from others e.g. people who were perceived to be biologically inferior and/or a risk factor for health issues (Davidson, Liu, & Sheikh, 2010; Singer, 2012).

In contrast, ethnicity has taken over from the term race to define culture (Afshari & Bhopal, 2010). The definition of ethnicity can be fragmented due to being dependent upon the history of various countries and physical born attributes of a person that cannot be modified or changed e.g. skin colour, language spoken, religious beliefs, place of birth, diet/food, beliefs, behaviours, ancestry and other physical characteristics (Davidson, Liu, & Sheikh, 2010; Liu et al., 2016). Even though, the term race has been rarely used in research today, it has been argued that the concept has permeated into thinking around ethnicity; since the term ethnicity has subtle power to define and create fixed boundaries between groups of people (Ahmad & Bradby, 2008), and does not always consider contextual factors such as migration, acculturation[13] and lived experiences of asthma (Afshari & Bhopal, 2010; Liu et al., 2016; Sam & Berry, 2010). For example, if the British partition of 'India' had not taken place, all Bangladeshi and Pakistani communities would be known as 'Indians' today, as they were before the partition (Chatterji & Washbrook, 2014).

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[11] Hierarchical entities can be defined as dominant elites/classes who have access to resources (Haugaard, 2002; Zoller & Dutta, 2009)

[12] Power 'over' (also known as conflictual power) consists of the capability of individuals/groups/institutions to prevail over another in doing something that a person is resistant to, would not normally do and is not in their interest. This form of power is based on social relations (Haugaard, 2002)

[13] Acculturation is the cultural changes influenced by encountering another mainstream culture (Berry, 1997; 2005; Sam & Berry, 2010)

The use of proxy terms to define culture has the danger to associate certain cultural attributes with negative stereotypes of poor health behaviours, which can lead to culture blaming e.g. disabilities in children can be frequently blamed on intra-family marriages which are common in some cultural groups such as Pakistanis (Ahmad & Bradby, 2008). Sometimes, culture blaming can lead to the idea that cultures need saving, civilising or liberating by adopting the norms of the dominant group who are able to define the best interest of others with their own cultural values (Ahmad & Bradby, 2008). Poor health then becomes the responsibility of the individual/group who does not comply with mainstream norms. Therefore, culture becomes a cause and solution for interventions (Ahmad & Bradby, 2008; 2007).

Social categorisations and social comparisons can be strategies used to identify and understand culture (as mentioned in the social identity theory; see section 2.2.4) (Tajfel & Turner, 2004). Sometimes, people can categorise other cultures as primitive or backwards, when ideas or standards are not shared by everyone (Rachels, 2007). This view is known as *ethnocentrism*; the practice of judging a culture compared to standards of another culture, where another culture is deemed as inferior to one's own culture that is judged as the better society due to the perception of keeping up with the progression of time e.g. one's eating norms are better or healthier than other cultures (Billet, 2016; Rachels, 2007). In contrast, *universalism*; the belief that there are fixed universal cultural realities regardless of time e.g. universal meaning and values of health and illness (Billet, 2016; Kagitcibasi, 2017; Rachels, 2007). Both universalism and ethnocentrism can lead to cultural misinterpretations e.g. over-generalisations, stereotypes and perception bias towards a culture. For instance, the perspective that all South Asian culture revolves around the family (whether as part of an indigenous or ethnic minority population), can be over-generalised to all individuals within that group (Billet, 2016; Kagitcibasi, 2017; Yadav & Yadav, 2015).

People can attribute the cause of asthma as 'God's will' (particularly for Muslims and Hindus), which has been negatively interpreted by many researchers as 'fatalism'; a term that has negative connotations devaluing religious beliefs and creating a selective picture without considering the broader perspective. Islamic teachings suggest that belief in God's will also means that individuals have responsibility for own health and available resources should be used for treatment, and it may mean that people have accepted their illness (Ahmad &

Bradby, 2008; Yadav & Yadav, 2015). For instance, a mixed methods study found that even though Indian, Bangladeshi, Pakistani and Nepalese individuals believed in the will of God, it did not negate the fact that they believed one of the causes of diabetes was due to genetics (Patel et al., 2015). Research on migrant paradox such as the healthy immigrant effect refute the static view and implementation of culture and suggests that South Asian migrants in the UK are more likely to be healthy in South Asia compared to those resident in the UK, therefore the norms of the mainstream UK group may not reflect the ideal health for other cultures (Falicov, 2009; Kennedy et al., 2015; Roura, 2017).

The perspective of culture as dynamic

If culture is treated as dynamic, an entity that constantly shapes and reshapes over time and space, it indicates that active cognitive learning of a culture takes place e.g. shared patterns, symbols or perceptions amongst people (Barrera et al., 2013; Castro et al., 2010; Fortun et al., 2014; Yadav & Yadav, 2015). People create, learn, use tool-kits (sets of resources) and evaluations that underpin decisions and influence others. In this respect, interventions can be developed considering people as active learners of culture and variable decision-makers, who choose behavioural options depending on a given situation (Castro et al., 2010).

Approaching culture from a dynamic viewpoint

The social identity theory has shown that social categorisations and social comparisons can be strategies used to identify and understand culture (see section 2.2.4) (Tajfel & Turner, 2004). People tend to categorise others in terms of cultural comparisons made on the correct or erroneous behavioural codes, patterns and norms, particularly if the people that are being defined are different (Billet, 2016; Kagitcibasi, 2017; Yadav & Yadav, 2015). A philosophical approach used in medical anthropology to conceptualise and interpret how others perceive, characterise and make sense of the dynamic and changing nature of an individual's culture and health behaviours can be appreciated by drawing on ideas of cultural relativism (relative truths on perceptions, assumptions and questions that are objective or subjective insights) (Harris, 2010; Rachels, 2007). *Cultural relativism* is the belief that culture should be judged by its own merits rather than the culturally bounded values and standards of another, and cultural diversity should be recognised and respected (there are no correct cultural codes). Cultural relativism is the understanding of how people interpret and understand South Asian

culture and their sociocultural context from an impartial perspective. Holistically, cultural relativism can be viewed as a process where perceptions and experiences are connected to form a cultural reality that may be different to another reality. Recognising different perspectives in perceiving and experiencing different realities, therefore accounting for the dynamic nature of culture (Billet, 2016; Kagitcibasi, 2017).

3.2.2 Differentiating between culturally relevant intervention designs

Defining culture as static or dynamic has important implications for intervention development. However, there are other terms commonly used in the area which also need to be understood and considered.

Cultural relevance (deep and surface structures) in interventions

The term *cultural relevance* is the principal of making interventions culturally relevant to the needs and preferences of a group, which increases the level of participation and effectiveness (Castro et al., 2010; Castro, Barrera, & Martinez, 2004). Cultural relevance has been characterised as:

- Comprehension - the content needs to be understandable and matched linguistically, educationally and developmentally to the target group.
- Motivation - the content needs to be captivating and significant to the target group.
- Relevance - the content and material need to be applicable to the daily life of the target population (Castro et al., 2010; Castro, Barrera, & Martinez, 2004).

Deep structures and surface structures relating to intervention content can have different levels of cultural relevance, which was coined by Resnicow et al. (1999). *Surface structures* are observable and superficial cultural characteristics of a population targeted in interventions by identifying appropriate channels (e.g. the media), which enhance receptivity acceptance of health messages (e.g. language, skin colour, music, food and clothing). *Deep structures* are identified cultural characteristics derived from working collaboratively with a population which increases acceptability of messages and also helps change behaviours e.g. beliefs (Resnicow et al., 1999).

Cultural modified interventions

Culturally modified interventions (or sometimes researchers use other words such as culturally adapted, attuned or informed) has been defined as, *"The systematic modification of an evidence-based therapy or intervention protocol to consider language, culture, and context in such a way that is compatible with the client's cultural patterns, meanings and values"* (as cited in Bernal et al., 2009, pg. 362). Culturally modified interventions have been therefore understood to be the middle ground between two positions (Falicov, 2009):

1) The universal top-down approach of targeting a group as a homogeneous entity and not altering intervention characteristics or content to the cultural needs and preferences of a group.

2) The specific bottom-up approach stresses interventions need to consider cultural factors and context of an individual for tailoring before developing an intervention (Falicov, 2009). Generally suggested to be more effective than generic top-down interventions (Bailey et al., 2009).

The culturally modified method draws on both perspectives, where modifications are more specific to a group than a top-down approach, however interventions are modified to apply to ethnic groups using various strategies without adjusting the content e.g. translated languages, using images of relevant ethnic minorities and educators from similar ethnicity as the target individual. This approach maintains the idea that core components of mainstream interventions should be replicated while adding on culturally relevant features (this is applicable to most existing interventions today) (Bailey et al., 2009; Falicov, 2009). Cultural modifications can also be referred to as culturally informed interventions; however, this term is not widely adopted. Sometimes, researchers use the term culturally adapted instead of modified. Similarly, cultural attunement refers to evidence-based interventions which focus on the process of delivering the intervention (rather than intervention content) that enhances engagement and retention of cultural groups in treatment e.g. language (Falicov, 2009). In this thesis, the term culturally modified is used (Bailey et al., 2009; Falicov, 2009).

Culturally targeted interventions

Culturally targeted interventions is a bottom-up process to intervention development that can be defined as, *"The use of a single intervention approach for a defined population subgroup that takes into account characteristics shared by the subgroup's members"* (as cited in Kreuter et al., 2003, pg. 136). Targeting assumes that there are some homogeneous factors in a target population (e.g. shared cultural values at a group level such as beliefs) that

can be used as a strategy to reach members of that community (Crowder & Broome, 2012; Kreuter et al., 2003, 2013). For instance, if an intervention uses a targeted approach in the Latino population, educational materials may include bold and bright colours according to the preference of the community (Pérez-Stable et al., 1996). Targeting can increase intervention effectiveness and promote behaviour change (Ahmed et al., 2018; Crowder & Broome, 2012; Kreuter et al., 2013).

Culturally tailored interventions

Culturally tailored intervention is a bottom-up approach to intervention development defined as, *"Any combination of information or change strategies intended to reach one specific person, based on characteristics that are unique to that person, related to the outcome of interest, and have been derived from individual assessment'* (as cited in Kreuter et al., 2003, pg.137). Hence, tailored interventions are suggested to have a collection of messages or strategies related to health and behavioural outcomes aimed at a target individual in a group, rather than a collection of individuals (Kreuter et al., 2003). Tailored strategies therefore identify cultural dimensions that are applicable to health (e.g. religiosity and racial pride) and individual differences can be measured in these dimensions, and delivery can be individualised matching an individual's endorsement of different cultural dimensions (Hawkins et al., 2008; Kreuter et al., 2003, 2013).

The difference between culturally tailored and culturally targeted interventions is that in the former, interventions are aimed at individuals based on measured differences that exist within a group (e.g. the level of religious spirituality or practicing a religion), which suggests there needs to be an understanding of how individuals perceive their own culture and the extent that they identify with it (Kreuter et al., 2003). In contrast, culturally targeted interventions are aimed at groups of individuals (e.g. grouped by religion). Arguably, culture may be shared but people in a culture can also have various levels of cultural characteristics (Castro et al., 2010; Castro, Barrera, & Martinez, 2004; Kreuter et al., 2003, 2013).

Cultural competence in interventions

Cultural competence is the inclusion of cultural variables in interventions, research or healthcare practice defined as a, *"Set of congruent behaviours, attitudes and policies that*

come together in a system, agency or amongst professionals and enables that system, agency or those professionals to work effectively in cross-cultural situations" (as cited in Cross, 1989, pg.7). Cultural competence refers to HCP's (or sometimes healthcare services) capability to interact successfully and respond to individuals from different backgrounds e.g. diverse staff which reflect the community, bilingual interpreters, and cultural and linguistic training for HCPs. Ethnic-matching of provider and patients has been recommended to be the minimum requirement to build cultural competence (Leong, Ramsey, & Celedón, 2012). Cultural competence can also overlap with other concepts e.g. cultural targeting and tailoring (Castro et al., 2010; Kreuter et al., 2003, 2013).

3.3 Behaviour change theories in cultural contexts

Adequately defining culture, sets the basis of holistically understanding asthma self-management behaviour in some populations. Health behaviour change theories have been argued to be crucial for intervention effectiveness (Bartholomew, Parcel, & Kok, 1998; Craig et al., 2008; Michie & Prestwich, 2010), however whether theories are relevant for a cultural group needs to be considered further (in this section health psychology theories were emphasised on) (Burke et al., 2009a; Storey, 2010).

3.3.1 The importance of behaviour change theories, models and frameworks

One definition suggests theory is, *"A coherent description of a process that is arrived at by a process of inference, provides an explanation for observed phenomena and generates predictions"* (as cited in West & Brown, 2013, pg. 16). Behaviour change theories can be from various disciplines e.g. health psychology and social psychology (Michie et al., 2014). Evidence suggests that the use of theory can help tailor interventions and improve effectiveness (Cane, O'Connor, & Michie, 2012; Craig et al., 2008; Michie & Prestwich, 2010). The use of theory has been widely recommended in intervention development guidelines e.g. the MRC (Craig et al., 2008), and the Intervention Mapping Framework (Bartholomew, Parcel, & Kok, 1998). Although, arguably theories may not always be helpful e.g. understanding common-sense behaviours (Burke et al., 2009a; Marteau, Hollands, & Fletcher, 2012; Pasick et al., 2009a). Use of theory (with clear descriptions and explanations) can promote an approach to identifying the 'active ingredients' of interventions (Michie & Prestwich, 2010; Nilsen, 2015), and it can allow a greater understanding of why, when and

how self-management behaviour does or does not occur in a population (Michie et al., 2014; Michie & Prestwich, 2010), including:

- Constructs - key concepts related to behaviour that interventions are based on e.g. self-efficacy leads to behaviour change.
- Recipients - selecting participants most likely to benefit from the intervention e.g. people with asthma.
- Causal determinants - intervention component techniques that causally determine behaviour e.g. mastery of experience can determine self-efficacy.
- Predictors - construct that is targeted in interventions to predict/correlate with/causes behaviour change e.g. age.
- Intervention techniques - strategies used to change behaviour, construct or predictor e.g. information provided on consequences such as modelling behaviour (Michie & Prestwich, 2010).

Michie and Prestwich have suggested proper application of theory should be explicitly described (Michie & Prestwich, 2010). However, theory is not always applied in this way e.g. many authors do not define theory (Birken et al., 2017; Michie & Prestwich, 2010). In addition, the extent to which authors appropriately apply theory and whether this is done in a meaningful way is often unclear (Michie & Prestwich, 2010). Reasons for this may include unfamiliarity with or under-utilisation of different types of theory/models/frameworks reducing potential benefits. Hence, the continual use of familiar theories can hinder the progress of shared understanding or generalisation of findings (Birken et al., 2017). Inadequate descriptions and implementation of theory may also lead to conclusions on outcome effectiveness without truly representing sufficient evidence (Michie & Prestwich, 2010), e.g. self-efficacy is sometimes used as a single construct of Bandura's social cognitive theory (Bandura, 1977).

3.3.2 The relevance of behaviour change theories in the general South Asian sociocultural contexts

The sociocultural contexts in which behaviour change theories were produced, tested and from which assumptions are drawn from, need to be recognised and made explicit to help understanding of whether theories are universally applicable to all people e.g. cultural norms. Some theories are developed in a specific population and some that are culturally

set, but the question remains on which theory is relevant to use to understand asthma self-management in the Bangladeshi and Pakistani population (Burke et al., 2009a).

Theory according to 'assumed norms'

Generally, behaviour change theories are standardised according to the invisible 'assumed norms' of the majority population's social, cultural and historical contexts of practicing health behaviours, typically from White, middle-class backgrounds in developed countries (Burke et al., 2009a; Michie & Prestwich, 2010), e.g. European and Northern American countries (Rogoff, 2007). Arguably, theories built on 'assumed norms' of one group pushes other cultures towards conforming to these norms as a solution for health problems e.g. the standard Body Mass Index does not account for cultural differences (Burke et al., 2009a; Pasick et al., 2009a). Non-conformity to these norms can lead to blaming a culture or treating culture as a cause, risk factor and solution for supposed poor health outcomes built around 'assumed norms' (Ahmad & Bradby, 2008; Yadav & Yadav, 2015). This can be perceived as a subtle expression of conflictual power, since one group is preferred over the other, whether this is intentional or unintentional (Ahmad & Bradby, 2008; Yadav & Yadav, 2015). In this respect, some behaviour change theories can be viewed as ethnocentric[14], where the point of view or way of living of one cultural group was given more precedence than another culture (Billet, 2016; Kagitcibasi, 2017).

Theory according to individual or collective cultures

It can be argued that the mainstream White Caucasian population mainly have an individualistic[15] culture (Cohen, Wu, & Miller, 2016; Triandis, 2018). Behaviour change theories developed and tested on these populations may focus heavily on individual cognitions often abstracted from social context, though they casually recognise some social factors e.g. social norms. Therefore, theories that have a universal approach can marginalise

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[14] Ethnocentrism is the practice of judging a culture compared to standards of another culture, where another culture is deemed as inferior to one's own culture that is judged as the better society due to the perception of keeping up with the progression of time (Billet, 2016; Rachels, 2007)

[15] Individualistic cultures tend to cognitively convert situations using individual settings and therefore prioritise individual perceptions and goals (Triandis, 2018)

the essence of collective cultures[16] (Fortun et al., 2014; Pasick et al., 2009a). This is important because individual and collective aspects of culture can be equally relevant to different South Asian groups depending on the context (see section 2.2.4) (Sinha, 2014; Triandis, 2018). For instance, cancer screening interviews on ethnic minorities (African American, Chinese, Filipino and Latino), revealed questions focussed on individual cognitions were more aligned with theories and constructs[17] (e.g. intentions, self-efficacy, perceived susceptibility, perceived benefits and subjective norms), but not their contextual factors (Pasick et al., 2009a). Another study found that intentions in cancer screening can have various meanings (e.g. 'yes' may mean 'no') and some women may be screen without an intention e.g. to please other people (Pasick et al., 2009b).

The meaning and interpretation of theoretical constructs, health beliefs and illness constructions can also be culture-specific, rather than a standard definition (Burke et al., 2009b). Self-efficacy is one particular example which has been shown to be important in self-management (Bandura, 1977; Burke et al., 2009b), where it is argued that self-efficacy can be influenced by culture and therefore functions differently (Klassen, 2004, 2008). The self[18] in self-efficacy may be congruent (Klassen, 2008; Triandis, 2018). Currently, self-efficacy has an individual cultural basis and a few contextual recognitions, however some research has shown that in some cultures self-efficacy can be gained from the collective perception of others such as through social comparisons of the ability to successfully complete a task (Klassen, 2008; Triandis, 2018). Klassen (2008) reviewed twenty studies and found the existence of collective self-efficacy was more prominent in Asians compared to the White population since focusing on oneself was not culturally valued hence they had modesty bias, illustrating how self-efficacy works differently across cultures. Therefore, using one definition of self-efficacy in different cultural groups can restrict interpretations made from measurements (Burke et al., 2009b). It has been suggested that self-efficacy based on mastery of experience (past experience) and emotional states are more aligned with individual-based cultures, in contrast to vicarious experience and social/verbal persuasion that are more aligned with collective cultures (Klassen, 2008; Triandis, 2018). This implies

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[16] Collective cultures tend to cognitively convert situations using collective settings (and therefore prioritise collective perceptions and goals (Triandis, 2018)

[17] Constructs are key concepts related to behaviour that interventions are based on (Michie & Prestwich, 2010)

[18] The self can be broadly defined as direct or indirect statements that comprise of the self referring to *'I', 'me', 'mine', 'myself'* in social motivations, attitudes, beliefs, intentions, norms, roles and values (Cooley, 2017; Triandis, 2018).

that interventions, where information presented reflects and is consistent with the definitions of the cultural self in self-efficacy may be processed positively (echoing the cultural relevance strategy) (Castro et al., 2010; Castro, Barrera, & Martinez, 2004).

In addition, it is argued that self-efficacy in self-management can only be relevant if sociocultural capital (e.g. the body, resources, significant relationships, prestige, social honour and preventative strategies), are in place in a sociocultural context e.g. what does self-efficacy mean if individuals from developing countries cannot access treatment resources such as inhalers (Burke et al., 2009b; Thompson, 2009). The social cognitive theory revised for cultural contexts (Bandura, 2002), has placed self-efficacy in a sociocultural context considering access to sociocultural capital (which can be understood as collective efficacy). The theory recognises that migration experiences may mean losing or changing sociocultural capital, therefore self-efficacy can decrease during migration to a new environment and increase after accomplishments are made in a new environment (Bandura, 2002). But, this can be widely unrelated to the sociocultural perceptions, meanings and experiences of self-efficacy e.g. what and why these accomplishments are needed is not explained, how accomplishments are related to health and the impact of the health of migrant offspring who are not migrants themselves (Burke et al., 2009b). For instance, a mammogram screening study found that Latino and Filipino women had high self-efficacy from having stable relationships with others (through collective means), compared to individual development (individualistic means) (Burke et al., 2009b).

There are some theories which consider culture; but face various criticisms (Burke et al., 2009b; Pasick et al., 2009a). As mentioned, the social cognitive theory in cultural context (Bandura, 2002), treats all collective cultures as homogenous groups and does not capture differences in conceptual cultural meanings attributed by each group e.g. what self-efficacy means in one population may be different to another community (Burke et al., 2009b). There are also theories that lack consensus on how to define culture and these theories can be viewed as undeveloped in that respect (Pasick et al., 2009a), e.g. the socio-ecological model (Panter-Brick et al., 2006), considers the organisation, SES and political factors that have an impact on health in an individual's context, but does not adequately define culture at all (Burke et al., 2009b).

Theory according to conscious and unconscious health behaviours

Often, theories can assume that behavioural intention and change are deliberate, actively controlled or a conscious thought process (Burke et al., 2009a). However, this may not always be the case. For instance, self-management behaviours can be associated with sociocultural factors that are routines based on past and traditional influences, known as habitus (Bourdieu, 2017, 2018). *Habitus* is a silent system that operates in the background, consisting of internalised dispositions of second nature social rules and categorisations on perceptions, thoughts and behaviours that are predicted by past experiences, and cultural, social and economic capital. Habitus produces and reproduces from external factors across time and space e.g. social structures of ethnic minorities, conformity and relationships. Therefore, the practice of behaviour becomes neutralised as a collective norm, rendered as common-sense, observable but unconsciously intended and acted upon without reflection. Therefore, some health beliefs are often unlikely to be reported or discussed even though they are acted upon (Bourdieu, 2017, 2018). Habitus also works in the perception of and how the body can be treated during illness. In this respect, individuals can become passive in terms of not being entirely aware of why they conform to certain rules and the meanings they apply to them (Bourdieu, 2017, 2018; Burke et al., 2009a), e.g. health behaviour around beliefs on how the body functions around hot and cold constructs such as weather (Harver & Kotses, 2010).

Bourdieu argues that the idea of deliberate and conscious intentions, choice or practice in theory are not enough to explain the daily health behaviours around habitus (not just exclusive to cultural practice), unless people receive education to raise awareness through social discourses and learning from reflective questioning (Bourdieu, 2017, 2018). The ability to pass on or describe health behaviours do suggest to some extent individuals can become familiar with some behaviours based on habitus, even though they may not know the rationale behind it (Kellerman, 2016). In this sense, consciousness or awareness can be raised (e.g. to the level of decision-making), with some form of reflection and it can be reportable to this extent e.g. interviews can allow people to describe and reflect on behaviour based on habitus (even though they may not know the rationale behind this) (Burke et al., 2009a). Added to this, it is argued that theories that target beliefs assume active and effortful information processing takes places in thinking, but do not acknowledge how beliefs can be targeted if individuals themselves are not fully aware of the rationale behind their beliefs (Bourdieu, 2017, 2018; Burke et al., 2009a), or whether it is culturally sensitive to target

beliefs for change according to the 'assumed norms' of others (Ahmad & Bradby, 2008; Pasick et al., 2009a).

A similar idea to habitus is the idea of habits by Gardner (2012). Habits are automatic mental responses triggered by daily environmental and contextual cues and past/repeated experiences that influence health behaviours. Conscious intentions in habits are not always required (habits are not judged by frequency of behaviour). In this respect, targeting motivation in interventions is not always required since environmental cues are enough to trigger behaviour. It has been proposed that behaviour change interventions that focus on building unconscious habits can be beneficial in sustaining automatic behaviour (Gardner, 2012). Initially, habit formation may be effortful but this later becomes automatic e.g. healthy eating (Lally, Wardle, & Gardner, 2011), or brief advice on habits by HCPs associated with context such as time and resources, can render other behavioural options to be less accessible (Gardner, Lally, & Wardle, 2012). A qualitative study looking at building habits around supported asthma self-management in organisational routines and available resources in primary care found that strategies such as remote modes of consultations (telephone, skype and email) for people who do not attend routine asthma reviews helped with barriers such as consultation time (Morrow et al., 2017).

Notably, the distinction between habits and habitus are not clear-cut (Crossley, 2013). Habitus is the French word for infinity rather than habits or customs (Bourdieu, 2017, 2018). Some debates on differences include:

- Habitus is a acquired flexible and collective deposition of represented expertise on practical reason ingrained in the memory of a group of people, differing in each society, education, property, fashion and prestige (Bourdieu, 2017, 2018; Crossley, 2013), rather than individually conditioned or repeated responses in habits (Crossley, 2013; Gardner, 2012).
- There are individual variations in habits, but habitus is varied between social groups. Habitus is produced and reproduced in line with social structures over time such as culture and history (Crossley, 2013).
- Most habits require knowledge and understanding of effortful processing at some stage compared to habitus which works in the background (Crossley, 2013; Gardner, 2012).

- Habits can also be intentionally broken (Crossley, 2013), e.g. eating habits during special occasions and weekends (Lally, Wardle, & Gardner, 2011). Habitus is less likely to be shattered on daily basis, except in crisis such as political upheaval (Crossley, 2013).

- Targeting unconsciousness in interventions can relate to habits, but not all unconscious behaviours are habits and not all habits are unconscious. Unconscious behaviours are not always dependent on environmental cues (Marteau, Hollands, & Fletcher, 2012).

It can be debated that habits may become collective over time in a group and may develop deeper orientation towards social structures, becoming a form of habitus (Crossley, 2013).

Understanding usefulness of theories for South Asians

Evidence on the application of behaviour change theories to asthma self-management in South Asians has been limited (Pasick et al., 2009a). One ethnographic study found that behaviour change theories (e.g. theory of reasoned action and the health belief model), explained individual cognitions on safe sexual behaviours for sex workers in India (e.g. condom use to protect against HIV), but not in collective contexts e.g. self-efficacy and formulation of behavioural intentions was not available to the wider occupational context of practice, where sex workers autonomy and negotiation in encounters can involve up to four people including customers, madams, pimps and other power structures, and norms specific to Indian brothels including structural barriers such as limitation in resources, poverty and access (Evans & Lambert, 2008). A mixed methods study (using a questionnaire and one-to-one interviews) found that the common sense self-regulatory theory did not fully describe illness beliefs for Indian, Bangladeshi, Pakistani and Nepalese individuals self-managing their diabetes. Cognitions and emotions in the theory are mainly based on individual level explanations, but the role of others (larger social networks) relevant for these communities with diabetes was not considered e.g. emotional distress of a person was reduced by others in their social spaces for diet control and lifestyle modification; the greater the social support the less emotional distress people had about their diabetes (Patel et al., 2015).

Developments in the field of behaviour change theories in cultural contexts

There have been no recent theoretical developments in asthma research; however, literature has been slowly growing in cancer screening research for ethnic minorities in America (e.g. Joseph et al., 2009; Pasick et al., 2009b; Pasick & Burke, 2008; Washington, et

al., 2009), which suggest that sociocultural contexts of individuals need to be recognised by either culturally tailoring theory in interventions (Pasick, Burke, & Joseph, 2009; Washington, et al., 2009), or consulting other disciplines to complement behaviour change theories e.g. cross-cultural psychology and anthropology (Hay & Lee, 2009; Pasick et al., 2009b; Shelton, Griffith, & Kegler, 2017). Additionally, better qualitative research can add to revisions of standard theories e.g. the meaning of theoretical constructs within its social context. This ensures that interventions consider a more holistic, including socially contrasted outlook, rather than a universal understanding of behaviour change (Hay & Lee, 2009; Pasick, Burke, & Joseph, 2009; Shelton, Griffith, & Kegler, 2017; Washington et al., 2009). A literature review has found perceived benefit (beliefs about positive outcomes of a behaviour based on perceived threats) did not consider the use of complementary medication use in Latina and Filipinas women (Joseph et al., 2009). In addition, a qualitative study found subjective norms (perceived social pressure to perform or not to perform a behaviour) does not consider the role of others outside of the immediate social circle of Mexican and Filipina communities e.g. support from other cancer survivors (Washington et al., 2009). In addition, a review found intentions (explicit decisions to behave in a certain way) may mean 'yes' but in the context of 'no' in collective aspects of Filipina and Latina culture e.g. agreement or consent may be made to avoid conflict with others such as disrespecting instructions from elders but in reality there was no intention to screen for cancer (Pasick et al., 2009b).

3.4 Cultural health beliefs and self-management practices

Research on asthma prevalence, adequately applying cultural terms and cultural behaviour change theories need further investigated for a holistic and foundational understanding of asthma self-management in a cultural setting. Cultural health beliefs and self-management practices that are part of culture also need to be considered and understood.

3.4.1 Beliefs about asthma causation

Individuals with asthma can make sense of how asthma was caused at various levels (that can occur in combination) (George, 2001):

- Individual causes - asthma is perceived to be caused by not conforming to cultural (religious or moral) behavioural codes on healthy living e.g. smoking behaviour caused asthma.

- Natural world causes - asthma is perceived to be caused by symbolic imbalances in the body e.g. air pollution exposure caused asthma.

- Social world causes - asthma is perceived to be caused by magic or physical and emotional stress e.g. evil eye caused asthma.

- Supernatural world causes - asthma is perceived to be caused by spiritual failing or a test of faith e.g. lack of commitment to God caused asthma (George, 2001).

A combination of social and supernatural beliefs have been shown to increase the possibility of complementary and alternative medicine (CAM) use (Rand & Apter, 2008). Some studies have found that different South Asian groups can be unaware of what caused asthma (Hussein & Partridge, 2002; Lakhanpaul et al., 2014b), though there has been little research in the area (Davidson et al., 2010).

3.4.2 Beliefs around body function

There are two relevant asthma beliefs around body function (Holland, 2017): the hot and cold beliefs (Harver & Kotses, 2010), and cleansing model beliefs (Helman, 2007, 2014).

Hot and cold beliefs about asthma

Hot and cold beliefs about illness and treatment are widespread amongst various ethnic groups e.g. South Asians, South East Asians, Chinese, Middle-Eastern, Puerto Ricans, Latino Americans and so forth. These beliefs can influence self-management behaviour (Harver & Kotses, 2010; Holland, 2017). Hot and cold beliefs refer to the representative and symbolic power or forces found in hot and cold elements (not the physical temperature itself), e.g. in food, herbs, weather, colour, medicine and emotions (Ahmed et al., 2017; Harver & Kotses, 2010). Good health is believed to be attained, and asthma eliminated or treated, through the balance of hot and cold energies, comparable to yin (negative) and yang (positive) forces within the body. This determines how individuals respond to asthma and medical ideas about treatment. These beliefs are heavily ingrained into community perceptions that most individuals are not consciously aware of the terminology, its existence and cannot pinpoint its origins, therefore rules and behaviours around hot and cold beliefs are more likely to be unconsciously applied (George, 2001; Holland, 2017). Hence, hot and cold beliefs can play out behaviours related to habitus (Bourdieu, 2017, 2018). Consequently, interventions

targeting unconscious collective beliefs may be useful (Marteau, Hollands, & Fletcher, 2012; Triandis, 2018).

There may be South Asian subcultural differences in classifying which illness or treatment constitutes as hot or cold (Harver & Kotses, 2010). Most respiratory illnesses (e.g. asthma, cold and flu), are perceived to be cold, triggered by the excessive exposure to cold elements and the unevenness of temperatures, causing an imbalance of hot and cold energies (George, 2001; Holland, 2017). A qualitative study showed that the combination of hot days and cold nights was perceived to increase the risk of catching a cold in people from Bangladesh, therefore self-management meant using hot remedies to restore the original balance; good health and enhance healing (Nizame et al., 2011). Other examples of hot treatments used by some South Asians is dry/wet cupping (a cup treatment placed on the body and used as a vacuum to pull out excess cold and heat up the lungs), dressing up warm, recurrently heating the house and avoiding contact with cold weather or breezes. Ideas around food are typically hot or cold; hot foods are generally those that are salty, sour and high in animal protein which are believed to increase emotions and body temperature, comparable to how alcohol intoxicates. In contrast, cold food are largely sweet, bitter and astringent, and is believed to cool body temperature, produce tranquil emotions and create happier and stronger individuals (George, 2001; Holland, 2017). UK based qualitative studies have found that different South Asian subgroups (including parents of children with asthma) avoided cold food to maintain good asthma control (e.g. banana, cold milk/drinks, ice cream, yoghurt and grapes), because it was believed that these cold foods/drinks aggravated the throat (Cane, Pao, & McKenzie, 2001; Hawthorne et al., 2007; Lakhanpaul et al., 2014b).

Cleansing model beliefs

Cleansing model beliefs suggest that asthma symptoms and attacks can occur from the accumulation of mucus, bacteria or other impurities clogging up the lungs and causing an imbalance in the body, which require cleansing remedies (Helman, 2007, 2014). Cleansing treatment strategies are usually emetic, purge or cathartic e.g. provoking coughing and sneezing (Helman, 2014). A UK based qualitative study found that Indians and Pakistanis believed their lung tubes were blocked during asthma events, though they were undecided on whether air gets trapped there or if air does not flow into the lungs. Little research in this area means detailed understanding of beliefs is needed (Hussein & Partridge, 2002).

3.4.3 The use of complementary and alternative medicine

Alternative medication literally means a substitute to orthodox biomedicine treatment, whereas complementary medication refers to use of other treatments alongside biomedicine (Micozzi, 2014), though the boundaries of CAM are not always clear (Ma et al., 2016). For instance, acupuncture (yoga and exercise) which was originally part of traditional Chinese or Indian medicine (practiced for generations) was labelled as a CAM (Ma et al., 2016). Acupuncture treats health as a harmonious balance of energies (where imbalances are restored via lifestyle changes). Due to its popularity and growing evidence on effectiveness in the field (neurophysiological or chemical benefits e.g. endorphins), it has been integrated into the mainstream biomedical model in the UK (Ma et al., 2016; Micozzi, 2014). Similarly, ruqyah shariah; an Islamic treatment and healing strategy for physical, mental, spiritual and supernatural illnesses, consisting of devotion to worship (e.g. prayer, reading Qur'an and supplication), and lawful incantations based on the Qur'an and the sayings of the Prophet read on various substances such as certain herbs and foods (Eneborg, 2013), has grown from treatment delivered at home to established centres around the UK, particularly in East London. There is another type of ruqyah (prohibited incantation) where strategies for healing may be similar, but it is believed to be based on magic e.g. teachings from Kabbalah magic (Ahmad et al., 2014; Eneborg, 2013). Research on ruqyah shariah has been mostly recognised in mental health rather than physical health e.g. depression and schizophrenia (Afifuddin & Nooraini, 2016; Eneborg, 2013; Rassool, 2015). Hence, what may be categorised as CAM in a Western social contexts may be part of the mainstream treatment in another country, or there may be cultural shifts towards holistic treatments in Western communities (Ma et al., 2016; Micozzi, 2014).

CAM is used by various ethnicities including White Caucasians. However, most CAM is widely under researched in the UK and its benefit or harms are not well established (Micozzi, 2014). Although, yoga (widely used in countries such as India) has shown some evidence of beneficial impact for asthma in Indians (e.g. significant psychological stress relief) (Nagarathna & Nagendra, 2010). CAM use for most South Asians in South Asia and other countries are mainly used as complementary to biomedicine (Cane, Pao, & McKenzie, 2001; Griffiths et al., 2001; Hazir et al., 2002; Lal, Kumar, & Malhotra, 1995), e.g. relaxation techniques, homeopathy, Chinese herbalism, home acupuncture kit, ruqyah shariah and

dietary changes in alignment with Islamic and Ayurveda medicine such as using hot food; ginger, turmeric and so forth (Cane, Pao, & McKenzie, 2001; Griffiths et al., 2001; Lakhanpaul et al., 2014a). A UK based qualitative study by Hussein & Partridge found that if biomedicine was not perceived to be effective (particularly if asthma worsened), Pakistanis and Indians described willingness to try CAM. The use of some CAM was also initiated by hot and cold beliefs about food e.g. drinking ginger juice as a hot remedy (Hussein & Partridge, 2002). A systematic review found that alongside biomedicine Pakistani parents in Pakistan commonly used traditional healers (e.g. hakims) and homeopathic treatments, and Indians from India also used homeopathy, in addition to yoga and Ayurveda treatments (Lakhanpaul et al., 2014a).

3.4.4 Beliefs about asthma medication

The perceptions and practicalities approach (PAPA) framework by Horne (2001) is one behaviour change framework that provides an understanding of various factors that can predict asthma medication adherence over time. Perceptions of asthma medications are important because medication beliefs are powerful predictors[19] of adherence behaviour (Horne & Weinman, 2002). There are two overlapping predictors of non-adherence that may be intentional or unintentional (Horne, Taylor, & Harding, 2001):

1) Intentional non-adherence is said to be related to motivation, including:

- 'Motivation and beliefs' e.g. motivation to get better. A systematic review found that South Asians readily accept their medications to improve asthma (Miles et al., 2017).

- 'Perceptual barriers' e.g. beliefs about medication needs and preferences (Horne, Taylor, & Harding, 2001). Underlying 'perceptual barriers' are two beliefs that determine decision-making about medicine adherence, known as the necessity-concerns framework comprising of beliefs about necessity and concern of overuse (Horne et al., 2013)-

   → Beliefs about necessity e.g. long-term treatments based on a chronic plans may be less helpful if South Asians believe in the acute nature of asthma that requires medical attention during certain periods of time e.g. the belief that medication is necessary during asthma attacks (Bedi, 2007; Hussein & Partridge, 2002).

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[19] Predictors are a construct that is targeted in interventions to predict/correlate with/causes behaviour change (Michie & Prestwich, 2010)

→ Concerns of overuse e.g. concerns about asthma medicine in some South Asians can revolve around believing medication is addictive, concerns about side-effects and ensuring that asthma does not progress into adulthood by continuous treatment (Horne, Taylor, & Harding, 2001; Leong, Ramsey, & Celedón, 2012; Smeeton et al., 2007). The latter may be explained by awareness of or the experience of the low prevalence of asthma in South Asia. In addition, many children, especially boys have less trouble with their asthma becoming teenagers and young adults (Kuehni et al., 2007).

2) Unintentional non-adherence is related to ability on two factors (Horne, Taylor, & Harding, 2001):

- 'Capacity and resource limitations' e.g. access to medication.
- 'Practical barriers' e.g. visiting the pharmacy.

Evidence suggests that some South Asians find it difficult to process information on asthma medication (Davidson, Liu, & Sheikh, 2010; Miles et al., 2017; Moudgil & Honeybourne, 1998), e.g. knowing the difference between the reliever and preventer (Hussein & Partridge, 2002; Lakhanpaul et al., 2014b). Low health literacy may be one explanation for explaining why some elderly South Asians may not understand asthma medicine (though they constitute a small proportion of the UK population), complicated by the use of interpreters which may cause discrepancies in language translation (Sharif, 2012). These factors can be understood as both capacity and resource limitation and practical barriers (Horne, Taylor, & Harding, 2001). A systematic review found that new migrant Punjabi Indians in Canada had barriers in understanding e.g. different use of terminologies and symptoms (e.g. wheeze), and preference for HCPs from their own ethnic background who spoke the same language (Poureslami et al., 2007). Addressing both 'perceptual barriers' and 'practical factors', determine 'motivation and beliefs' and 'capacity and resource limitations' that help tailor medicine to the needs of individuals (Horne, Taylor, & Harding, 2001).

3.4.5 Religious beliefs and sensitivities

Studies on identity of some South Asians in the UK have shown that the majority of UK born/raised Muslim South Asians (depending on level of spirituality), preferred to define themselves away from adaptive forms of religion (that are merged with traditions, and oral hearsays), by learning the religious texts and so forth (Robinson, 2009; Tobin, 2016). This has been suggested as one reason why there is more literature on Muslim transformations

compared to other South Asian religions (Davidson, Liu, & Sheikh, 2010; Hollins, 2016; Koenig & Shohaib, 2014). Religious coping can be used by many Muslims to self-manage asthma e.g. ablution before prayer (washing parts of the body in a set pattern for purity in prayer and other forms of worship), and prayer which involves a series of actions and invocations that can provide inner peace and contentment with living with asthma, and improve breathing and blood flow (Koenig & Shohaib, 2014; Yucel, 2010). However, little research around religious coping in asthma for all South Asian religions means this area of research needs to grow further (Davidson, Liu, & Sheikh, 2010; Hollins, 2016; Koenig & Shohaib, 2014).

Identified Islamic beliefs around asthma were:

- Beliefs around predestination that nothing happens without the will of God, but at the same time individuals have freewill and must use available means to seek treatment (Hollins, 2016; Koenig & Shohaib, 2014).

- Belief that hardship is a part of life which gives inner strength and comfort for individuals to cope with asthma, while expiating sins and rewarding the person with good deeds due to their patience in coping with their condition (Hollins, 2016; Koenig & Shohaib, 2014).

- Fasting during the month of Ramadhan (sunrise to sunset) is a basic tenet of Islam. Ramadhan plays an important role for Muslims with asthma and their attitude towards medication, but it has been poorly researched in the South Asian population in the UK (Canino, McQuaid, & Rand, 2009; Leong et al., 2012). In Qatar, a large cross-sectional study that focussed on Muslims (authors did not describe ethnicity) found that Ramadhan had no impact on asthma hospitalisation before, during or after the month, compared to non-fasting months (Bener et al., 2006). In addition, studies have found improvements of health outcomes in Ramadhan such as asthma symptoms, weight loss and peak expiratory flow reading (PEFR) (Moosavi et al., 2007; Norouzy et al., 2013). Some individuals prefer to fast even though they may be exempt due to limited ability (Aydin et al., 2014). Medicine intake may be rearranged around fasting times, however insufficient religious and medical guidance and interventions on whether individuals can use asthma medication during fasting times sometimes led to confusion in both people with asthma and HCPs, compared to other illnesses such as diabetes and cardiovascular disease (Aydin et al., 2014; Erkekol et al., 2006). Confusions around medication use during fasting hours can be related to the PAPA framework. For instance, 'perceptual barriers' may be confusion around medication use that influences 'motivation and beliefs' of intentional non-adherence. 'Capacity and resources' may be inadequate

knowledge provisions that influence unintentional non-adherence during Ramadhan (Horne, Taylor, & Harding, 2001).

There are beliefs around cultural/religious rules on what food worsen asthma symptoms and can be used as medication e.g. hot and cold food (Cane, Pao, & McKenzie, 2001; Davidson, Liu, & Sheikh, 2010; Hollins, 2016). Sometimes, biomedical treatments can conflict with the religious belief and codes e.g. capsules using animal gelatine coating are important to avoid for Hindus, Muslims and Sikhs and aerosol asthma inhalers may contain ethanol alcohol as a co-solvent (important to avoid for Muslims) (Alrasbi & Sheikh, 2008).

3.4.6 Beliefs around asthma stigma

Studies from South Asia have found that stigma around diagnosis (Lal, Kumar, & Malhotra, 1995; Shivbalan, Balasubramanian, & Anandnathan, 2005), concerns around using medicine in social settings (Hazir et al., 2002), and beliefs that asthma is contagious (Hazir et al., 2002; Lal, Kumar, & Malhotra, 1995; Shivbalan, Balasubramanian, & Anandnathan, 2005). The latter agrees with findings of qualitative studies in the UK, who found that there was perceived social stigma around the contagious nature of asthma (Cane, Pao, & McKenzie, 2001; Lakhanpaul et al., 2014b). UK based qualitative studies have found that parents avoided social events as a strategy to protect their children, prevent instances of stigma and practical problems e.g. concerns around triggers such as food, dressing their children in warm clothes, passive smoking behaviour, physical activity, and potential marriage prospects especially for girls (Lakhanpaul et al., 2014b). Avoiding the use of medication in social settings can be related to 'perceptual barriers' in the PAPA framework, which can influence 'motivation and belief' of intentional non-adherence in social situations (Horne, Taylor, & Harding, 2001). Another UK based qualitative study found that social stigma for asthma diagnosis was missing in families and peers, but not employers (Hussein & Partridge, 2002). This agrees with another study that found there was parental concern for future employment opportunities for children with asthma (Lakhanpaul et al., 2014b). Overall, it was unclear how the findings on stigma related to different levels of stigma e.g. perceived (expected) or actual (experienced) stigma (Goffman, 2009). Stigmatisation around asthma in the UK needs further research in the UK (Lakhanpaul et al., 2014b).

3.5 Cultural competence in the healthcare service

Health beliefs and practices may be important for most South Asians, however there may be differences in understanding culture and health beliefs/practices at clinical, structural and organisational levels of the healthcare service, which needs to be understood and considered (Joseph et al., 2009).

Ongoing cultural competence (defined in section 3.5), means adequate service should to be provided at all levels in cross-cultural situations (working alongside each other), to maintain good quality of care (Betancourt et al., 2016). There is little evidence for developing cultural competency in South Asians with asthma e.g. models, guidelines and studies (Giger, 2016; Purnell, 2014). Cultural competence should be at three levels (Betancourt et al., 2016):

1) Clinical cultural competence (patient-provider interactions) e.g. relationships and under-diagnosis or under/over prescribing in a population. Misunderstandings around health beliefs and behaviours amongst patients and providers generally indicate low quality of care, when differences are not either accepted, appreciated or understood (Betancourt et al., 2016). Knowledge of CAM use can be one area where there is potential for improvement. Current discussions around CAM may be limited due to various issues e.g. HCPs concerns around effectiveness of CAM (Micozzi, 2014). Griffiths et al. (2001) and Hussein & Partridge (2002); two UK based qualitative studies found that most South Asians had fewer personal relationships with their GPs. Most South Asians were not confident in their GPs and they were dissatisfied with asthma care received including diagnostic delays, lack of information provided (verbal/written). GPs were also perceived to have limited knowledge of asthma and poor access to appointments if asthma worsened (Griffiths et al., 2001; Hussein & Partridge, 2002). When GP relationship with South Asians was compared to White individuals with asthma in one UK based qualitative study, some White people were on a first name basis (this may be due to the length of registration at practices) (Griffiths et al., 2001). However, another UK based qualitative study found that Indians and Pakistanis were satisfied with the care received by nurses, pharmacists and accident and emergency staff in terms of the information provided on asthma and inhaler technique (Hussein & Partridge, 2002). Similarly, a UK based qualitative study found that Bangladeshi mothers preferred their GP as their first point of reference for asthma support before attending the emergency department (Cane et al., 2001).

2) Structural cultural competence (processes of care that is typically based on economic factors). Disparities in the process of care refer to the delivery and quality standards provided by HCPs e.g. staff, equipment, referral process, medical errors due to linguistic or cultural factors including the lack of interpreters and time restrictions (Betancourt et al., 2016). A UK based qualitative study by Griffiths et al. found that South Asians had limited specialist referrals, difficulty accessing primary care during asthma attacks, e.g. reception staff were perceived to block access to GPs, the GPs themselves refused appointments/referrals to secondary care and offered telephone advice or a prescription instead of a consultation. GPs were therefore referred to as a last option (Griffiths et al., 2001). Lack of awareness and ownership of PAAPs in South Asians is a structural barrier (this may also be relevant to other ethnicities) (Foster et al., 2005; Griffiths et al., 2001; Hussein & Partridge, 2002). A synthesis of systematic reviews found that factors such as differences in perceptions of patients and HCPs on plans either facilitated or hindered its use e.g. plans that do not compliment a patient views on asthma or management strategies. Therefore, individuals may find plans unhelpful, and HCPs can vary in their view on who would benefit from PAAPs e.g. patients who are educated, independent and motivated are more likely to be perceived as capable and are therefore given plans (Taylor et al., 2014). This is further echoed in a UK based qualitative study, where GPs perceived PAAPs as unfeasible and too clinical to use with some South Asians (Griffiths et al., 2001). This process of not implementing PAAPs in primary care was termed a 'vicious cycle' (Ring et al., 2015). Multifaceted interventions backed by organisational support were recommended to break this cycle e.g. collaboratively developing holistic plans with the expertise of individuals with asthma (Ring et al., 2015; Taylor et al., 2014).

3) Organisational cultural competence (compromising of leadership of individuals who design services/workforce that carry out tasks) e.g. representations of cultural diversity among the leaders, HCPs and bureaucratic processes (Betancourt et al., 2016). Organisational barriers can subtly play out as *institutional racism*, which can be defined as, *"The collective failure of an organisation to provide an appropriate and professional service to people because of their color, culture, or ethnic origin. It can be seen or detected in processes, attitudes and behaviours which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantage minority ethnic people''* (as cited in Macpherson, 1999, pg.18). When institutional racism is applied to the healthcare system it refers to a UK public institution's response of ignorance to the needs of ethnic minorities that is not directly

obvious (whether this is intentional or unintentional) (Ali & Atkin, 2004; Ramaswamy & Kelly, 2015). It can be argued that if the mainstream White population are favoured as the preferred and healthy norm in healthcare services (e.g. in the standardisation of behaviour change theories), it portrays a 'one size fits all' approach without recognising diversity and difference in its approach/policies (Ramaswamy & Kelly, 2015). Studies have found examples of organisational barriers for some South Asians including insufficient considerations of whether treatments are compatible with religious observations (e.g. alcohol-based inhalers), medication use during Ramadhan, lack of cultural training for HCPs and inadequate language provisions. For instance, poor language provisions may mean HCPs and patients may be reliant on family members to be interpreters including young children who can be confronted with complex medical jargons, or distressing, sensitive and embarrassing information about the patient (Alrasbi & Sheikh, 2008; Car & Sheikh, 2004; Foster et al., 2005; Griffiths et al., 2001). Institutional racism may be difficult to combat since minority representation of power in hierarchical decisions are limited, change may be riskier to implement and tailoring services may be perceived as 'bending over backwards' (Ramaswamy & Kelly, 2015).

3.6 Chapter summary

This literature review has shown that various factors need to be considered to explore culture and asthma self-management, but this has not been reflected or researched well, therefore progress is needed to understand what can optimise self-management in detail. Factors that may need consideration include:

- Asthma prevalence is higher in developed countries compared to South Asia. Most South Asians in the UK have poorer asthma outcomes and higher unscheduled care compared to the mainstream White population and other ethnic minorities (Beasley, 1998; ECRHS, 2002; Netuveli et al., 2005; Sheikh et al., 2016). Research on migrant paradox suggests that individuals from developing countries have better health until they migrate to developed countries (Holmboe-Ottesen & Wandel, 2012; Lesser, Gasevic, & Lear, 2014).

- There are power dynamics in researching culture (Storey, 2010), e.g. classifying culture as static (fixed) rather than dynamic (recognising its heterogeneity) (Castro et al., 2010; Davidson, Liu, & Sheikh, 2010; Liu et al., 2012), ability to define ideal cultural norms and abnormal deviations (Ahmad & Bradby, 2008; Yadav & Yadav, 2015), and the lack of

representation of cultural competence at high healthcare levels to respond to the needs of ethnic minorities (Ali & Atkin, 2004).

- Standard behaviour change theories may not apply to all cultures; evidence shows that theory only partially explained health behaviours for South Asians (Burke et al., 2009a; Evans & Lambert, 2008; Pasick et al., 2009a), since theories are standardised in cultures prioritising individual cognitions, rather than collective cognitions and the consideration of sociocultural contexts (Sinha, 2014; Triandis, 2018). This implies that different South Asian subgroups may have different cultural norms, meanings and interpretations of theoretical constructs (e.g. self-efficacy), illness representations (e.g. cold represents asthma), and targeting unconscious beliefs around habitus[20] may be necessary (Bourdieu, 2017, 2018; Burke et al., 2009a; Pasick et al., 2009a). Arguably, theories that consider culture either do not adequately define culture or they are generic and paint all cultures as the same (Burke et al., 2009b).

- Cultural beliefs/practices are an important part of culture that can influence asthma self-management behaviour (e.g. beliefs about causation, body function, CAM use, medication, religion and stigma), suggesting that self-management may be experienced differently in different cultural groups (Holland, 2017; Wray & Bartholomew, 2010).

This chapter described literature on various factors that need to be considered to develop a holistic comprehension of asthma self-management in South Asians. However, there remains little understanding in this area of research (Sinha, 2014; Triandis, 2018). The next chapter outlines the aims and objectives of the research in this thesis.

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[20] Habitus is the internalised dispositions of second nature social rules and categorisations on perceptions, thoughts and behaviours predicted by past experiences, and social, cultural and economic capital (Bourdieu, 2017, 2018)

Chapter 4. Aims and objectives of the thesis

The literature reviews (chapter 2 and 3) have shown that asthma, self-management and the South Asian culture have dynamic characteristics that change over time. Holistic asthma self-management interventions that consider the South Asian perspective and expertise of living with asthma may be one approach that effectively incorporates and optimises all these factors (Schulman-Green et al., 2012; Trappenburg et al., 2013; Udlis, 2011). However, this has not been reflected or researched well in existing studies that are used to inform interventions. Evidence is scarce (e.g. Evans & Lambert, 2008; Sheikh et al., 2016), outdated (e.g. Beasley, 1998; ECRHS, 2002), or has various power implications (Ahmad & Bradby, 2008; Ali, 2008; Storey, 2010; Yadav & Yadav, 2015). Therefore, there is a need to understand self-management in detail; unique to the self-management of Bangladeshis and Pakistanis with asthma in the UK. The two subcultural groups Bangladeshi and Pakistani populations were included due to time/resource restrictions, and the complexity and dynamic nature of culture. South Asians are not a homogenous group therefore specific features of diverse cultures and subcultures needed consideration.

The overarching aim of the thesis was to understand the role of UK Bangladeshi and Pakistani culture on asthma self-management behaviour, which can help set the foundations for developing holistic bottom-up interventions (which is explicitly recommended in guidelines for asthma) (NICE, 2013; SIGN, 2016). The earliest phase of the MRC framework for developing and evaluating complex interventions (Craig et al., 2008), suggests to do this, there needs to be an understanding of what should be part of the intervention in the first place, this was done by fulfilling the following aims and objectives:

1) **Systematic review**

There needs to be an understanding of what has been included and worked/not worked in previous interventions. The systematic review aimed to synthesise the findings of RCTs in South Asians (and as a comparator the Black population) to explore the extent to which variance in self-management may be due to ethnicity and/or various sociocultural contexts:

- Describe features of culturally relevant asthma self-management interventions.
- Synthesise the evidence for the effectiveness of asthma self-management interventions.
- Identify barriers and facilitators of implementing asthma self-management behaviour.

- Establish the extent to which theory has been used in interventions.
- Identify and describe theoretical intervention components.
- Examine the relationship between reported barriers and facilitators and theoretical intervention components.
- Synthesise the relationship between theory use and intervention components to asthma outcomes.

The systematic review aims are addressed in chapter 5.

2) Qualitative research on Bangladeshis and Pakistanis

Bangladeshi and Pakistani perspectives on asthma self-management were explored. The primary aim of the qualitative study was to understand the role of culture in self-management by exploring perspectives of the first, second, third and fourth generations.

Other aims of the qualitative study were to:
- Identify the categories of HCP that were most significant for participant care from interview data (not necessarily the individual's own HCP).
- Explore what type of asthma self-management interventions Bangladeshi and Pakistani individuals feel would be useful for themselves and/or their community.

The qualitative research aims are addressed in chapter 7.

3) Qualitative research on healthcare professionals

HCP's perspective on supported self-management were explored. The primary aim of the qualitative study was to understand HCP's perspective on Bangladeshi and Pakistani patients (i.e. cultural realities) and the provision of supported self-management given to these communities.

Other aims of the qualitative study were to explore what type of asthma self-management interventions HCPs believe would be useful for Bangladeshi and Pakistani patients with asthma and for their future practice needs.

The qualitative research aims are addressed in chapter 8.

Chapter 5. Systematic review: Interventions enhancing the adoption of asthma self-management behaviour in the South Asian and Black population

Literature reviews (chapter 2 and 3) have shown that asthma self-management in South Asians may be distinct and dynamic, but existing research to inform interventions have not been explored exhaustively. This chapter describes a systematic review; synthesising evidence from RCTs of asthma self-management interventions for South Asians (and the Black population) to understand what has been included and worked/not worked in previous interventions. The Black population was used as a comparator to explore the extent to which variance in self-management may be due to ethnicity and/or various social contexts. The analysis/discussion of the chapter has been separated into two sections: 1) the characteristics and effectiveness of interventions, and the identification of barriers and facilitators to implementing self-management behaviour and, 2) the extent theory and theoretical intervention components have been applied to interventions and its effectiveness. The first analysis has been published (Ahmed et al., 2018) (see Appendix 1)

5.1 Rationale for the systematic review

GINA and SIGN/BTS guidelines recommend that self-management strategies consisting of providing education, PAAPs and supportive discussions improve asthma self-management (GINA, 2016; Pinnock et al., 2017; SIGN, 2016). There are concerns that asthma self-management interventions are less effective for the South Asian and Black population (Netuveli et al., 2005; Phelan & Link, 2005). This raises questions of whether poor asthma outcomes in South Asians in the UK can be explained by their minority-status in a country and/or by their relative social deprivation (sociocultural capital e.g. opportunities, status and wealth) (Asbroek et al., 2005; Lakhanpaul et al., 2014a). One systematic review by Lakhanpaul et al. (2014a) distinguished between barriers and facilitators to asthma care in South Asian children according to social context (indigenous and ethnic minorities). They found several ethnic specific barriers (e.g. lack of asthma knowledge in families and HCPs and dependency on emergency department), and minority-status barriers e.g. patient-provider communication problems and non-adherence to medication. Positive attitude to HCPs was noted as a facilitator (Lakhanpaul et al., 2014a).

Culture is a dynamic and ongoing process, depending on an individual's interaction with and ability to respond to the variability in their environment (see chapter 2 and 3). Overlooking information on 'contextualisation' may hinder adoption of self-management behaviour, as it enhances meaning, receptivity, relevance and processing of information for a particular individual from a specified background (Ahmad & Bradby, 2008; Liu et al., 2016; Resnicow et al., 1999). There are various distinctions between culturally relevant trials: 1) 'culturally modified' interventions; developed for a majority population but modified to apply to other ethnic groups using various strategies (Bailey et al., 2009; Falicov, 2009), 2) 'culturally targeted' interventions; bottom-up interventions that account for the shared characteristics of a cultural group during development (Kreuter et al., 2003) and, 3) 'culturally tailored' interventions; bottom-up interventions aimed at individual differences in a cultural group (see section 3.2.2 for further explanation) (Kreuter et al., 2003). Culturally targeted or tailored interventions are generally suggested to be more effective than modified interventions, though the evidence for this has focussed mainly either on children (Bailey et al., 2009; Lakhanpaul et al., 2014a; McManus & Savage, 2010), or is limited or outdated (Bailey et al., 2009; Davidson, Liu, & Sheikh, 2010; Liu et al., 2012; McManus & Savage, 2010; SIGN, 2016).

Evidence suggests that the use of theory can be beneficial for intervention tailoring and effectiveness (Cane, O'Connor, & Michie, 2012; Michie & Prestwich, 2010). Usefulness of theories are also dependent upon whether theory was accompanied with good descriptions and explanations (Michie & Prestwich, 2010). Arguably, theories may not always be helpful e.g. understanding common sense behaviours (Burke et al., 2009a; Marteau, Hollands, & Fletcher, 2012; Pasick et al., 2009b). The context in which theory was produced, tested and from which assumptions were drawn from need to be recognised and made explicit, but not enough is known about the use of theory for South Asians in the UK (Burke et al., 2009a; Pasick et al., 2009a).

5.2 Aims for the systematic review

There needs to be an understanding of what has been included and worked/not worked in previous interventions. This systematic review aimed to syntheses the findings of RCTs in South Asians (and as a comparator the Black population) to explore the extent to which

variance in self-management may be due to ethnicity and/or various sociocultural contexts, to:

- Describe features of culturally relevant asthma self-management interventions.
- Synthesise the evidence for the effectiveness of asthma self-management interventions.
- Identify barriers and facilitators of implementing asthma self-management behaviour.
- Establish the extent to which theory has been used in interventions.
- Identify and describe theoretical intervention components.
- Examine the relationship between reported barriers and facilitators and theoretical intervention components.
- Synthesise the relationship between theory use and intervention components to asthma outcomes.

The Black population was included because prior scoping work indicated that there was important literature on self-management (particularly in African American communities). This also allowed exploration of both the role of South Asian ethnicity in self-management and the impact of various social contexts (e.g. 'minority'/'majority' status and SES) on asthma self-management outcomes. Hence, South Asian countries where the population forms a majority was defined as *'majority' South Asians*, and interventions from countries where the population forms an ethnic minority were categorised as *'minority' South Asians* or *'minority' African Americans* (Lakhanpaul et al., 2014a; Netuveli et al., 2005).

5.3 Methodology for the systematic review

The review protocol has been registered with the PROSPERO database (registration number CRD42015020174). We followed the systematic review procedures described in the Cochrane handbook for systematic review of interventions (Higgins & Green, 2014).

5.3.1 Study design

RCTs evaluating asthma self-management were included. Any observational, qualitative and other quantitative designs were not eligible for the review.

5.3.2 Inclusion and exclusion criteria

Population

Studies were included if the population comprised of South Asian communities (Indian, Pakistani, Bangladeshi or Other), or Black populations (African, Caribbean or Other), who were asthma patients, their parents/carers, healthcare or lay professionals. The search considered all population ages and countries.

Intervention

Asthma self-management interventions in any healthcare, community or remote settings were included. The self-management definition of the US Institute of Medicine was used: *"The tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their conditions"* (as cited in Adams et al., 2004 pg. 57).

Comparator

Either asthma patients, parents/carers of children with asthma or healthcare/lay professionals supporting people with asthma, who did not receive asthma self-management intervention.

Outcomes

Outcomes of interest were:
- Clinical: 1) current asthma control, defined as the degree to which different asthma manifestations were reduced or eliminated by treatment. Here, main categories included clinical asthma control levels; 2) reducing future risk of adverse events and unscheduled healthcare utilisation. These clinical outcomes align with the American Thoracic Society/European Respiratory Society (ATS/ERS) Task Force standardised definitions (Reddel et al., 2009).
- Process: any outcome that occurred from steps in a process e.g. knowledge and self-efficacy.
- Behavioural: outcomes related to self-management behaviour e.g. medicine adherence and inhaler technique.

Exclusion Criteria

The exclusion criteria included:

- All studies that did not explicitly specify the population e.g. trials which did not provide details on which ethnic group they are referring to when they used broad terms such as 'West Indians' and 'Asians'.

- Studies of multiple ethnic populations that did not state outcome data separately for the South Asian and the Black ethnic groups or subgroups.

- All secondary studies (e.g. literature reviews, systematic reviews and conceptual or philosophical discussion articles), however systematic reviews were used as a reference to identify further relevant studies from its reference list.

- If the study design was observational, qualitative or other quantitative.

- If the study did not describe a self-management intervention, behaviour or process which fitted the definition of self-management described (the term self-management did not need to be used) (Adams et al., 2004).

5.3.3 Search strategy and terms

Search strategy

RCTs were searched for in:

- Published studies - eight electronic databases were searched in February 2015 *(Medline, EMBASE, Web of Science, PsycINFO, Scopus, Elsevier Science Direct, Cochrane Library and Google Scholar)*. All reference sections of identified systematic reviews were examined to detect further relevant studies.

- On-going studies - any ongoing systematic reviews and primary studies were identified by searching three research registers *(the PROSPERO database, http://www.crd.york.ac.uk/PROSPERO/search.asp; the University of York's Centre for reviews and dissemination database, http://www.crd.york.ac.uk/CRDWeb/, and the clinical trials database https://www.clinicaltrials.gov/)*. Unpublished trials were not considered. Any identified systematic reviews acted as a reference point to detect further potentially relevant published studies.

- Individual journals - manual search of relevant journals *(Patient Education and Counselling, Health Psychology and Ethnicity and Health)*.

The article search was not confined by publication year or language.

Search terms

Table 2 shows the key search terms in the search strategy including 'asthma' 'AND' 'self-management' 'AND' the relevant population ('South Asian' and 'Black' communities) (see Appendix 2 for search strategy details).

Table 2. Search strategy terms

Asthma	Self-management	Population search
Asthma	Self management OR Asthma control OR Self care Barriers OR Facilitators Beliefs OR Attitudes Knowledge OR Asthma education	South Asians Bengali OR Bangladeshi OR Bangladesh Indian OR India Pakistani OR Pakistan Black OR African OR Afro Caribbean Ethnic OR Ethnicity

5.3.4 Data selection and collection

Study selection

A PRISMA flow diagram was used to report the number of identified, screened, eligible and the final list of included studies (see Figure 3; see Appendix 3 for the PRISMA checklist for systematic review).

Screening of titles and abstracts

As the first reviewer, I independently searched and imported all citations of potentially relevant studies found from literature searches into the reference software Endnote and excluded duplicate studies. The first reviewer then reviewed all titles and abstracts by referring to the selection criteria and excluded any irrelevant studies. Second reviewers (Liz Steed and Hilary Pinnock) checked this for accuracy by reviewing ten per cent of the eligible studies. Any disagreements between the decisions made by the first and second reviewers were resolved by discussion and clarification of the exclusion/inclusion criteria as necessary.

Screening of full texts

The full texts of potentially eligible studies were retrieved. As the first reviewer, I reviewed all the full texts of articles with the selection criteria and the second reviewer (Liz Steed) randomly reviewed a proportion of eligible articles for accuracy. If there were any disagreements, it was resolved through further discussion and clarification of the criteria. If consensus was not achieved, a third reviewer (Hilary Pinnock) was consulted (see Appendix 4 for details on all excluded trials).

Data extraction and risk of bias

A standardised data extraction sheet was modified for this study (The Cochrane Public Health Group, 2017), and we used the Cochrane EPOC Risk of Bias Assessment checklist alongside this to evaluate bias for each study (Cochrane, 2015). Reviewers used these checklists to review all included studies. I completed all data extraction. Data extracted on intervention description, characteristics, outcomes, barriers and facilitators and risk of bias were independently checked for accuracy by a second reviewer (Katherine Harris). Outcome data was further checked by Hilary Pinnock, and data extracted on theory use and theoretical intervention components was independently checked for accuracy by another reviewer (Liz Steed). Any discrepancies were resolved by further discussions between reviewers until consensus was achieved. If consensus was not achieved, third reviewers (Liz Steed and/or Hilary Pinnock) were consulted. Any missing, unclear or additional data required were noted and the trial authors contacted by email. If contact with the author failed, the uncertainty was noted on the data extraction form.

Dealing with unclear or duplicate studies

If access to a full text article was not successful, articles were labelled as a 'potentially relevant study' (see Appendix 4 for details). Any missing, unclear or additional data required were marked clearly on the data extraction form and the primary author were contacted by email. If contact with the author failed, the uncertainty was noted.

5.3.5 Method of analysis

Descriptive summary

All data extracted from eligible studies were summarised into a table and a descriptive summary was included (see Table 3).

Analysis of outcomes

Outcomes were too heterogeneous to conduct a meta-analysis, therefore a narrative synthesis was used; we used harvest plots to illustrate this visually (Ogilvie et al., 2008). Harvest plots are an approach to illustrating the findings of a narrative synthesis (comparable to forest plots in a meta-analysis), which facilitates easy comparisons across studies. Additionally, they allow graphic identification of interesting patterns amongst varying outcomes compared to conventional tables and large narrative texts. They also highlight areas of possible concern and the strongest or the most inconsistent evidence (Ogilvie et al., 2008).

If there were various outcomes in one outcome category (e.g. the asthma control category may include a validated questionnaire, symptom scores or days off work, or possibly asthma-related QOL, with a range of significant and non-significant findings), the overarching outcome was determined according to predefined criteria (see notes to Table 5), where greater weight was dependent upon priority of evidence in the following order:

- Defined primary outcomes in an adequately powered sample/subgroup analysis (for the latter the subgroup analysis had to be defined a priori).
- Outcomes measured using a validated instrument (as opposed to non-validated instruments).
- Outcomes that were clinically and statistically significant (e.g. achieved the defined minimum clinically important difference).
- If doubts remained, the author's interpretation was considered to provide context for the final decision.

Additionally, for QOL the overall score (as opposed to domain subscale scores) was used. If an overall score was not given, the outcome was not plotted. Moreover, asthma-related QOL scales were given priority (e.g. AQLQ), over generic QOL scales (e.g. EQ5D). For the clinical asthma control category, validated asthma control scores that asked about symptoms were

given priority over other outcomes in the same category, as it is a better indicator of asthma control. Hatched plots on the graph illustrated inconsistent findings within one category. I applied all the harvest plots and this was agreed by Hilary Pinnock and/or Liz Steed (Ogilvie et al., 2008). The sizes of lines and colour hatchings were used to illustrate features of the trial according to a defined convention (see footnote to Figure 4 and detailed descriptions in Table 5).

Identification of barriers and facilitators of self-management

Barriers were defined as components which interrupt the successful attainment and maintenance of asthma self-management e.g. health-seeking behaviours, language and communication, diagnosis/treatment factors and pragmatic factors such as transportation access and busy work life (Seid, 2008). Facilitators were defined as components aiding the attainment and maintenance of asthma self-management that provided explanations or solutions e.g. trigger awareness (Lakhanpaul et al., 2014b). Barriers and facilitators were identified and interpreted from data and/or interpretations of study authors. These were identified and distinguished according to whether they were:

- Generic - frequently occurring across all ethnic populations and social contexts.
- Minority-status related - those frequently occurring in both South Asian and Black ethnicities where they are a part of a 'minority' population.
- Ethnic-specific - either, 1) those frequently occurring in a particular ethnic group and social context (described by authors as ethnic-specific) or, 2) those frequently occurring in South Asians independent of whether they constitute a 'majority' or 'minority' population in a country.

Coding the use of theory using the Theory Coding Scheme

Theory was coded on whether it was acknowledged and/or targeted by using the Theory Coding Scheme (TCS) (Michie & Prestwich, 2010); a validated strategy for articulating the degree to which behavioural interventions are based on theory, consisting of 19 items that are classed as either 'yes', 'no' or 'don't know' requiring detailed supporting evidence. Items 1 to 11 were used to evaluate the extent interventions were based on theory because these items focus on identifying underpinning theory (items 1, 3), the use of theoretical constructs informing interventions (items 2, 5, 7 to 11), the use of theoretical predictors to indirectly

identify intervention population (item 4), or delivering/tailoring interventions (items 6) (see Table 6) (Michie & Prestwich, 2010). TCS has been widely adapted as a quantitative checklist to establish the degree theory has been used in interventions using these 11 items (Ayling et al., 2015; Prestwich et al., 2014; Taylor, Conner, & Lawton, 2012; Webb et al., 2010). Other items concentrate on methodological factors and theory refinement e.g. the way theory explains its impact on intervention outcomes (items 12 to 16), the relationship between theory and outcomes (items 17 to 18), and theory refinement due to study outcomes (item 19); all of which were either not relevant for these interventions (assessed in our scoping review) (Michie & Prestwich, 2010), or addressed by the analysis of outcomes on harvest plots in this review (Ogilvie et al., 2008).

Coding intervention components using the Theoretical Domains Framework

Theoretical Domains Frameworks (TDFs) were used (a validated framework of 14 domains and 84 constructs related to various psychological and organisational theories which promote understanding of what is relevant to a specified behaviour change), to identify and describe theoretically informed intervention components for both individuals with asthma and providers in included trials (Cane, O'Connor, & Michie, 2012). If trials referred to other articles/websites describing the intervention in greater depth, the full-text of these papers were acquired. Any coding from these additional papers were underlined in Table 7 (decisions for coding TDFs are defined in the footnote to Table 7) (American Lung Association, 2002; Bailey et al., 1990; Bolton et al., 1991; Clark et al., 1998; Creer, Kotses, & Reynolds, 1989; Fisher et al., 1994; Kaur et al., 2002; Lorig et al., 1999; Poureslami et al., 2011).

Linking the relationship between TDFs (intervention components) and reported barriers and facilitators

Reported barriers and facilitators in implementing asthma self-management behaviour in this review were narratively examined to see if there were underlying theoretical components which could explain these or components tailored to address the barrier/facilitator.

5.4 Descriptive summary for the systematic review

5.4.1 PRISMA flow diagram
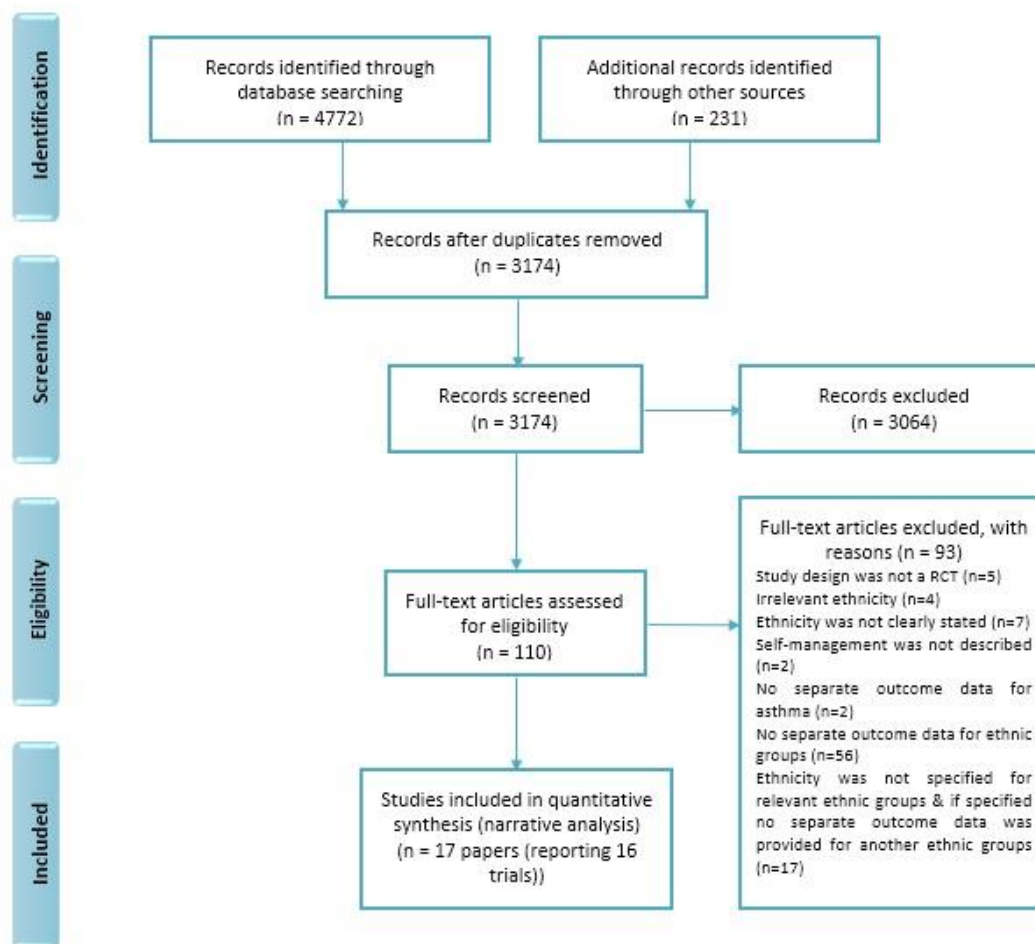
Figure 3. PRISMA flow diagram

A total of 17 papers reporting 16 trials were identified for inclusion in the review (see Figure 3). The search on eight electronic databases (n=4772), three research registers, manual search of three journals and reference lists of identified systematic reviews (n=231), provided a total of 5003 citations. After adjusting for duplicates, 3174 citations remained. Of these, 3064 articles were disregarded after reviewing titles and abstracts which did not match the inclusion criteria. In addition, 93 articles were excluded from 110 studies due to examining full texts in more detail.

5.4.2 Study characteristics

The RCTs were conducted from 1995 to 2016 and focussed on asthma alone (see Table 3). There were:

- Four 'majority' South Asian trials from India (Agrawal et al., 2005; Behera et al., 2006; Ghosh et al., 1998; Shanmugam et al., 2012).

- Four 'minority' South Asian trials from the UK (e.g. East London and Birmingham) (Griffiths et al., 2004, 2016; Moudgil, Marshall, & Honeybourne, 2000), and Canada (Poureslami et al., 2012).

- All nine Black population trials were African American interventions from the USA e.g. St. Louis, Memphis, Midwestern city, Chicago and other unspecified locations (Blixen et al., 2001; Fisher et al., 2004, 2009; Ford et al., 1997; Kelso et al., 1995, 1996; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005).

Facility and setting of included trials

All 'majority' South Asian trials were conducted in tertiary care hospitals (Agrawal et al., 2005; Behera et al., 2006; Ghosh et al., 1998; Shanmugam et al., 2012). In contrast, 'minority' South Asian trials were conducted in primary care GP services (Griffiths et al., 2016; Moudgil, Marshall, & Honeybourne, 2000), and two trials used a combination of settings: home/community, primary care and hospital (including secondary/tertiary services) (Griffiths et al., 2004; Poureslami et al., 2012). Similarly, African American trials were conducted in various settings including primary or secondary schools (Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005), tertiary care hospitals (Blixen et al., 2001; Kelso et al., 1995), the emergency department (Ford et al., 1997), and three trials used a combination of settings: community, secondary school or hospital (including emergency/secondary or tertiary services) (Fisher et al., 2004, 2009; Kelso et al., 1996).

Geographical area and SES

Amongst the 'minority' trials that specified geographical area of participants, these were described as urban in six trials (Fisher et al., 2009; Griffiths et al., 2004, 2016; Moudgil, Marshall, & Honeybourne, 2000; Velsor-Friedrich et al., 2004, 2005); and one African American trial was conducted in mixed urban and rural areas (Ford et al., 1997). In addition, five South Asian and five African American trials did not state where the study took place.

Seven trials (two 'minority' South Asian; six 'minority' African American) were described as from economically deprived or low income areas (Fisher et al., 2004, 2009; Griffiths et al., 2004, 2016; Kelso et al., 1995; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005), and one 'minority' African American and one South Asian trial was conducted in low/working and middle class areas (Kelso et al., 1996; Moudgil, Marshall, & Honeybourne, 2000). Five studies (four 'majority' and one 'minority' South Asian; two African American) did not describe SES setting (Agrawal et al., 2005; Behera et al., 2006; Blixen et al., 2001; Ford et al., 1997; Ghosh et al., 1998; Poureslami et al., 2012; Shanmugam et al., 2012).

Participant characteristics in included trials

'Majority' South Asian trials comprised of Indian participants (Agrawal et al., 2005; Behera et al., 2006; Ghosh et al., 1998; Shanmugam et al., 2012). 'Minority' South Asian trials included Indians (Poureslami et al., 2012), and mixed subcultural groups (e.g. Bangladeshi, Pakistani, Indian or Sri Lankan), with another ethnicity e.g. White Caucasian, White European, Chinese, Black African/Caribbean and Others (Griffiths et al., 2004, 2016; Moudgil, Marshall, & Honeybourne, 2000). Black population trials studied African Americans (Blixen et al., 2001; Fisher et al., 2004, 2009; Kelso et al., 1995, 1996; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005), and one African American trial also focussed on White Caucasian and Other ethnicities alongside African Americans (Ford et al., 1997). Most trials did not define ethnicity; only three 'minority' South Asian trials defined ethnicity according to self-identification or language spoken (Griffiths et al., 2004, 2016; Poureslami et al., 2012).

All trials aimed interventions at asthma patients, whether this was children, adolescents, adults or elders (age ranging from two to 70) (Agrawal et al., 2005; Behera et al., 2006; Blixen et al., 2001; Fisher et al., 2004, 2009; Ford et al., 1997; Ghosh et al., 1998; Griffiths et al., 2004, 2016,; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012; Shanmugam et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). One 'majority' South Asian trial did not specify the age of participants (Shanmugam et al., 2012). In addition, four trials (two 'majority' South Asian and two 'minority' African American) also targeted parents of children with asthma (Agrawal et al., 2005; Fisher et al., 2004, 2009; Ghosh et al., 1998). Two trained

African American coaches and/or residents (Fisher et al., 2004, 2009), and five trials trained HCPs (primary/secondary care clinicians and/or nurse specialists) (Agrawal et al., 2005; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Moudgil, Marshall, & Honeybourne, 2000).

Gender was described in 13 trials (out of 17 trials); of which four trials focussed on females (Behera et al., 2006; Blixen et al., 2001; Ford et al., 1997; Kelso et al., 1996), two trials focussed on males (Fisher et al., 2004; 2009), and seven trials looked at mixed genders (Griffiths et al., 2016; Kelso et al., 1995; Poureslami et al., 2012; Shanmugam et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). Asthma severity studied in interventions was vaguely described by three trials; two studies reported that they looked at a range of severity (Moudgil, Marshall, & Honeybourne, 2000; Velsor-Friedrich, Pigott, & Louloudes, 2004), and one study mentioned all participants had similar severity (Griffiths et al., 2016).

Consideration of intergroup subcultural heterogeneities or acculturation

None of the trials considered intergroup subcultural similarities or differences or acculturation[21].

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[21] Acculturation is the cultural changes influenced by encountering another mainstream culture (Berry, 1997; 2005; Sam & Berry, 2010)

Table 3. Overview of study characteristics

Study, design, country (bias)	Population characteristics			Intervention characteristics				Modified; targeted; tailored
	Aim	Ethnicity; participants; sample age; sample size (I/C)	Study setting; SES/area	Intervention description/length	Control /other group descriptions	Delivery (ethnicity/ language)	Mode of delivery	
'Majority' South Asians trials								
Agrawal (2005) India	Evaluated efficacy of PAAPS for asthma control	Indian Children, Parents 2-12 60 (32/28)	Tertiary (university clinic) -	• Education - sessions, training including on asthma symptom diary & peak flow measurements • PAAPs • Asthma therapy / -	No PAAP, standard asthma therapy & education	Trained physician; social scientist (-)	Individual; Written material	Modified
Behera (2006) India	Assessed knowledge of self-care needs	Indian Adult 18-60 523 (260/263)	Tertiary (outpatient university clinic) -	• Education - booklet included a PAAP • Booklet evaluation / -	No specific instructions /Collaborative ly developed booklet (n=45)	- (Hindi)	Written material; Other methods not stated	Targeted
Ghosh (1998) India	Assessed the impact of self-management education & training	*Indian* Children/adolescent/ adult, Parents 10-45 276 (140/136)	Tertiary (university clinic) -	• Education - sessions, training, written instructions, audio-visual aids, role models, group/scenario discussions • Daily diary included symptom assessment & financial workbook • Asthma therapy • *PAAPs* /Four two-hour sessions	Regular care e.g. drug administration	Trained social scientist (-)	Group; Written material	Modified

Table 3 continued								
Shanmugam (2012) India	To provide pharmaceutical care for good asthma control	Indian Patients Age; - 66 (33/33)	Tertiary (university hospital) -	• Education - sessions, asthma care diary included a leaflet, PAAP & symptom log sheet • Medication counselling /not stated	No pharmaceutic al care	Not stated (English & Tamil)	Written material; Other methods not stated	Modified
'Minority' South Asians trials								
Griffiths (2004) UK	Tested whether specialist nurses can reduce unscheduled care	South Asian (mostly Bangladeshi) White Caucasian, Other (Black/African Caribbean/Other) Children/adolescent/ adult 4-60 164 (95/69)	Primary/ secondary (out of hours GP service/ hospital) Deprived/ urban	• Education - training based on guidelines and nurse review with advice • PAAP explained in English & Sylheti • Ongoing clinical support for professionals on computer prompts • Peak flow meters provided • Oral corticosteroids /Two one-hour visits for GP practices; 194 days	Usual care - single nurse visits discussed asthma guidelines & checked inhaler technique	Trained nurse specialists (partially; PAAPs explained in Sylheti)	Individual; Written material; Telephone	Modified
Griffiths (2016) UK	Tested impact of education adapted from USA interventions reduced unscheduled care	South Asian (Bangladeshi, Pakistani, Indian, Sri Lankan) Children/adolescent/ adult Primary/secondary care clinicians 3 & above 375 (183/192)	Primary (GP) Deprived/ urban	• Education - session included PAAP, nurse follow-ups to book appointments (Chronic Disease Self-Management Program; CDSMP), research training with a video based on guidelines & manualised program (Physician Asthma Clinical Education; PACE) /PACE; two seminars; CDSMP; two-hour session	Usual standardised consultation	PACE - nurse specialist; academic GP CDSMP - trained nurse specialists (South Asians)	Group; Video/DVD; Written material	Modified

Table 3 continued

Moudgil (2000) UK	Tested impact of bilingual education	South Asian (mainly Indian & Pakistani) White European Children/adolescent/ adult, GP 11-59 344 (171/173)	Primary (GP) Low or medium deprivation/ urban	• Education - community sessions delivered in South Asian languages included written literature, educational follow-up • Booklet included PAAP (based on BTS guidelines) & peak flow measurements • GP trained on prescribing, optimal treatment, knowledge & medication • Peak flow meters provided • Asthma therapy /40 minutes	Usual asthma care follow-up	Trained GP (South Asian)	Individual; Written material	Modified
Poureslami (2012) Canada	Explored effectiveness of different information formats & impact on self-management	South Asian (Indian Punjabi) Chinese Adult 21 & above 45 (33/12)	Other/ tertiary (home, university clinic) -	• Education - videos (physician-led, community & physician-led/community combination) • Peak flow meter • PAAPs /One month	Pictorial pamphlet (Mandarin, Cantonese or Punjabi)/ Collaborative intervention development (n=35); focus group (n=40)	Research facilitator (South Asian)	Group/ Video	Targeted
'Minority' African Americans trials								
Blixen (2001) USA	Tested feasibility of an in-patient education program for hospitalisation	African Americans Children/adolescent/ adult 8-50 28 (14/14)	Tertiary (hospital) -	• Education - sessions & video, asthma workbook using African American images, references to famous celebrities; posted as follow-up • Peak flow meter; MDI spacer provided • Toll free numbers for asthma organisations /Three one-hour sessions	Usual care	Trained nurse (-)	Individual; Video/ DVD; Written material	Modified

Table 3 continued

Fisher (2004) USA	Tested a community-based intervention	African American White Caucasian Others Children/adolescent, Parents 5-14 249 (100/149)	Other (community, school) Low income	• Education - promotion campaigns, sessions, training residents to support children/adolescent in schools & the community /12 months	4 areas in the same location with similar SES characteristics	Trained university staff/ residents (African American)	Group; Individual	Modified
Fisher (2009) USA	Tested impact of community health workers	African American Parents, African American Coaches Child's age 2-8 191 (97/94)	Other/ secondary (community, hospital) Low income/ urban	• Education - sessions based on guidelines & parental support contacts/meetings for readiness to change & training for asthma coaches (including PAAPs) /Two years	Usual care - inpatient education, discharge planning with PAAP & a suggested follow-up in primary care within a week of discharge	Nurse; psychologist; trained coaches (African American)	Individual; Group; Telephone	Modified
Ford (1997) USA	Reanalysed an education program aimed to assess the effects on asthma outcomes	African American Adult 18-70 241 (119/122)	Secondary (emergency department) Urban & rural	• Education - sessions & follow-ups, handout & mailed sessions for non-attenders • Visual medical card • Wallet sized card (with medication list, dose, frequency) • Placebo inhaler to practice /Three sessions	-	Trained HCPs; nurses (not stated)	Group; Written material	Modified
Keslo (1995) USA	Provided major long-term therapeutic intervention & education	African American Adult 18 & above 52 (30/22)	Secondary /tertiary (emergency department/university clinic)	• Education - sessions based on NIH guidelines • Follow-up clinics • Education booklet included diary card for measurements & one-page	Usual care	Pharmacy researcher; pulmonologist (not stated)	Individual; Telephone; Written material	Modified

Table 3 continued

			Low; deprived	summary of asthma prevention, medications, triggers & peak flow meter product literature • Asthma therapy for ICS • Peak flow meter (with colour-coded stickers), inhaled beta-agonist & aero chamber provided /One-hour session				
Keslo (1996) USA	Testing if a long-term management program emphasising on ICS & education	African American Adult 18 & above 39 (21/18)	Tertiary (university-based clinic) Low; working & middle-class	• Education - session • Educational booklet • Written instructions on asthma crisis management • Asthma therapy & peak flow meters (colour coded stickers), MDI & other medications • Follow-up clinics (included a diary) /Two years	Usual care	Pharmacy researcher (-)	Individual; Group; Written material	Modified
Velsor-Friedrich (2004) USA	Tested the effect of a school-based education program (Open Airways)	African American Children/adolescent 8-13 102 (40/62) Low/Urban	Other (eight public primary schools with nurse clinics)	• Education - sessions /Two weeks, six 45-minute sessions per week •	Usual care - received Open Airways education after intervention	Academic professor; nurse (-)	Group	Modified
Velsor-Friedrich (2005) USA	An extension of the study above (Velsor-Friedrich 2004): Tested a two-part school-based education program	African American Children/adolescent 8-13 52 (28/24) Low/Urban	Other (eight public primary schools with nurse clinics)	• Education – sessions • Five-month visit with nurse involving education reinforcement, a packet of asthma information reviewed, PAAPs adjusted, clinical assessments on medication & peak flow monitoring /Seven weeks, 45-minute sessions once per week	Usual care - received Open Airways education after intervention & PAAP	Academic professor; academic nurse (-)	Individual; Written material	Modified

Table 3 continued

Velsor-Friedrich (2012) USA	Evaluated efficacy of a school-based asthma education program	African American Adolescent 13-19 137 (74/63)	Other (five secondary schools) Low	• Education - sessions, coping skills training including role-playing & technology use (with a booster session as follow-up) • Nurse practitioner reinforcement & clinic visit • Provided MDI, hydro fluoroalkane & static free chamber • Peak flow diary • PAAP /Six 45-minute sessions over six weeks	Routine education	Clinician; nurse; clinical psychologist; trained doctoral student (-)	Individual; Group	Modified

Note: missing data obtained from authors were noted in italic in the table

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5.4.3 Intervention characteristics

Description of interventions

Table 3 shows that all interventions included patient education, though the approach, method of delivery and content varied. Most trials had more than one educational approach, except for Behera et al. (2006). Examples include:

- Participant education sessions or classes on asthma and/or self-management (Agrawal et al., 2005; Blixen et al., 2001; Fisher et al., 2004, 2009; Ford et al., 1997; Ghosh et al., 1998; Griffiths et al., 2016; Kelso et al., 1996, 1995; Moudgil, Marshall, & Honeybourne, 2000; Shanmugam et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005).

- Participant training (Agrawal et al., 2005; Fisher et al., 2004, 2009; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Velsor-Friedrich et al., 2012), e.g. asthma measurement materials such as asthma symptom diary, peak flow monitoring (Agrawal et al., 2005), and cognitive skills training (Velsor-Friedrich et al., 2012).

- Training for HCPs, coaches or residents (Agrawal et al., 2005; Fisher et al., 2004, 2009; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Moudgil, Marshall, & Honeybourne, 2000).

- Written education (Behera et al., 2006; Ford et al., 1997; Ghosh et al., 1998; Griffiths et al., 2016; Kelso et al., 1995, 1996; Shanmugam et al., 2012), for instance:

  → Asthma care diary (Ghosh et al., 1998; Shanmugam et al., 2012), that included a PAAP, symptom log sheet, leaflet and images (Shanmugam et al., 2012), and symptom assessment and financial workbook (Ghosh et al., 1998).

  → Written instructions and use of audio-visual aids (Ghosh et al., 1998).

  → Visual medical card, and a wallet sized card which included medication list, dose and frequency (Ford et al., 1997).

  → Booklet (Behera et al., 2006; Kelso et al., 1995, 1996) including a PAAP (Behera et al., 2006), a diary card for measurements, a one-page summary of information on asthma (e.g. asthma medications, triggers, peak flow meter product literature and prevention of asthma attacks) (Kelso et al., 1995), and written instructions on asthma crisis management and diary (Kelso et al., 1996).

- Education in video format (Blixen et al., 2001; Griffiths et al., 2016; Poureslami et al., 2012).

- Education in the form of social support (Fisher et al., 2009).

- Local education/promotional campaign (Fisher et al., 2004).

Strategies for reinforcing knowledge or other self-management behaviour included:

- Follow-up classes (Moudgil, Marshall, & Honeybourne, 2000; Velsor-Friedrich et al., 2012), e.g. a booster coping skills training session (Velsor-Friedrich et al., 2012).
- Nurse clinics (Griffiths et al., 2004, 2016; Kelso et al., 1996, 1995; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Srof, 2005), e.g. school nurses conducted clinical assessments, reinforced education, peak flow monitoring and adjusted PAAPs (Velsor-Friedrich et al., 2005).
- Written materials (Blixen et al., 2001; Ford et al., 1997), e.g. asthma workbook with African American images and references to African American celebrities, and a written education session was posted to attenders and non-attenders (Blixen et al., 2001; Ford et al., 1997).

Most trials described other intervention components used in parallel to education, including:

- The use of PAAPs in all South Asian trials (Agrawal et al., 2005; Behera et al., 2006; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012; Shanmugam et al., 2012), and some African American trials (Fisher et al., 2009; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Srof, 2005).
- Providing asthma medication/therapy (Agrawal et al., 2005; Blixen et al., 2001; Ghosh et al., 1998; Griffiths et al., 2004; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Velsor-Friedrich et al., 2012), and provision of emergency steroid courses (Griffiths et al., 2004).
- Providing medical resources including peak flow meters/monitoring materials (Agrawal et al., 2005; Blixen et al., 2001; Griffiths et al., 2004; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Srof, 2005), and placebo inhalers to practice inhaler technique (Ford et al., 1997).
- Asthma diary (Agrawal et al., 2005; Ghosh et al., 1998; Shanmugam et al., 2012), and workbook (Blixen et al., 2001).
- Medication counselling (Shanmugam et al., 2012).
- Offering free asthma organisation helplines (Blixen et al., 2001).

In seven trials, the intervention strategies were based on specific guidelines e.g. National Institute of Health (NIH), National Heart Lung and Blood Institute, GINA and SIGN/BTS (Fisher

et al., 2009; Griffiths et al., 2004, 2016; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Shanmugam et al., 2012).

Description of control groups

There were various forms of 'usual care' in control groups, described by studies as:

- Illustrative leaflets in participant language (Poureslami et al., 2012).

- Standard education classes (Velsor-Friedrich et al., 2012).

- Standard inpatient education and PAAPs before discharge (Fisher et al., 2009).

- Usual nurse consultations (Griffiths et al., 2004, 2016).

- Standard medicine treatment (Ghosh et al., 1998).

- Asthma therapy (Agrawal et al., 2005).

- Recruiting similar neighbourhood areas to the intervention sites (location and SES) (Fisher et al., 2004).

- No pharmaceutical care were provided (Shanmugam et al., 2012).

- Other trials described their control group as usual care or no intervention (Behera et al., 2006; Blixen et al., 2001; Ford et al., 1997; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000).

Asthma education after the intervention period was provided in two trials (Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005).

Intervention length and follow-up length

Intervention and follow-up varied in length. Intervention duration lasted a total of:

- 40 minutes (Moudgil, Marshall, & Honeybourne, 2000)

- One hour (Kelso et al., 1995)

- Three hours (Blixen et al., 2001)

- Four hours (Griffiths et al., 2016)

- Eight hours (Ghosh et al., 1998)

- Two weeks (Velsor-Friedrich, Pigott, & Louloudes, 2004)

- One month (Poureslami et al., 2012)

- Six weeks (Velsor-Friedrich et al., 2012)

- Seven weeks (Velsor-Friedrich, Pigott, & Srof, 2005)

- 194 days (Griffiths et al., 2004)

- One year (Fisher et al., 2004)
- Two years (Fisher et al., 2004; Kelso et al., 1995)

Three trials from India did not specify intervention duration (Agrawal et al., 2005; Behera et al., 2006; Shanmugam et al., 2012), and an African American trial only stated that there were three sessions without specifying duration (Ford et al., 1997).

Follow-up lengths varied from:
- One month (Shanmugam et al., 2012)
- Four months (Agrawal et al., 2005)
- Five months (Kelso et al., 1995)
- Six months (Blixen et al., 2001; Poureslami et al., 2012)
- One year (Behera et al., 2006; Ford et al., 1997; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Kelso et al., 1995; Moudgil, Marshall, & Honeybourne, 2000; Velsor-Friedrich et al., 2012, 2004)
- Two years (Fisher et al., 2009; Velsor-Friedrich et al., 2005)
- Three years (Fisher et al., 2004)

Intervention delivery and format

14 out of 17 interventions (two 'majority' South Asian; four 'minority' South Asian; eight 'minority' African American) were delivered by HCPs e.g. clinicians, nurses, psychologists, researchers and pulmonologist (Agrawal et al., 2005; Blixen et al., 2001; Fisher et al., 2004, 2009; Ford et al., 1997; Ghosh et al., 1998; Griffiths et al., 2016, 2004; Kelso et al., 1996, 1995; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). Five of whom were specifically trained to deliver the intervention (Agrawal et al., 2005; Blixen et al., 2001; Ford et al., 1997; Ghosh et al., 1998; Griffiths et al., 2016). Two interventions were delivered by trained African American lay residents and university staff who were residents of the community (Fisher et al., 2004, 2009). The intervention delivery was not described for two 'majority' South Asian trials (Behera et al., 2006; Shanmugam et al., 2012). For 'minority' South Asian trials, three interventions were delivered in South Asian languages by HCPs or research facilitators (Griffiths et al., 2016; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012), and two 'majority' South Asian trials consisted of written

materials: a booklet in Hindi (Behera et al., 2006), and an asthma care diary in English and Tamil (Shanmugam et al., 2012).

Interventions were delivered in numerous combinations of formats:

- Written format (Agrawal et al., 2005; Behera et al., 2006; Blixen et al., 2001; Ford et al., 1997; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Shanmugam et al., 2012; Velsor-Friedrich et al., 2005).
- Video format (Blixen et al., 2001; Griffiths et al., 2016; Poureslami et al., 2012).
- Telephone contacts (Fisher et al., 2009; Griffiths et al., 2004; Kelso et al., 1995).
- At an individual level (Agrawal et al., 2005; Blixen et al., 2001; Fisher et al., 2004, 2009; Griffiths et al., 2004; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Srof, 2005).
- At a group level (Fisher et al., 2004, 2009; Ford et al., 1997; Ghosh et al., 1998; Griffiths et al., 2016; Kelso et al., 1996; Poureslami et al., 2012; Velsor-Friedrich et al., 2012, 2004).
- In two 'majority' South Asian trials, authors did not describe who delivered a written booklet and pharmaceutical education (Behera et al., 2006; Shanmugam et al., 2012).

Intervention fidelity

Study fidelity was assessed in two 'minority' trials (South Asian and African American) from developed countries (UK and USA). Authors described using audio formats to ensure fidelity (Griffiths et al., 2016; Velsor-Friedrich et al., 2012). For instance, an education program was manualised and delivered using a DVD (Griffiths et al., 2016), and education sessions were audio-taped and reviewed by a researcher (Velsor-Friedrich et al., 2012).

Risk of bias in included trials

The overall risk of bias within a study were assessed using Cochrane guidelines (Higgins & Green, 2014). The most important risk of bias domains was prioritised and ranked according to: 1) allocation concealment, 2) blinding researcher to allocation of outcomes and 3) protection against contamination. The overall risk of bias (see Table 4) was generally uncertain, with low bias mainly found in 'minority' country trials (Fisher et al., 2009; Griffiths et al., 2004, 2016), compared to 'majority' South Asian trials which had unclear (Agrawal et al., 2005; Shanmugam et al., 2012), or high risk (Behera et al., 2006; Ghosh et al., 1998).

'Minority' country trials also had unclear risk (Fisher et al., 2004; Kelso et al., 1995; Poureslami et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005), and high risk (Blixen et al., 2001; Ford et al., 1997; Kelso et al., 1996; Moudgil, Marshall, & Honeybourne, 2000; Velsor-Friedrich et al., 2012).

Table 4. Summary of risk of bias

Trial	Allocation sequence	Allocation concealment	Similarity of baseline outcome measurements	Similarity of baseline characteristics	Incomplete outcome data	Blinding researcher to allocation of outcomes	Protection against contamination	Selective outcome reporting	Other risks of bias	Overall risk of bias (within a study)
Agrawal 2005	+	+	+	+	+	?	?	−	?	Unclear
Behera 2006	+	?	+	?	?	?	−	+	?	High
Ghosh 1998	?	?	+	+	?	+	−	+	?	High
Shanmugam 2012	?	?	?	+	?	?	?	+	?	Unclear
Griffiths 2004	+	+	+	+	+	+	+	+	+	Low
Griffith 2016	+	+	−	+	+	+	+	+	+	Low
Moudgil 2000	+	+	+	−	+	+	−	+	+	High
Poureslami 2012	?	?	+	+	?	?	?	+	+	Unclear
Blixen 2001	−	?	+	+	+	+	−	+	?	High
Fisher 2004	?	+	−	+	+	?	+	+	+	Unclear
Fisher 2009	+	+	+	−	+	+	+	+	+	Low
Ford 1997	+	+	+	−	+	+	−	+	+	High
Keslo 1995	?	?	+	+	+	?	+	+	+	Unclear
Keslo 1996	−	−	+	+	?	?	−	+	+	High
Velsor-Friedrich 2004	−	+	+	−	+	?	+	+	+	Unclear
Velsor-Friedrich 2005	+	+	+	+	+	?	+	+	+	Unclear
Velsor-Friedrich 2012	?	+	+	+	+	−	+	+	+	High

5.5 Analysis one: culturally relevant intervention features, outcomes analysis and barriers and facilitators of self-management

5.5.1 Describing features of culturally relevant asthma self-management interventions

Culturally tailored interventions

We did not find any culturally tailored[22] interventions (see section 3.2.2 for a detailed explanation) (Kreuter et al., 2003).

Culturally targeted interventions

Two out of 17 trials (Behera et al., 2006; Poureslami et al., 2012), evaluated culturally targeted[23] interventions (see section 3.2.2 for a detailed explanation) (Kreuter et al., 2003). Behera et al. (2006) a 'majority' South Asian trial at high risk of bias, provided a written self-care booklet in Hindi (including a PAAP) developed collaboratively with participants, relevant literature and expert advice. In contrast, Poureslami et al. (2012) a 'minority' South Asian trial at unclear risk of bias, collaboratively developed educational videos using community members and HCPs. The educational videos included three intervention possibilities: 1) scientific knowledge, 2) community opinions/narratives and, 3) a combination of both scientific and community narratives, that targeted cultural relevance by incorporating cultural beliefs and attitudes of target population (e.g. cultural gestures, humour, storytelling and social interaction styles appropriate for Punjabi Indians), hence allowing participants to develop trust in the community member and/or clinician who delivered the intervention (Poureslami et al., 2012). These interventions were pilot tested in focus groups for clarity, relevance and acceptability, and refined before evaluation (Behera et al., 2006; Poureslami et al., 2012).

Both interventions were delivered to the specified cultural group without distinguishing or measuring individual differences within that group, therefore they were not categorised as culturally tailored interventions (Behera et al., 2006; Poureslami et al., 2012). Both trials significantly improved knowledge (e.g. of asthma, symptoms, triggers and factors causing worsening of asthma) (Behera et al., 2006; Poureslami et al., 2012), inhaler use, adherence

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[22] Culturally tailored interventions are bottom-up interventions that consider cultural dimensions unique to individuals within a group (Kreuter et al., 2003)
[23] Culturally targeted interventions are bottom-up interventions that account for the shared characteristics of a cultural group during development (Kreuter et al., 2003)

to HCP's instructions on medication (Poureslami et al., 2012), reduced symptoms, hospital admissions and use of breathing exercises during acute attacks (Behera et al., 2006). Although, Poureslami et al. achieved significant findings on all outcomes for Punjabi Indians, the Chinese population (who were studied as a parallel group with their own customised intervention), performed even better. Authors explained this may be related to participant demographics in the study; the Punjabi Indians were much older and less educated than the Chinese community (Poureslami et al., 2012).

Culturally modified interventions

In contrast, 15 out of 17 trials (Agrawal et al., 2005; Blixen et al., 2001; Fisher et al., 2004, 2009; Ford et al., 1997; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Shanmugam et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005), were found to be culturally modified[24] (see section 3.2.2 for a detailed explanation) (Bailey et al., 2009; Falicov, 2009). They used strategies such as adapting existing interventions or materials for the target ethnic group e.g. from the USA to India (Ghosh et al., 1998; Griffiths et al., 2016; Kelso et al., 1995, 1996), e.g. an African American training video was re-recorded with South Asian actors in the UK (Griffiths et al., 2016), and ethnically relevant images were used e.g. African American celebrities (Blixen et al., 2001; Griffiths et al., 2004, 2016). Other studies did not consider cultural differences when various ethnic groups were included in the same trial. Hence, the intervention was applied to all ethnic groups irrespectively, by providing written or oral education (e.g. classes, PAAPs and workbooks), translated from English to the target participant language or using bilingual educators, without adjusting intervention content (Griffiths et al., 2004, 2016; Moudgil, Marshall, & Honeybourne, 2000; Shanmugam et al., 2012).

Overlap between culturally relevant interventions

The distinction between different forms of bottom-up culturally relevant interventions are not clear-cut. Both the targeted trials also incorporated some modified components in their

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[24] Culturally modified interventions are developed for a majority population but modified to apply to other ethnic groups using various strategies (Bailey et al., 2009; Falicov, 2009)

interventions (Behera et al., 2006; Poureslami et al., 2012), e.g. adaptation of language in existing PAAPs to meet the target population needs (Behera et al., 2006).

5.5.2 Synthesising the evidence for the effectiveness of asthma self-management interventions

In the harvest plot (see Figure 4 and Table 5), the four outcome categories (i.e. unscheduled care, asthma control, process and behavioural outcomes), are plotted for the three groups, 'majority' South Asian, 'minority' South Asian and 'minority' African American. The harvest plots showed that the interventions in the 'majority' South Asian trials were effective, though notably all were conducted in tertiary care settings with perhaps relatively severe populations with greater potential for improvement (Agrawal et al., 2005; Behera et al., 2006; Ghosh et al., 1998; Shanmugam et al., 2012). Risk of bias, however was either high (Behera et al., 2006; Ghosh et al., 1998), or unclear (Agrawal et al., 2005; Shanmugam et al., 2012), and two of these trials had short follow-ups (one or four months) (Agrawal et al., 2005; Shanmugam et al., 2012).

Figure 4. Harvest plots illustrating the effectiveness on clinical, process and behavioural outcomes of self-management interventions across different cultural groups and social contexts

The height of bars: 'Majority' South Asian (60, 66, 276, 523); 'Minority' South Asian (164, 344, 375); 'Minority' African American (28, 39, 52, 52, 102, 137, 163, 191, 249)
Cochrane EPOC-R overall risk of bias within studies reflected on top of bars (Low, High, Unclear)

In contrast, trial outcomes both 'minority' communities were inconsistent, though more trials were at low risk of bias, in contrast to 'majority' South Asian trials (Fisher et al., 2009; Griffiths et al., 2004, 2016). 'Minority' South Asian trials showed that most of the outcomes did not show significant benefit (Griffiths et al., 2004, 2016; Moudgil, Marshall, & Honeybourne, 2000). The exception was improved QOL in one trial at high risk of bias (Moudgil, Marshall, & Honeybourne, 2000), and improved self-efficacy at three months which was not sustained at 12 months (Griffiths et al., 2016). Similarly, in 'minority' African American trials (all but one were either at high or unclear risk of bias) (Fisher et al., 2009), most interventions were ineffective (Blixen et al., 2001; Fisher et al., 2004; Ford et al., 1997; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005), or inconsistent (Kelso et al., 1995; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). In addition, one trial at unclear risk of bias had a negative impact on unscheduled care (Velsor-Friedrich et al., 2012). Three trials had positive outcomes (unscheduled care and behavioural) (Fisher et al., 2009; Kelso et al., 1996; Velsor-Friedrich et al., 2005), of these one trial was at a low risk of bias (Fisher et al., 2009), and one trial reported the findings of the second part of another study (Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005).

Table 5. All included trial findings as reported and the decisions underpinning the harvest plots

Citation, Sample size/group Study follow-up Overall risk of bias	Outcome categories, FU	Reported outcomes - values for Intervention (I)/Control (C) *indicates the primary outcome (if stated)	Researcher's interpretation for the harvest plot
Agrawal et al. (2005) n=60 children	Clinical - Unscheduled care, 4m	Compared to controls, children in the intervention group had: **Fewer acute asthma events** I: 0.50 (SD 0.71) vs 1.0 (SD 0.61) p=0.02	Illustrated as a consistent significant *positive* effect.
FU: 4m Overall risk of bias: Unclear	Clinical - Asthma control, 4m	Compared to controls, children in the intervention group had: **Improved symptom score** (from the symptom diary) I: 21.9 (SD 14.4) vs C: 33.7 (SD 10.9) p=0.0006 **Fewer nocturnal awakenings** I: 1.75 nights/month (SD 1.30) vs C: 3.25 (SD 1.20) p=0.001 **Reduced school absenteeism** I: 1.5 days/month (SD 1.4) vs C: 2.54 (SD 1.79) p=0.015	Illustrated as a consistent significant *positive* effect.
	Process	Not assessed	-
	Behavioural	Not assessed	-
Behera et al. (2005) n=523 adults	Clinical - Unscheduled care, 1yr	**A reduction in hospital admissions** is illustrated graphically (the authors state that there was a significant decrease in hospital admissions in the intervention group at FU compared to the control group)	Illustrated as a consistent significant *positive* effect.
FU: 2wks, 6m, 1yr Overall risk of bias: High	Clinical - Asthma control, 2wks, 6m, 1yr	**Symptom scores** decreased in both groups**.** I: Baseline: 18.14 (SD 41.23) vs FU 1yr: 12.61 (SD 28.66) C: Baseline: 18.76 (SD 42.64) vs FU 1yr: 10.69 (SD 24.30) Logistic regression: Compared to the control group, more intervention group participants showed a significant improvement in symptom scores at 2w, 6m and 1yr (p<0.001)	Illustrated as a consistent significant *positive* effect.
	Process, 2wks, 6m, 1yr	**Knowledge** scores increased significantly in the intervention group and fell in the control group; I: Baseline: 13.04 (SD 4.06) vs FU 1yr: 28.13 (SD 15.70) p=<0.001 C: Baseline: 11.44 (SD 4.0) vs FU 1yr: 9.47 (SD 2.89) p=<0.001 Logistic regression: Compared to the control group, more intervention group participants showed a significant increase in knowledge scores at 2w, 6m and 1yr (p<0.001)	Illustrated as a consistent significant *positive* effect.
	Behavioural, 2wks, 6m, 1yr	**Reported self-care in acute attacks** showed no change in attitudes in either group, but significantly more participants in the intervention group adopted the recommended position	Illustrated as a significant *positive*

Table 5 continued

		(sitting, leaning forward) and practiced breathing exercises during an acute attack as compared to control patients	effect but hatched to show inconsistency.
Ghosh et al. (1998) n=276 adult, adolescent, children/parent FU: 4m, 8m, 1yr Overall risk of bias: High	Clinical - Unscheduled care, 1yr (assessed by diary in months 4, 8 & 12)	Fewer total number of **ED visits**, but no between group difference in proportion with ED visit -Number of ED visits in the three-month diary: I: 11.6 (SD 16.2) vs C: 21.8 (SD 25.0) p=0.002 -Proportion with ED visits in the three-month diary: I: 42.9% vs 50.0% (p=0.117) **Number & duration of hospitalisations** were both significantly reduced Hospital days in the three diary months: I: 5.8 (SD 10.7) vs 12.5 (SD 19.8) p=0.016 Proportion hospitalised in the three diary months: I: 27.1% vs C: 36.8% p=0.043	Illustrated as *positive but hatched to indicate inconsistency.*
	Clinical - Asthma control, 1yr (assessed by diary in months 4, 8 & 12)	Fewer **productive days lost** in the intervention group during the three diary months Day lost: 17.6 (SD=24.2)/34.1 (SD=38.8) p=0.003 **PEFR** was significantly improved in the intervention group relative to the control group; Mean PEFR from diary cards I: 332 (SD 50.78) vs 290 (SD 77.69) p=<0.001	Illustrated as a consistent significant *positive* effect.
	Process	Not assessed	-
	Behavioural	Not assessed	-
Shanmugam et al. (2012) n=66 FU: 29 days Overall risk of bias: Unclear	Clinical - Unscheduled care	Not assessed	-
	Clinical - Asthma control, 29th day	**Asthma control** improved in the intervention group compared to the control group. Mean ACT score for each question was greater in the intervention group at FU: p<0.05 (Overall mean ACT scores are not reported) **Lung function** showed a greater increase in the intervention group compared with control PEFR (L/min): Baseline: I: 282 (SD 95) vs C: 265 (SD 93); FU: I: 336 (SD 88) vs C: 268 (SD 85) p=<0.05	Illustrated as a consistent significant *positive* effect.
	Process	Not assessed	-
	Behavioural	Not assessed	-

Table 5 continued			
Griffiths et al. (2004) n=44 practices/324 – (South Asians I: 95 C: 69 n=164), Adults, adolescents, children

FU: 2m, 9m, 1yr Overall risk of bias: Low | Clinical - Unscheduled care, 1yr | [Note: these data are an *a priori* sub-group analysis] ***Time to first unscheduled care** effect on South Asians was not significant between intervention and control; South Asians HR 0.72, 0.48 to 1.09 ***Proportion attending unscheduled asthma care** No between group differences in whole population. No data for South Asian sub-group, but authors state that 'intervention effect was non-significant for other subgroup analysis' | Illustrated as a consistent *no effect*. |
	Clinical - Asthma control, 2m, 1yr	[Note: these data are an *a priori* sub-group analysis] **Symptoms** No between group differences in the whole population. No data for South Asian sub-group, but authors state that 'intervention effect was not significant for other subgroup analysis'	Illustrated as a consistent *no effect*.
	Process	Not assessed	-
	Behavioural, 2m, 1yr	[Note: these data are an *a priori* sub-group analysis] **Self-management behaviour** No between group differences in whole population. No data for South Asian sub-group, but authors state that 'intervention effect was not significant for other subgroup analysis'	Illustrated as a consistent *no effect*.
Griffiths et al. (2016) n=84 practices/375 Elders, Adults, adolescents, children, Primary & secondary care clinicians

FU: 3m, 1yr Overall risk of bias: Low | Clinical - Unscheduled care I: 171 days/C: 189 days I: 72 days/ C: 339 days 1yr | **Unscheduled care** There was no between group difference in healthcare use -*Time to first unscheduled contact FU: HR=1.19 (0.92 to 1.53) p=0.185 - Proportion without unscheduled care FU: OR=0.72 (0.45 to 1.16) p=0.175 -Time to first unscheduled primary care contact FU: HR=1.20, 0.92 to 1.57 p=0.177 -Time to first routine review in primary care FU: HR=2.22, 1.67 to 2.95 p=<0.001 **Corticosteroid prescriptions** There was no between group difference in steroid prescriptions -Steroids FU: I: 1.16 vs 0.98 Adjusted Incidence Rate Ratio: 1.14 (0.87 to 1.49) | Illustrated as a consistent *no effect*. |
| | Clinical - Asthma control, 3m, 1yr | **Asthma control** There was no between group difference in symptom score -Symptom score FU 1yr: 9.9 (SD 5.0) vs C: 10.1 (SD 4.2) AHR: -0.04 (-1.16 to 1.09) p=0.949 | Illustrated as a consistent *no effect*. |
| | Process, 3m, 1yr | **Self-efficacy** was improved at 3m but not at 1yr follow-up; At 3 months: I: 6.7 (2.1) vs C: 6.3 (1.9) AHR: 0.44 (0.05 to 0.82) p=0.027 At 12 months: I: 6.4 (1.8) vs C: 6.3 (1.6) AHR: 0.25 (-0.13 to 0.63) p=0.188 | Illustrated as a consistent no effect. Another bar plotted to illustrate the 3m finding – as a |

Table 5 continued

			consistent significant *positive* effect.
	Behavioural	Not assessed	-
Moudgil et al. (2000) n=689 (White Europeans 345, South Asians 344); Adults, Adolescents, Children	Clinical - Unscheduled care, not stated SA: n=294 (I: 151 C: 143)	[Note: these data are an *a priori* sub-group analysis] **Number of asthma events/episodes** for South Asians: no between group differences -*Proportion with an admission. I: 5.3% vs C: 6.3% OR 0.83 (0.28 to 2.44) p=0.9081 -Proportion with an A&E attendance. I: 1.4% vs C: 4.0% OR 2.92 (0.52 to 21.2) p=0.3184 -Proportion with out-of-hours primary care. I: 2.8% vs C: 2.6% FU: OR 0.95 (0.19 to 4.60) p=1 -Proportion with a GP consultation. I: 55 9% vs 50.3% OR 0.80 (0.49 to 1.30) p=0.3971 -Proportion with a steroid course. I: 20.3% vs 19.9% OR 0.97 (0.53 to 1.79) p=1	Illustrated as a consistent *no effect*.
	Clinical - Asthma control, 1yr SA n=280	[Note: these data are an *a priori* sub-group analysis] **Quality of life** in South Asians was significantly better in the intervention group Change in AQLQ FU: I: 0.11 vs -0.15. Between group mean difference 0.26 (0.17 - 0.36) p=<0.001	Illustrated as a consistent significant *positive effect*.
FU: 4m, 8m, 1yr Overall risk of bias: High	Process	Not assessed	-
	Behavioural	Not assessed	-
Poureslami et al. (2012) n=92 (47 Chinese, 45 Punjabi); Adults	Process, 3m, 6m Punjabi n=43	[Note: these data are an *a priori* sub-group analysis] ***Knowledge** No comparison data for intervention and control groups	Insufficient data.
FU: 3m, 6m; one telephone survey interview Overall risk of bias: Unclear	Behavioural, 3m, 6m Punjabi n=43	[Note: these data are an a priori sub-group analysis] **Understanding physician instructions; on *Medication & Proper inhaler use skills** No comparison data for intervention and control groups	Insufficient data.
Blixen et al. (2001) n=28, Adults	Clinical - Unscheduled care, 3m, 6m	**Healthcare use** No data provided, though stated as no significant between group differences.	Illustrated as a consistent *no effect*.

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Table 5 continued			
FU: 3m, 6m Overall risk of bias: High	Clinical - Asthma control, 3m, 6m	**Quality of life** There was no significant between group differences. Overall AQOL score. FU 6m: I: 4.59 (SD 1.48) vs C: 4.43 (SD 1.52) p=0.12	Illustrated as a consistent **no effect**.
	Process	Not assessed	-
	Behavioural, 3m, 6m	**Self-management behaviours** No data, though stated as no-significant between group differences.	Illustrated as a consistent **no effect**.
Fisher et al. (2004) n=249 Adolescents, children, parents	Clinical - Unscheduled care, Quarterly for 3yrs	*Acute care** No data given (results illustrated graphically), though authors stated no significant between group differences in acute care (hospitalisations & ED attendances p=0.35)	Illustrated as a consistent **no effect**.
FU: 3, 6, 9, 12, 16, 20, 24, 28, 32, 36m Overall risk of bias: Unclear	Clinical - Asthma control	Not assessed	-
	Process	Not assessed	-
	Behavioural, Every quarterly until 3yrs	*Asthma management** No significant between group differences in the non-validated assessment of parent's reported attitude about asthma and asthma management. -Attitudes about asthma FU: I: 2.34 vs C: 2.24 (p=0.35) -Appropriate thresholds for seeking help Baseline: I: 30% vs C: 47%; FU: I: 51% vs C: 53% p=0.77	Illustrated as a consistent **no effect**.
Fisher et al. (2009) n=191/Parents, Coaches	Clinical - Unscheduled care, 1yr, 2yr	*Hospitalisation** Compared to controls, the intervention group had fewer hospitalisations; -Hospitalised at least once FU I: n=35/96 (36.5%), 55 vs C: 55/93 (59.1%); 95% CI (0.11-0.34) p.002	Illustrated as a consistent significant **positive** effect.
FU: 6, 12, 18, 24m Overall risk of bias: Low	Clinical - Asthma control	Not assessed	-
	Process	Not assessed	-
	Behavioural	Not assessed	-
Ford et al. (1997) n=241 (African American=163,	Clinical - Unscheduled care, 4m, 8m, 1yr	*ED visits** No impact [Note: these data are an *a priori* sub-group analysis] ED visits/year I: Baseline: 5.0 (SD 3.6) vs FU 2.7 (SD 3.3); C: Baseline: 6.7 (SD 8.4) vs FU: 4.8 (SD 6.8) No between group comparisons reported	Illustrated as a consistent **no effect**.

Table 5 continued			
White Caucasian=78)	Clinical - Asthma control, 4m, 8m, 1yr	**Limited days of activity** No impact [Note: these data are an *a priori* sub-group analysis] Days/person**:** I: Baseline: 20.6 (SD 25.4); FU: 18.7 (SD 36.8) C: Baseline: 27.8 (SD 33.4); FU: 27.9 (SD 55.7), no between group differences reported	Illustrated as a consistent *no effect*.
FU: 4m, 8m, 1yr Overall risk of bias: High	Process, 1yr	***Knowledge & Beliefs** No effect [Note: these data are an *a priori* sub-group analysis] Mean scores I: Baseline: 14.1 (SD 2.9); FU: 14.6 (SD 3.2) C: Baseline: 14.3 (SD 2.3); FU: 14.7 (SD 2.3) No between group differences reported	Illustrated as a consistently *no effect*.
	Behavioural	Not assessed	-
Keslo et al. (1995) n=52 Adults

FU: 1yr, telephone every 2wks to every 6m | Clinical - Unscheduled care, 1yr | **Unscheduled care** Compared to controls, the intervention reduced **ED visits** but not hospitalisations -*Change in ED visits Baseline: I: 4.4 (SD 2.7) vs C: 3.4 (SD 2.6); FU: I: 2.6 (SD 2.6) vs C: 3.5 (SD 2.7) Between group difference p=<.01 -Change in hospitalisations Baseline: I: 1.3 (SD 1.3) vs C: 1.0 (SD 1.2); FU: I: 0.5 (SD 0.8) vs C: 0.5 (SD 0.9). Between group difference p=0.37 | Illustrated as a significant *positive effect but* **hatched to show inconsistency.** |
Overall risk of bias: Unclear	Clinical - Asthma control	Not assessed	-
	Process, After intervention	No data reported for **Knowledge** No data reported for **Medicine treatments**	Insufficient data.
	Behavioural	Not assessed	-
Keslo et al. (1996) n=39, Adults	Clinical - Unscheduled care, 1yr, 2yr	**Unscheduled care** Intervention group had a greater reduction in hospitalisations and ED visits -*Change in ED visits. Median (IQR) visits 2 years, I: 0 (0, 0) vs C: 2 (1.5, 2) p=<0.05 -*Change in hospitalisations. Median (IQR) hospitalisations, I: 0 (0, 0) vs C: 0.5 (0, 1) p=<0.05	Illustrated as a consistent significant *positive* effect.
FU: Every month then every 2-3m Overall risk of bias: High	Clinical - Asthma control 6m, 1yr, 18, 2yr	No control group data reported for **Quality of life, Asthma bother or Peak flow**	Insufficient data.
	Process, Before & after intervention	No control group data reported for **Knowledge** No control group data reported for **Medicine treatments**	Insufficient data.
	Behavioural	Not assessed	-

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Table 5 continued			
Velsor-Friedrich et al. (2004) n=102, children	Clinical - Unscheduled care, 2wks, 5m, 1yr	**Unscheduled care** The intervention group had significantly more unscheduled visits at 5m and 1yr -Medical visits at 5m. Mean (SE) I: 0.12 (0.05) vs C: 0.02 (0.04) -Medical visits at 1yr. Mean (SE) I: 0.07 (0.03) vs C: 0.00 (SD 0.02) p=0.01	Illustrated as a consistent significant *negative* effect.
FU: 2wks, 5m, 1yr Overall risk of bias: Unclear	Clinical - Asthma control, 2wks, 5m, 1yr	**Symptom days** Greater reduction in days with symptoms in intervention compared to control -Symptom days at 5m. Mean (SE). I: 2.15 (SE 0.30) vs C: 1.42 (SE 0.21) -Symptom days at 1yr. Mean (SE). I: 1.26 (SE 0.33) vs C: 1.49 (SE 0.23) p=0.047 **PEFR** Intervention group had greater increase in PEFR at both FU time points - % increase in PEFR at 5m. I: 2.9% (SE 2.0%) vs C: 2.9% (SE 1.0%) - % increase in PEFR at 1yr. I: 7.5% (SE 2.0%) vs C: 2.9% (SE 1.2%) p=0.046 **School absences** No between group difference in days absent from school -Days absent at 1yr. I: 9.03 vs C: 14.4 days	Illustrated as a consistent *positive effect but hatched to show inconsistency.*
	Process, 2wks, 5m, 1yr	**Knowledge, self-efficacy and self-esteem/motivation** No significant between group differences -Asthma knowledge test at 5m: I: 14.05 (SE 0.55) vs C: 13.35 (SE 0.38) -Asthma belief survey at 5m. I: 4.23 (SE 0.10) vs C: 4.15 (SE 0.08) -Self-perception inventory at 5m. I: 2.80 (SE 0.08) vs C: 2.85 (SE 0.05)	Illustrated as a consistent *no effect*.
	Behavioural, 2wks, 5ms	**Self-practice/Asthma self-care** No significant between group differences -Denyes self-care agency instrument at 5m: I: 72.03 (SE 2.46) vs C: 70.57 (SE 1.68) -Asthma self-care instrument at 5m I: 68.87 (SE 2.89) vs C:70.41 (SE 2.00)	Illustrated as a consistent *no effect*.
Velsor-Friedrich et al. (2005) n=52, children	Clinical - Unscheduled care, 2wks, 5m, 1yr	**Urgent medical visits (and medications)** No significant between group differences at any time point -Urgent doctor visits at 12m. I: n=4 (14%) vs C: n=5 (20%) -No data; some data on medicine use was provided	Illustrated as a consistent *no effect*.
FU: 2wks, 5m, 1yr, 2yr Overall risk of bias: Unclear	Clinical - Asthma control, 2wks, 5m, 1yr, 2yr	**Symptoms, PEFR and School absences** No significant between group differences at any time point -Proportion with > one day with symptoms/2wks at 1yr. I: 14 (50%) vs C: 13 (54%) -% increase in PEFR from baseline at 1yr. I: 26.21% (SD 0.22) vs C: 27.80% (SD 0.31) -Average days absent from school. I: 9.03 vs C: 14.4	Illustrated as a consistent *no effect*.

Table 5 continued

	Process, 2wk, 5m, 12m	**Knowledge & Self-efficacy** Intervention group had higher scores at all time-points, but neither group improved over time -Asthma knowledge test at 1yr. Adjusted mean I: 14.28 (SE 0.80) vs C: 11.88 (SE 0.87) p=0.03 -Asthma belief scale at 1yr. Adjusted mean I: 4.09 (SE 0.14) vs C: 3.82 (SE 0.15) p=0.01 **Self-esteem** No significance between group differences at any time point -Self-perception inventory at 1yr. Adjusted mean I: 2.71 (SE 0.08) vs C: 2.78 (SE 0.10)	Illustrated as a consistent *positive effect but hatched to show inconsistency*.
	Behavioural, 2wks, 5m, 1yr	**Asthma self-care practice/General self-care** Intervention group had higher scores at all time-points, but neither group improved over time -Denyes self-care agency instrument. I: 75.55 (SE 2.60) vs C: 67.41 (SE 2.82) p=0.01 -General self-care. adjusted mean I: 72.99 (SE 3.26) vs C: 63.75 (SE 3.53) p=0.2	Illustrated as a consistent *positive* effect.
Velsor-Friedrich et al. (2012) n=137, Adolescents FU: 2m, 6m, 1yr Overall risk of bias: High	Clinical - Unscheduled care, 6m, 12m	**Hospital visits** No significance between group differences p>0 .05 (no other data provided)	Illustrated as a consistent *no effect*.
	Clinical - Asthma control, 6m, 1yr	**Symptoms** reduced in both groups; no significant between group differences **PEFR** No significance between group differences **School absences** reduced in both groups; no significant between group differences	Symptom takes priority. Illustrated as a consistent *no effect*.
	Process, 6m, 1yr	**Knowledge, self-efficacy** improved in both groups; no significant between group differences **Coping frequency/efficacy,** no significance between group differences	Illustrated as a consistent *no effect*.
	Behavioural, 6m, 1yr	**Self-care practice,** no significance between group differences	Illustrated as a consistent *no effect*.

Abbreviations in the table - FU: Follow-up, wk: week/m: month/yr: year, RCT: Randomised control trial, CCT: Clinical control trial, ED: Emergency department, I: Intervention, C: Control, CI: Confidence interval, AQLQ: Quality of life questionnaire, AQ20: The airways questionnaire 20, ACT: Asthma control test, F: F Statistics, AHR: Adjusted hazard ratio, HR: Hazard ratio, OR: Odds ratio, PEFR: Peak expiratory flow rate, SD: Standard deviation, SE: Standard error, EES: Estimated effect size, DF: Degree of freedom

5.5.3 Identifying barriers and facilitators of implementing asthma self-management behaviour

Figure 5. Identified barriers and facilitators of self-management in interventions across different cultural groups

'MAJORITY' SOUTH ASIANS

√ Practicing self-management (Ghosh 1997)

√ PAAPs (Agrawal, 2005)

√ Written reinforcement (Behera, 2006)

SOUTH ASIANS

√ Education

(cultural/ linguistic)
(Behera 2006; Moudgil
2000; Poureslami 2012)

GENERIC

X Lack of knowledge

(Behera, 2005; Moudgil 2000;
Poureslami 2012; Ford 1997)

√ Education (Behera 2005;
Ghosh 1998; Kelso 1995; 1996;
Poureslami 2012; Velsor-Friedrich
2012)

√ Self-management

support (Behera 2006; Ghosh
1998; Kelso 1996; Poureslami
2012: Velsor-Friedrich 2005)

'MINORITY' SOUTH ASIANS

'MINORITY' AFRICAN AMERICANS

X/√ Culture specific

stressors (Velsor-Friedrish 2012;
Blixen 2001; Fisher 2009**)**

√ Continuous social support

(Fisher 2009)

MINORITY STATUS (Moudgil
2000; Poureslami 2012; Velsor-Friedrich
2012)

X/√ Individual learning

X Barriers √ Facilitators

A range of barriers and facilitators to asthma self-management were identified and differentiated according to ethnicity and sociocultural context (see Figure 5).

Generic barriers and facilitators (across all ethnic groups and social contexts)

Identified generic barriers and facilitators (across all ethnic groups and social contexts) were:

1) The lack of knowledge and understanding of asthma and its management (e.g. difficulty understanding the chronic nature of asthma, self-management, information on preventative medicine/treatment and side-effects), was found to be a generic barrier (Behera et al., 2006; Ford et al., 1997; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012). This barrier was further highlighted in most trials by comparing findings for South Asians with another ethnic group, where the latter performed better on outcomes (clinical, QOL and knowledge), even though knowledge was provided in various South Asian languages (Ford et al., 1997; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012). For instance, Behera et al. (2006) (at high risk of bias) reported that mean knowledge scores improved significantly in 'majority' South Asians in India, but knowledge of treatment only improved after an initial decline and this improvement was sustained until one-year follow-up, suggesting that education on this aspect of asthma knowledge (asthma medication) may be more challenging for Indians to comprehend in contrast to other forms of asthma information. Intervention components which may have enhanced, or reinforced knowledge included having a written self-care booklet to refer to and regular consultations with clinicians to rehearse learnt or practiced self-management behaviours.

2) Providing education (some of which included educational training) improved various asthma outcomes (Behera et al., 2006; Ghosh et al., 1998; Kelso et al., 1995, 1996; Poureslami et al., 2012; Velsor-Friedrich et al., 2012). For instance:

   - Educational training sessions on how to respond to asthma information significantly improved hospitalisation, PEFR, productive days lost (Ghosh et al., 1998).
   - A self-care booklet was reported to have significantly increase asthma knowledge (Behera et al., 2006).
   - An educational video (culturally and linguistically relevant) significantly improved knowledge and inhaler use (Poureslami et al., 2012).
   - Education in emergency departments significantly reduced the number of visits (41% reduction) (Kelso et al., 1995), and significantly reduced hospitalisation in another study (Kelso et al., 1996).

- A coping skills training sessions reduced asthma symptoms through using relevant interactive technology techniques for African adolescents e.g. video gaming (Velsor-Friedrich et al., 2012).

3) Self-management support from HCPs (with continuity of care) was found to be a general facilitator (Behera et al., 2006; Ghosh et al., 1998; Kelso et al., 1996; Poureslami et al., 2012; Velsor-Friedrich et al., 2005). For instance:

- Inhaler technique training in consultations (on an ongoing basis for a month) significantly reduced hospitalisations (Ghosh et al., 1998).

- Repeated consultations on proper inhaler use significantly improved symptoms and knowledge (Behera et al., 2006).

- Education from clinicians significantly improved knowledge, proper inhaler technique and adherence to HCP's instructions (Poureslami et al., 2012).

- Authors speculated that clinicians trained on NIH guidelines (promoting communication skills and partnership) developed patient satisfaction (Kelso et al., 1996).

- Ongoing follow-up by nurses (reinforcing asthma knowledge and PAAPs) significantly improved asthma knowledge, self-efficacy and general/asthma self-care practices in a follow-up study, rather than in the first phase of the intervention where non-significant findings were found for the same outcomes (Velsor-Friedrich et al., 2004).

Minority-status related barriers and facilitators (amongst South Asians and African Americans who are a part of a 'minority' population)

Identified barriers and facilitators related to minority-status were:

1) Individual learning styles in education was a barrier 'minority' South Asians (Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012), e.g. age/cognitive decline (Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012), gender (Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012), and level of education (Poureslami et al., 2012), even though language adjustments were made (Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012). For instance, younger aged Punjabi Indians (with higher education than older and less educated participants) significantly higher improved knowledge and Punjabi men had significantly higher knowledge scores compared to females (Poureslami et al., 2012).

2) Individual learning style also was identified as a facilitator to self-management for 'minority' African Americans (Velsor-Friedrich et al., 2012), e.g. the use of culturally and age specific self-management strategies (e.g. peer leaders, listening to music, watching TV, playing video games and sports), were described as helping to engage adolescents in training compared to generic breathing and relaxation techniques, though the study outcomes were mostly non-significant. Authors explained that the six-week education/training sessions may not have been enough to deal with the unexpected levels of stress in these adolescents e.g. neighbourhood violence (Velsor-Friedrich et al., 2012).

Ethnic-specific South Asian barriers and facilitators (those occurring across South Asians who are part of the indigenous and 'minority' population)

A facilitator that specifically occurred in 'majority' and 'minority' South Asians was providing culturally and linguistically appropriate education materials which improved health outcomes (Behera et al., 2006; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012), e.g. education delivered in South Asian languages significantly improved QOL (Moudgil, Marshall, & Honeybourne, 2000); improved knowledge for a written self-care booklet due to the participant's ability to recollect and refer back to the information provided (Behera et al., 2006); and videos that targeted culturally relevant information (e.g. the use of cultural gestures), allowed information to be applicable (Poureslami et al., 2012). It should be noted that African Americans do not have language barriers as their primary language is English.

Barriers and facilitators specific to ethnicity and social context

Identified barriers and facilitators specific to ethnic and sociocultural contexts were:
1) Generic self-management strategies were identified as a facilitator for 'majority' South Asian trials (Agrawal et al., 2005; Behera et al., 2006; Ghosh et al., 1998), e.g. practising preventative behaviour such as avoiding asthma triggers significantly reduced acute asthma hospitalisations (Ghosh et al., 1998); PAAP use had significantly fewer acute asthma episodes, school absenteeism and nocturnal awakenings (Agrawal et al., 2005); and written self-management reinforcements in the form of a booklet improved knowledge, symptoms and inhaler use (Behera et al., 2006).

2) 'Minority' African American specific barriers and facilitators related to:

- One trial showed that adolescents were more stressed about environmental stressors (e.g. neighbourhood violence affected sense of security and well-being), that interfered with focusing on generic self-management such as relaxation and breathing exercises e.g. refusal to close their eyes to practice self-management due to anticipated stress of violence. The intervention length was six weeks and the authors mentioned this was not enough to deal with high stressors in the sample, which may explain non-significant findings on asthma outcomes e.g. unscheduled hospital visits, symptoms, PEFR, school absences, QOL, knowledge, self-efficacy, coping frequency/efficacy and self-care practice (Velsor-Friedrich et al., 2012).

- Three African American trials incorporated discussions of managing common stressors in daily African American lives as a facilitator that allowed individuals to focus on asthma (Blixen et al., 2001; Fisher et al., 2009; Velsor-Friedrich et al., 2012). For instance, discussions and images of African American celebrity role models self-managing relevant stressors (and skills for daily living with asthma) were presented in a discharge workbook e.g. employment difficulties, replacing jargon medical terms with lay language, techniques in communicating with HCPs such as using an audio recorder during consultations and providing free telephone numbers for asthma organisations and charities. The impact of this workbook was not measured or evaluated (Blixen et al., 2001).

- Closely related, another African-American trial identified social support as a facilitator to encouraging discussions on daily stressors and developing trust with professionals. This helped reach and sustain engagement with (98.5%) (Fisher et al., 2009).

5.6 Discussion for analysis one

5.6.1 Main findings

16 RCTs (17 papers) were identified which tested asthma self-management interventions for South Asian or African American communities (most at unclear or high risk of bias). The trials used diverse strategies, where education was central to all interventions, but content, model of delivery and additional strategies varied. Other strategies used in parallel to education included providing asthma therapy (and resources/treatment), support from HCPs, ongoing

clinical support for HCPs and social support networks and mediation counselling. Most interventions were delivered by HCPs (14/17 trials), where five trials were delivered in South Asian languages (Ghosh et al., 1998; Griffiths et al., 2004, 2016; Poureslami et al., 2012; Shanmugam et al., 2012), and two trials consisted of African-Americans delivering the interventions (Fisher et al., 2004, 2009). Only three South Asian trials defined ethnicity according to self-identification or language spoken (Griffiths et al., 2004, 2016; Poureslami et al., 2012). Intervention fidelity was assessed in two trials (Griffiths et al., 2016; Velsor-Friedrich et al., 2012).

The main findings which answer the objectives were:

- *Describe features of culturally relevant asthma self-management interventions:* only two interventions were culturally targeted (Behera et al., 2006; Poureslami et al., 2012), in contrast to 15 culturally modified interventions (there were no culturally tailored interventions) (Agrawal et al., 2005; Blixen et al., 2001; Fisher et al., 2004, 2009; Ford et al., 1997; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Shanmugam et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005).

- *Synthesise the evidence for the effectiveness of asthma self-management interventions:* trials based in 'majority' South Asian countries (Agrawal et al., 2005; Behera et al., 2006; Ghosh et al., 1998; Shanmugam et al., 2012), were more effective than those delivered to 'minority' populations (for both South Asians and African Americans) (Blixen et al., 2001; Fisher et al., 2004, 2009; Ford et al., 1997; Griffiths et al., 2004, 2016; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). However, none of the 'majority' South Asian trials were at low risk of bias and they all targeted populations based in tertiary hospitals (in whom it may have been easier to demonstrate health benefits) (Fisher et al., 2009; Griffiths et al., 2004, 2016). It was unclear whether culture or the minority-status of an ethnic group influenced the variance in self-management outcomes.

- *Identify barriers and facilitators of implementing asthma self-management behaviour:* Education (with on-going professional support) was identified as a generic facilitator to asthma self-management in all groups (Behera et al., 2006; Ghosh et al., 1998; Kelso et al., 1995, 1996; Poureslami et al., 2012; Velsor-Friedrich et al., 2012). Other facilitators were aiming education to individual learning styles in 'minority' populations (Velsor-

Friedrich et al., 2012), culturally and linguistically appropriate education for South Asians (for indigenous and 'minority' populations) (Behera et al., 2006; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012), generic self-management strategies for 'majority' South Asians (Agrawal et al., 2005; Behera et al., 2006; Ghosh et al., 1998), and strategies for dealing with stress and social support in African American communities (Blixen et al., 2001; Fisher et al., 2009; Velsor-Friedrich et al., 2012). Barriers to asthma self-management in all groups were a lack of knowledge (Behera et al., 2006; Ford et al., 1997; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012), little consideration of individual learning styles for 'minority' populations (Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012), and culture-specific stressors for African Americans (Velsor-Friedrich et al., 2012).

5.6.2 Interpretation of findings in relation to previously published literature

A previous systematic review (Bailey et al., 2009), found that a culturally tailored[25] intervention by La Roche, Koinis-Mitchell & Gualdron (2006) (in line with definitions with the current review) was more effective than generic programmes in improving asthma outcomes (e.g. QOL in adults and knowledge and exacerbations in children), and revealed that most interventions were culturally modified[26] (Bailey et al., 2009; Falicov, 2009). We found only two culturally targeted[27] interventions (Behera et al., 2006; Poureslami et al., 2012), suggesting that evidence is still limited and progress in this area of research has not advanced nor recommendations taken into consideration. This may be due to the expensive and lengthy nature of developing targeted or tailored interventions compared to the ease of adapting or re-testing modified interventions (Bailey et al., 2009; McManus & Savage, 2010). In trials, which studied a range of cultures, ethnic groups were considered as homogenous e.g. they did not consider variation amongst smaller subcultural groups of South Asians or African Americans, or the influence of acculturation[28] in minority communities, potentially important for developing interventions (Blixen et al., 2001; Fisher et al., 2004, 2009; Ford et

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[25] Culturally tailored interventions are bottom-up interventions that consider cultural dimensions unique to individuals within a group (Kreuter et al., 2003)

[26] Culturally modified interventions are developed for a majority population but modified to apply to other ethnic groups using various strategies (Bailey et al., 2009; Falicov, 2009)

[27] Culturally targeted interventions are bottom-up interventions that account for the shared characteristics of a cultural group during development (Kreuter et al., 2003)

[28] Acculturation is the cultural changes influenced by encountering another mainstream culture (Berry, 1997; 2005; Sam & Berry, 2010)

al., 1997; Griffiths et al., 2004, 2016; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005).

Both the culturally targeted trials included some modified characteristics e.g. language adaptation for PAAPs, so the distinction between different culturally relevant interventions is not absolute. This is supported by a systematic review (Liu et al., 2012), which found interventions labelled as targeted or tailored also incorporated modified features e.g. community/participatory approach to smoking cessation. It may be that modification of certain proven asthma self-management strategies (e.g. PAAPs), together with bottom-up culturally relevant components may be an optimal approach. Moreover, there are debates over whether the sole investment of interventions in ethnic minorities can be justifiable on the grounds of equity of distributed resources on high risk individuals, particularly since evidence may be scarce on whether such interventions reduce inequalities and are cost-effective (even though there is a small, strong and growing evidence in the field) (Hallam, 2008; Lakhanpaul et al., 2014b).

Targeted trials focused more on customising the development of the interventions to a cultural group rather than just adapting the content (Behera et al., 2006; Poureslami et al., 2012), e.g. collaboratively developing interventions with target groups helped self-management strategies to be linguistically and culturally relevant (Behera et al., 2006; Lakhanpaul et al., 2014a; Moudgil & Honeybourne, 1998; Poureslami et al., 2012). This can be further understood as aiming at deep structures (e.g. cultural beliefs, norms, lifestyles, environment and social contexts), which help receptivity of information and behaviour change. The Person-based approach to intervention development suggests comprehensive user perspective and context based on qualitative studies at every stage of intervention development can be central to customisation (Yardley et al., 2015). In contrast, modifying surface structures to observable traits (e.g. ethnicity and food), are likely to influence information processing but not behaviour change (a common characteristic of culturally modified interventions) (Resnicow et al., 1999). For instance, two 'minority' South Asian trials modified intervention content according to language with mostly ineffective outcomes (Griffiths et al., 2004, 2016), suggesting merely focussing on language modifications may be not be enough (SIGN, 2016). However, more rigorous trials are needed, as both targeted interventions had either high or unclear risk of bias (Behera et al., 2006; Poureslami et al.,

2012). In addition, the culturally modified interventions in 'majority' countries demonstrated effectiveness, which arguably may be explained by poor risk of bias in trials (Agrawal et al., 2005; Ghosh et al., 1998; Shanmugam et al., 2012).

Similarly, some 'majority' South Asian interventions were modified from generic programmes rather than developed for their own community (Agrawal et al., 2005; Ghosh et al., 1998; Shanmugam et al., 2012), e.g. Ghosh et al. (1998), a trial from India, adapted self-management strategies from a intervention from Colorado, USA (Creer et al., 1988, 1989). Trials from diverse sociocultural contexts and different cultural groups demonstrate the potential complications of extrapolating findings from one context and applying it to another (Bhopal & Sheikh, 2009; Lakhanpaul et al., 2014b; Liu et al., 2016). A possible explanation for 'majority' South Asian trials incorporating culturally modified strategies may be that they were following recommendations found in international clinical practice guidelines for respiratory diseases (Agrawal et al., 2005; Behera et al., 2006; Ghosh et al., 1998), e.g. GINA (GINA, 2016), which promote a generic model of self-management evidencing interventions from high income populations and intending it to be adapted to LMICs (Asbroek et al., 2005; GINA, 2016). For LMICs, this may be challenging due to the lack of resources, training and manpower, as well as public health priorities and models of care focusing on communicable rather than long-term conditions (Asbroek et al., 2005; WHO, 2007; Yorgancioglu et al., 2016). GINA guidelines acknowledge these difficulties, but do not offer customised self-management guidance and may need regular updating as culture is dynamic and change over time (Klesges et al., 2005); rather the focus is on offering cost-effective options for diagnosis and treatment specific to LMICs (GINA, 2016; WHO, 2007).

Moreover, the reported barrier; individual learning styles suggest participant demographics and sociocultural characteristics need to be considered to make information relevant, alongside language (Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012; Velsor-Friedrich et al., 2012). This is supported by previous studies e.g. memory impairments in older African Americans was found to be a barrier in learning about asthma medication (Baptist et al., 2010). A review suggested individual learning styles are also relevant for clinicians from South Asia e.g. younger clinicians performed better on knowledge scores compared to older clinicians (Lakhanpaul et al., 2014a). In addition, the facilitation offered by providing culturally and linguistically appropriate education for South Asians (Behera et al., 2006; Poureslami et al., 2012) has been supported by a systematic review on asthma

health literacy (Poureslami et al., 2007), and other studies (Moudgil & Honeybourne, 1998; Moudgil, Marshall, & Honeybourne, 2000). Exemplifying how the lack of culturally and linguistically appropriate education can be a barrier to understanding information in consultations and education if it is not widely accessible/available (Hussein & Partridge, 2002; Poureslami et al., 2007).

Conceptualising culture with its interaction with context offers new avenues of comprehending the role of culture in health. Apart from the 'majority' South Asian trials being based in tertiary care settings (with greater potential for improvement), and where asthma outcomes were better compared to 'minority' communities (Agrawal et al., 2005; Behera et al., 2006; Ghosh et al., 1998; Shanmugam et al., 2012), poor reporting with limited descriptions of SES (Agrawal et al., 2005; Behera et al., 2006; Blixen et al., 2001; Fisher et al., 2004; Ghosh et al., 1998; Kelso et al., 1995, 1996; Poureslami et al., 2012; Shanmugam et al., 2012; Velsor-Friedrich et al., 2012), and diversity of settings in which trials were conducted (Fisher et al., 2004, 2009; Ford et al., 1997; Griffiths et al., 2004, 2016; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005), meant the review was restricted in drawing relationships to most contextual data. This could be an important point since variations in class in the same culture has been suggested to determine health outcomes e.g. restrictions in accessing services (Nazroo, 2006; Smith, Kelly, & Nazroo, 2009). In LMICs such as India, where self-management initiatives and programs are limited, tertiary care may currently be the only practical setting for delivering asthma self-management interventions, which may be due to the lack of community-based expertise, primary/secondary care led research, as well as social and financial barriers which result in under-diagnosis, under-treatment and treatment availability. In the absence of adequately resourced primary care, it can be common for individuals in these populations (particularly for children) to first access healthcare and benefit from treatment during exacerbations, rather than receiving preventative care (WHO, 2007; Yorgancioglu et al., 2016).

5.7 Analysis two: theory use and theoretical intervention components

5.7.1 Establishing the extent to which theory has been used in interventions

Theory use in trials assessed by TCS is summarised in Table 6.

Table 6. Interventions based on theory

Trial (trial effectiveness)	Fisher 2009 (Positive)	Ghosh 1998 (Positive)	Griffiths 2004 (No effect)	Griffiths 2016 (No effect)	Poureslami 2012 (Positive)	Velsor-Friedrich 2004/2005 (Unclear)	Velsor-Friedrich 2012 (Unclear)
1. Theory/model of behaviour mentioned	Transtheoretical model	Social learning theory	Liaison model of specialist nursing	Self-regulation theory; Social cognitive theory	Adult learning theory	Orem's self-care deficit theory of nursing	Social cognitive theory; Orem's self-care deficit theory of nursing
2. Targeted construct mentioned as predictor of behaviour	√	√	✗	✗	√	√	√
3. Intervention based on single theory	√	√	√	✗	√	√	✗
4. Theory/predictors used to select recipients for the intervention	✗	✗	✗	✗	✗	✗	✗
5. Theory/predictors used to select/develop intervention techniques	√	√	√	√	√	√	√
6. Theory/predictors used to tailor intervention techniques to recipients	✗	✗	✗	✗	✗	✗	✗
7. All intervention techniques are explicitly linked to at least one theory-relevant construct/predictor	√	√	√	√	✗	√	✗
8. At least one but not all, of the intervention techniques are explicitly linked to at least one theory-relevant construct/predictor	√	√	√	√	√	√	√
9. Group of techniques are linked to a group of constructs/predictors	√	√	√	√	√	√	√
10. All theory-relevant constructs/predictors are explicitly linked to at least one intervention technique	√	√	√	✗	√	√	√
11. At least one but not all, of the theory relevant constructs/predictors are explicitly linked to at least one intervention technique	√	√	√	√	√	√	√

Note: Additional papers that the intervention Griffiths at al. (2016) was based on was relevant for TCS and referred to (Clark et al., 1998; Lorig et al., 1999)

Identifying underpinning theory (items 1, 3)

Nine out of seventeen trials did not apply the use of theory to any degree (Agrawal et al., 2005; Behera et al., 2006; Blixen et al., 2001; Fisher et al., 2004; Ford et al., 1997; Kelso et al., 1996, 1995; Moudgil, Marshall, & Honeybourne, 2000; Shanmugam et al., 2012). Eight trials that mentioned theories/models were from the disciplines health psychology, nursing and/or education (Fisher et al., 2009; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Poureslami et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). Most (six out of eight) trials cited a single theory (Fisher et al., 2009; Ghosh et al., 1998; Griffiths et al., 2004; Poureslami et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005); where two trials mentioned the theoretical models e.g. the Liaison model of nursing and Transtheoretical model (Fisher et al., 2009; Griffiths et al., 2004). Two trials mentioned a combination of theories; the self-regulation theory, the social cognitive theory and/or Orem's self-care deficit theory of nursing (Griffiths et al., 2016; Velsor-Friedrich et al., 2012). However, the Orem's self-care deficit theory of nursing was used to illustrate ideas in these three interventions (Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005).

Use of theory/predictors to select recipients for the intervention (item 4)

None of the interventions used theory or predictors[29] to identify the population likely to benefit from the intervention based on a particular score/stage of a theoretical construct[30] or predictor.

Use of theory/predictors to tailor intervention techniques to recipients (item 6)

None of the interventions tailored or delivered techniques to the needs of the target participant (e.g. subgroups), varying on a psychological construct or predictor at baseline.

Use of theory/constructs/predictors informing the intervention (items 2, 5, 7-11)

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[29] Predictors are a construct that is targeted in interventions to predict/correlate with/causes behaviour change (Michie & Prestwich, 2010)
[30] Constructs are key concepts related to behaviour that interventions are based on (Michie & Prestwich, 2010)

The main purpose of theory was to inform the intervention such as identifying and describing relevant constructs/predictors of self-management behaviour (Agrawal et al., 2005; Behera et al., 2006; Blixen et al., 2001; Fisher et al., 2004, 2009; Ford et al., 1997; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012; Shanmugam et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). For instance:

- Six out of eight trials targeted theoretical constructs that predicted behaviour (item 2) (Fisher et al., 2009; Ghosh et al., 1998; Griffiths et al., 2016, 2004; Poureslami et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). For instance, one construct 'reciprocal determinism' (from the social learning theory) that involves personal factors (e.g. cognitive and physiological), and environmental factors (e.g. physical and social), was proposed to predict self-management behaviour in a training intervention (Ghosh et al., 1998).

- All eight trials used theory or predictors to select or develop intervention techniques (item 5) (Fisher et al., 2009; Ghosh et al., 1998; Griffiths et al., 2016, 2004; Poureslami et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005).

- Six out of eight trials explicitly linked all intervention techniques to one theory relevant construct or predictor (item 7) (Fisher et al., 2009; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005).

- All eight trials had one intervention technique explicitly linked to one theory-relevant construct/predictor (item 8), and had a group of techniques linked to a group of constructs/predictors (item 9) (Fisher et al., 2009; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Poureslami et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005).

- Theoretical construct or predictor stated in a theory (item 5) was linked to an intervention technique in seven out of eight trials (item 10) (Fisher et al., 2009; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Poureslami et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005).

- All eight trials linked at least one construct/predictor to at least one intervention technique (item 11) (Fisher et al., 2009; Ghosh et al., 1998; Griffiths et al., 2016, 2004;

Poureslami et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005).

For instance, Ghosh et al. (1998) can be used to illustrate the example of when theory related construct/s or predictor/s were linked to an intervention technique. Training in this intervention was based on the social learning theory (Bandura & Walters, 1977), where the 'learning performance dichotomy' (the assumption that learning occurs due to education and performance), where learning implemented into a behaviour was linked to the intervention technique education (e.g. learning about consequences of asthma triggers such as breathlessness) under the supervision of a clinician that could improve individual understanding and recollection of information, and therefore leading to self-management behaviour e.g. avoiding asthma triggers or using medication after exposure. Self-management strategy that had beneficial impact is more likely to be repeated (Ghosh et al., 1998).

5.7.2 Identifying and describing theoretical intervention components

Table 7 shows the intervention components identified using TDFs (Cane et al., 2012).

Table 7. Identified TDF intervention components

Trial (Risk of bias/effectiveness)	Theoretical Domains Framework													
	Knowledge	Skills	Social/professional role & identity	Beliefs about capabilities	Optimism	Beliefs about consequences	Reinforcement	Intentions	Goals	Memory, attention & decision processes	Environmental context & resources	Social influences	Emotion	Behavioural regulation
Participants with asthma														
Agrawal 2005 (unclear/positive)	√	√							√	√	√	√		√
Behera 2006 (high/positive)	√	√							?	√	√		?	√
Ghosh 1998 (high/positive)	√	√		√					√	√	√	√		√
Shanmugam 2012 (unclear/positive)	√	?							?		√			√
Griffiths 2004 (low/no effect)	√	?					√		√	√	√			√
Griffith 2016 (low/no effect)	√	√		√					√	√	√	√		√
Moudgil 2000 (high/unclear)	√						√		√	√	√			√

Table 7 continued

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Poureslami 2012 (unclear/positive)	√			<u>√</u>		√			?		√	√	<u>√</u>	√
Blixen 2001 (high/no effect)	√	√				√					√	√	√	√
Fisher 2004 (unclear/no effect)	√			√					?	<u>√</u>		√	<u>√</u>	
Fisher 2009 (low/positive)	√	<u>√</u>	<u>√</u>	<u>√</u>		√	√	√	√	√	√			√
Ford 1997 (high/no effect)	√	√		√	√	√				<u>√</u>	√		√	
Keslo 1995 (unclear/positive)	√	√		√	√	√					√	√		√
Keslo 1996 (high/positive)	√	√				√					√	√	√	√
Velsor-Friedrich 2004 (unclear/unclear)	√	?	√	√		√					√	√		√
Velsor-Friedrich 2005 (unclear/unclear)	√	√	√			√		√			√			√
Velsor-Friedrich 2012 (high/no effect)	√	√		√		√	√		√	√	√	√	√	√
Providers														
Griffiths 2004 (low/no effect)	√	√	√			√				√	√			
Griffith 2016 (low/no effect)	√	√	√			<u>√</u>					√	√		
Moudgil 2000 (high//unclear)		?	√								√			
Poureslami 2012 (unclear/positive)			<u>√</u>								<u>√</u>			
Fisher 2004 (unclear/no effect)	√	√	√	√				√			√	√	<u>√</u>	
Fisher 2009 (low/positive)	√	√	√							<u>√</u>	√	<u>√</u>		

Underlined ticks = coded from articles/websites that included trials were based on (American Lung Association, 2002; Bailey et al., 1990; Bolton et al., 1991; Clark et al., 1998; Creer et al., 1989; Fisher et al., 1994; Kaur et al., 2002; Lorig et al., 1999; O'Brien et al., 2007; Poureslami et al., 2011).

Decisions made for categorising TDFs included;
1) The inclusion of parents was classified as 'social influences' ('social support')
2) Guidance on PAAPs were classed as 'behavioural regulation' ('self-monitoring'; 'action planning') and 'goals' ('implementation intentions'). Unless explicitly depicted the domain 'goals' ('goal/target setting') were not

categorised. The traffic light system on PAAPs and/or peak flow meter, were classed as a decision process or a decision-making tool ('memory, attention and decision processes') and 'behavioural regulation' ('self-monitoring')

3) 'Skills' were categorised if there was explicit behavioural practice.
4) 'Memory, attention and decision processes' was categorised where there was active cognitive prompts or cues (not just reference to this) e.g. ability to retain information.

Any categorisation of decisions that were unclear were marked with a question mark in the table e.g. education on skills and any insinuations that these 'skills' may have been practiced were categorised as unclear.

Summary of TDF intervention descriptions (participants with asthma; 16 trials - 17 papers)

All trials used the domain 'knowledge' (an awareness of the existence of asthma), and both the constructs 'scientific knowledge' and 'procedural knowledge' in various forms e.g. asthma education/training, medication and inhaler technique (Agrawal et al., 2005; Behera et al., 2006; Blixen et al., 2001; Fisher et al., 2004, 2009; Ford et al., 1997; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012; Shanmugam et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). 'Knowledge of task environment' e.g. avoiding asthma triggers was used in most trials (14 out of 17 trials) (Behera et al., 2006; Blixen et al., 2001; Fisher et al., 2004, 2009; Ford et al., 1997; Ghosh et al., 1998; Griffiths et al., 2016; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005).

All South Asian trials used the domains:

1) 'Environmental context and resources' (using a variety of 'resources/material resources')
-

- 'Barriers and facilitators' e.g. addressing language barriers was reported in all interventions for South Asian ethnic minorities (Griffiths et al., 2016, 2004; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012), and some 'majority' South Asian trials (Behera et al., 2006; Shanmugam et al., 2012).

- The construct 'person x environment interaction' was used in three interventions (Ghosh et al., 1998; Moudgil, Marshall, & Honeybourne, 2000; Shanmugam et al., 2012).

2) All South Asian trials also used 'behavioural regulation' in the form of peak flow monitoring and/or using PAAPs ('self-monitoring' and 'action planning') (Agrawal et al., 2005; Behera et al., 2006; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Moudgil & Honeybourne, 1998; Poureslami et al., 2012; Shanmugam et al., 2012). In 'majority' South Asian interventions, 'goals' were used in two trials (Behera et al., 2006; Shanmugam et al., 2012), but it was unclear in two other trials (Agrawal et al., 2005; Ghosh et al., 1998). Similarly, 'goals' incorporated in PAAPs were also used in three South Asian ethnic minority trials (Griffiths et al., 2004, 2016; Moudgil, Marshall, & Honeybourne, 2000), though this was unclear in another trial (Poureslami et al., 2012).

Most African American trials (eight interventions out of nine papers) used the domain 'reinforcement' and the construct 'reinforcement' (Blixen et al., 2001; Fisher et al., 2009; Ford et al., 1997; Kelso et al., 1995, 1996; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005), in addition to one trial that used 'incentives' alongside this (Blixen et al., 2001). For example, clinical and educational follow-ups and written/visual reinforcements (Blixen et al., 2001; Fisher et al., 2009; Ford et al., 1997; Kelso et al., 1995, 1996; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). In addition, most African American trials (eight interventions out of nine papers) used 'environmental context and resources', primarily using 'resources/material resources' (e.g. written materials or supplying inhalers and peak flow meters), alongside a mixture of constructs e.g. 'person x environment interaction', 'environmental stressors', 'barriers and facilitators' and 'organisational culture/climate' (Blixen et al., 2001; Fisher et al., 2009; Ford et al., 1997; Kelso et al., 1995, 1996; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005), and this was unclear in another trial (Velsor-Friedrich, Pigott, & Louloudes, 2004).

Seven out of nine trials used 'memory, attention and decision processes' (all of which used 'decision-making' (e.g. problem-solving) (Fisher et al., 2004, 2009; Ford et al., 1997; Kelso et al., 1995, 1996; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004), and alongside this some trials used 'memory' and 'attention' (Fisher et al., 2004; Ford et al., 1997). Seven out of nine trials used 'behavioural regulation' (all of which used 'self-monitoring' e.g. PEFR, with some using 'action planning' alongside this) (Blixen et al., 2001; Fisher et al., 2009; Kelso et al., 1995, 1996; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). 'Skills' were used in seven out of nine trials using various constructs such as 'skills development', 'practice', 'skills assessment', 'interpersonal skills' and 'skills' e.g. inhaler technique and peak flow monitoring (Blixen et al., 2001; Fisher et al., 2009; Kelso et al., 1995, 1996; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). The domain 'optimism' was not used in any trial.

Summary of TDF intervention descriptions (provider; six trials)

Interventions which targeted the role of providers all included 'social/professional role and identity' ('professional role'), and 'environmental context and resources' (with a mixture of constructs and 'organisational culture/climate'). For instance, 'professional role' was targeted through training given to providers (Fisher et al., 2004, 2009; Griffiths et al., 2004, 2016; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012). Additionally, most interventions included 'knowledge' (all with 'scientific knowledge' and a mixture of other constructs) (Fisher et al., 2004, 2009; Griffiths et al., 2004, 2016), and skills (with a mixture of constructs) (Fisher et al., 2004, 2009; Griffiths et al., 2004, 2016). The domains 'optimism', 'beliefs about consequences', 'goals' and 'behavioural regulation' were not used at all (Fisher et al., 2004, 2009; Griffiths et al., 2004, 2016,; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012).

5.7.3 Relationship between barriers and facilitators to intervention components

Barriers and facilitators to asthma self-management were identified in section 5.5.3 (see Figure 5). I identified that targeting the domains 'beliefs about capabilities' and 'beliefs about consequences', as underlying theoretical components that could address the identified barrier lack of knowledge (Behera et al., 2006; Ford et al., 1997; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012), and enhance identified facilitators; self-management support from healthcare professionals (Behera et al., 2006; Ghosh et al., 1998; Kelso et al., 1996; Poureslami et al., 2012; Velsor-Friedrich et al., 2005), and culturally/linguistically appropriate education (Behera et al., 2006; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012). For instance, an effective 'minority' South Asian trial (at an unclear risk of bias) suggested that targeting the construct 'beliefs about capabilities' and 'beliefs about consequences' around asthma and its management enhanced participant ability to actively practice self-management e.g. by collaboratively developing the intervention with the community they were able to identify beliefs about CAM or medication use during symptomatic periods that influenced outcomes such as inhaler technique (Poureslami et al., 2012). The authors of a 'minority' South Asian trial (at high risk of bias) speculated that beliefs need to be targeted even though language-appropriate 'knowledge' and 'material resources' were provided (Moudgil, Marshall, & Honeybourne, 2000). Trials which noted that the lack of knowledge was a barrier highlighted this by comparing findings of South Asians and African Americans with another ethnic group in whom, the intervention was more effective at improving clinical, QOL and knowledge outcomes (Behera et al., 2006;

Ford et al., 1997; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012), though in Poureslami et al.'s study, South Asians still performed less well than the parallel Chinese group, suggesting further domains other than just incorporating 'beliefs' to 'knowledge' may need to be explored (Poureslami et al., 2012).

5.7.4 Relationship between theory use and intervention components to asthma outcomes

Three out of eight theoretically-informed interventions (using the transtheoretical model, social learning theory and adult learning theory) improved asthma outcomes e.g. knowledge, hospitalisations, PEFR, productive days lost and understanding instructions on inhaler technique (Fisher et al., 2009; Ghosh et al., 1998; Poureslami et al., 2012), though in general it was unclear whether the use of theory had an impact on asthma outcomes (see Table 6) (Griffiths et al., 2004, 2016; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). There was no difference between those interventions that used theory and those that did not. When specific intervention components were linked to specific outcomes there were no clear patterns. The domain 'knowledge' was linked to the impact on knowledge in six trials: three had positive findings (Agrawal et al., 2005; Poureslami et al., 2012; Velsor-Friedrich, Pigott, & Srof, 2005), however three trials showed no impact (Ford et al., 1997; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004). In another trial, for the construct 'self-efficacy' an intervention designed to address 'self-efficacy' had no impact (measured by internal reliable and valid questionnaire scales) (Velsor-Friedrich et al., 2012). Additionally, 'beliefs about capabilities' were linked to measurements of self-efficacy or self-esteem in three trials, which all showed no impact (Ford et al., 1997; Griffiths et al., 2016; Velsor-Friedrich et al., 2012). Although, Velsor-Friedrich, Pigott, & Srof (2005) measured 'self-efficacy', it was not described in the paper and therefore not coded as a TDF construct for that intervention.

5.8 Discussion for analysis two

5.8.1 Main findings

This review has focused on 16 RCTs (17 papers) testing asthma self-management interventions targeted at South Asians and African Americans. Main findings related to the objectives were:

- *Establish the extent to which theory has been used in interventions:* half of the trials did not describe a theory-based approach (Agrawal et al., 2005; Behera et al., 2006; Blixen et al., 2001; Fisher et al., 2004; Ford et al., 1997; Kelso et al., 1995, 1996; Shanmugam et al., 2012), and two interventions used models (Fisher et al., 2009; Griffiths et al., 2004), though the difference between theory and models was sometimes obscure and interchangeable (Nilsen, 2015). Theory/models were mainly used to inform intervention-relevant constructs[31] or predictors[32] of self-management behaviour, but theory was not based on selection on the intervention population or tailoring/delivering intervention techniques to the target recipients.

- *Identify and describe theoretical intervention components:* authors did not explicitly use TDF terminology to describe intervention strategies. 'Knowledge' was central to all interventions (targeting participants with asthma and providers) and was provided in appropriate languages. 'Environmental context and resources' (e.g. language appropriate education), and 'behavioural regulation' (e.g. goal setting in action plans) were often typical in all South Asian trials (Agrawal et al., 2005; Behera et al., 2006; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012; Shanmugam et al., 2012). Most African American trials also used 'reinforcement' and 'environmental context and resources' (Blixen et al., 2001; Fisher et al., 2009; Ford et al., 1997; Kelso et al., 1995, 1996; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). The description of interventions targeting providers was limited in papers, though the domains 'social/professional role and identity', 'environmental context and resources' and 'knowledge' were targeted in all trials which described this (Fisher et al., 2004, 2009; Griffiths et al., 2004, 2016; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012).

- *Examine the relationship between reported barriers and facilitators and theoretical intervention components:* 'beliefs about capabilities' and 'beliefs about consequences' need further consideration to combat the barriers lack of knowledge and individual

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[31] Constructs are key concepts related to behaviour that interventions are based on (Michie & Prestwich, 2010)

[32] Predictors are a construct that is targeted in interventions to predict/correlate with/causes behaviour change (Michie & Prestwich, 2010)

learning styles, and enhance facilitators culturally/linguistically appropriate education and individual learning styles (Behera et al., 2006; Ford et al., 1997; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012). Targeting beliefs needs to be framed around the way information is learnt, processed and is meaningful for a cultural group (Castro et al., 2010).

- *Synthesise the relationship between theory use and intervention components to asthma outcomes:* It remains unclear whether the use of theory or interventions with theory-based components improved asthma outcomes.

5.8.2 Interpretation of findings in relation to previously published literature

This review could not determine whether the use of theory improved asthma outcomes and therefore could not help towards understanding what theories were important for the South Asian or African American culture (Fisher et al., 2009; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Poureslami et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). This is in contrast to previous literature which suggests theory-based interventions are more effective in the general population (Cane, Pao, & McKenzie, 2001; Michie & Prestwich, 2010), but others claim behaviour change is common sense on how and why something works or not in a given situation (Burke et al., 2009a; Marteau, Hollands, & Fletcher, 2012; Pasick et al., 2009b). My findings suggest that simply identifying and applying theory does not determine intervention effectiveness. In part, this may be related to the lack of explicit reporting of intervention components and theory, hence the difficulty in evaluating and drawing conclusions on its association with effectiveness. Arguably from this review, theories that could be used to further build an evidence base for these populations in future interventions (evidenced by overall significant findings), are some trials that implemented a single theory rather than a combination of theories: social learning theory (Ghosh et al., 1998), adult learning theory (Poureslami et al., 2012), and transtheoretical model (Fisher et al., 2009). It remains tentative whether other theory/models were beneficial (e.g. the liaison model of nursing), which may not be useful for future interventions (Griffiths et al., 2004).

'Knowledge' was identified as a central component of all interventions, only some of which were effective, suggesting that solely relying on this component may not be enough. This finding agrees with a systematic review of asthma that found education and improving

knowledge was an essential component of supported self-management, but in isolation, it lacked effect to create change (Pinnock et al., 2017). Previous studies (Lakhanpaul et al., 2014b; Moudgil & Honeybourne, 1998) including systematic reviews (Lakhanpaul et al., 2014a; Miles et al., 2017), agree that South Asians find it challenging to understand information on asthma treatment/medication and preventative care. In addition, African American literature suggest similar findings e.g. inability to recall information on medication, triggers and doctor's advice (Biksey, 2011). To illustrate this further, beliefs (also important for, say, medication adherence) need to be framed around how information is learnt in a cultural group, arguably suggesting that even if generic education was provided understanding may not always be addressed in these communities (Behera et al., 2006; Ford et al., 1997; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012). For example, self-relevant information such as those geared towards beliefs are more readily understood due to aiming at deep structure learning (Castro et al., 2010; Resnicow et al., 1999; Triandis, 2018).

The need to account for South Asian beliefs in self-management behaviour have been reported in a previous study (Hussein & Partridge, 2002), and a systematic review analysing health literacy in asthma (Poureslami et al., 2007). Both 'beliefs about capabilities' and 'beliefs about consequences' were targeted in two trials in this review (using the constructs 'beliefs', 'self-efficacy' or 'outcome expectancy') (Ford et al., 1997; Poureslami et al., 2012). In one trial by Poureslami et al. (2012) South Asians still had lower significant outcomes compared to Chinese participants, and there were non-significant findings on knowledge and self-efficacy in another trial (Ford et al., 1997). In the former, authors suggested that Punjabi Indian participants were older and less educated than the Chinese community (Poureslami et al., 2012), but this was not the case for the latter trial (which did not use any theory), suggesting that something else was missing and needs further exploration. Addressing 'beliefs about capabilities' were linked to the self-efficacy outcome in three trials, but they were not beneficial (Ford et al., 1997; Griffiths et al., 2016; Velsor-Friedrich et al., 2012), suggesting that it was not enough to change self-efficacy outcomes in this context (Burke et al., 2009b). Perhaps, self-efficacy may have varied meanings for different cultural groups and need to be explored further e.g. low resource healthcare settings in developing countries often focus on communicable illnesses rather than preventative treatment; undoubtedly individuals can be less aware of these concepts, strategies and access to resources (Burke et al., 2009a; Griffiths et al., 2016; Thompson, 2009; Velsor-Friedrich et al., 2012).

One way to understand cultural health behaviour is to apply the concept of habitus[33] to behaviours that people may not be fully aware of (Bourdieu, 2017, 2018; Burke et al., 2009a). Many self-management behaviours that are related to cultural beliefs are unconscious collective routines that have become common sense but are not reportable, though there is recognition that there are some levels of deliberate intentions (Bourdieu, 2017, 2018; Kellerman, 2016). Hence, there may be difficulty in enhancing individual awareness or discussion on some beliefs in the conscious realm e.g. people from some cultures may base their intentions to change on collective social rules and reasoning rather than on individual cognitions (Bourdieu, 2017, 2018; Burke et al., 2009a; Triandis, 2018). This suggests that current theoretical explanations on deliberate intentions and conscious thoughts or actions (that may or may not predict behaviour change), might not be universally applicable (Burke et al., 2009a). Interventions raising consciousness or unconscious behaviours may be helpful (Marteau, Hollands, & Fletcher, 2012). Arguably, this raises questions on whether standardised theories that are developed using norms and measurements of the general population's health behaviours (usually middle-class White people) can be applied to the unique sociocultural context of South Asians or African Americans - or any other sociocultural group (Bernal et al., 2009; Burke et al., 2009a; Prestwich et al., 2014).

5.9 Strengths and limitations of the systematic review

To my knowledge, this review was one of the few studies synthesising the effectiveness of asthma outcomes, theory use and theoretical intervention components of South Asian or African American asthma self-management interventions. By identifying barriers and facilitators across two different ethnic groups, sociocultural contexts and varying age groups, the review can inform the future customisation of interventions (Bhopal & Sheikh, 2009; Ghosh et al., 1998; Griffiths et al., 2016). The barriers and facilitators identified in this review do not entirely imply they are specific to a certain ethnic group or social context, as it is likely that if more trials were included, there may have been more overlapping barriers or facilitators found that could push them towards another grouping e.g. from an ethnic specific to the generic category. Therefore, there may be a danger of oversimplifying or over-

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[33] Habitus is the internalised dispositions of second nature social rules and categorisations on perceptions, thoughts and behaviours predicted by past experiences, and social, cultural and economic capital (Bourdieu, 2017, 2018)

categorising these barriers/facilitators into specific categories and should not be taken as static, however the approach taken by this review was one perspective to further understand this area of research (Lakhanpaul et al., 2014a).

There was a good number of trials included in the review, in contrast to other reviews (Bailey et al., 2009; Barrera et al., 2013; McManus & Savage, 2010), though the exclusion criterion of requiring separate outcome data for the groups of interest may have restricted the number of articles available, or authors could have been contacted to provide separate data. Identification of more culturally targeted and even some tailored trials would have been informative. Limited descriptions of the interventions and theory use (or even in the case of describing the provider part of the intervention), made it difficult to know how the interventions were developed or what they were based on, particularly in reference to 'majority' South Asian trials (Agrawal et al., 2005; Ghosh et al., 1998; Shanmugam et al., 2012). Given that supported self-management has been found to be important, it is equally crucial that the description of the participant with asthma and provider parts of the intervention are adequately noted to provide a fuller picture of the components that were used (Ahmed et al., 2018; Pinnock et al., 2015; Taylor et al., 2014). To synthesise findings on theory use and intervention components, the issue of reporting was minimised by examining original articles on which trials were based and requesting additional data, however these papers may have similar limitations of reporting (American Lung Association, 2002; Bailey et al., 1990; Bolton et al., 1991; Clark et al., 1998; Creer et al., 1989; Fisher et al., 1994; Kaur et al., 2002; Lorig et al., 1999; O'Brien et al., 2007; Poureslami et al., 2011). For this reason, although TCS can be a reliable and comprehensive method of determining the extent theory was used across interventions (Michie & Prestwich, 2010), it was unclear whether some trials used theory but did not report it in published articles. In addition, no response from some of the authors contacted meant that one of the targeted trial was excluded from the harvest plot analysis (with missing data on between group differences) (Poureslami et al., 2012).

Some harvest plot analysis relied upon subgroup analysis which reduced study power and thereby could have increased the potential for null findings (Ford et al., 1997; Griffiths et al., 2004; Moudgil, Marshall, & Honeybourne, 2000). However for clarity, hatched bars were added to illustrate inconsistent findings and to limit over-interpretation (Ogilvie et al., 2008; Pinnock et al., 2015). Subjectivity in assessing the outcomes for the harvest plot was minimised by specifying predefined criteria (see note to Table 5) that were replicable, and

all the judgements were checked by at least two reviewers. Additionally, even though harvest plots are a very good technique of combining heterogeneous findings and personalising to the requirements of the review, they can obscure some important outcomes that cannot be reported in the plots and overemphasise others (Ogilvie et al., 2008).

TDFs can be applied in various ways to understand the specified behaviour change, which can later be selected to facilitate intervention development, but this can also act as a limitation (Cane et al., 2012). Typically, existing TDF use guidance has been confined to qualitative approaches, thus further direction is required for its use in systematic reviews (Atkins et al., 2017). There may be several subjectivity issues with using TDFs in the review. Although, we tried to minimise this by independent coding of TDF data by a second reviewer (Liz Steed), the narrative linkage of TDFs to barriers and facilitators can be open to interpretation and based on author descriptions in articles. New ideas have, however, emerged from using this approach that could be targeted to improve evidence-based interventions by aiding understanding of barriers and facilitators and what can be done differently (Newlands et al., 2016). Finally, several barriers and facilitators (e.g. PAAPs, practicing self-management, written reinforcements, providing education, supported self-management, African American cultural stressors and social support) could not be linked to TDFs as they were either based on one trial or limited author descriptions, and need further exploration.

5.10 Conclusions and implications for future research

When developing, delivering and evaluating self-management interventions targeted at different cultures, the influence of sociocultural contexts (including whether participants are from a minority or indigenous population) are important for conceptualising culture and customising self-management strategies appropriately. This systematic review looked at understanding of what has been included and worked/not worked in previous interventions:
- Interventions used diverse self-management strategies; education/'knowledge' formed a central component. 'Behavioural regulation' and 'environmental context and resources' were part of all South Asian trials. Findings suggest interventions could be improved by aiming at participant beliefs. Little is known about targeting collective unconscious beliefs and behaviours around habitus (Bourdieu, 2017, 2018).

- Asthma self-management interventions delivered to 'minority' South Asian and African American communities were less effective compared to interventions in 'majority' South Asian countries, though the latter trials were at greater risk of bias. Most trials from India did not design interventions for their community, instead followed guideline recommendations from studies in high income countries (Agrawal et al., 2005; Ghosh et al., 1998; Shanmugam et al., 2012). Targeting or tailoring self-management to culture and other features of the specified population, rather than 'translating' effective interventions from the main population was important. Targeted or tailored intervention development does not exclusively include collaboratively developed components aimed at beliefs and needs of the target ethnic group, but may also include adaption of existing resources, healthcare systems and sociocultural contexts. Gaps in research demonstrate the complexity of comparing and contrasting studies (Lakhanpaul et al., 2014b). Rigorous trials of culturally targeted or tailored interventions are needed.

- Barriers to self-management included: the lack of knowledge, the consideration of individual learning styles, and cultural stressors (for African Americans). Facilitators to self-management included: ensuring culturally/linguistically appropriate education (for South Asians), adapting to individual learning styles, addressing daily cultural stressors/social support (for African Americans) and other generic self-management strategies.

- Most interventions did not define culture adequately; as three 'minority' South Asian trials defined ethnicity according to self-identification or language spoken and culture was not considered, and/or perceived to be synonymous to ethnicity. There needs to be standard recommendations on how trials verify participant ethnicity/culture, (Griffiths et al., 2004, 2016; Poureslami et al., 2012).

- The MRC framework and other intervention guidelines highlight the significance of theory in the development of interventions (Bartholomew et al., 1998; Craig et al., 2008), yet eight trials considered theory and recommendations of using/testing theory for cultural relevance has been limited for South Asians and African Americans, though it was unclear whether theory or theoretical components had an impact on intervention effectiveness. Intervention development guidelines therefore need to take a step further from stressing the significance of theory to providing guidance on the selection and utilisation of theory in cultural contexts, which could be emphasised in clinical guidelines for asthma. Indeed, it is recognised that there may not be a specific theory that is the most appropriate for asthma self-management or in cultural contexts, though criteria for

implementation can be developed e.g. what population theories have been standardised and tested on. When reporting theory-based interventions, authors need to be explicit in describing theory use, the rationale behind the choice of theory and intervention components that were used, importantly for both participants with asthma and provider part of the intervention.

- Growing literature on the relevance of theory in cultural contexts suggest it may be useful to consult cultural theories from other disciplines that may clarify cultural complexities (supplemented with behaviour change theories), and/or conduct qualitative research to redefine theoretical factors relevant to a cultural group e.g. how South Asians understand self-efficacy. These approaches need further exploration (Hay & Lee, 2009; Pasick et al., 2009b; Shelton, Griffith, & Kegler, 2017; Washington et al., 2009).

- Studies that improve understanding of sociocultural contexts, allow a deeper appreciation of customising interventions and thinking about how to prevent inequalities in self-management, which are needed to inform international asthma guidelines. Intergroup subcultural heterogeneities, cultural changes over generations (due to acculturation[34]) and individual learning styles, add to the complexity of self-management behaviour and all need to be explored further.

This chapter synthesised evidence on what has been included and worked or did not work in previous self-management interventions for South Asians and African Americans. The next chapter describes two cross-cultural theories; the acculturation model and the cultural hybridity theory (Hall, 2014; Sam & Berry, 2010). Both theories are related to health that may increase understanding of the individual and/or collective cultures in the UK (Triandis, 2018), as a basis for conducting interviews with Bangladeshi and Pakistani individuals with asthma and HCPs who support them (see chapter 7 and 8) (Hall, 2014; Sam & Berry, 2010).

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[34] Acculturation is the cultural changes influenced by encountering another mainstream culture (Berry, 1997; 2005; Sam & Berry, 2010)

Chapter 6. Model/theory underpinning the qualitative research

The last chapter systematically reviewed existing self-management trials for South Asians (and African Americans) to understand what has been included and worked or did not work in interventions. In light of the paucity of research and concerns that existing behaviour change theories for South Asians may only partially explain health behaviours based on individual cognitions and particular social contexts (Burke et al., 2009a; Evans & Lambert, 2008), cross-cultural health psychology theories related to health may be useful to fill in gaps in holistically understanding the Bangladeshi and Pakistani UK sociocultural context (see section 3.3.2) (Hay & Lee, 2009; Pasick et al., 2009b; Shelton, Griffith, & Kegler, 2017; Washington et al., 2009). In this chapter, the acculturation model (Berry, 1997, 2005; Sam & Berry, 2010), and the cultural hybridity theory are considered (Hall, 1990, 2014), to frame understanding of Bangladeshi and Pakistani culture and its interaction with the healthcare service in the coming qualitative studies (see chapter 7 and 8). Both of which are recurring in the background literature that focusses on Bangladeshi and Pakistani identity formations in the UK (e.g. Ali, 2008; Bhatia & Ram, 2004; Robinson, 2009; Small et al., 2005; Werbner, 2004).

6.1 The acculturation model

6.1.1 Description of the acculturation model (Berry's cross-cultural health psychology theory 1997, 2005, 2010)

Acculturation is a process of cultural changes influenced by encountering another mainstream culture (see section 2.3.5 for an explanation of acculturation). Berry's acculturation model suggests individuals or groups can freely adapt to a new/mainstream environment in one of four ways over time or generations, and its flexible nature can be dependent on a given situation (these are known as acculturation strategies) (Berry, 2005; Sam & Berry, 2010):

1) *Integration* - Individuals maintain their original culture and also integrate with the mainstream culture.

2) *Assimilation* - Individuals disconnect from their original culture to fit in with the mainstream culture.

3) *Separation* - Individuals hold on to their original culture and avoid any adaptation or contact with the mainstream culture.

4) *Marginalisation* - Individuals lose maintenance and contact with both original and mainstream cultures.

There are two levels of adaptation when two cultures acculturate that occur over an extended space of time. These adaptations may or may not be positive and typically involve a process of negotiation to avoid conflict (see Figure 6) (Berry, 2005; Sam & Berry, 2010):

- Individual/psychological level (changes at an individual behavioural level).
- Group/cultural level (changes in social, cultural and organisational levels).
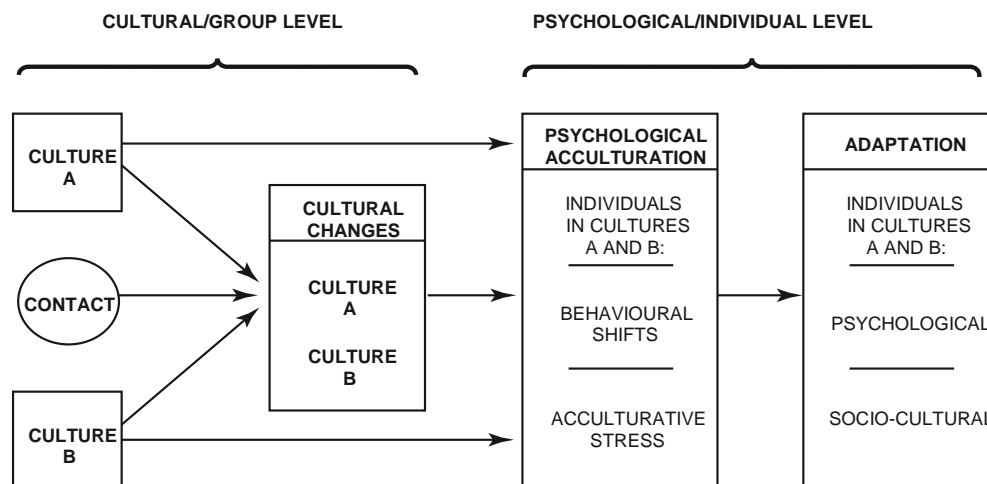
Figure 6. The individual and group levels of cultural and psychological adaptations during acculturation (Sam & Berry, 2010)

To comprehend the psychological (individual) and cultural (group) features of acculturation, the baseline descriptions of two cultures, the nature of contact and the cultural transformations in both groups need to be determined (whether minor or major), as this contact predicts compatibility or incompatibility of values, norms, characteristics and attitudes. For cultural groups, acculturation changes occur at a collective level (e.g. communities, states or intuitions), where they negotiate how to avoid conflict (Berry, 2005; Sam & Berry, 2010). Group level acculturation can influence individual level adaptations

depending on the extent to which individuals engage e.g. purpose and motivation (Berry, 2005; Sam & Berry, 2010). At the individual level, psychological acculturation can be either:

- Behavioural shifts e.g. manner of speaking, dress sense, accents and eating habits.
- Acculturative stress (the reaction and experience of daily stress and degree of psychological/sociocultural adaptation challenges resulting from encountering a larger mainstream society), e.g. anxiety or depression.

These two forms of acculturations can lead to either:

- Psychological adaptations to new situations e.g. sense of well-being or self-esteem based on personality factors, experiences and social networks.
- Sociocultural adaptations (the degree of daily coping in a new sociocultural environment) e.g. learning a new language, behavioural difficulties, school modifications and social capability.

Time periods and predicted experiences are important e.g. in sociocultural adaptation initial contact with another culture may comprise of more difficulties but may improve over time with more knowledge of a culture, the degree of contact with a culture and positive attitudes inside the cultural group (Berry, 2005; Sam & Berry, 2010).

In addition, the mainstream group can influence the potential to acculturate through social factors e.g. discrimination, exclusion and migration policies (Sam & Berry, 2010). There are four ways acculturation can occur in the mainstream group, which are viewed as reciprocal processes and the acculturation in individuals/groups (see Figure 7) (Berry, 2005; Sam & Berry, 2010):

1. *Multiculturalism* (equivalent to integration[35]) - when cultural diversity is fully supported as a feature of the mainstream society. The correct atmosphere needs to be in place for the integration strategy to be chosen and sustained.

2. *Melting pot* (equivalent to assimilation[36]) - where the mainstream society is more dominant than the individual's own cultural group.

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[35] Integration is an individual/group level acculturation strategy where individuals maintain their original culture and also integrate with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

[36] Assimilation is an individual/group level acculturation strategy where individuals disconnect from their original culture to fit in with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

3. *Segregation* (equivalent to separation[37]) - where the mainstream society tries to force separation of the individual from their society.

4. *Exclusion* (equivalent to marginalisation[38]) - when both mainstream society and the individual's cultural group force exclusion through various societal factors.

Maintenance of heritage culture and identity
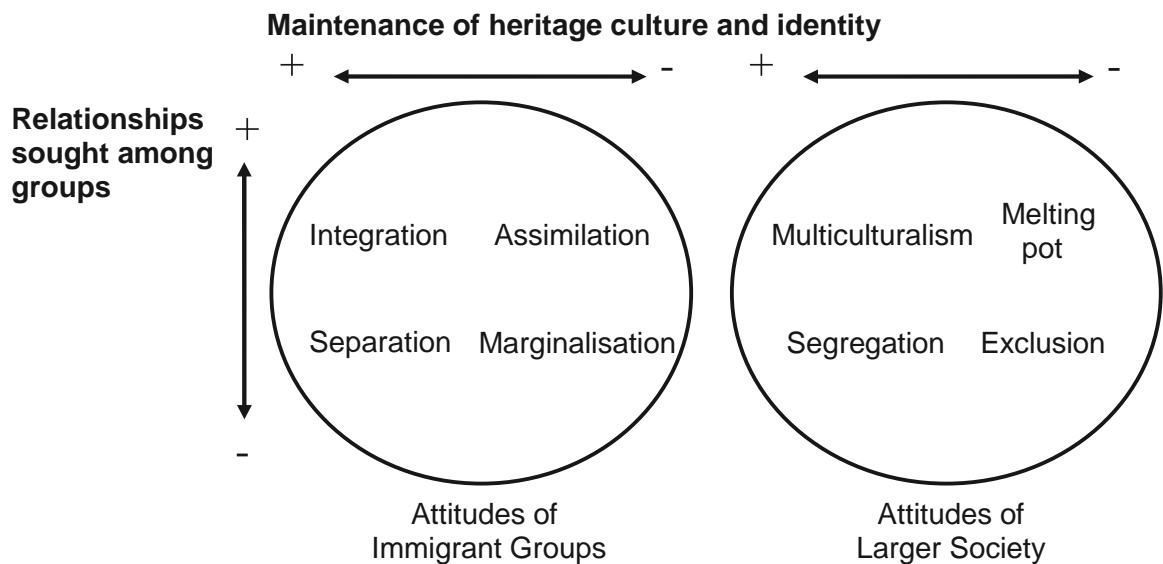
Figure 7. Acculturation strategies in individuals/groups and the larger mainstream society (Berry, 2005; Sam & Berry, 2010)

6.1.2 Acculturative stress (psychological acculturation)

Acculturative stress refers to the reaction and experience of daily stress and degree of psychological/sociocultural adaptation challenges resulting from encountering a larger mainstream culture (the mainstream culture is less likely to face acculturative stress when encountering a minority culture). This stress may be higher in the absence of social support (e.g. loss of social, cultural and economic capital during migration) (Roura, 2017; Sam et al., 2008), and appropriate coping strategies e.g. self-management concept or behaviour (Berry,

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[37] Separation is an individual/group level acculturation strategy where individuals hold on to their original culture and avoid any adaptation or contact with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

[38] Marginalisation is an individual/group level acculturation strategy where individuals lose maintenance and contact with both original and mainstream cultures (Berry, 2005; Sam & Berry, 2010)

2005; Sam & Berry, 2010). Acculturative stress has an influence on individual/group level acculturation strategies (see Figure 7):

- The integration strategy (where both cultures are important) predicts less acculturative stress and better adaptation since it involves less conflict, negotiation and mediation.

- Assimilation (where mainstream culture is more important) and separation strategies (where original culture is more important), both have possibilities of intermediate stress and adaptation. For assimilators, this can typically be resolved with conforming to mainstream cultural norms and for those who choose separation, this can be resolved through withdrawal from acculturating.

- Marginalisation strategy (where both cultures are insignificant), conflict becomes a part of daily life and little involvement/interest in cultures are maintained to cope (Berry, 2005; Sam & Berry, 2010).

At an individual level, acculturative stress refers to how individuals who are part of different groups negotiate living together to avoid conflict. At a group level, acculturative stress can involve collective problem-solving and negotiation on how to interact with others to avoid conflict (Sam & Berry, 2010).

Generally, more acculturative stress means less positive attitudes towards the mainstream culture, which can differ across generations (Ali, 2008; Sam & Berry, 2010). Arguably, the first migrant generation have widely adapted to the separation strategy due to difficulties with language, lifestyle, historical and other factors e.g. attitudes towards the British colonisation of 'India', the rejection of South Asian education in the UK and the widespread experience of discrimination and racism during the 1980s and 1990s (Basit, 2017; Shaw, 2014). It is suggested that a potential solution to negotiate this stress is to learn culture specific behavioural skills e.g. learning the mainstream language can enhance cultural contact with others (Sam & Berry, 2010). It is argued that children who were raised but not born in the UK are more likely to retain their traditional culture if they are residents of urban areas with a highly dense population from their same cultural group, as these environments are more likely to discourage acculturation. Therefore, at times this can cause acculturative stress when individuals cannot stop acculturation in different directions due to involvement in various activities e.g. education. This highlights the importance of social context and generational status in considering the process of acculturation and its varying stress, and the problem of generalising findings of a culture from one country to another (Sam & Berry, 2010; Schwartz & Zamboanga, 2008).

6.1.3 Empirical support for the acculturation model

The acculturation model (Berry, 1997, 2005, 2010) has been one of the most popular acculturation theories with a large empirical foundation e.g. the two dimensions of acculturation (individual/psychological and cultural/group) and the four individual/group strategies are well tested, distinct and linked to health outcomes (Berry, 2005; Sam & Berry, 2010). For instance, compared to other strategies, integration promoted dual cultural competences (e.g. access to resources), and was therefore found to be highly correlated with better health outcomes for various cultures including Hispanics and Japanese (Berry et al., 2006; Maskarinec, & Noh, 2004; Schwartz & Zamboanga, 2008). Younger individuals have been found to prefer acculturate in the integration strategy (e.g. language use, ethnic and national identities and peer networks), though other adaptation strategies may also be used (Ali, 2008; Berry et al., 2006; Maskarinec, & Noh, 2004; Schwartz & Zamboanga, 2008). However, application of the model to South Asians with asthma has been non-existent, but the literature review suggests acculturation was important for Bangladeshis and Pakistanis in the UK (see section 2.3.5). Most acculturation research for South Asians in the UK has been around other health issues e.g. breastfeeding practices (Choudhry & Wallace, 2012), cardiovascular illness (Kalra et al., 2004), musculoskeletal pain (Palmer et al., 2007), body image and eating attitudes (Iyer & Haslam, 2003). In addition, there has been some research on South Asian acculturation and health in America e.g. tobacco use (Mukherjea, Modayil, & Tong, 2018), and atherosclerosis (Bharmal et al., 2018; Volgman et al., 2018).

6.2 The cultural hybridity theory

6.2.1 Description of the cultural hybridity theory at an individual/group level

The *cultural hybridity theory* suggests that individuals who have integrated with two or more cultures tend to become bi-culturally competent, with mixed identities emerging across national and local levels (Hall, 1990, 2014). Individuals who are hybrids tend to seek out which aspects of their cultures are most significant to them (e.g. religion, career and health beliefs), allowing them to use various resources (e.g. utilisation of different cultural collections, switching language codes and blending cultural symbols in hybrid ways), in a state of constant negotiation (Hall, 2014; Koenig & Shohaib, 2014). For instance, some South

Asians (mostly Bangladeshis and Pakistanis) may perceive their main identity as orthodox Muslim above the traditionality and/or British identity, which creates an international sense of belonging (Afshar, 2012; Basit, 2017). This is reinforced by Islamic teachings that all people from different ethnicities are the same in front of God and the belief in one God joins Muslims in community/unity (Basit, 2017). Cultural hybridity may be a part of different generations, but it may be more prominent in UK born/raised generations (Chatterji & Washbrook, 2014; Hall, 2014). Little research in the area of cultural hybridity in self-management of chronic illness meant relying on describing studies that were not very current (e.g. Hawthorne et al., 2007; Small et al., 2005).

6.2.2 Description of the cultural hybridity theory at a healthcare level
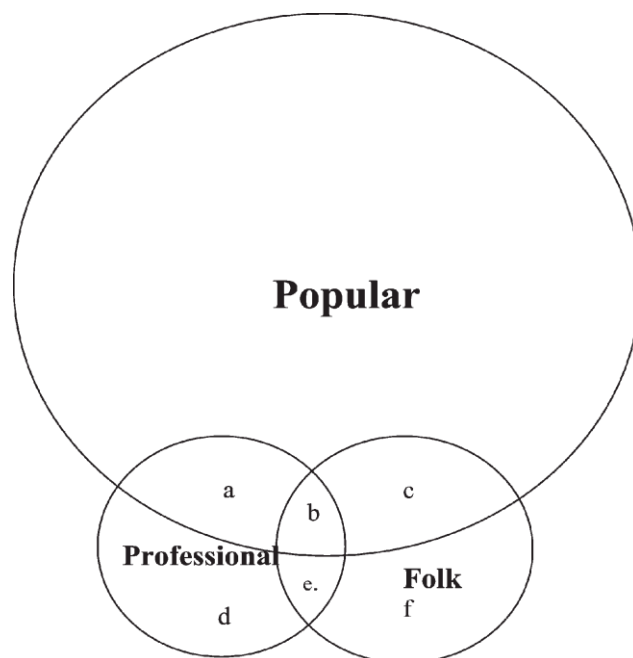
Figure 8. Cultural hybridity model: The health system (Small et al., 2005)

Figure 8 above describes Kleinman's model of cultural hybridity adapted by Small et al (2005), which presents the healthcare system from the perspective of the individual as an holistic cultural system that overlaps. An individual's healthcare system can be perceived as three realms of overlapping zones, where hybridity can be established and various illness negotiations take place (Small et al., 2005):

1) Popular zone: the individual, family and community (the cultural environment where the illness was first defined and that initiated actions).

2) Professional zone: the healthcare system of a society e.g. the NHS, HCPs and their representations and actions.

3) Folk zone (the non-professional sector): traditional cultural practices in the community (Marks et al., 2015; Small et al., 2005), e.g. seeking treatment from either a doctor and/or community healer for CAM or explaining illness with medical and/or spiritual meanings or explanations (Small et al., 2005).

All three sectors do not have any boundaries and can work in combination to accommodate various health beliefs, practices or treatment preferences (Small et al., 2005). In this manner, the process is constantly challenged, and the correct belief or practice refined in response to a given situation. This also involves thoughts on reflecting on choices made based on expectations (Marks et al., 2015; Micozzi, 2014; Small et al., 2005). This highlights the need for researchers to understand the importance and implications of these hybrid zones (e.g. accessing treatment), which can allow the healthcare services to respond to numerous cultural milieus (Small et al., 2005).

In the popular sector (see Figure 8), when an illness is first encountered initial decisions are made e.g. decision-making on treatment. Subsequently, either or both folk and professional sectors are accessed. The folk and professional sectors are smaller than the popular sector, since health beliefs from the popular sectors are used to approach and define how these beliefs are understood in the professional and community sectors (zone a and c), and functions aligned with individual and communal knowledge and perceptions. A hybrid area has been illustrated by zone b, where knowledge and perceptions are combined from all three sectors and appropriate actions are negotiated. Zones d, e and f represent actions that place individuals under the care of others, which might contradict or agree with their own cultural health beliefs or values e.g. in situations where people feel helpless due to ineffectiveness of treatment. The application of the cultural hybridity in the healthcare system (Small et al., 2005), can overlap with Leventhal's theory on cognitive and emotional illness representation (that refer to rules of norms to make sense of the threat of illness) (Marks et al., 2015). The theory suggests that illness and common-sense beliefs are formulated from associating interactions between the individual, social and professional realms. Thereafter, these representations may guide appropriate actions (e.g. coping behaviour), and sometimes inappropriate actions (e.g. maladaptive behaviours) (Marks et al., 2015; Morrison & Bennett, 2009). These individual beliefs create differences in illness perceptions between the person (and/or their cultural groups) and HCPs who may or may

not emphasis on disease management of asthma e.g. views on breathlessness may vary (Marks et al., 2015; Sidora-Arcoleo et al., 2012).

6.2.3 Empirical support for the cultural hybridity theory

Evidence focussing on understanding identity of South Asians in the UK have shown the presence of dual identity self-reported by young Pakistanis and Indians e.g. Pakistani-British, even though they faced discrimination and had conflicting emotions of belonging to the UK (Afshar, 2012; Basit, 2017; Robinson, 2009; Vadher & Barrett, 2009). On one hand, participants had strong ethnic pride in cultural roots due to situations where the mainstream UK culture may be perceived as creating a climate that treats ethnic minorities with hostility/tension and as inferior, which can reinforce the perception of 'otherness' (Afshar, 2012; Vadher & Barrett, 2009). This can be related to acculturation at a mainstream society level; the separation[39] strategy, does not promote multiculturalism[40] (support cultural diversity), therefore at an individual level the adaptation or contact with the mainstream culture becomes less (Sam & Berry, 2010), and this may lead to questioning identity and holding onto ethnic, cultural and religious roots (Afshar, 2012; Vadher & Barrett, 2009). Evidence suggests orthodox Islamic religion may be a priority over traditionality or cultural influences on what religion should consist of (e.g. oral hearsays) for most individuals born and raised in the UK (Ahmad & Bradby, 2008; Basit, 2017; Hall, 2014).

Code switching[41] (a form of language crossing/shift) in bilinguals or multilinguals is another form of hybridity (Hall, 2017; Rampton, 2014), e.g. strategic mixing of English with South Asian languages (written or spoken) that allows a distinctive sense of identity due to adaptations made, thereby separating themselves from other groups e.g. cultural expressions such as metaphors (Jaspal, 2010). Code switching has been extensively studied particularly in the field of computer coding in corpus linguistics (a system of coding based on

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[39] Separation is an individual/group level acculturation strategy where individuals hold on to their original culture and avoid any adaptation or contact with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

[40] Multiculturalism is a mainstream acculturation strategy when cultural diversity is fully supported as a feature of the mainstream society. The correct atmosphere needs to be in place for the integration strategy to be chosen and sustained (Berry, 2005; Sam & Berry, 2010)

[41] Code switching is the switching between two languages in a sentence, phrase, conversation and so forth (Rampton, 2014)

statistical methods for various purposes), but the evidence base for its application to asthma research and the understanding of cultural hybridity has been little (Rampton, 2014). For instance, corpus linguistics are used to create a dictionary for spoken Sylheti, writing South Asian languages in Roman alphabets, transcription schemes for transcribers and noting differences in language evolved in the UK (Chandra, Kundu, & Choudhury, 2013).

6.2.4 Empirical support for the cultural hybridity theory for South Asians with asthma

To my knowledge, there are only two dated qualitative studies which consider cultural hybridity in long term illnesses (Hawthorne et al., 2007; Small et al., 2005). Hawthorne et al. (2007) looked at cultural shifts in managing chronic illnesses (mainly diabetes) using one-to-one semi-structured interviews with Bangladeshis aged 22 to 68 in Cardiff and found the following:

- Participants readily accepted Western values about illness explanations and practices (e.g. the medical cause of viral respiratory infections), however they still held cultural views alongside this (e.g. avoiding banana during flu), although younger women rarely followed these traditional practices despite seeking advice from elders who held such beliefs.

- Some elders with diabetes were taking CAM alongside biomedical medication e.g. dried leaves and herbs that are bitter and sour from Bangladesh which were thought to burn fat and cleanse the blood, and ruqyah shariah[42] to protect and heal from illness. Nevertheless, there was an acknowledgment that CAM treatment was more beneficial for aches and pains rather than healing from diabetes itself.

- In addition, the local Imam encouraged individuals to not to expose themselves to the cold for their asthma (Hawthorne et al., 2007). This can be linked to hot and cold beliefs (see section 3.4.2) (Harver & Kotses, 2010).

- Likewise, other influences included the role of men in traditional families as health decision-makers. However, since some fathers worked long hours in settings such as restaurants, this restricted their role in helping family members to access healthcare services e.g. married women. Family members were also taken to appointments for

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[42] Ruqyah shariah is an Islamic treatment and healing strategy for physical, mental, spiritual and supernatural illnesses, consisting of devotion to worship (e.g. prayer, reading Qur'an and supplication), and lawful incantations based on the Qur'an and the sayings of the Prophet read on various substances such as certain herbs and foods (Eneborg, 2013)

translation purposes, however due to cultural changes (e.g. bilingualism), these findings do not apply to all younger families today.

- Participants were more aware of primary care services than other related services for their illness and they trusted their GP. Most of the younger generations lived or hoped to live as a nuclear family, contradicting the general stereotype that Bangladeshis live with extended families who provide healthcare support (Hawthorne et al., 2007).

The study concluded that as generational status extends, it complicates generalising previous findings to the community e.g. it may be that some Bangladeshis do not live within a nuclear family anymore (Hawthorne et al., 2007). Therefore, there is a need for ongoing research on cultural changes in self-management (e.g. how illness perception might have changed over time), but little research developments have taken place. If there are fewer language barriers amongst these individuals, other problems can be determined e.g. medicine adherence or availability of family members such as male decision makers (Hawthorne et al., 2007).

Another example of research focussing on cultural hybridity was conducted by Small et al. (2005) on epilepsy in Pakistani Muslim adults in the UK (Bradford). They conducted interviews which focussed on the healthcare sector interactions and negotiations and how this influenced patient comprehension of epilepsy; in line with the cultural hybridity model in the health system (see Figure 8 and section 6.2.2). Findings of constant negotiations included:

- Complex causations and explanations were made using the biomedical and religious e.g. epilepsy was perceived as a mental illness, predestination, expiation of sin, and a test or punishment by God.

- The meaning and importance of epilepsy e.g. disclosure of epilepsy was dependent upon fears of stigmatisation, quality of relationship and previous reactions. Individuals used emotive language to refer to epilepsy e.g. madness.

- Participants fused beliefs and practices from two domains e.g. using biomedical and CAM alongside each other through ideological struggles and negotiation from recommendations of significant others.

6.3 Chapter summary

This literature review described a model and a theory; the acculturation model (Berry, 2005; Berry, 1997; Sam & Berry, 2010) and the cultural hybridity theory (Hall, 1990, 2014). Both

were used to better understand the Bangladeshi and Pakistani culture and interaction with the healthcare service in the qualitative research (see chapter 7 and 8) (Sinha, 2014; Triandis, 2018). There has been little research in applying these two theories to asthma research for Bangladeshis and Pakistanis. Hence, the difficulty of drawing comparisons in findings with dated studies, which themselves state ongoing research to account for the dynamic nature of culture and health are paramount in the UK (Hawthorne et al., 2007; Small et al., 2005). Application of these cross-cultural theories, sometimes overlapped with behaviour change theories e.g. common sense model of self-regulation (Leventhal, Benyamini, & Shafer, 2007; Leventhal, Meyer, & Nerenz, 1980; Marks et al., 2015), was similar to the cultural hybridity model of health systems (Small et al., 2005), that showed there may be differences in illness representations of individuals from different cultural groups and HCPs (Marks et al., 2015; Sidora-Arcoleo et al., 2012).

The acculturation model (Berry, 2005; Berry, 1997; Sam & Berry, 2010) and the cultural hybridity theory (Hall, 1990, 2014), were explored in this chapter which the next chapter considers as the foundation of understanding qualitative interviews for Bangladeshi and Pakistani individuals with asthma.

Chapter 7. Qualitative study: Exploring the perspective of Bangladeshi and Pakistani individuals on their asthma self-management behaviour

The acculturation model (Berry, 2005; Berry, 1997; Sam & Berry, 2010) and the cultural hybridity theory (Hall, 1990, 2014), described in the last chapter informed the qualitative study in this thesis chapter. Following on from the systematic review (chapter 5) that revealed that there was a need to consider the sociocultural context of South Asians in the UK. This chapter presents the qualitative study that looks at the role of culture in asthma self-management, by exploring and comparing the perspective of Bangladeshi and Pakistani individuals across the first, second, third and fourth generations.

7.1 Rationale for the qualitative research

Asthma guidelines recommend that self-management interventions should be culturally relevant (GINA, 2016; SIGN, 2016), but culture, asthma and self-management are all dynamic, therefore making sense of these factors is necessary (Castro, Barrera, & Steiker, 2010; Pavord et al., 2017; Udlis, 2011). Holistic self-management (explained in section 2.2.2) can help account for these heterogeneities by considering the expertise of individuals living with asthma in context (or others who support them), e.g. recognising that individuals learn, experiment and explore boundaries of self-management over time (Fortun et al., 2014; McCorkle et al., 2011). Therefore, the person (Bangladeshi and Pakistani self[43]) in self-management needs to be explored (Kralik et al., 2004), to provide a more holistic and less fragmented picture (Schulman-Green et al., 2012; Trappenburg et al., 2013; Udlis, 2011).

7.2 Aims for the qualitative research

The perspective of Bangladeshi and Pakistani individuals with asthma on self-management were explored. The primary aim of the study was to:

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[43] The self can be broadly defined as direct or indirect statements that comprise of the self referring to *'I', 'me', 'mine', 'myself'* (Triandis, 2018), in social motivations, attitudes, beliefs, intentions, norms, roles and values (Cooley, 2017; Triandis, 2018)

- Understand the role of culture in self-management by exploring perspectives of the first, second, third and fourth generation Bangladeshi and Pakistani individuals with asthma.

The secondary aims were to:

- Identify the categories of HCP that were most significant for participant care from interview data (not necessarily the individual's own HCP).

- Explore what type of asthma self-management interventions Bangladeshi and Pakistani individuals feel would be useful for themselves and/or their community.

The research questions were:

1) How cultural variations across Bangladeshi and Pakistani generations in the UK influence asthma self-management behaviour?

2) Which HCPs are the most significant for Bangladeshis and Pakistanis for their asthma care?

3) What type of intervention/s Bangladeshis and Pakistanis feel would be useful for themselves and/or their community in the UK?

7.3 Methodology for the qualitative research

7.3.1 Study design

This qualitative research involved one-to-one semi-structured interviews. The COREQ checklist for reporting qualitative research was used to structure this chapter (Appendix 5). After reviewing previous asthma literature on recruitment of South Asians in research (MacNeill et al., 2013; Rooney et al., 2011; Stirland et al., 2011; Suh, Kagan, & Strumpf, 2009), this informed various decisions about the appropriate methodology to choose for this qualitative study:

- The aim of one-to-one interviews is to gather in-depth information about a person, compared to focus groups which can involve collective opinions with less attention on the individual e.g. suggestions and reactions on a topic (Krueger & Casey, 2014).

- Trust through building a relationship was important for South Asians with asthma, therefore one-to-one interviews would be an ideal atmosphere to develop this (MacNeill et al., 2013; Rooney et al., 2011; Stirland et al., 2011).

- Maintaining confidentiality for a condition where privacy was important for participants would mean one-to-one interviews are ideal where individuals who can feel comfortable

in disclosing their stories (MacNeill et al., 2013), rather than providing a situation in focus groups where they may bump into other people into the community that they may know e.g. due to perceived fear of stigma (Rooney et al., 2011; Stirland et al., 2011). In addition, gender segregation and modesty was shown to be imperative for females who stated that they were unable to express themselves in mixed gender focus groups (Suh, Kagan, & Strumpf, 2009).

- The plan was that one-to-one interviews would allow me to easily accommodate for participants who may want to speak in different languages and recruit relevant interpreters (MacNeill et al., 2013). Since the interviews were geared towards different generations (first to fourth), a common level of understanding would be needed in focus groups, therefore perhaps various focus group sessions would need to be planned accounting for generation and language (Rooney et al., 2011).

- Practically, multiple interview and recruitment sites meant considering travel distances and other commitments (work, education or family). For participants, a researcher flexible with time and location of the interview for an individual may mean better participation rates and the avoidance of unnecessary burden and research fatigue, which may be easier to negotiate in one-to-one interviews e.g. interviews scheduled on the weekends or after working hours (Rooney et al., 2011).

7.3.2 Participants

Recruitment of organisations (healthcare and community/voluntary services)

There was a mixed-approach to recruiting organisations who helped recruit participants:

- <u>Primary care services:</u> invitations to take part in the study were sent to 141 GP practices by the NIHR Clinical Research Network (CRN), to Tower Hamlets, Newham and Waltham Forest Clinical Commission Group services on two different occasions (25.05.17; 04.08.17). Five practices expressed an interest in participating; one practice dropped out after deciding they were not interested; there was a lack of response to researcher follow-up from another surgery. It was difficult to set up an initial site visit with another practice despite several attempts; this may have been due to pressures of workload. As a result, two practices were recruited with the aid of CRN (East One Health in Tower Hamlets and Addison Road Practice in Waltham Forest). Through a work colleague, I recruited Jubilee Street Practice in Tower Hamlets. In addition, another practice (Esk

Road Medical Practice in Newham) agreed to display the study recruitment poster on their noticeboard (see Appendix 6).

- Secondary/tertiary care services: participant recruitment took place at The Barts Hospital and Whipps Cross Hospital (general and severe asthma clinics), where study information was distributed, and potential participants were followed up for an interview. Additionally, Whipps Cross Hospital Chest Clinic and The Royal London Hospital Acute Services were approached by me (the principal researcher) and agreed to display the study poster in their waiting rooms (see Appendix 6).

- Community and voluntary services: several organisations and services were contacted (including mosques), and some agreed to help advertise the study recruitment poster/information (see Appendix 6 for posters in English, Standard Bengali and Urdu), inviting participants to contact the researcher for further information by telephone or email (depending on their preference). These organisations included:

1) Queen Mary, University of London Staff Bulletin.

2) Queen Mary, University of London Student Bulletin.

3) Newsletters and Facebook pages of student societies at Queen Mary, University of London (Barts and the London Muslim Medics and Dentists, Barts Language and Culture Society, and Barts and the London Dentist Society). Study information and poster was also disseminated using Twitter.

4) Posters were displayed on boards at sixth form schools and colleges (Waltham Forest College, Leyton 6th Form College and George Green School).

5) Posters were displayed on boards at community centres (Queens Road Learning Centre, Manor Park Community Organisation and The Mill Walthamstow), and verbal announcements were made at Asian Women's support group at The Mill Walthamstow.

6) A poster was displayed in the window at Quality Foods Limited (a grocery shop in Tower Hamlets).

Recruitment of participants

All participants were recruited using purposeful sampling to ensure each generation, ethnic group and where possible gender were represented. Study invitations were given to participants (see Appendix 7), and they were asked to reply using an expression of interest

form using a prepaid envelope, from which purposeful sampling was carried out (see Appendix 8). The generational status of participants was defined as:

- First generation (1G) - those born in South Asia or a country other than the UK and who had settled in the UK.

- Second generation (2G) - those born in the UK or arrived in the UK as a child under the age of 16, and at least one parent who was born in a country other than the UK.

- Third generation (3G) - those born in the UK, where at least one parent was born in the UK or arrived in the UK as a child under the age of 16, and grandparents who migrated to the UK having been born abroad.

- Fourth generation (4G) - those born in the UK and at least one parent and one grandparent was born in the UK.

Choice of questionnaire to assess acculturation[44]

In this qualitative study, to identify the degree of acculturation amongst participants, different acculturation scales were reviewed according to whether, i) they complemented Berry's acculturation model (Sam & Berry, 2010), ii) they have been used in physical/chronic health research, iii) they have been validated with the South Asian population and, 4) a scale that complements qualitative research (Parker, 2011; Trinh et al., 2009). Most acculturation scales were not validated in the South Asian population (Shah et al., 2010), therefore existing qualitative studies compromised on using non-validated adaptions of acculturation questions in interviews from various acculturation scales validated in other populations e.g. Choudhry & Wallace (2012) explored breastfeeding practices and combined structured items of acculturation measures that was pilot tested with open-ended questions.

One of the acculturation scales validated in the South Asian population in developed countries was the Suinn-Lew Asian Self-Identity scale (SL-ASIA), which tested the relationship of South Asians with the mainstream culture focussing on physical health (eating disorders and body image) (Iyer & Haslam, 2003; Suinn et al., 1987). The original scale (Suinn et al., 1987) was adapted by minor word replacements and tested in the USA (Iyer & Haslam, 2003). The scale yields high reliability (α. 86) and internal consistency for language and ethnic-interaction related items. The scale assesses values and behavioural self-identity e.g.

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[44] Acculturation is the cultural changes influenced by encountering another mainstream culture (Berry, 1997; 2005; Sam & Berry, 2010)

relationship adherence to original and mainstream culture (South Asian or western values), and measures language, identity, behaviours, generational status, geographical history and attitudes (psychological adjustments). (Hsueh et al., 2015; Suinn et al., 1987). A systematic review of SL-ASIA scales used in mental and physical health by Hsueh et al. (2015), showed that most SL-ASIA questionnaires that had been adapted for different populations were not validated (e.g. they were translated into another language without validation) (Hsueh et al., 2015). This also included one study from India aimed at coronary artery disease in the Indian Gujrati population (Dodani & Dong, 2011). Therefore, with limited options, the SL-ASIA scale for South Asians was chosen as the most suitable measure of acculturation for this study (Iyer & Haslam, 2003; Sam & Berry, 2010; Suinn et al., 1987). However, when this scale was tested with Bangladeshi and Pakistani patient and public involvement (PPI) colleagues for face validity for this study, we found difficulties across generations in completing the questionnaire. Issues described included the length of the survey, not understanding various concepts/words used and questions were raised regarding missing cultural hybridity[45] answers e.g. the inclusion of religious prioritise. This may be explained by recognising the evolving and dynamic nature of culture that may be specific to the UK context, since the scale was validated in 2003 in America (a different sociocultural context) (Castro, Barrera, & Steiker, 2010; Iyer & Haslam, 2003). We therefore decided (in the absence of adequate questionnaires) not to use the whole instrument, even though this invalidated the score. So, a few relevant questions from SL-ASIA were placed in the expression of interest form to give an indication of the level of acculturation in the sample, separate to the interview questions (see Appendix 8).

An acculturation scale by Palmer et al. (2007) was considered alongside the SL-ASIA was a validated questionnaire for South Asians in the UK for pain, consisting of 28-items, based on language, clothing style and use of cultural media. The scale was pilot tested and complied from literature reviews, existing acculturation scales validated in other communities and discussions held with community workers from the South Asian backgrounds. But, the SL-ASIA scale was the preferred method in this study, since it closely aligned with the aim of the study and Berry's acculturation model (Sam & Berry, 2010), and has been widely used and tested in various cultures and research settings (Hsueh et al., 2015; Iyer & Haslam, 2003), though Palmer et al.'s scale was better in incorporating a question on religion which was

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[45] Cultural hybridity is the bi-cultural competence and negotiations of being a part of two or more cultures with a new sense of belonging (Hall, 1990, 2014)

missing in the SL-ASIA (Palmer et al., 2007; Iyer & Haslam, 2003). Other acculturation scales that were considered for this study including an acculturation scale (the traditional cultural beliefs scale) looking at food preferences in the USA (Kanaya et al., 2014), and the cultural values conflict scale validated for South Asians in the USA (with internal consistency and test re-test reliabilities), but they were not suitable e.g. the latter scale looked at intimate relations and sex role expectations that were important for females in the first and second generation (Inman et al., 2001), therefore its focus on acculturative stress[46]; one aspect of individual/psychological acculturation was not appropriate (Sam & Berry, 2010).

7.3.3 Selection inclusion/exclusion criteria

The inclusion criteria for participants included:

- From a Bangladeshi or Pakistani ethnic origin (including mixed raced individuals who have at least one parent from the Bangladeshi or Pakistani origin), self-identified by participants or healthcare organisations.
- Aged over 16 and above.
- Participants with an active medical diagnosis of asthma (self-reported by participants or reported by healthcare services). For the latter, it was defined as a coded diagnosis of asthma and being in receipt of a prescription for asthma medication in the previous year.

Participants were excluded if:

- They were unable to give full written or verbal consent e.g. due to the lack of capacity or understanding related to language (although language appropriate resources and interpreters were used where possible and appropriate).
- Participants who had a COPD diagnosis alongside their asthma.

7.3.4 Interview schedule

The interview schedule consisted of main topic areas and several prompt questions (the detailed interview schedule is in Appendix 9). The topics related to:

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[46] Acculturative stress is the reaction and experience of daily stress and degree of psychological/sociocultural adaptation challenges resulting from encountering a larger mainstream culture (Berry, 2005; Sam & Berry, 2010)

- The meaning of asthma and self-management to the participant.

- Strategies used by participants to self-manage their asthma.

- Participant confidence in asthma self-management.

- Factors which Influence asthma self-management e.g. religion.

- Understanding of asthma medication.

- The perceived view of other people in the community on asthma self-management.

- Thoughts on a prospective intervention and suggestions on improving action plans (all participants were shown the Asthma UK action plan whether they owned a plan or not) (Asthma UK, 2016c).

7.3.5 Study procedure

PPI colleagues from Barts and the London and Bangladeshis and Pakistanis from the community were consulted to ensure study materials were fit for purpose. Materials reviewed included an study invitation letter (see Appendix 7), recruitment posters (see Appendix 6), expression of interest form (see Appendix 8), the SL-ASIA (Iyer & Haslam, 2003; Suinn et al., 1987), participant information sheet (PIS; see Appendix 10 and 11), consent form (see Appendix 12), and interview questions (see Appendix 9).

The study procedure included:

1) Participants identified in asthma clinics or GP asthma registers that fitted our inclusion/exclusion criteria were sent an envelope consisting of a personally addressed study invitation letter (see Appendix 7), PIS (see Appendix 10 and 11), consent form (see Appendix 12), expression of interest form and a pre-paid envelope to reply with (see Appendix 8).

2) Participants were asked for informed consent to participate in an audio recorded semi-structured interview (see Appendix 12 and 9). Consent was taken by me (the principal researcher). All participants were informed they could withdraw from the interview at any time. They were further assured that any data collected would remain confidential and anonymous (see Appendix 10 and 11). If participants were not able to read, write or speak in English, an audio recorded translation of the PIS on a CD or an online audio format in the relevant languages; Sylheti or Urdu and English, was given (see Appendix 11). Thereafter, plans were in place for verbal consent to be audio recorded if participants could not understand the consent form, provide initials or signatures. For

this, established procedures recommended by Lloyd et al. (2008a) were followed to achieve full informed consent. The procedure for providing language appropriate resources included:

- The audio recorded PIS was given to participants. They were also given an English written copy of the PIS and consent form so that they could have the option of consulting their family members or others to read the information out for them.

- As the principal researcher, I called participants and asked if they listened to the audio recorded PIS given to them and if they had any questions. If needed, another chance to listen to the audio recording before taking written informed consent in the interview was given (Lloyd et al., 2008a).

3) I (the principal researcher; a female PhD student; BA Hons, PGDip, MSc) carried out one-to-one interviews. I had previous qualitative research experience. Interviews were collected/analysed until data saturation was achieved with respect to the research questions (i.e. when there was a comprehensive understanding of perspectives) (Saunders et al., 2017). Interviews were carried out at Queen Mary, University of London, GP practices, asthma clinics and local cafes in the language preferred by participants. Urdu translators were recruited in case I recruited Urdu speaking participants who could not understand English or Punjabi Urdu speakers.

4) Reflexive notes in a research journal were taken by the researcher after each interview and supervisor and peer consultations took place when necessary (some of which are detailed in section 9.5).

7.3.6 Model/theory underpinning the study

Berry's acculturation model (1997, 2005, 2010)

The study explored acculturation[47], and its influence on self-management behaviour from Berry's cross-cultural health psychology theory which has a large empirical basis (see chapter 6 for a full explanation of the acculturation model) (Berry, 2005; Sam & Berry, 2010). In this study, psychological acculturation (behavioural shifts or acculturative stress[48], adaptations

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[47] Acculturation is the cultural changes influenced by encountering another mainstream culture (Berry, 1997; 2005; Sam & Berry, 2010)

[48] Acculturative stress is the reaction and experience of daily stress and degree of psychological/sociocultural adaptation challenges resulting from encountering a larger mainstream culture (Berry, 2005; Sam & Berry, 2010)

(psychological and sociocultural adaptations to new situations), and the four acculturation strategies at individual or group level e.g. integration[49], assimilation[50], separation[51] and marginalisation[52] were explored (see sections 2.3.5 and 6.1) (Berry, 2005). Explorations on the role of acculturation was drawn from comparing acculturated individuals to non-acculturated individuals within the same ethnicity (e.g. amongst Bangladeshis), contrasting the acculturated group to other acculturated groups in a new society (e.g. amongst Bangladeshis and Pakistanis in the UK), and comparing the acculturated culture to the mainstream (larger) culture (see Figure 7; Sam & Berry, 2010). In this study, the latter was not explored (the contrast between an acculturated group to non-acculturated mainstream group), as this requires a more longitudinal study with a different study design looking at contact between both groups over time (from initial interaction) (Sam & Berry, 2010).

Cultural hybridity theory

The cultural hybridity theory suggests that bi-cultural competency allows utilisation of different cultural collections, switch codes and blend cultural symbols in hybrid ways in a state of constant negotiation between identities (Hall, 1990, 2014), that involves a certain level of experimentation, negotiation, learning and articulation between the combinations of cultural identities to seek out which aspect of culture is the most important to an individual (see sections 2.3.6 and 6.2) (Chatterji & Washbrook, 2014; Hall, 2014; Tarlo, 2010). In this study, hybrid behaviours in pursuing responses to asthma were considered as the ongoing reflected, disputed and redefined factors due to the struggle of ideas on what is the correct belief and practice. This can occur from the use of various domains to meet the needs and different expectations of one's society (Small et al., 2005).

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[49] Integration is an individual/group level acculturation strategy where individuals maintain their original culture and also integrate with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

[50] Assimilation is an individual/group level acculturation strategy where individuals disconnect from their original culture to fit in with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

[51] Separation is an individual/group level acculturation strategy where individuals hold on to their original culture and avoid any adaptation or contact with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

[52] Marginalisation is an individual/group level acculturation strategy where individuals lose maintenance and contact with both original and mainstream cultures (Berry, 2005; Sam & Berry, 2010)

7.3.7 Data transcription

Interviews were audio recorded and transcribed verbatim. Due to contextual and grammatical differences in languages, verbatim translation to English is nearly impossible, therefore to increase reliability, most interviews were transcribed and analysed in the languages participants first chose to speak in, to retain cultural and linguistic specific meanings, expressions, traditions and concepts (Suh, Kagan, & Strumpf, 2009). To do this and account for languages which have no written form e.g. Sylheti (Lloyd et al., 2008a), interviews were transcribed using the 'Bengalish' (Chandra, Kundu, & Choudhury, 2013; Sultana, 2014), or 'Urlish/Roman numerals' strategy (Nadeem, 2012); both of which are the mixing of two languages that retains the pronunciation of the Bangladeshi and Pakistani language but the words are written using the English Alphabet (to note: this is a popular communication strategy widely used by bilingual individuals on social platforms). To date, code switching[53] in language has been increasingly studied in corpus linguistics; a system of language coding based on statistical methods e.g. creating a dictionary for spoken Sylheti (Baker et al., 2000; Chandra et al., 2013). Some individuals can use South Asian words/phrases to express themselves culturally and linguistically and to create certain meanings which they might not be able to do using English (a form of cultural hybridity). Bilingual transcribers were used to complete transcriptions (including myself). This strategy can fill in a much needed cultural and linguistic gap in transcribing data (Ahmed & Tinny, 2013; Sultana, 2014).

7.3.8 Data analysis and interpretation

Interviews were digitally recorded, transcribed and entered into QDA Miner for analysis. The data were analysed using thematic analysis guidelines suggested by Braun and Clarke (2006). Thematic analysis was chosen because it matches the aims of this study. Decisions underpinning the thematic analysis were (Braun & Clarke, 2006):

- The theoretical framework of a contextualist method, where analysis combines two methods of thematic analysis: 1) essentialist - which focusses on individual experiences, meanings and realities and, 2) constructionist - which focusses on patterns of socially produced events, realities, meanings, experiences arising from structural conditions

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[53] Code switching is the switching between two languages in a sentence, phrase, conversation and so forth (Rampton, 2014)

and/or sociocultural contexts. The combination of both methods considers the individual perspective on the meanings of experiences, motivations and interactions and how this has an impact on the wider sociocultural influences on the production of these meanings and realities.

- Patterns or themes were identified with an inductive 'bottom-up' data driven approach; a strategy of data coding without fitting data into a pre-existing coding framework or analytical perception of the researcher, therefore it is an analysis which emphasises on and is driven by data.

- The level at which themes were identified were at a latent, which describes the form and meaning of interview transcripts at the surface stages (explicit level), and further detects, examines and interprets the underlying ideologies, assumptions and concepts which were thought to shape these descriptions (interpretative level) (Braun & Clarke, 2006).

Data interpretation used a combined emic-etic approach to understand the role of culture and cognitions (Punnett et al., 2017). To explain, the etic approach (outsider perspective) is where the researcher makes interpretations of data on culture and may be other factors, whereas the emic approach is culture-specific (insider perspective), where data interpreted by researchers is either readjusted or verified by study participants (Morris et al., 1999). In this study, one participant was consulted for the emic perspective. Moreover, 11% of the interviews were independently coded by a second coder (Susanna Dorwick) for reliability and comparison. The codes and coding framework were reviewed and discussed with two other researchers (Liz Steed, Hilary Pinnock). Participant quotations were presented to illustrate the findings (for anonymity ethnicity and numerical codes were used).

7.3.9 Ethical approval

The study gained NHS ethical approval on 23rd January 2017 (IRAS ID 200955; REC reference 16/YH/0524). Governance approval 011599 (see Appendix 13 for HRA ethics approval letter).

7.4 Results for the qualitative research

7.4.1 Participant characteristics

Participant demographics

There were 49 expressions of interests out of 171 primary care study invitations mailed to participants and 28 invitations given to participants in asthma clinics. No participants were recruited outside of primary and secondary/tertiary care settings. A few responders did not participate: most second and third generation who declined participation described being too busy, some were due to travel to Pakistan, one Bangladeshi male reported anger (which was diagnosed in his medical history) preventing him from participating and one Bangladeshi female reported her husband would not allow her to participate. Other participants were interested in the study but could not be recruited due to time (study length and participants reported being too busy), and achieving data saturation in respect to the research question (i.e. when there was a comprehensive understanding of perspectives) (Saunders et al., 2017).

27 participants were recruited (13 Bangladeshi; 14 Pakistani) (see Table 8); interview duration ranged from 20 minutes to over two hours. There were 14 females and 13 males, between the ages of 16 to 72; recruited from primary care (n=15), secondary care (n=11), and tertiary care (n=1). Participants resided in the London Boroughs; Tower Hamlets (n=15), Waltham Forest (n=11) and Redbridge (n=1). There were ten first generation participants (five Bangladeshi; five Pakistani), ten second generation participants (five Bangladeshi; five Pakistani), seven third generation participants (two Bangladeshi; four Pakistani), and one fourth generation participant (one Bangladeshi). Most second and third generation participants had asthma since childhood (including one first generation Pakistani participant; n=12). Most first-generation participants decided to speak in their mother-tongue in the interviews even though they could speak English (Sylheti n=3, Standard Bengali n=1, Urdu n=3).

Degree of acculturation in the sample

Questions from the SL-ASIA was used to identify the degree of acculturation amongst participants (Iyer & Haslam, 2003; Suinn et al., 1987). In response to the question; *how do you identify yourself? -*

- Most participants identified themselves as either 'British Bangladeshi' or 'British Pakistani' (n=22), and one participant identified themselves as 'British South Asian'. This

may reflect that both cultures were important; the integration[54] strategy of acculturation (Sam & Berry, 2010).

- Four first generation participants showed a 'South Asian' identification (identifying themselves as 'South Asian Bangladeshi' or 'South Asian Pakistani'), which may reflect the separation[55] strategy of acculturation (Sam & Berry, 2010).

- None of the participants identified themselves as 'British' only.

In response to the question; *how would you rate yourself? -*

- Twelve participants identified themselves as 'bicultural', which may reflect the integration strategy of acculturation.

- Nine participants had South Asian identifications ('very or mostly South Asian' n=9; mainly from the first generation, n=7), which may reflect the separation strategy of acculturation.

- Four participants identified themselves as 'mostly westernised' and one participant identified themselves as 'very westernised, which may reflect the assimilation[56] strategy of acculturation.

In response to the question; *what language/s can you speak? -*

- Most participants rated themselves as 'bicultural' (n=12; mainly from the second generation, n=7), which may reflect the integration strategy of acculturation.

- A few participants had western identifications ('very westernised' n=1; 'mostly westernised' n=5; mainly from the third generation, n=3), which may reflect the assimilation strategy of acculturation.

- All participants could speak English to varying levels: 'mostly South Asian with some English' (n=7; all from the first generation), 'bilingual' (n=11), and 'mostly English with some South Asian languages' (n=9), which may mainly reflect the integration strategy of acculturation.

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[54] Integration is an individual/group level acculturation strategy where individuals maintain their original culture and also integrate with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

[55] Separation is an individual/group level acculturation strategy where individuals hold on to their original culture and avoid any adaptation or contact with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

[56] Assimilation is an individual/group level acculturation strategy where individuals disconnect from their original culture to fit in with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

- South Asian languages spoken alongside English ranged from Standard Bengali, Sylheti, Urdu, Punjabi, Hindku and Mirpuri (see Table 8).

Table 8. Participant characteristics (Bangladeshis and Pakistanis with asthma)

Ethnicity/ Generation	Gender	Age	Selected SL-ASIA questions			
			How do you identify yourself?	What language/s can you speak?	South Asian languages spoken?	How would you rate yourself?
Bangladeshi						
First	Male	45	South Asian: Bangladeshi	Mostly South Asian, Some English	Standard Bengali; Sylheti	Very South Asian
First	Female	32	British Bangladeshi	Mostly South Asian, Some English	Standard Bengali; Sylheti	Mostly South Asian
First	Male	52	South Asian: Bangladeshi	Mostly South Asian, Some English	Standard Bengali	Mostly South Asian
First	Male	50	British Bangladeshi	Bilingual	Standard Bengali	Mostly South Asian
First	Female	40	British Bangladeshi	Mostly English, some South Asian	Standard Bengali; Sylheti	Very South Asian
Second	Female	49	British Bangladeshi	Mostly English, some South Asian	Standard Bengali	Mostly westernised
Second	Female	34	British Bangladeshi	Bilingual	Standard Bengali	Bicultural
Second	Female	21	British Bangladeshi	Mostly English, some South Asian	Sylheti	Very westernised
Second	Male	39	British Bangladeshi	Bilingual	Sylheti; Urdu	Bicultural
Second	Female	29	British Bangladeshi	Bilingual	Sylheti	Bicultural
Third	Male	29	British Bangladeshi	Bilingual	Standard Bengali; Sylheti	Mostly westernised
Third	Female	20	British Bangladeshi	Mostly English, some South Asian	Standard Bengali	Mostly South Asian
Fourth	Male	22	British Bangladeshi	Mostly English, some South Asian	Standard Bengali	Bicultural
Pakistani						
First	Female	43	British Pakistani	Mostly South Asian, Some English	Urdu; Hindku; Sylheti	Mostly westernised
First	Female	72	British Pakistani	Bilingual	Urdu	Bicultural
First	Female	65	South Asian: Pakistani	Mostly South Asian, Some English	Urdu	Very South Asian
First	Male	56	South Asian: Pakistani	Mostly South Asian, Some English	Punjabi	Bicultural
First	Male	57	British Pakistani	Mostly South Asian, Some English	Urdu; Punjabi	Very South Asian
Second	Female	49	British Pakistani	Bilingual	Urdu	Bicultural
Second	Male	43	British Pakistani	Bilingual	Urdu; Punjabi	Bicultural
Second	Female	42	British Pakistani	Bilingual	Urdu; Punjabi	Mostly South Asian
Second	Male	41	British Pakistani	Bilingual	Urdu; Punjabi	Bicultural
Second	Male	43	British Pakistani	Mostly English, some South Asian	Urdu; Punjabi	Bicultural
Third	Male	18	British Pakistani	Mostly English, some South Asian	Urdu; Punjabi	Mostly westernised
Third	Female	20	British Pakistani	Mostly English, some South Asian	Urdu; Punjabi; Mirpuri	Bicultural
Third	Female	16	British Pakistani	Bilingual	Urdu; Punjabi; Mirpuri	Bicultural
Third	Male	22	British South Asian	Mostly English, some South Asian	Urdu; Punjabi	Most westernised

7.4.2 Summary of themes
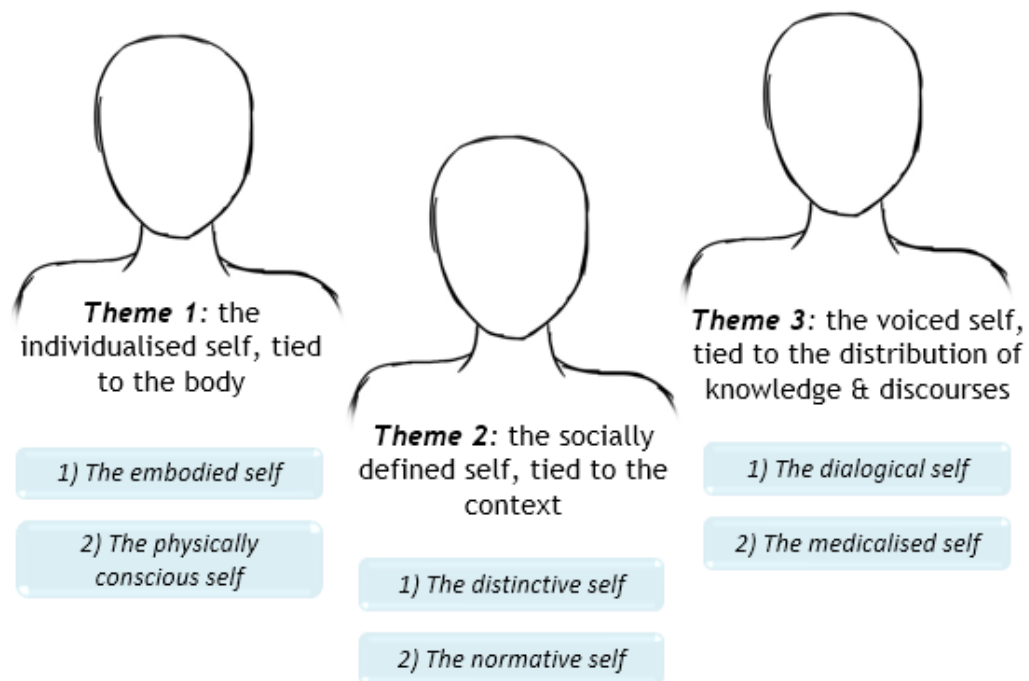
Figure 9. Thematic schema: Identifying the Bangladeshi and Pakistani 'self' in self-management

To understand the dynamic role of Bangladeshi and Pakistani culture and asthma self-management, data showed that parts of the self[57] were important to pull together for a holistic understanding of how the participant self-managed asthma across different situations. Several sub-themes emerged from the data which were collated and linked to three main findings (see Figure 9):

- Theme one - *The individualised self, tied to the body;* the self that made sense of asthma self-management when the body experienced asthma symptoms, *1) The embodied self:* the Bangladeshi and Pakistani self that made sense of asthma around the body, *2) the physically conscious self:* the self that became physically conscious of the impact of asthma on the body and therefore initiated self-management around balancing the body from experiencing asthma.

- Theme two - *The socially defined self, tied to the context;* the Bangladeshi and Pakistani self that made sense of asthma self-management when the self encountered others in

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[57] The self can be broadly defined as direct or indirect statements that comprise of the self referring to *'I', 'me', 'mine', 'myself'* (Triandis, 2018), in social motivations, attitudes, beliefs, intentions, norms, roles and values (Cooley, 2017; Triandis, 2018)

different social spaces and became aware of the symbolic gaze of others, *1) the distinctive self:* the self that was aware of others while understanding themselves in social spaces and making ongoing negotiations on the correct/incorrect self-management behaviours, *2) the normative self:* the self that was aware of others (their cultural expectations e.g. gender roles and comparisons made on their asthma self-management behaviour), influenced self-management.

- Theme three - *The voiced self, tied into the distribution of knowledge and discourses;* the Bangladeshi and Pakistani self that made sense of available information/discourses on asthma self-management from the society and healthcare services, which later shaped asthma self-management; *1) the dialogical self:* the extent the self had dialogues and communicated about asthma with others shaped self-management and the type/level of social support given, *2) the medicalised self:* the self that relied heavily on disease management approach to self-management (e.g. asthma medication and monitoring), due to selective information distributed, regulated and reinforced by HCPs and healthcare settings.

The final section describes findings related to participant thoughts on which HCP was the most important in their asthma care and opinions around intervention needs and PAAP improvements.

7.4.3 Theme one: The individualised self, tied to the body

This theme illustrates how participants made sense of asthma self-management when the body experienced asthma symptoms; 1) *the embodied self:* the self that revolved around understanding the body with asthma, as a feeling inside the body, transformations on the body and how the body functions with asthma and, 2) *the physically conscious self:* the self that became conscious due to the impact of asthma on the body, therefore self-management revolved around the need to balance the body from experiencing asthma e.g. maintaining asthma control, keeping the body away from environments that can worsen asthma and regulating the body.

1) The embodied self

Most participants believed self-management was a form of control and discipline of the body. Participants localised asthma as a feeling inside the body; describing asthma as

something that was present (e.g. depending on feeling or noticing bodily symptoms), or absent e.g. the feeling when asthma was controlled or maintained that suggested normality. Participants described body fluctuations or body transformations (asthma aged the body), e.g. *'asthma comes and goes'* and/or asthma *'just suddenly happens'*. The quote below illustrates this point by the participant using a metaphor:

"So, I kind of, transitioned from that to, the point where now I don't have to think about it anymore [referring to asthma and self-management]*, it's only when I'm ill when I'm thinking, 'Shit, I'm going to have to look after myself. Otherwise, that phantom asthma is going to come back again'… So" (Bangladeshi, 3G, p21).*

One participant described how her asthma physically transformed her body from a girl to a woman, but not psychologically. The quote below illustrates how her belly aged becoming bigger and fuller which prevented the free flow of her breath from going in and down her belly properly:

"Mai slim, smart, young larki thi (laughs) woman bana diya. Iss ne mujhe woman bana diya hai. I am 43 years old. But I am still a young girl. I'm not thinking myself I'm old, but iss ne na, iss breath kay problem ne, mera, paet bahir nikal diya hai. Kuin kay, poori tarah woh saahs neeche nahee jata".

"I was a slim, smart, young girl (laughs) it [referring to asthma] made me into a woman. It made me into a woman. I am 43 years old. But I am still a young girl. I'm not thinking myself I'm old, but you know this, this breath problem, my, made my belly go out. That's because, the breath does not go down properly" (Pakistani, 1G, no1).

Additionally, metaphors were used to describe the body by providing an imagery on how the body functions with asthma (the meaning and feeling of asthma), e.g. the metaphor *'phantom asthma'* was used to illustrate its elusive nature of coming and going and the metaphor *'the enemy of asthma'* was used to symbolise its relationship to allergy as something that needs to be battled with. Hence, metaphors of the body were also used to describe the internal struggles of fighting or surviving against controlling asthma e.g. the metaphor *'beat everything's', 'beat asthma',* and *'save self', 'save the body'* was used to describe a sense of fighting and protection, and *'fire extinguisher'* was used to describe the impact of the reliever on the body:

"I mean, I don't want to get beaten by disease, I want to beat disease (laughs)" (Bangladeshi, 1G, p4).

Metaphors of feelings were also used to conceptualise the healthy body before having asthma e.g. describing the oneself as a *'horse that never sits'*; and *'feeling like a horse'* to demonstrate the strength of the healthy body:

> *"I used to think myself that I am like you know, horse. Horse never sits, I can work whole day, I had this record. I went to central London, I went to Hyde Park, I walked there, I loved it in summer time, I loved to walk, from here I used to go to you know, Tower Bridge, everywhere. I feel like I am horse. I am not even after one, two, three, four hours walking, I don't feel tired, I used to feel like this" (Bangladeshi, 1G, p4).*

External triggers and clinical validations were described as the source of feeling asthma e.g. physical activity and medication side-effects:

> *"…'Erm… Asthma… for me asthma ha? Asthma I don't know, before I no feeling asthma. Because when you go to this 'erm… Hospital, doctor say you have asthma. Because when you're working and running, too much 'erh… (demonstrates breathing in and out)" (Bangladeshi, 1G, p3).*

When participants described the presence of asthma around the body, most of the time it was restricted to the time of year (e.g. becoming asthmatic or feeling asthma during winter), though a few participants who had allergies attributed asthma triggers to the summer. Asthma was perceived to be a cold illness sporadically triggered by cold or caused by other cold illnesses (e.g. chest/lung infections, flu, cold, pneumonia), and/or feeling cold constructs that make the chest cold (the physical impact on the body) e.g. the UK cold weather, the cold environment, cold sweat and cold food/drinks.

> *"Ze ami konu tandah desho takhar karoneh oilo ni nah kittah? Ami toh, maneh, ekhon bishi, ottah-o sinta kori zeh... mono kao ekk motroi zeh different weather-o, ammar zor moi eek zagath, brought, brought up o ekk zagath, born oisi ekk zagath, brought oisi ekk zagath. Toh ekta different, ekta laghi hee weatheror logi ehh weather completely, different. Maneh different. So… moo ottobar weatheror karoin neh ita oisi".*
>
> "Is it because I am staying in a cold country, is that why? I, I mean, now too much, I worry about that [referring to what may have externally caued asthma]… Maybe it is because of different weather, I was born in one place, brought, brought up in one place, born in one place, brought up in one place. So, it's different, it's like that weather with this weather is completely different. Meaning different. So… It's [referring to asthma] because of the weather it's happened" (Bangladeshi, 1G, p1).

Some participants across all generations described that they knew that asthma was a chronic illness, however they still described asthma as a dormant bodily feeling that comes and goes,

e.g. asthma was described as something that *'flares up', 'supressed', 'deep down somewhere'*, and *'more prominent'* in certain conditions:

"Not really, I understand obviously it's [referring to asthma] just a long-term thing that, I have to kind of deal with but 'erm, I don't feel 'erm… For me I find it comes and goes, like, most days I don't find like I had, I don't feel like I had asthma. Some days when it's cold or, when I'm ill, I find that it flares up. Yeah, it might be there every day, but I don't, feel it as much. If I'm doing an extreme exercise, where I got a cardio exercise, sometimes it might flare up then, but on a day-to-day basis I don't feel like it's there all the time" (Pakistani, 3G, p26).

Numerous emotions were reported by participants either as causing/triggering asthma or existing in the body with asthma, including:

- Stress e.g. the stress of work, home life (including children), family responsibilities, relationships, student life, lifestyle in the UK, finance, lack of privacy in traditional Bangladeshi and Pakistani culture and family involvement.

- Depression e.g. thinking too much about the impact of asthma, family reaction to asthma and the UK lifestyle which can worsen asthma.

- Anger e.g. anger towards primary care services, racial attitudes of other cultures, family members, traditional cultural expectations placed on females, lack of privacy in the Bangladeshi and Pakistani culture and bereavement.

- Anxiety or fear e.g. from not carrying the inhaler, being careful around triggers, restrictions in social life, accessing healthcare services, employment loss fears, societal reactions to asthma, stories or experiences of asthma deaths, flashbacks of breathlessness and fears of asthma medication side-effects in developing further complications.

- Astonishment of receiving an asthma diagnosis was described by some first generations due to not being able to feel asthma inside the body or comparing their own asthma to family members who have worse asthma control.

- Worrying about the future was specific to the first generation where they were concerned about dealing with the chronic nature of asthma while ageing e.g. the fear of losing of self-efficacy, confidence, mental strength/control.

Descriptions of emotions were similar to expressions of asthma e.g. anger and depression was described as *'coming and going'* or *'just happening'*, and stress and anxiety was described as building up inside the body which needed to be released.

> *"Bas phir. Thora jab, ghussa aata hai. Phir hatt jata hai".*
>
> "That's it, after. After a little, anger comes. After it goes away" (Pakistani, 1G, p8).

Some participants either reported feeling asthma before receiving a diagnosis or others were only able to recognise their asthma after clinical diagnosis. The need for clinical validation was important for the participant to form an asthma identity and transition the self into management e.g. two first generation Bangladeshi participants were prescribed inhalers by their GPs but struggled to receive a diagnosis. The quote below illustrates this and how time of year influenced asthma perception (as noted above):

> *"Ami doctore kotoh bar geshi, summar ailoh ammar asthma oi zai. Teh doctore zawar foreh, doctore kali inhaler dain, ammar diagnosis laghe fataisoin na, teh ami koi ekk bar koisi zene buzai zai ammar asthma oi geshi".*
>
> "I went to the doctor several times, when summer happens my asthma happens. After going to the doctors, the doctor keeps giving me inhaler, he doesn't send me for a diagnosis, so I, a couple of times said that I think I developed asthma" (Bangladeshi, 1G, p5).

On the other hand, two Pakistani participants who received asthma diagnosis had little degree of acceptance. They described needing further clinical validation or reaffirmations of having asthma. This was related to not having the space or comfort to speak about their diagnosis with HCPs, even though they felt asthma and received asthma treatment e.g. one participant was confused about observing asthma severity/variability in others:

> *"I want to know. I want to clearly, I want to know, do I have asthma or not? Because still I'm not sure. Inside, I'm thinking maybe I have asthma, because I saw the lots of people they have symptoms, they got totally different than me. Yeah" (Pakistani, 1G, p6).*

2) The physically conscious self

The feeling of asthma (and emotions that worsen it) taking over the body or beliefs around body transformations enabled participants to become consciously aware of asthma in the embodied self influencing behaviour. This meant several things for self-management (sometimes clinical diagnosis of asthma was necessary for self-management to occur); becoming physically conscious for the need for asthma control, keeping the body away from environments that can worsen asthma and regulating the body to maintain natural balance.

Consciousness of the need for control

The absence of asthma meant that there was little need for control and self-management. This was independent of whether participants had a recent asthma attack and whether they were receiving care from secondary asthma clinics. Therefore, these participants questioned whether there was a need to attend regular appointments, adhere to medication or doubted the need to carry an inhaler. Most participants described that they learnt through experience when they could lose asthma control (this influenced their sense of perceived self-efficacy).

Consciousness of the body in the environment

The self that physically removed the body away from environments where participants felt asthma occurred in various ways:

- Asthma triggers avoidance occurred, even though most first generation participants were unfamiliar with the concept 'trigger'. Smokey environment was mentioned as being more prominent in Bangladeshi and Pakistani culture e.g. men who smoke and certain fumes from Bangladeshi cooking styles was described as something that was common in culture. On the other hand, two Bangladeshi participants from the second and fourth generation tried smoking to deal with stress and improve breathing.

> *"Should I tell you something funny? Like, it's weird but… There was like few times where I was feeling really wheezy, and then I had a cigarette and it made it better. I'm not joking, honestly (laughs). It's like, I think it's because that, the smoke is going and coming out or something it, or it made me feel a bit calm or something, I don't know" (Bangladeshi, $g, p27).*

- Participants carefully planned and avoided risks, and over-exertion in physical activity e.g. talking too loudly or too much, extraneous work, avoiding family responsibilities, walking, running, riding a bike or heavy lifting. Household chores were sometimes delegated to family members as a last resort. For some participants, self-management (control) also meant that the self needed to be physically active in learning preventative measures (e.g. exercise), adjusting medicine dosage and carrying the inhaler.
- At times, the physical act of taking asthma medication or attending asthma appointments sometimes reinforced the presence of feeling asthma without asthma symptoms.

Consciousness of body regulation

During the presence of asthma, the self which employed self-management that involved strategies that balanced the fluctuations of feeling asthma inside the body in the following ways:

Using treatment reactively -

- Treatment was applied periodically e.g. medication use and adjusting dosage when asthma was perceived to be present allowed asthma to go away.

Maintaining psychological peace -

- Maintaining psychological peace while feeling emotions (and asthma) inside the body. This sometimes meant taking feelings from inside the body and releasing it outside:

"Yes, you can say that sort of helps the breathing if like, if you've got like shallow breathing, then you can relax and just take the stress out, take breaths" (Bangladeshi, 2G, p12).

This was achieved by:

→ Taking breaks or relaxation e.g. after inhaler use, closing the eyes/sleeping, keeping calm, going quiet, resting after activities, exercise/driving, avoiding others, smoking or doing nothing.

→ Diverting attention e.g. reducing stress and depression through smiling, keeping busy/distractions with social or religious activities, reassurance through changing the topic or questioning one self and grounding the self (strategies to be present) with thoughts of family responsibilities especially for children.

→ Changing one's environment e.g. escaping by going outside of the house or locking the self in the room, space away from family responsibilities and avoidance of others and situations. For instance:

"No one else has asthma in my house, so doesn't really come up, unless I'm having an episode then I basically tell everyone, leave me alone for a little while, so don't bring me your troubles and your, problems, firefight yourself for a little while, just let me recover basically so, that's the only time I'll bring it up" (Bangladeshi, 3G, p21).

Although, sometimes avoidance meant also avoiding learning about asthma which was perceived to be a method of reducing stress.

- Religious coping was a part of maintaining psychological peace with asthma and emotions (except for three participants most individuals were orientated towards practicing Islam). This self managed asthma around religious worship which helped regulate emotions. This was described to be helpful for various purposes; feeling a sense of peace, relief, help, hope, refreshed, managing negative thoughts, grounding strategies to become present, and protecting themselves from bad habits e.g. smoking or the belief that external harm was prevented by divine intervention through worship.

"When I was a kid, I would pray every day, that my asthma gets better, so I guess you could say that, that was my sort of, psychological relief or help or hope, that you would basically, throw away" (Bangladeshi, 3G, p21).

A range of activities were described as useful religious self-management strategies e.g. prayer, ablution (washing parts of the body in a set pattern for purity in prayer and other forms of worship), reading the Qur'an, reading the explanation of the Qur'an (tafsir), attending religious lectures, contemplating on life and death, fasting in Ramadhan, dua (supplication) allowed an avenue to speak to God, trust in God, and performing ruqyah shariah[58].

"Yeah. I would say the movements in prayer, it helps your body, it helps breathing and feeling that, yeah praying, it makes you that feel that peace inside and, it helps your breathing. Personally, I find that the case" (Bangladeshi, 4G, p27).

Counterbalancing the physical -
- Another way of maintaining the harmony inside the body was to counter balance cold triggers or causes with hot remedies, including:
  → Dressing up warm or wearing layers of clothing e.g. gloves, socks, coat, jumpers/hoodies/cardigans, shawls, caps, thermal clothes and using a blanket.
  → Increasing walking outside and exercising in the summer to feel the heat (apart from participants who suffered from allergy), and there was a decrease in motivation to be active in cold weather.

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[58] Ruqyah shariah is an Islamic treatment and healing strategy for physical, mental, spiritual and supernatural illnesses, consisting of devotion to worship (e.g. prayer, reading Qur'an and supplication), and lawful incantations based on the Qur'an and the sayings of the Prophet read on various substances such as certain herbs and foods (Eneborg, 2013)

→ Avoiding cold environments e.g. avoiding going outside the house, using the swimming pool, fridges in retail stores, washing the dishes, ablution (washing parts of the body in a set pattern for purity in prayer and other forms of worship) with cold water, showering too much and damp housing. But, participants increased use of hot environments e.g. using the sauna, steam room, heater and the hot water bottle.

→ Avoiding cold food/drinks (e.g. fizzy drinks, juice, smoothies, ice cream, banana, watermelon, yoghurt, milk, cheese, pineapple and mango), and indulging in hot food/drinks especially in the winter e.g. tea, soups, warm water, coffee, hot rice, chocolate, crisp, honey and ginger. Sometimes, there were comprises made on consuming cold food by making them hot:

"Dhori lowka yoghurt oh zodeen khai nani, freezo zodeen yoghurt takhe, teh ami microoveno deh shamainoh ghorom kori (laughs). Ami zani ikta, khawa illah tikh nai ghorom koriya yoghurt. But, ami shamainoh ghorom kori khai, ammar dhor kore zain khaile asthma bari zai".

"Take for example if I eat yoghurt, if the yoghurt is in the fridge, then I heat it up slightly in the microwave (laughs). I know this is, eating it like this is not right, by heating the yoghurt up. But, I slightly heat it up and eat it, I'm scared that if I eat it asthma will be worse" (Bangladeshi, 1G, p5).

→ Two Bangladeshi first generations out of the whole sample had beliefs around sweating which was perceived to worsens asthma. One participant believed that the sweating process and continuous ablution (washing parts of the body in a set pattern for purity in prayer and other forms of worship) drained away the impurities from inside the body to make it natural again. Another participant described hot sweat needed to be wiped with a tissue or towel before it gets cold and makes asthma worse as illustrated by the quote below:

"Toh, ghoromor shomoi ektok tah, aitiya zeh shomoi ami ghami zai, oh gham takhe ammar oi zai. Toh ami loghe, loghe barah takhle oh ami tissue diya ammar, gholah tah ba, joh tah ektok niray zahgath giya musi. Nah ghoroh aiyo, ghoroh aiyah ami tissue deh ba towel deh ami shoril mushi zene, ami buzi ghond. Gham takhe ammar tanda aiyah asthma oi zai, ar shash khosto oi zai"

"So, during hot times, if I walk a bit and I sweat, from this sweat it [referring to asthma] happens. So immediately I, immediately I use a tissue if I'm outside, on the neck and I go to a quiet place and wipe. Or if I am at home, after coming home I use the tissue or towel to wipe my body, I feel the stink. From the sweat the cold comes and my asthma happens, and I start having breathless" (Bangladeshi, 1G, p5).

7.4.4 Theme two: The socially defined self, tied to the context

This theme illustrates how participants made sense of asthma self-management when the self encountered others in different social spaces (close, distant, new or old), and became aware of their symbolic gaze; *1) the distinctive self:* the self that was aware of others while understanding themselves and making ongoing negotiations on the correct/incorrect self-management behaviours, *2) the normative self:* the self that was aware of others (their cultural/social expectations e.g. gender roles and comparisons made on their asthma self-management behaviour), while negotiating self-management needs.

1) The distinctive self

The self in social spaces of others can define how the self is characterised and transformed according to context. This can involve a process of ongoing negotiations, assessments and reflections on understanding oneself and boundaries of what is the correct or incorrect health behaviours.

Distinctiveness of Bangladeshi and Pakistani culture

Participants described what they believed was distinct about the Bangladeshi or Pakistani culture which influenced thinking around self-management of asthma, including:

- Smoking was described as a part of culture and family especially for men e.g. growing up with male relatives smoking was perceived to be a major contributing factor in worsening asthma, which participants perceived was difficult to escape since it had deep roots in family/culture:

> *"For me personally, my family is not a really much of a smoking family so, I don't really have that issue, but I know for Asians in general I know that a lot of people especially males, do smoke. So, I think in terms of culture it can have an effect* [referring to asthma]*, especially if you're surrounded by a lot of smokers, for me I've only got a few people that smoke, so I'm not really too connected with it, but for a lot of other people understand that, it is quite a lot, especially if it is, most of their families smoking"* (Pakistani, 3G, p23).

- Food habits e.g. rice for Bangladeshis/biryani for Pakistanis, curries (fish curries especially for Bangladeshis), avoiding dairy products especially milk (believed to increase cough/sputum amongst Pakistanis), and the amount of oil used in cooking. Bangladeshis

mentioned narratives around avoiding specific food that worsens asthma e.g. fish (Ilisha and Boal; names of Bangladeshi fishes, and Shrimp), aubergine and red meat (goat or beef).

- Some participants described practical family support was a part of culture, even though this could worsen asthma e.g. helping in domestic duties. On the other hand, there were other practical family support which helped participants (e.g. keeping an inhaler in the houses of different relatives), and examples of where participants helped others in the family with their asthma e.g. distributing the inhalers of participants to relatives/peers and even to family in South Asia.

"Yeah, I've got a, my uncle's daughter back home. She's got asthma but 'erm, they give my medication to her like 'cause, because the inhalers there, here, what we've got is expensive back home" (Bangladeshi, 2G, p13).

- The use of CAM was variable across generations (mostly used alongside biomedicine). This was mainly the use of tea with other additions e.g. honey, lemon, lime, ginger and black pepper. Other forms of CAM used were spiritual healing and chewing ginger. CAM specifically described in Pakistani participants was homeopathic medication use and malathi (a wooden stick to chew on which helped blockage in the throat). Two participants described that CAM use was promoted/recommended on Bengali TV (e.g. wearing amulets to cure asthma) and salt mines were widely recommended in Pakistan, but these were not followed.

- Exercise was identified as something that was not part of the traditional Pakistani culture in older people.

- In the first generation, there were narratives of the original country (the country in South Asia where participants were born/raised in) as the better country for health (e.g. the UK was perceived to be a cold country which either caused or worsened asthma), and South Asia had better paid access to seeking good quality healthcare compared to the UK (despite being a third world country with low resources):

"But, in this situations, I feel 'erh, Bangladesh are more lucky, Bangladeshi people. If you pay, you see a good doctor. There are so many good doctors, if you pay, you can see good doctor. If you have money, you can have good treatment, but here I don't know what to do (laughs)" (Bangladeshi, 1G, p4).

In addition, some Pakistani first generations sought treatment from Pakistan on homeopathic medicine e.g. one participant had powder delivered to the UK.

Distinctiveness of cultural shifts in the UK

There were various examples of cultural changes across generations which influenced thoughts around asthma self-management. For instance, participants who spoke in English used South Asian languages to culturally express themselves which could only be illustrated in their mother-tongue and negotiations on individual behaviours around food choices. For example, Pakistanis parents believed that there was strength in their national food roti which children need to consume for good asthma health:

"I have a mixture. So, I mean I eat less, Asian food 'erm, but that's not because I don't like it. It's just, you just can't have it every week, every day. It just gets too much now, I mean we're, we're a different generation than our parents were. They would think, okay, this, this strength is in this [referring to food] *and if you don't have that, then, you're not going to get any strength, but, they'll kill all the vegetables and everything, there's nothing left in there (laughs). 'Erm, but we've got options of more variety now, so, may be, our, couple of days a week I'll have Asian food, couple of days a week I'll have non-Asian food" (Pakistani, 2G, p17).*

Cultural changes and negotiations made around asthma self-management, included:

- Experimentation with asthma self-management strategies ('trial and error'), which involved learning, trying out and exploring boundaries of different asthma self-management strategies e.g. moving away from the biomedical instructions by playing with medication intake/dosage, or seeking out other preventive strategies such as exercise, and using CAM such as Chinese medication. Continual use of these self-management strategies was validated by beneficial experience. Experience (or expertise) of self-managing asthma was described as more important than medical expertise. Experimenting with asthma self-management strategies was perceived to be alien in the older first generation by non-first-generation participants, though cultural endorsements transpired if this aligned with traditions or cultural norms relevant to the first generation. For example, the quote below illustrates that trying different asthma self-management strategies such as exercise may be novel to some individuals in the Bangladeshi community which may questioned or criticised:

"Them, I usually fit in really well [referring to the White population]*. They are usually quite embracive of, pushing your boundaries, trying different things, you don't get the*

sort of, why would you do that for? Sort of comments and 'erm, the sort of I don't know, people more ambitious I think, in the Bengali community I think people are ambitious only in a financial regard. If you're basically pursuing finance then everyone's very supportive, and they want in on it as well. Whereas, if you are saying you're going to have boxing match, you're crazy! If you tell someone you do like a military assault course, they'd be like why would you do that? Why don't you just go around the park? Why you going to do a marathon for? Or flying planes for example, actually flying planes people love that, Bangali qoun, 'Pilotor license anrai ni?' (Bengalis say, 'Are you get a pilot license?') …You know typical Bengalis. But, sailing for example, why you going to sail for? Go Bangladesh and, I don't know. It's not as, because it's alien in the community a lot of things are alien and anything the alien, is either frowned upon or ridiculed. Some people embrace it, some people are like, 'Wow, what you do is interesting what different', those sorts of things, not really, gel with Bengali community as much, my colleagues are a lot more, I guess the type of people I hang around with" (Bangladeshi, 3G, p21).

- UK born/raised participants exchanged personas according to context. For instance, in family settings they can be more traditional compared to peer settings where they were less traditional, therefore asthma self-management behaviour became fluid according to this (the quote below described how they perceived attitude towards asthma self-management according to different settings):

"Comparing university to home. I mean to, if there's a family event, then I think people are more cultural and more back-home minded. Even though we're here in the West, like when in those family groups, people take a step back into culture and they talk Bengali and this… But then the same people if they are in a university area, they'd be more open to it, and they'd be like okay like, it'd be looked at like more of a you know, under control thing" (Bangladeshi, 4G, p27).

- Religious identity was important to most participants. Asthma self-management behaviours related to religion were given precedence over traditional Bangladeshi and Pakistani culture. Therefore, asthma self-management was arranged around religious beliefs (e.g. respect for treating the body well), therefore prioritising self-management and maintaining trust/reliance on God for coping with asthma. For example, a participant described how her connection with God was a form of support that helped her with asthma self-management:

"No, I think if anything, that makes you stronger… I think just, genuinely knowing that you have, someone that you could, whose there for you, who listens to you… And gives you guidance, it's a good benefit, it's a great benefit" (Pakistani, 2G, p18).

There were concerns around correctly practising religious duties in Ramadhan while managing asthma e.g. uncertainty around whether asthma medication invalidate fasts and the need for clarification on this:

> *"Well… Because Ramadhan is approaching. So, that I think you have to manage asthma right. And it's interesting because some people they say, 'It breaks your fast', some people say, 'It doesn't break your fast'. So, I'm still trying to figure it out. I mean, for the past however many years I've been keeping fasts. I always use the inhaler and I still kept the fast but only in the past two years, I found out that when you have the inhaler that your fast is not accepted, so now I'm having to think, what am I going to do in this Ramadhan and how I'm going to handle it"* (Bangladeshi, 4G, p27).

Some participants also articulated that they were concerned about self-management behaviour of family members with asthma during Ramadhan:

> *"Oh, my little sister, she's got asthma. And I do ask her like you know, because her one, it's a little bit worse than my one. Yeah. So, like, so, I do ask her like, 'Do you need any more?' Or like 'How are you feeling'? But she's a weirdo, like last night, I went to her room and then I see she's like wheezing, and I go, 'Why don't you use the inhaler'? And she goes, 'Nah, I'm training myself for Ramadhan' (laughs). I was like that doesn't make sense (laughs)"* (Bangladeshi, 4G, p27).

Distinctiveness of acculturative stress

There was evidence of various forms of acculturative stress[59] across different generations. The first generation had distinctive acculturative stress due to migration and survival in the UK that worsened their asthma, including:

- Educational attainment or previous work credentials had no value in the UK, therefore some participants described hardship living in the UK since they had to push themselves in working in a lower employment setting that could trigger their asthma. Survival in the UK society was given more priority over asthma control which meant that participants could not concentrate on their asthma self-management and/or made compromises for their asthma self-management. For example, in the quote below a participant described how he had a better lifestyle in Bangladesh with a well-paid job and benefits, however when he settled in the UK he had to compromise for a managerial retail job that revolved

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[59] Acculturative stress is the reaction and experience of daily stress and degree of psychological/sociocultural adaptation challenges resulting from encountering a larger mainstream culture (Berry, 2005; Sam & Berry, 2010)

around cold environments such as the freezer which worsened his asthma, and his living standards became poor compared to South Asia (e.g. damp housing and mould in the rooms affected his asthma). He described the deterioration of his self-efficacy and confidence by living in the UK environment e.g. losing economic capital after migration:

> *"I am in depression, like you know I have, those things also because of my depression, stress, and this is the by-product of European environment. We are, I am came here ah to change my conditions, but I could not change my conditions, rather, I make some by-product. What I am earning here, I used to earn more than this while I was in Bangladesh. I am paying you know, in my Bangladesh, in Dhaka, if I discuss with my friends, that you see, my house size is, I think is a bit bigger than your store size, but I am living in a small room, but how in Bangladesh our you know, toilet is like this (laughs)" (Bangladeshi, 1G, p4).*

- Another participant emphasised that the UK environment has given him so much stress that led him to have psychological issues which distracted him from concentrating on his worsening asthma. He described how the government were trying to stop him from being together with his family from Pakistan, by not allowing him permission to bring them to the UK. Therefore, he blamed the government for his poor asthma and mental health issues.

- Bringing up children and grandchildren in the UK meant that for some first generations, they were faced with challenging asthma advice from their family members that did not agree with since it did not comply with their way of understanding self-management, therefore they resisted any advice given (illustrated in the quote below):

> *"You know, children are, they advise me (laughs). They children, they advise me (laughs). She say, 'Grandma, you don't know. You do what you know. This* [referring to asthma advice]*, I know better, I know better' (laughs)… Yeah, they said, yeah, other day they said to me, 'Grandma, don't worry, we know, we read it'. And you know when, when I was young, we said to our parents. Yeah. Because younger mind is a, whole world is mine (laugh). Yeah. This is my children you know" (Pakistani, 1G, p7).*

Acculturative stress in second generation revolved around struggling against prioritising asthma self-management against the expectations of older generations on following traditional norms which can compromise good asthma self-management. This can involve a series of negotiations and assessments on which aspect of identity may be more important while struggling against expectations. For instance:

- Traditional expectations and gender pressures on females (e.g. that they should not smoke, socialise at night, they need more protection than men, they need to share

housework with extended families and they need to carry out domestic chores), created a cultural conflict described as a *'clash'*, since females were expected to conform to these expectations sometimes as a priority over asthma self-management and at other times produced stress that could worsen asthma (as the quote below illustrates):

> *"It's still there like* [referring to traditional South Asian culture in London]*, I think the, the talks, the, I think the way people are back home, I think is exactly here like, you can't have the privacy, you can't, like do what you need to do you're not, you're, you're in the 21st century. But, there are people here, in especially this area like, they have this, traditional mind that they think as though like, 'Oh, girls should be treated differently from guys, or guys can be out late and that whereas girls can't'. And I just don't see it like that. I think like, if you wanna treat your daughter as it is and, keep it to yourself, or take her back home. But then it's like lifestyle here is different. Everything. I think it's the culture clash and it's how people think and how people are like, the way they think. That's what annoys me. You can't do certain things because you think, you're worried about how, bad news and how's it's spreading in the community" (Bangladeshi, 2G, p13).*

• The perceived enforcement of the lifestyle of the first generation on participants as the healthiest option produced acculturative stress in self-managing asthma e.g. enforcing Asian lifestyle or food as healthy/gives strength and taking it easy from work for good asthma control. This was linked to the resistance of the first generation in listening to advice on what was the good asthma self-management strategy from other generations, as illustrated by the quote below:

> *"...'Erh, so there's always that battle between, our generation and our, parent's generation. 'Erm there's the battle in terms of, listening to people, there's the battle in terms of what you eat as well. We can't live the lifestyle that they have lived. They've lived a more, labour, hard work lifestyle, very little for reward, yeah. We get a lot more reward, from work, or we can't eat, and just sit down and just, nap, nap, nap all day like they do (laughs). 'Erm... So, that's why we have a slightly different life to them as well. We, they wouldn't like to go out and eat, with, we would go out and eat. Yeah, not all the time, but it's nice like once in a while to go out and eat, they wouldn't like it at all. So, there's always kind of, ego within our own communities, and in our own families there's always that kind of culture clash, a generation clash of how we want to do things, compared to how they want to do things* [referring to self-management strategies]. *So... 'Erm... It is different, one generation to another generation. Our generation to the next generation will be completely different. I don't know what they're going to do" (Pakistani, 2G, p17).*

Acculturative stress in the third and fourth generation was around the older aged first generations (grandparents/parents) imposing the practice of CAM for their asthma on them as a child such as homeopathic medication. Most participants reported little interest in using

these CAMs as an adult but expressed conflict as a child. For example, spiritual healing was used by a participant for his asthma but he did not complete his treatment:

> *"This one is a little bit funny, but my family said to, you know when you get like those, like they said that I need to do some… Spiritual healing and stuff (laughs)* [referring to spiritual healing treatment for asthma]*, like it might help, or spiritual fheers (healers) like, so I tried that. A little bit of that. I don't think it made a difference. Umm, I think that's about it… It involved like having like (laughs), I don't think it's like… Yeah. Okay so the spiritual healing, what it is was, you just have like water and, mint tea or something and, you listen to few stuff and it was something like that. I done it few, I think once or twice I done it. I got forced into it… It's something yeah, it is a bit religious, I think. It was like, the first time I done it in this house, the, some guy who came, and he had like little sweets and stuff and he read like Qur'anic ayahs (verses) and stuff, my grandma like said, 'You need to get fouw done (blown on) or something' (laughs). So, I was like, I didn't know any better at the time, and then he done something. I don't know if it helped or not, and then he gave me a few stuffs to eat and this and that, and then I didn't taste it, or I didn't finish it. And then she goes; 'Oh, because I didn't finish it, now it didn't work or something, whatever'. So that's one of the spiritual like treatments outside of the… Yeah" (Bangladeshi, 4G, p27).*

2) The normative self

Boundaries of norms around asthma self-management were established by making social comparisons to others with asthma and/or complying with roles according to gender expectations determined by cultural changes.

Norms based on social comparisons

Social comparisons were often used as mirrors for establishing norms. Acculturation was also a part of the normative self. For instance, the idea of having asthma was normalised and acceptable as an identity in UK born/raised generations (mainly the third generation), e.g. *'learning to live with it', 'it's part of life', 'day to day routine',* and *'part of my day'.*

> *"My inhalers 'erm, 'erm, nothing it's just, literally my asthma, I've had it for so long so (laughs), I'm used to it now. It's just medicine (laughs)" (Pakistani, 2G, male, p19).*

Normalisation was achieved through the experience of one's own asthma and level of contact with others with asthma. Sometimes, family comparisons were made as benchmarks in determining if one's own asthma was controlled or not. In one instance, symptoms became normal and less noticeable; however social observation from others who noticed

her asthma symptoms helped enforce awareness that self-management behaviour was needed:

"I'm not very good at managing my asthma, because I, where I see my mom, whose, when we were little she was always in and out from hospital with asthma, and I compared myself to her, and she was always bad, you know she's been in ICU, but she's been what I remember bad, and I compare myself to her, I don't think I'm that bad, so I don't act, where I need to act. You know, it's just when I am around people, people notices and then, I get encouragement from people, to act on it, because otherwise I you know, live with it, tolerate it" (Pakistani, 2G, female, p18).

Normalisation increased familiarity (e.g. of asthma triggers) and enhanced self-efficacy beliefs around asthma self-management. Self-efficacy was described as something external to participants e.g. self-efficacy beliefs increased by making social comparisons on how relevant others are managing their asthma and whether they can do this themselves. However, normalisation of asthma also meant developing the belief that further support for asthma was not needed e.g. discussions around asthma, supported self-management from HCPs and social networks. Additionally, social comparisons were made to other cultures (mainly the White Caucasian population; referred to as English by some first-generation participants).

"Definitely, that's for sure, my chief, or other people I have talked to about their asthma management, they see it as a very structured, very clear way of doing things. They've got an understanding it's almost like brushing your teeth, it's kind of really simple straight forward, whereas obviously I am isolated I kind of, kept to myself, if I talked about it to others, maybe I'd have a different, over 25 people or something like that so…" (Bangladeshi, 3G, male, p21).

Hence, it was believed that White Caucasian cultures had better self-management/control and were more active with their asthma (e.g. education, medication and social support), compared to Bangladeshis/Pakistanis. UK born/raised Bangladeshi and Pakistani generations attributed better self-management/control in 'other' cultures due to the specific cultural stress that they encounter in their generation such as collective strategies in dealing with problems and family specific etiquettes and responsibilities (e.g. looking after and respecting elders), reduce the possibility of focussing on asthma self-management and/or situations develop or compromises are made that worsen asthma:

"So, we… (laughs) tend, unfortunately to, have a lot of stressors [referring to stress that triggers asthma] *in our Asian, families, whether it's the house that you're living in, whether it's the kids or parents or extended families. I mean, one issue, one issue would go around*

that home; family, and everybody gets involved and everybody gets stressed about something, and everyone has to to be like, kind of, 'erm so, we tend to find out within our own communities, there is a lot more stress than, 'erh non-Asians. To the point where you sometimes you even say that, a 'Ghoreh' (White person) *they don't deal with any of this rubbish. Why is it, only, only in our households, 'erm… Maybe because this is togetherness in our community that they don't have...That we have to deal with these things as well... So 'erm… Yeah definitely, I think because they have a lot less things that they worry about and stress about. 'Erm, we have a lot of things to, think about, and worry about whether 'erh… Whether its children, or whether it's, older parents and stuff like that which... To a lesser degree they don't. They don't care about these things, I mean they are like, 'Okay, but I'm old enough to leave the house now, I'm leaving kinda thing. I don't need to worry about your trials and tribulations and rubbish, I don't need to listen to your rubbish and stuff like that', but okay, those things tend to… It does, in some way are controlled in our communities, so, it's kind of side-effect of that, you could say that, because of that togetherness, trying to deal with things together, it will, kind of, bring its own stresses and, those people don't deal with, or even think about" (Pakistani, 2G, male, p17).*

Most norms were not consciously reportable; some participants were not directly aware of cultural influences and could not answer questions related to this, but answers were apparent when unprompted e.g. cultural eating routines to prevent asthma worsening. At times, the normative self became more conscious of norms in self-management through participant reflections on interview questions (see researcher reflexivity notes in section 9.5).

Norms based on gender roles

Masculinity and femininity (products of cultural norms) revolved around self-managing/controlling asthma according to cultural expectations of gender roles which was sometimes a struggle to maintain.

- Females in the first generation pushed themselves with domestic chores and their role as a mother, even though its worsened asthma e.g. feeling tired or breathlessness:
  → Self-management/control around asthma then revolved around slight adjustments to roles such as letting go of some physical activities which was acceptable for others to take over e.g. hoovering, grocery shopping or taking children out to social activities. Other activities were perceived to be an obligation or duty where these tasks needed to be completed regardless of consequences (hence complying with traditional Bangladeshi and Pakistani cultural expectations), e.g. cooking (cooking different curries every day was attributed to be an Bangladeshi and Pakistani thing), washing dishes, taking breaks and starting chores again to finish the task, using gloves for housework and using candles or covering the face with a scarf while cooking.

→ Some mothers refused to delegate domestic tasks to children due to the belief that children need to focus on education.

→ Social roles were performed and completed even though they were unable to fully enjoy themselves in those social activities e.g. playing with their children, eating their own cooked food (due to the beliefs that some food can worsen asthma), and the need to stay at home was described as either a part of Bangladeshi and Pakistani culture or being a good mother. Being free of duty was described by one participant as her children were all grown up and her husband did not expect traditional demands from her as a wife:

> *"Just relax it, yes. Then I feel okay. I have, no any duty (laughs), only husband (laughs). He helped me. His 'erh, his a, his good, because a lot of men, they are always really terrible, 'I want coffee, I want tea' (laughs). 'This is my, dinner time, or look at time' (laughs). It's very hard duty" (Pakistani, 1G, p7).*

→ Prioritising Islamic beliefs over traditional Bangladeshi and Pakistani cultural expectations in managing asthma meant that some females in the second generation were battling with traditional expectations and restrictions placed on them compared to men. Sometimes, participants used Islamic teachings to justify non-conformity to traditional expectations e.g. that women should cook and clean, women need to look after the children and women need more protection than men and should not be out late or indulge in behaviours associated with men such as smoking (all of which can tarnish family reputation). These expectations can produce acculturative stress and pressure for not managing asthma adequately, thus role management of asthma involved prioritising asthma health above these expectations and duties, including managing emotions such as anger and frustration that result from battling these expectations. On the other hand, one participant described that her mother cooked for her, but she wanted to be more independent with this to prepare herself for marriage (a traditional expectation that seemed to be more acceptable).

> *"They should do what the doctors say to them. Yeah 'erm, if they think that you know, whatever triggers it, to just stay away from it, and I know how things are in the housework, but I mean like, taking out from the kids is not bad. We should take less you know, responsibilities that could've, because the more responsibility is triggering your asthma as well. I mean obviously there, everybody is told what to do or not to do, it's, people themselves especially the family, should understand, you know they should be really helpful. Because the thing is, we're not them though. That's one*

- Masculinity was challenged for all Bangladeshi men and generations. When the ill body (and asthma symptoms) became socially visible to others, it reflected a lack of control over the body and ageing in the first generation e.g. inability to show others physical/mental strength and ability. In addition, masculinity was challenged when they were perceived as vulnerable such as *'fragile', 'handicapped', 'weaker',* and *'inferior'*. If the body appeared normal this meant good health and expressed masculinity.

"I think it's a big taboo whenever people knew I had asthma they saw me as handicapped, and you, so they saw me as handicapped, so for example if there was a fight or something like that, no one would pick on me because they thought I was a cripple, if that makes sense? So, everyone was like he's asthmatic, so he might die, sort of even joking, that sort of a perception, and at home it would be like, 'Oh, he's asthmatic he's fragile, so can't let him do anything'. They wouldn't let me do stuff, so kind of like if I wanted to go out and ride a bike, my mum would be like, 'Careful, careful'. When I started boxing or stuff like that, everyone would be like, 'Oh you got to be careful, you've got asthma', whenever we do anything my old friends will always remind me, how I have asthma and that's why I can't do something, afterwards they get amnesia and forget. So, yeah, it's one of the things" (Bangladeshi, 3G, p21).

Often, comparisons were made on the masculine self that was healthy before having asthma and comparing themselves to other men who were perceived to be healthy non-asthmatics. The example below illustrates how a metaphor of an animal was used to illustrate the good health of another men who had mental speed in achievements that the participant does not have which he speculates may be due to his asthma:

"Mental speed especially. So, that is the main things, I don't know why I am not getting, mental these things [referring to the aftermath of receiving asthma diagnosis]. *I have one friend, and I can't believe this, that he is very industrious. Sometimes he says that, he is here from 2007, he says that, after all he is almost 9, 10 years that, I tried so many times to call in sick to his work, but he never ever fallen sick (laughs). He is such a fit, and he can work like you know animals. And also, so… Is like you know very I mean, speed. He always*

> *has some speed, he always, someone telling him to do this, to do this, to achieve this. But, I lack in fact this one. Sometimes I lack this. But I don't know, I don't get that speed, mental, that these things I don't know why. Asthma is one of the reason or I don't know"* (Bangladeshi, 1G, p4).

7.4.5 Theme three: The voiced self, tied into the distribution of knowledge and discourses

This theme illustrates the Bangladeshi and Pakistani self that made sense of available information/discourses on asthma self-management from the society and healthcare services, which later shaped asthma self-management; *1) the dialogical self:* the extent the self had dialogues and communicated about asthma with others shaped self-management and the type/level of social support given, *2) the medicalised self:* the self that relied heavily on disease management approach to self-management (e.g. asthma medication and monitoring), due to selective information distributed, regulated and reinforced by HCPs and healthcare settings.

1) The dialogical self

Dialogues and communications on asthma were restricted, therefore participants received little social support for their asthma. Participants described a lack of awareness in the community about asthma, though they believed that some attitudes towards asthma has changed over time in the UK e.g. moving away from describing asthma symptoms as an infectious illness, and using terminologies such as *'asthma'* and *'asthma pump'*:

> *"And some people they don't, know much about it, because they still think, yeah so some people don't know much about it when it comes to wheezing and inhaler. But then again, I've noticed in the past few of years, that a lot of elderly people are saying the word, 'Asthma', and they're saying the word 'Asthma pumps'. So, that means that, they do know how to cure it, or they do you know, you know. Maybe they might normally say, 'Oh, put vicks there', but now they're saying it's asthma, like. Yeah, so that's a good thing. But I think, you know with the symptoms, I don't think they know much about the symptoms, I think, they just know that asthma is a thing that it affects your breathing if you can't breathe, get an asthma pump. But I think there are other symptoms to it. For example, say if I'm sitting in my living room, I've got asthma, they might start coming and brooming it, but they don't know that, oh this brooming is going to trigger it. Do you know what I mean? So, little stuff like that"* (Bangladeshi, 4G, p27).

The information available for the community was understood to be limited, particularly on the serious implications of asthma. Asthma was also not typically spoken about in certain contexts e.g. in family settings there was an unwritten cultural rule but mutual understanding for this. Generally, participants viewed communications around asthma as a private/personal thing (apart from some second/third generations). For example, in the example below the participant describes how asthma was not discussed in the Pakistani culture because asthma was perceived as private, which was reinforced by his family:

"I think generally it's [referring to asthma]*, people do view it as a serious thing, and they do try and make sure you do... Manage it properly, 'erm I just don't think it's discussed as much, in our culture, in our community. Which is purely because of the way, people are, especially like the first and second generation, they don't really go into depth when talking about, their personal lives so much, in that sense, like that the, personal type of things. I feel like, especially my family they don't really, divulge into that stuff much or like, where I've had like medical conditions and I am talking to people about it, I feel like I'm being told, 'Oh nah, you shouldn't really say that or you shouldn't really talk about it'… Purely because, it's just a private thing to yourself, you shouldn't really, divulge that information to other people... I don't know" (Pakistani, 3G, p26).*

There were various reasons for this:

- Participants felt that they needed to be comfortable with asthma disclosure with others due to unpredictable reactions e.g. fear, apprehension, shock, awkwardness and sympathy:

"About asthma 'erm, they don't, they don't like it I mean, asthma like any diseases but, 'erm, it's just one of those things, you got it, you got it. But, the issues with the, they always like, when you tell them you got asthma, they're really apprehensive. They get scared. They think you know, that this stuff is just, it could be swollen, you know. There's some people I've seen, they're more scared than me (laughs). The way they react it's like, 'Oh you got asthma' you know (laughs)... I dunno, it's just, maybe they had their son or daughters of family members on it. They've been such a hard time, and when you, when you say, 'I got asthma', they say, 'Oh yes! Well just keep going on', who said I can't? (laughs)" (Pakistani, 2G, p19).

This was tied into how people viewed asthma and the body in the society (observable characteristics of asthma such as symptoms and medication), which may have produced actual or feared stigma including descriptions such as *'vulnerable', 'weak', 'ill', 'sick', 'handicapped', 'fragile', 'disabled',* and *'cripple'.* In the example below a metaphor was used to illustrate this point:

> *"No, because of that stigma, because they see weaker, in the community or they see it as handicapped, there's that kind of stigma, from my experience it's kind of like, it's kind of like wearing glasses, but a more extreme version, it's kind of like being four eyes but with your lungs" (Bangladeshi, 3G, p21).*

This can create an atmosphere of being made to feel different through social awkwardness, exclusion, embarrassment and unwanted attention or repercussions. Hence, asthma remained private and self-management behaviour became secretive around new or distant people due to the fear of disapproval, fear of losing employment and the fear of using the inhaler outdoors. In another example, people blamed a participant for having asthma, by speculating that he must have smoked to be diagnosed with asthma (even though he did not smoke), and therefore passed on asthma to his children. For example, one participant struggled with taking his inhaler in certain social situations. He only used the inhaler in private when he perceived that social circumstances were adequate:

> *"Umm (Pause), well, to be honest, there's a big stigma to it [referring to asthma and its treatment], because say there's a new family members or extended family members and you, you try using your inhaler, and they'll say, 'Oh, this one is ill'. Like you've got some sort of, you know someone who's sick. Like they say 'His bemari' (the ill one/patient), like you know. But then, if you don't use it [referring to the inhaler] and you start wheezing and everyone starts looking around and asks, 'Are you okay? What's up'? You know 'cause people, there are people that they don't know what, when you're wheezy, they don't know what it means so they don't pick up on it and stuff. And then, there are other people that, as soon as they hear a little bit of wheeze, they jump straight at you……….. Yeah, because still I wouldn't use it here. I wouldn't use it, I wouldn't pull it out [referring to the inhaler]. Like if I'm outside, I might just go to the side, quickly have it, or like just walking, even still, like if I was in a shopping centre I'd find it awkward. But, I do know I need it, so I need to, quickly like go somewhere legit, I don't know, if that's a good thing or a bad thing, I don't know" (Bangladeshi, 4G, p27).*

- Asthma and its treatment were perceived to be a unworthy condition for general discussion, particularly in comparison to other illnesses e.g. allergy, diabetes or epilepsy:

> *"Not that I would deliberately not tell them, if it came up I would say I had it in the past, I might have episode sometimes if they, if they had asthma, if they don't have asthma, that topic would be a very weird topic to come up. As in, it would be unusual for someone to say… It's not like I'm vegetarian, where everyone will tell you they are vegetarian in the first five seconds, it's one of those things I think. So, how many times, obviously you're doing it for your PhD but, in a general conversation the topic of asthma never comes up, allergy may be, may be, hay fever those sorts of things, but never asthma" (Bangladeshi, 3G, p21).*

Social support networks were more likely to know about other illnesses compared to asthma (e.g. diabetes) and they provided a variation of support for this. Social acceptability of other chronic illnesses was greater due to the belief that illnesses such as diabetes were more common in Bangladeshis and Pakistanis, however in relation to asthma, it was normal to just take medication and move on (nothing else was needed especially if asthma was perceived to be mild):

"I think because it's such an, like it's an easy, not easy but it's kind of easy to kind of, not cure yourself, but look after yourself, like if you're starting to feel asthmatic and you take your pump and then you calm down, it's kind of the end of it, so it finishes there, like there's no problem but with something else, if you're, say if you have epilepsy or something like that, if you have a fit, then there's a lot more to it than just take a pump and then it's kind of finished, does that make sense? That's why I don't feel like it is talked about, because it's so just normal like, you literally take a pump and you're calm again kind of thing, but for other things maybe it's not like that" (Pakistani, 3G, p21).

- Most family support (e.g. revolving around moral or practical help/advice) was dependent on whether asthma symptoms were observable or not:

"Only one of my aunts, who, she… Well actually I don't speak to her about it unless it's, for example, a few times when the inhalers weren't working, so she would call the ambulance and that's when they would say, 'Oh, is it purple? This and that… It's like you know, when someone calls an ambulance, it's like something serious. But then, as soon as they give the, strong dose of the gas, you kind of come back to yourself, and be normal again, within those few minutes, or within 10 minutes you're back to normal, and you're thinking, all of this, like ambulance outside, the paramedics inside, their bags and the gas and, all of that just for… Just for a little bit of gas, and now you're fine, you don't need to go to the hospital, now you're back to normal, you know. Whereas, moments ago you were struggling to breathe, something so it could escalate really quickly, but at the same time you can cure it so quickly so… Because you know, in general when you do call the ambulance, people say, 'Oh, nozor (evil eye) what happened?' Like you know, how do you say it in English? They think something happened. They say stuff like that, you know…" (Bangladeshi, 4G, p27).

Physical ability (e.g. appearing to be healthy such as participating in boxing) allowed others to overlook that a person has asthma due to little social visibility:

"So, once I had the self-belief, most would have forgotten because of the sort of stuff that I've done over the last several years, people have forgotten that I have asthma, so I know if bringing up eyebrows and eyes would light up, people would be like (gasp) that sort of thing" (Bangladeshi, 3G, p21).

- Participants felt that they could discuss asthma if there was an asthma-to-asthma connection with others (i.e. if another person has asthma in close social spaces). Often, these discussions related to narratives around social comparisons on treatment e.g. comparing or swapping inhalers, treatment advice and inhaler technique. Comparisons and discussions were also a strategy of determining who has better self-management (control) and/or visualising the management of others. Both of which provided confidence and reassurance to the participants that asthma can get better.

"No, no I think I know a few of my friends, but them, they don't need the medicine everyday like me… It would just be about, the medication, what pumps they have and which ones I have, that would be about it, but we don't talk about how we deal with it or anything" (Bangladeshi, 3G, p22).

Participants also spoke about asthma to others who they perceived to be knowledgeable in the field (including consulting the internet), though seeking information was relatively easy, different opinions (including whether information was updated due to scientific transformations over time), led participants to become confused. Therefore, the credibility of information was desired across generations e.g. verification of information from accredited internet sites or HCPs. For example, the quote below illustrates how a participant found it easy to seek information on the internet but preferred a one-to-one contact due to concerns around making correct interpretations:

"By internet it is easy [referring to searching for asthma information]*, but it's more easy, just 'erm discussing with you. It's more easy. You know why, because, in the, internet, I can just, read myself. I can't, you know get a, I can't make a result, or I can, make lots of idea myself. Maybe, these are ideas are wrong. Because, if you are doing something yourself, and, some, definitely something's gonna bad… Something is gonna wrong. But if I am discussing with you then you can give me an, idea. You can tell me, 'Oh this idea is not good, or you shouldn't try this one, this one and not medicine, one…' (laughs)"* (Pakistani, 1G, p6).

2) The medicalised self

Explaining medicalisation

The medicalised self; the self focussed on disease management approach to asthma self-management, materialised from the selective medical information provided and reinforced by HCPs e.g. emphasis on how and when to take medication rather than why medication

needs to be taken. Therefore, most participants viewed the solution for self-management and good asthma control was to take medications and medically monitoring the body (e.g. using the spacer, peak flow meter and so forth). This reassured participants that no further support was needed, especially in the first generation who were more reliant on medical advice from HCPs. Further complicated by factors such as the lack of language interpretation to access more knowledge from HCPs for some first generations. This illustrates how the distribution of knowledge/discourses can shape thoughts around asthma self-management. The medicalised self led to a simplified and automatic way of thinking about asthma and its treatment. For example, using a metaphor a participant described that she does think about asthma too much, rather instead she described her 'simple' approach to using medication:

"I dunno, not too much really [referring to self-management around asthma medication]*, like paracetamol really (laughs)… Just don't see it as an issue really. Like if you got a headache you take paracetamol, you know" (Bangladeshi, 2G, p12).*

None of the participants received any information on asthma (though there were two isolated descriptions involving nurse advice on exercise/smoking and wearing tight clothing).

"Nothing! I don't know about my asthma. I only know like, how to use it, I don't know even what it is, what asthma is. I know it's a breathing condition. It affects your lungs when it gets too tight, and everything, it's to do with like small air lungs init. That's what I know. I don't know much about asthma" (Bangladeshi, 2G, p13).

The lack of basic knowledge on asthma was widespread across generations e.g. participants did not know about asthma, often describing the location of asthma in the lungs and describing symptoms. However, they knew more about how medication worked:

"That it's obviously, a lung disease. I mean that's what I think it is but I'm probably wrong. Yeah, I've never, they've never really like, explained it so much. Obviously, I understand, how my medicine helps me, but 'erm never really understood the, history of the disease or anything about it, I've never really had that explanation or anything" (Pakistani, 3G, p26).

Generally, there was a fair understanding of the difference between a reliever and preventer inhaler. Majority of the first generation did not know this difference (one participant did not know the terms but was familiar with the distinction and purpose between inhalers). One first generation Bangladeshi participant continuously used her inhaler but described not being able to feel it (she did not realise the inhaler was empty). Medical terminologies for inhalers were used across second, third and fourth generations (including one first

generation). At times, some participants described that it was difficult to retain information related to asthma monitoring if it was not reinforced e.g. peak flow monitoring was described to be difficult for some participants. There was a thirst for learning about asthma. Most participants saw the researcher as an expert) (see reflexivity note in section 9.5). There were various ways participants reflected their self-management needs around the researcher:

- Some participants felt the researcher was a learning point e.g. bringing their questions into the interviews (inherently in the first generation). Sometimes, they reiterated what their doctor's advice consisted of, but they could not understand it and/or could not ask them for clarifications e.g. one participant reported a consultant doctor told him that the reliever inhaler should be used when necessary but did not explain when it was necessary, giving him the impression that the reliever inhaler was dangerous. He reported that the reason why he came to the interview was to get this question answered:

> *"Ey janno, apni dharo aysi, ami shikmo je khoon shomoe dharkar? Ar khoon shomoe dharkar nai".*
>
> "For this, I have come to you, I will learn what time is it necessary? Or what time is it not necessary?" (referring to the reliever inhaler) (Bangladeshi, 1G, p3).

- Some participants also illustrated to the researcher that they were adhering to their medication by showing they carried inhalers with them.

Explaining medicalised relationships with inhaler devices

Even though the medicalised self was prominent, majority of the participants had little relationship with their HCPs for their asthma, particularly for UK born/raised generations as illustrated in the quote below.

> *"I rarely see them, it's yeah, I don't think they know me well at all, or know my symptoms or, things"* (Bangladeshi, 2G, p12).

However, participant narratives suggested that they had a close relationship with their inhalers (except for the first generation, where the inhaler and HCPs advice was both important). Most participants carried their inhalers with them, particularly the reliever inhaler. Many participants described this as an obligation or need; for emergency,

reassurance or felt it was normal. The quote below demonstrates this point by using metaphors:

"Brown one I know obviously, that one's kind of like, it represents the past, and the blue one is like a blue, emergency pump, for me it's like a fire extinguisher, I hope I never need to use it, but it's there reassuring me, all the time…" (Bangladeshi, 3G, p21).

Explaining degree of medicalisation

Table 9. Comparisons of different forms of medicalised selves across generations

Generation	Levels of medicalisation
Older first generations	• Strict with taking medications on time • Medication believed to be a solution for all illnesses • Prefer to be alone during worsening of asthma e.g. rest/sleep; reluctance to speak about asthma and seek medical aid • Strict adherence to CAM alongside inhalers
Other first generations	• Adherent to medication but often forgot • Sought medical aid
UK born/raised generations	• Adherent to medication but cautious about medication decisions • Discussed asthma when it was necessary
Across generations	*De-medicalisation:* • Medical instructions and treatment were questioned • Active seeking of other sources of information • Preference for HCPs to provide individualised supported self-management • General distrust for HCP opinion/advice • Belief that self-management should be holistic based on other preventative factors than just medicine

Participant described that there were slight generational differences in the medicalised self (see Table 9):

• Most of the older aged first generations were perceived to be ideal medical patients due to strictly adhering to medication on time, following advice from HCPs and they believed that medication was the solution for all illnesses. However, older aged first generations were less active in seeking medical aid, alongside this some also strictly enforced CAM use (even though they used CAM as complementary to biomedicine). In the former, they preferred to struggle with their asthma in isolation (away from other people), reluctant to speak about their asthma and seek healthcare aid e.g. descriptions often involved scenarios where asthma medication was taken and/or then they would be patient by resting and/or sleeping.

"I think so yeah 'cause with my grandma, she takes it literally on the dot, this time, this time, whatever medication, 'cause I remember she had this circle one at one point, I don't know what the circle one was, but there was a circle she had, so I know she takes it literally whenever the doctors said to take it, and with all of her other health problems, it's like on the dot, this time, everything properly, bag that, medication and everything, for me, it's like I've got the pumps in the draw, if it finishes then I go grab it, sometimes I forget to take it, I don't even know if I took it today, I think I might have taken it today (laughs), I can't remember so, actually yeah I did, I did (laughs)… Yeah (laughs), that's me but then my mom and grandma, and may be a few other people in my family take it, strictly whereas me I might not take it, so strictly" (Pakistani, 3G, p23).

One reason to explain why elderly Bangladeshi and Pakistani individuals do not seek medical aid despite worsening asthma may be due to being accustomed to and developing routines from South Asian countries and the way the healthcare policies and systems are set up. For example, the quote below compares the asthma support available in Pakistan and the UK:

"Obviously… The medication is very new. 50 years ago, there was, probably no treatment [referring to asthma treatment]. *Definitely, no treatment in rural Pakistan, so people will have to live with it… In Pakistan it's, I don't think so. They need more years… It's the, it's the way they are taught or the way they are brought up. They can't see, in that much health education in Pakistan or social care in Pakistan, so I don't think there will any significant change in people, managing chronic illness. Other, there is more, dependence on family then here, because normally state intervenes in England. The state does not intervene in Pakistan. So, people have to look after their elders or… So, they do get a lot of emotional support, but I don't think they get practical support much" (Pakistani, 1G, p9).*

- In comparison, the younger first generations reported good adherence behaviour towards medication and they sought medical assistance when required, but they often forgot to take their medication.

- In contrast, UK born/raised generations were medicalised in the sense that they adhered to medication, sought medical aid, spoke about asthma as and when needed, but at the same time they were more cautious e.g. they made decisions around what medication to take rather than passively taking prescribed medication. In a sense, asthma was taken more seriously:

"I think, people take it a bit more seriously and are more open about it in like the, the newer generations than they are in the old ones, like, everyone in the older generation just take their medication, they don't consciously think about, how they can improve their asthma, how they can, better themselves in terms of reducing how much medication they are taking, they just take it as they're given. Whereas, I think more newer generation they

are more open to speaking about it, so like with their parents and things like that, you kind of, put in like plans of how to improve your, health and how to, 'erm better yourself basically, rather than just taking the medication or just, moving along with your life kind of thing" (Pakistani, 3G, p26).

The medicalised self was contested by a few participants, particularly if participants were more active in seeking information from other sources than HCPs (this can be referred to as the de-medicalised self). For example, a participant taught himself and followed preventative asthma strategies rather than the medication advice of HCPs:

"For me personally it was more of a journey of teaching myself [referring to self-management strategies]*, because the doctors they do what they do, which is basically, focus on, safety first, they just say this is what you're going through, you have to take this* [referring to medication]*, and your gonna die if you don't. And I was thinking partly true, yes definitely significantly true, if I don't manage it properly, but they would never focus on preventative measures, ways of basically, they did the basic most stuff like, stay away from smokers, and telling my dad to smoke outside the house, but they didn't really focus on exercise or, I don't know, other ways of trying to prevent it from happening, managing my triggers, those sorts of things so, I don't know they are busy people" (Bangladeshi, 3G, p21).*

These participants believed that HCPs should recognise that asthma was heterogeneous to each individual and that individualised care (advice and treatment) was needed, rather than a generalised medical approach to their asthma. For instance, HCPs can overgeneralise advice on the need to use monitoring devices for every patient as described by the participant below:

"No. One thing is this thing. I don't really need this… The spacer, and 'erh, the generalisation of the part of asthma professionals is slightly… They shouldn't be making too much effort on generalisation as, 'You should do this'. Same thing does not fit everyone… I use it for my son because he can't inhale properly. After 30 years of yoga, I have very precise control of my breathing… Not for asthma, I do it for part of Tae Kwan-Do, which I've been practicing for 30 years. But, I have very precise control of my breathing. So, but the geniuses, nobody would agree or nobody want to admit that… Don't generalise things… Don't force… Knowledge and these things." (Pakistani, 1G, p9).

An example of how the HCP's advice was not followed due to believing that they do not know the participants asthma very well and holistically consider the participant's perspective on asthma and their self-management:

"I don't know, they can give me their perspective and obviously the medical perspective, but I've never followed that. So, I don't know, they don't know, my situation, in that sense, like every single time I've tried communicating in my situation they always say, 'You're stupid',

not in those words but, 'they effectively say, 'That's not the medical stance', which is fine. But at the same time, I don't know I've learned to manage it if I follow their guidelines, I'd be still using a brown inhaler to this day probably, what, I'd still be using the blue inhaler on and off, I would never have done marathons triathlons, never of potentially, because I would have psychologically been dependent on those things and potentially affected me, physiologically if that makes sense? So, I don't know it's a bit chicken and egg, I can't guarantee that not listening to them, allowed me to do those things but, I don't know" (Bangladeshi, 3G, p21).

The quote below demonstrates how the participants understanding of asthma self-management was different to HCPs which was more medically focussed:

"Although the doctors like to say otherwise and tell me that I should be taking it every day [referring to asthma medication], I try and avoid it may be, may be self-consciously because of what, I've heard previously, and because I don't feel like I need to have it every day, I'm usually okay. So, I think in some aspects I do, manage it well but I probably don't manage it in the, medically well" (Pakistani, 3G, p26).

7.4.6 Identifying significant others in supported self-management

This section identifies who participants described as: the most significant HCPs in their asthma care and their first point of contact for problems related to their asthma.

Most significant HCP in asthma care

Participants described the most important HCP in their care as the following (most participants either choose the GP doctor because they reported that they did not have experiences with any other HCP group):

- GP doctor (n=8)

- Primary care nurse (n=4)

- No one for asthma (n=4)

"I'm not too sure because I've never had to be like looked after by a healthcare professional, does that make sense? So, I've never been to a hospital because of it" (Pakistani, 3G, 23).

- Emergency department (n=4)

- Secondary care asthma clinic (n=2); asthma consultant (n=1)

- GP doctor and severe asthma clinic (n=1)

- Study researcher (n=1) (see notes on reflexivity in section 9.5)

"I am thinking…You… Yeah. You can… Now you are asking me. Now, I will ask you, lots of questions. You can give, you can suggest me what I should be doing. You know GP, has no lots of time. Nurse gave me, she just give me 20 minute, and doctor still, but I can discuss with you because, I'm looking you have lots of time, and I can discuss with you really" (Pakistani, 1G, p6).

- Ambulance paramedics (n=1)
- Online forum doctors and patients (n=1)

First point of contact for problems related to asthma

GP doctors/nurses (n=7), no one (n=6), family (n=4), GP doctor and family (n=1), and emergency department (n=1) were described as the first point of access for problems related to asthma (the inhaler device was described by one participant as their first point of access). Other participants mentioned 'if needed' scenarios, for instance, the person/service consulted would depend on the severity of asthma e.g. asking a family member to understand whether they needed to seek GP or emergency department aid (n=2). If asthma symptoms were mild they would not access any services but would access the GP (n=1). If asthma symptoms were severe if access to primary care appointments were difficult they would access the emergency department (n=4). For some participants, they only had experience with primary care HCPs or services, therefore they mentioned these HCPs due to the lack of choice in the matter.

7.4.7 Exploring interventions that would be useful for participants and/or their community

This section explores thoughts on useful self-management interventions for participants and others in their community and suggestions on improving PAAPs.

Exploring the type of interventions that would be useful for the needs for others in the community

When asked about ideas on interventions, participants referred to 'others' as requiring more support. Often, the 'other' was viewed as the older first generation (even by the first generations themselves), as the most vulnerable and the most in need of an intervention.

Three Pakistani participants who resided in Tower Hamlets (an area densely populated with Bangladeshis compared to Pakistanis) referred to the 'other' as Bangladeshi first generations (rather than Pakistanis themselves). Sometimes, intervention suggestions were generalised from individual experiences of what worked for them e.g. if a participant only received education in asthma reviews therefore improvements in this was recommended and since third generation (experiment with their self-management), *'try out information'* was noted as the strategy that the first generation should be using.

> *"I don't know I think it's, it's trying to encourage them in a way that they're, able to speak up because if, like I was saying, they don't really talk about, medical issues that much. Purely in the older community, it's more about getting the information to them, so that they can understand it for themselves rather than them, not learning from it or not, not tryna get the information, they're not tryna talk about it so they're not, sharing the information between them, so people do have that information. I think they just need to target them in a way that they can get the information to those people. Maybe it's, maybe more regular, asthma check-ups, or ways that they can try out information so that it has, asthma open days where they can get people in, it could be people from other cultures as well, and then have them, just talk about their asthma. Like invite people their age where they can come in and like speak about it, like an environment where its encouraged to talk about rather than it being, 'Oh nah, you shouldn't really talk about it' in terms of, reasoning"* (Pakistani, 3G, p26).

Basic asthma education

16 out of 27 participants emphasised that there was a need to promote basic asthma awareness to the wider community. Most participants (nine out of 15) described the need for education in the form of a:

- Programme/workshop
- Opportunity to talk to HCPs without time restrictions
- Open days or fairs

Four participants described education needs to be in appropriate languages.

Improving primary care services

Three first generation Bangladeshi participants described quality of GP services needs to improve e.g. adequate diagnosis and extra care for flu (the latter was believed to be a cause of asthma).

Dealing with cultural norms and expectations

Three participants (from the second and third generation) reported that people in the community needed to overcome traditional cultural norms and expectations that hinder self-management (e.g. prioritising the management of asthma over traditional female domestic expectations/responsibilities and speaking about asthma despite this not being a norm).

Exploring the type of interventions that would be useful for participants

Intervention type and content

When participants were exploring ideas about interventions, all of them customised their own intervention ideas to their understanding of cultural diversity in the community. They often related ideas to different generational needs e.g. the assumption that the first generation are behind in using technology therefore interventions need to consider this. Participants described requiring various self-management needs; numerous needs were mentioned in the first compared to other generations. This revolved around education and/or improving the primary care service. For instance, suggestions around education included:

- Education on asthma, triggers, food, exercise, medicine/treatment and preventative strategies.
- Answers to specific questions e.g. why continuous medication is needed? Whether medicine is addictive? How to keep the chest clear? How asthma affects old age? Thinking about the future how can they *'save'* themselves and their children?
- Even though most participants from the first generation could speak or understand English they believed that education in their own language would be better.
- A Pakistani first generation suggested that if he was to receive education he would still prefer to verify facts by researching online since facts change over time with asthma variability e.g. definition of medications (a form of de-medicalised self; see theme 3).
- One Bangladeshi participant mentioned that she wanted to leave it to the experts to decide what the best intervention was for her and a Pakistani participant stated he was too stressed about his family situation to focus on his asthma (related to acculturative stress).

The second generation suggested education should include:

- Education goodies packs.

- Posters/leaflets.

- Education on the cause of asthma, lifestyle factors e.g. exercise, smoking, substance misuse and food/drink.

- Asthma control strategies other than using the inhaler e.g. breathing techniques.

- Answers to the specific questions - whether symptoms and triggers change over time and therefore needs to be tested over time.

- Three Bangladeshis wanted access to speak to an asthma specialist as time in consultation was limited.

- A few participants reported requiring services which already exists, but they are unaware of it e.g. hotline to speak to asthma specialists.

Better service access needs were reported by all generations. Majority of participants (especially in the first generation) were dissatisfied with their GP service. Concerns ranged from:

- The lack of access

- Delays and time of appointments

- Services losing repeat prescriptions

- GPs prescribing inhalers but not providing a diagnosis

- Participant perceived asthma was not taken seriously by primary care staff.

- Some participants suggested GPs needed to how more awareness of asthma and be more responsible and caring towards patients (though, there were also some positive experiences reported):

"I think it, it should be easy access, I mean, yeah, everywhere is easy access, and also, not taking long time… Because see if I go to, GP, I'll get 3 to 4 weeks to get appointment first, same day appointment okay, they tell to call at 8.30. When I, you know in 2014, when I pass so bad days, oh my God! I wake up, I am waiting from 8, 8 okay, one minutes, 2 minutes, and when it's, is 8:30, if you call before 8:30, it goes somewhere else, at 8:30, you don't get line, because so many people have been calling. Finally, when you get, connect them, they say that unfortunately there is no appointment. And, we have to go for work as well, we have to work, okay. So, you don't get appointment with your suitable time, so it's not only this but this is a national problem, it is getting worse, after BREXIT things. So, I don't know (laughs), what do to do, so, so easy those things, easy access, and that thing, and also you know, when you talk to GP, when you, somehow you know, okay someone will call you, 'erm if you talk to them, they said that you are nothing, okay it's fine, regular. Or… One day through telephone, I shout at one doctor over the phone, so that lady was shouting me, 'For this you don't need to call!' Then I shouted in return, I shouted at her, then 'How dare you talk to me like this? I

am paying you'. So, this type of things like you know… So, easy access, that is needed (laughs)" (Bangladeshi, 1G, p4).

Four participants (from the second, third, fourth generation) described a novel and creative way to achieve this would be to reference service help points depending on their location (in the form of a GPS smartphone app or leaflet). Participants described a reason for this was due to generational differences such as new experiences e.g. travelling to different countries and areas of London (for university, social and work purposes). In addition, participants described scenarios of uncertainty in accessing services when their asthma was not too serious for emergency service and/or when they could not access primary care promptly.

"Oh, wait. Hold it. So, yeah with the app, like nearest point of help or you know stuff like that or provide information. You can put your location on. Because with me, I like to go different, different places all the time, so that would be quite helpful" (Bangladeshi, 4G, p27).

Participants (some second generation and all third generation) described the idea of *'newness'* or *'freshness'* needed in interventions. In addition, those participants who had mild asthma or asthma since childhood felt asthma was normalised and there was no need to develop further self-management skills or knowledge for this (participants felt qualified through experience). Some participants related this to how asthma reviews (standardised information sources and procedures) have become less beneficial or stimulating over the years due to growing accustomed to it and therefore there was a need to advance the incorporation of other strategies. If there was new information, research, case studies, tips or updates (e.g. medication/treatments, viruses and so forth), participants were interested in this through signposting on technological platforms (e.g. text messages, emails and apps). This was thought to be more helpful compared to the traditional method of face to face interactions (due to their busy life and it was believed to be an outdated strategy in healthcare services). As an example, a 4th generation Bangladeshi participant reported how he remembers the upgrading of reminders on fridge magnets when he was young, but this needs to now progress and update or to smartphone apps (relevant to his generation). Three participants wanted credible information (e.g. under the umbrella of the NHS), as there were many sources of information and various opinions that can become confusing.

"Yeah so, it, it, you could look at it in two ways that, do, do you want people to come to you? So, you can tell them? Or, shall we actually do something to them? So even if I said, 'I'll come, we'll send the information to them', and the likelihood is that they might be reading this at home. Which is better, then them not turning up at all, and having no information, so. Just

having information in the post or, via email, most people, these days, our generation we just look at things on the phone. So just send it by email or, in the post and stuff like that. But, gone are the days where I think, people should expect people to just turn up. It is kind of, happening less and less now, more people are more into their phones and everything. 'Erm… and may be, healthcare is kind of a little bit outdated in that respect, that it needs to adapt. There are people's patterns are changing now" (Pakistani, 2G, p17).

Three participants reported wanting new or up-to-date treatments.

"Put me on better treatment. 'Cause I know like, there's good inhalers out there like, there's a new inhaler that just came out, recently, it's a very good inhaler. So, I think they need to take care of asthma people really carefully. They need to give priority to that, rather than, people coming in for other stuff" (Bangladeshi, 2G, p13).

A Bangladeshi fourth generation suggested a way to keep up with present times with inhalers may be having asthma packs (comparable to nicotine patches), or disguising inhalers as vapes to enhance medicine acceptability in social life (vapes are popular and socially acceptable in young people).

"This is a silly idea, but… Imagine if… Like the inhaler disguised as something else, you could use that. Or like 'erm, I'm tryna think. I think, the rota plan or some sort of plan, I think. Because at the moment, I know the choice is the inhaler and this and that, but if there was other ways that you can cure it, or you know other little things that you can implement in life and, it helps you. Then I would be interested in, investing in those, so… Yeah that's the thing. Like I've seen people do those 'erm, e-vapes and that. Like you know those, those things it's like a box with a pipe, like you know those e-cigarettes? But rather than looking like a cigarette, it's like a box with a pipe, and the person they go (sucks air in), like it's the same thing, like they're taking it in but, it's like a more of a vape style, it's trending a lot in the UK and America. Imagine if it was something like that. Because I've seen my grandma, she's got one that, you twist at the bottom, and then you use it, whereas the pressing one is better. So, imagine if you pressed it and it released it, when you, it would be something like an 'asthma vape' or something. Because that I've seen enough people doing it everywhere, they're doing it outside, they're doing it inside and everywhere. That's you know, but then again, I'm thinking may be, some cheeky people they might start smoking it, like there might be a no smoking sign and then they will say, 'Oh, it's an asthma thing'. So, there is a down side to it, so…" (Bangladeshi, 4G, p27).

Other forms of support mentioned by first/second generation participants included:

- Clear and succinct medication information in inhaler boxes
- Referrals for lung function test
- Inclusion of triage nurses in primary care
- Improving communication/language factors in consultations
- Continuous follow-up reminder/support from HCPs

Delivery of intervention

All participants agreed that the person that delivered the prospective intervention should be an expert in asthma. However, a few participants felt the expert should not be the GP:

"Yeah like from a professional not like a GP. A healthcare professional who is an expert in asthma, who's done, who provides a service to people who are suffering from asthma. Them sort of people. Not like people from GPs, they just don't know anything." (Bangladeshi, 2G, p13).

All participants felt that the ethnicity of the professional did not matter, though most participants from the first generation reported language-matching was important. Some participants other than the first-generation recommended delivery of interventions should be separate for young participants compared to older participants.

"Do practical workshops and everything. Do like a one hour plus teaching about asthma, but also you do like, get like, workshops with other young people, so like, not just have like girls there but have like, other, South Asian people like, especially like Bengalis like, mixed with other Bengali people, young people especially not like older people or young people together but, have like, two different 'erm, certain groups of, older generation, they can see how other people are doing it, but if you work with other Asians, other Asians, speak 'erm, about how they doing it, do workshops, and work together and that" (Bangladeshi, 2G, p13).

Intervention format and setting

Most participants wanted education in a group setting; they felt sharing ideas, thoughts and experiences would be beneficial. A Bangladeshi second generation stated she would like education in a university environment. Signposting information and other technology materials were wanted on an online format. Those participants who preferred education, talking to asthma specialists and updates wanted these to be integrated with reviews or wanted a one-to-one format in a convenient location e.g. GP surgery or medical health centre:

"Medical centres which I have been to, that would be nice because it's convenient, it's just literally like a little walk or drive. It's convenient because for me I have access to a car, I can walk, I can bus, but when you're looking at the elderly they would have to rely on someone else, to get them. It's like when you come to the hospital and you see, like a lot of elderly, waiting for taxis, taxis having to come all the way, somebody's having to call the taxis, for

the taxis to come and take them home. Whereas, for us walk in, my in-laws for example there is someone with them, I'm always with them to take them, if I can't park my car then one of my children will drop us off, or my husband will. So, they're not having to worry about how they will get home? How do I speak to this person? Do I understand this person? Or it might be mundane or silly but to them it's not, because they do worry, 'cause you are busy every single day, so convenience would be the main thing. That would be for me, easy for me. I wouldn't mind that because I don't think GP have any of that. With my GP, I don't think they have, maybe they do I don't know, maybe for them it might be easier to put it somewhere central, central like a medical centre so somebody could just go and you know sit there if they, GP would be your ideal, would be your ideal place, but it might not work in a GP" (Bangladeshi, 2G, p11).

Exploring improvements on asthma action plans

Ownership of PAAPs

Most participants had not been given and did not own an action plan (16 out of 27). Apart from the Bangladeshi first generations (only one Bangladeshi first generation had a plan), all other Bangladeshis had or previously had some form of a plan (written, verbal or short-term emergency plans). In contrast, only two second generation Pakistanis had action plans (all Pakistani participants from one GP surgery did not own a plan). Those participants (six out of eleven), who previously had a plan did not own a current plan; the explanation and terminology of an action plan was not provided by HCPs for two out of eleven participants, therefore they were not familiar with the concept until an explanation was given in the interview. Three participants out of eleven had positive attitudes towards their plans (noting its helpfulness as a reminder, as a guide, as an aid to monitor asthma medicine adherence and setting/achieving goals), compared to four out of eleven participants who described it as *'pointless', 'a piece of paper', 'no need',* and not fully applicable for severe asthma patients.

Suggestions for improving PAAPs

Participants were given a copy of the Asthma UK action plan and asked for their opinion regarding this (Asthma UK, 2016c). Most participants thought the plan was acceptable e.g. visually appealing, user-friendly, self-explanatory and simple. Others suggested further improvements can include:

- Language translations (or signposting language appropriate materials online)
- Incorporate email contact as an option for less urgent matters

- Place the plan on an app and text message reminders to comply with the plans

- Provide guidance on actions in different scenarios, breathing techniques and how to wean off medicine

- When participants compared their current plans to the Asthma UK plans, two patients stated that the latter was better, as their plans were photocopied Black and White versions with less information. There were suggestions that plans need to be less informational highlighting key information and consisting of more participatory elements e.g. fill in tracking charts.

"Like this one, guaranteed if the doctor gave this to me, I would take it in my pocket, I'll fold it in half and, when I got home I'll just leave it on the side of the table. Whereas, the one that my doctor gave me to put it on the wall, it was more like a table, chart. It was a similar thing, it had a lot of information as well. But that one, I actually put it up in my room, you know where there's privacy and I could keep a track of it. Here it's not really, you know. But this one I think it's more of an information piece, and you know, you just read it once and then you let it go, right? …Yeah. So, for that one, it was measuring, 'erm… One thing it done was to make sure that I was taking the morning and evening medication, so when you have it, you tick it off. And then, the second thing it was, was measuring my peak flow and if it's making an improvement or not. So, I think that's what it was. So, to do that I could see, hold on, it's actually helping me, it's not helping me you know, it's making a new improvement. Stuff like that. And then you know, after that if you can get better or not. What else was it? And then, she also gave that, you know the magnet one. I think the magnet thing is similar to this. Its colour coded… Hmm, I think you know what, the fridge magnet one, if that was in Bengali, that would be a good idea, because we look at this information, and with our grandparents and, some uncles and aunts, they wouldn't read this, they would just tell you to read it, they'll be like, 'It's something for you, not for us'. Whereas, with the other one, for example my sister if they had a Bengali one my grandma could understand and read it, and she would be able to keep an eye on my sister (laughs), and inform her and guide her a little bit" (Bangladeshi, 4G, p27).

Four participants stated plans were not needed or applicable to them due to never being in the red section/requiring emergency aid *('this is for sufferers')* or knowing their asthma well enough without written guidance (this was related to the process of normalisation).

"For me, 'cause like for me 'cause it's so normal and it's like part of my everyday thing I know, I know all of this without it being written down if that makes sense? But for others maybe beginning their asthma, maybe that might be a better… Yeah, if they've been diagnosed, then for them this would be a better start. For me someone whose had it for so long, to then be given that asthma plan, when I know, my ups downs, and all that stuff, it's like, I don't know how to describe it but obviously" (Pakistani, 3G, p23).

Some participants who did not have a plan felt they had to try using it before suggesting improvements. One participant used a metaphor to illustrate this:

"I will do first time. Then I can give you idea… Yeah. How much this was helping then… Before you go to water you can't, give you idea it's deep or not" (Pakistani, 1G, p6).

7.5 Discussion for the qualitative research

7.5.1 Main findings

This study explored the dynamic role of Bangladeshi and Pakistani culture in asthma self-management. Main findings related to the objectives were:

- *To understand the role of culture in self-management by exploring perspectives of the first, second, third and fourth generation Bangladeshi and Pakistani individuals with asthma: d*ata showed parts of the self[60] were important to pull together for a holistic picture on how self-management varies across different individuals and contexts -
    1) The individualised self, tied to the body: the self that made sense of asthma self-management when the body experienced asthma symptoms (localised as a feeling, body transformations and how the body functions with asthma), that enabled participants to become physically conscious of the need for self-management around the body (maintaining asthma control, keeping the body away from environments that can worsen asthma and regulating the body). For instance, some participants knew that asthma was a chronic illness but still described asthma being absent/present in the body. Participants had a lot of psychological/emotional issues that needed self-management e.g. using religious coping to maintain psychological peace inside the body. Health beliefs underpinned self-management strategies around body regulation.
    2) The socially defined self, tied to the context: The Bangladeshi and Pakistani self that made sense of asthma self-management after encountering others, and becoming aware and bouncing off from the symbolic gaze of others (e.g. on cultural expectations and self-management of others), while understanding themselves and negotiating boundaries of correct/incorrect self-management behaviours. For instance, participants described Bangladeshi or Pakistani culture and its influence on self-management (e.g. struggling with men smoking), and cultural changes and its

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[60] The self can be broadly defined as direct or indirect statements that comprise of the self referring to *'I', 'me', 'mine', 'myself'* (Triandis, 2018), in social motivations, attitudes, beliefs, intentions, norms, roles and values (Cooley, 2017; Triandis, 2018)

influence on self-management (e.g. experimenting with strategies, prioritising religious coping over traditional Bangladeshi and Pakistani cultural strategies and generational differences in acculturative stress). Additionally, social comparisons with others with asthma helped establish boundaries of normalisation and good control (the self-management of the White population were perceived to be better e.g. due to less culture-specific stress), and participants struggled to maintain a sense of masculinity and femininity roles originating from cultural/social expectations and norms e.g. keeping up with domestic chores that could worsen asthma.

3) <u>The voiced self, tied into the distribution of knowledge and discourses:</u> The Bangladeshi and Pakistani self that made sense of available information/discourses on asthma self-management (e.g. the extent asthma was spoken about in the community and the type of information given by HCPs), which later shaped asthma self-management. For instance, little asthma talk (due to asthma being perceived as a private condition) meant that there was less community awareness and less social support. Additionally, selective medical information given by HCPs (e.g. how and when medication should be taken), shaped reliance on the disease management approach to self-management.

There were various factors emerged in all the themes illustrating the fluidity of culture and self-management: participants believed self-management meant control and discipline; the use of metaphors provided imagery on how the body works e.g. internal struggles with asthma; subcultural differences in self-management were apparent between Bangladeshis (e.g. beliefs around sweating and maintaining masculinity), and Pakistanis e.g. use of homeopathic treatments and little acceptance of asthma; three Pakistani patients identified themselves with Bangladeshis due to living in predominately Bangladeshi neighbourhoods highlighting the flexible nature and influence of context in the UK.

- *To identify the categories of HCP that were most significant for participant care from interview data (not necessarily the individual's own HCP):* A variation of HCPs were identified as important for participant asthma care.

- *To explore what type of asthma self-management interventions Bangladeshi and Pakistani individuals feel would be useful for themselves and/or their community:* Exploring thoughts on interventions revealed that there was need to address community awareness, education, quality improvement in primary care services and prioritisation of asthma above traditional cultural norms/expectations (often referring to the first

generation as needing the most support). Most first generations (and all participants recruited from one GP surgery) did not own an action plan.

7.5.2 Interpretation of findings in relation to previously published literature

The exploration of the Bangladeshi and Pakistani self in self-management (e.g. the perspective and expertise of people) reflects that we can ponder on self-management in different ways. Therefore, holistic self-management should be considered as dynamic and placed into context; involving the process of 'being' or 'becoming' (hat changes across time and context (Fortun et al., 2014; Hashem & Merritt, 2018; Udlis, 2011). For instance, to define culture the study asked participants what they believed Bangladeshi or Pakistani culture consisted of which; family, men smoking, gender norms, community accountability for unapproved behaviours/lack of privacy, high value for medicine in the older first generation, CAM use, unfamiliarity with exercise, religious identity and food habits/food that worsen asthma e.g. aubergine and red meat. However, there is a paucity of studies on the South Asian self (and other populations) (Kralik, Paterson, & Coates, 2010; Sinha, 2014). In this study, Bangladeshis and Pakistanis believed self-management was a means of control over activities to create order and discipline, which is supported by other qualitative studies that have shown this belief was not exclusive to Bangladeshis or Pakistanis or asthma (Kralik et al., 2004; Lakhanpaul et al., 2017). But, Bangladeshi and Pakistani participants also related that good control was achieved in the absence of feeling asthma symptoms and using medication. The latter agrees with Lakhanpaul et al. (2017), who found some parents believed asthma control is achieved by consistent and appropriate use of medication. There were various beliefs around what caused asthma and sometimes there were a combination of suggested causes e.g. natural world causes such as cold and supernatural causes such as given by God, therefore painting a holistic perspective on asthma beliefs may avoid misinterpretations. For example, 'fatalism' can be attributed to individuals who believe in God's will as a cause for asthma, but this does not negate the fact that people believe another cause of illness can be due to genetics, as opposed to what the term fatalism suggests (Patel et al., 2015). One qualitative study aimed at Indians and Pakistanis in America found that behavioural, physical, psychosocial and spiritual explanations existed for asthma e.g. behavioural causations were common for men but Muslim men also believed that asthma was also caused by spiritual factors (Tirodkar et al., 2011).

Additionally, most participants believed they had a good level of self-efficacy[61] for managing their asthma without immense asthma knowledge, as opposed to findings from other qualitative studies which arguably assume self-efficacy can only be achieved if participants know about asthma (e.g. Griffiths et al., 2001), by using self-efficacy measurements typically developed around 'assumed norms' of White/middle class populations (Burke et al., 2009a; Kralik, Paterson, & Coates, 2010; Thompson, 2009). In this study, participants described self-efficacy as something external to them based on social capital e.g. social comparisons with others and norms such as who has better asthma control gained from the perceived perception of others on themselves. This agrees with other studies that have found that collective[62] self-efficacy (in addition to individualistic[63] self-efficacy) was important for South Asians (Klassen, 2008), and this was also the case for other ethnic minorities in the USA (Burke et al., 2009b; Schwarzer, 2014). Bandura (2002) also recognised the collective essence of self-efficacy e.g. the loss and gain of social capital during migration, however differences across cultures was not recognised. Perhaps, self-efficacy should be treated as a construct that differs across cultures and targeted accordingly in interventions (Kralik, Paterson, & Coates, 2010; Thompson, 2009).

Previous literature suggests HCPs and interventions have a rigid and structured manner of providing what they believed was beneficial/successful self-management strategies and various assumptions about the tasks patients ought to perform, without acknowledging the holistic perspective of self-management (Fortun et al., 2014; Hashem & Merritt, 2018; Schulman-Green et al., 2012). 'The medicalised self' was promoted by selective information given on the disease management of asthma by HCPs; restricted to how and when medicine should be taken rather than why or any other information on asthma. This shaped self-management since most participants believed self-management was control in using medication and monitoring asthma, and no other form of self-management was needed. Role and emotional management seemed to be largely disregarded, which agrees with previous research (Hashem & Merritt, 2018; Van Mens-Verhulst et al., 2004). If participants are medicalised, to a certain degree it may suggest power maintenance over people since it

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[61] Self-efficacy is the belief that one has the ability to complete a task (Bandura, 1977)

[62] Collective cultures tend to cognitively convert situations using collective settings (and therefore prioritise collective perceptions and goals (Triandis, 2018)

[63] Individualistic cultures tend to cognitively convert situations using individual settings and therefore prioritise individual perceptions and goals (Triandis, 2018)

shapes participants into the ideal medical patients (a form of conflictual power[64]). This has been speculated by many theorists e.g. Foucault's ideas on power suggest that the access to discourses (the production, distribution, and legitimisation of knowledge) is a form of control, where power tied to scientific knowledge can be rendered abstract to employ social discipline, compliance and knowledge that was not protested by people (McHoul, McHoul, & Grace, 2015). Freire (an influential philosopher) suggested that medicalisation is a form of oppressive prescription (the power of employing a choice/agenda over another's choice) since certain self-management strategies are employed and people may be unaware of its impact (Freire, 2018). For instance, those participants who perceived that they had mild asthma in this study, also believed that they only needed medicine to control their asthma and that action plans were less helpful and meaningful to them. But, the NRAD report found a significant proportion of asthma deaths occurred in people with mild/moderate asthma. It may be that those who believed that they had mild or moderate asthma had poor control or untreated asthma, rather than essentially having actual mild/moderate asthma (NRAD, 2014).

Undoubtedly, power dynamics can be part of any doctor-patient relationship and has been widely studied (Freire, 2018; McHoul, McHoul, & Grace, 2015). A systematic review synthesis by Joseph-Williams et al. (2014) found that the provision of knowledge by itself (e.g. of treatment options and personal goals and interests) from HCPs did not mean participants had the power to make decisions; which was the participant's ability to have an impact on participating in shared decision-making, confidence in the value of one's own knowledge on treatment options to participate or ability to seek out medical knowledge and self-efficacy to participate. Participants can become passive in doctor-patient encounters and are less likely to question them e.g. they may allow HCPs to make decisions for them because they want to be perceived as the easy/good patient. Sometimes, this was associated with the ethnic background of the participant e.g. ethnic differences between African American patients and HCPs meant they were less likely to receive information and have concerns addressed (Joseph-Williams, Elwyn, & Edwards, 2014). There were also different levels of becoming medicalised across generations, where older participants were more reliant on medication which may be due to being accustomed to health behaviour routines and systems

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[64] Power 'over' (also known as conflictual power) consists of the capability of individuals/groups/institutions to prevail over another in doing something that a person is resistant to, would not normally do and is not in their interest. This form of power is based on social relations (Haugaard, 2002)

in South Asian countries. This can be explained by ideas around habitus[65], where rules and customs are followed due to past experiences in Bangladesh or Pakistan (Bourdieu, 2017, 2018). This agrees with Lakhanpaul et al. (2017), who found parents of children with asthma prioritised discussions on medications e.g. medication intake, management and side-effects. There were also participants who resisted against being medicalisation due to receiving other information about asthma, suggesting that if participants were fully informed about asthma self-management this may transform attitudes towards becoming medicalisation across age groups (McHoul, McHoul, & Grace, 2015). The struggle of ideas against expectations of one's society can be a form of cultural hybridity since it involves ongoing reflections and clashes on what is the correct self-management behaviour. Similarly, struggling against prioritising asthma above cultural/social norms and expectations can also be a form of hybridity e.g. maintaining masculinity and femininity while having asthma (Small et al., 2005).

The findings that Bangladeshi and Pakistani participants had more knowledge about medications rather than asthma (e.g. how/when to take medications), challenges previous studies including systematic reviews that found they find it difficult to digest information on medication (Ahmed et al., 2018; Hussein & Partridge, 2002; Lakhanpaul et al., 2014a, 2017; Miles et al., 2017). Although, medical knowledge in other respect varied (e.g. UK born/raised generations knew the difference between the reliever and preventer inhalers by this was not known by most first generations), and a few participants across generations described the difficulty in retaining information related to monitoring asthma using devices e.g. peak flow monitoring. This may suggest that not all forms of medication knowledge are challenging and that knowledge on medication may be changing in other UK born/raised Bangladeshi and Pakistani generations. The diagnosis confirmation of feeling asthma was important to initiate self-management. In this study, some first-generation Bangladeshis had problems attaining diagnosis, they were prescribed asthma inhalers before diagnosis and they were confused, angry and frustrated at GPs for not providing diagnosis. This agrees with Lakhanpaul et al. (2017), who found similar findings for children with asthma; they found diagnosis is an avenue that provides relief, ensured the family and significant others (e.g. the schools) were aware of a child's condition and provided access to resources such as asthma reviews (Lakhanpaul et al., 2017).

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[65] Habitus is the internalised dispositions of second nature social rules and categorisations on perceptions, thoughts and behaviours predicted by past experiences, and social, cultural and economic capital (Bourdieu, 2017, 2018)

Family support is important since the health of others (e.g. family health), was part of the Indian self in India (Sinha, 2014). In addition, this study found one of the ways in which asthma diagnosis was normalised was by comparing one's own asthma to the asthma of family members e.g. to see who has better asthma control or it gave them a sense of self-efficacy that they are able to self-manage asthma since it is a part of family life (this can be categorised as a collective part of the Bangladeshi and/or Pakistani self). Similar findings on social comparisons were found in a mixed research study for Bangladeshi, Indian, Pakistani, Nepalese individuals with diabetes (Patel et al., 2015). Comparisons were also made between asthma and other illnesses (mainly diabetes). It is unclear why there was more social awareness, acceptability, discourse or social support for other illnesses compared to asthma, though one UK based qualitative study found disclosure to others about epilepsy in Pakistani communities was also dependent upon fears of stigmatisation, quality of relationship and previous social reactions (Small et al., 2005). Family support for asthma was fragmented; limited to the observability of asthma symptoms which required practical and moral support. Research has found that there was reduced support from extended family members for various South Asian communities with asthma in the UK and family support from close members was restricted to asthma attacks or the need for translation (Griffiths et al., 2001; Hussein & Partridge, 2002; Sharif, 2012). However, the level of support from immediate family for other illnesses (e.g. diabetes), was much higher (Hawthorne et al., 2007).

The way the body was spoken about and experienced in relation to asthma may be thought of as a form of cultural expression (e.g. talking about emotions and asthma using metaphors to illustrate body imagery such as fighting against asthma), demonstrating how participants normally talk and express themselves around health and illness may not always be universal (Burke et al., 2009a). Perhaps, interventions should consider including metaphors relevant to Bangladeshi and Pakistani cultures to allow information to be relevant to the population (Castro, Barrera, & Steiker, 2010). To my knowledge, research on the feeling of asthma around the body has not been reported before, but an very old study has suggested that the Indian self was bounded by the body (Marsella, De Vos, & Hsu, 1985). Previous studies have noted that South Asians and other cultures (e.g. African Americans) believed in the acute nature of asthma and its treatment (Bedi, 2007; Hussein & Partridge, 2002; Shendge, Deka, & Kotwani, 2012), however this study has shown that this was not exclusive to some

participants who believed in the absence/presence of asthma in the body even though they understood asthma as a chronic illness, suggesting that current thinking and interpretations of findings may need to be re-assessed (Kralik et al., 2010). Self-management behaviour around the internal regulation of the body has been supported by numerous studies that suggest collective beliefs about regulating body imbalance of impurities and/or hot and cold constructs can be found in various ethnicities (e.g. South Asians, South East Asians, Chinese, Middle-Eastern, Puerto Ricans and Latin Americans), though what is classified as hot or cold may vary across cultures (Harver & Kotses, 2010; Holland, 2017).

Asthma was perceived to be a cold illness. This study found that yoghurt, ginger, fizzy drinks and watermelon were cold food/drinks and hot remedies involved dressing up warm, using the heater/blanket and so forth. These beliefs can be interpreted/categorised as hot and cold beliefs (Ahmed et al., 2017; Harver & Kotses, 2010). Avoidance of cold food such as banana and ice-cream have been described in other UK qualitative studies but these studies did not explicitly link them to the collective hot and cold beliefs (Cane, Pao, & McKenzie, 2001; Lakhanpaul et al., 2017). Beliefs around sweating to improve asthma self-management can be interpreted as part of the cleansing model beliefs and/or hot and cold beliefs, since these beliefs are related to thoughts around balancing impurities from the body and managing the cold element of the sweat (Harver & Kotses, 2010; Helman, 2007, 2014). Most of the time, participants were not consciously aware of implementing the hot and cold or cleansing beliefs/norms, but rather they perceived these self-management behaviours as common sense. This was not surprising since these collective cultural beliefs are based on some facts e.g. cold weather can trigger asthma (Bourdieu, 2017, 2018; Holland, 2017). Since cold constructs such as the winter allowed participants to become more attentive to asthma self-management around the body (or develop the feeling of becoming asthmatic), it may be feasible to suggest that interventions may work better when the self is more conscious that self-management or support may be needed. Perhaps, participants need to also receive education on how asthma functions in the body (Bourdieu, 2017, 2018; Holland, 2017; Marteau, Hollands, & Fletcher, 2012).

The Bangladeshi and Pakistani participants in this study had a lot of emotional issues (some of which were culture and generation specific). In the latter, this study found that there was less generation specific acculturative stress in the third generation compared to the first generation. An emotion similar that was specific to the generation was worrying about the

future that can worsen asthma while ageing which can be targeted in interventions. Despite generational status, there was certain culture-specific stress e.g. family responsibility, cultural etiquettes and cultural problem-solving methods; which are part of the collective self (Sam & Berry, 2010). This agrees with previous literature that the Indian self was individual and collective e.g. consistent with values related to peace of mind, freedom from stress and one's place in the community (Sinha, 2014; Triandis, 2018). Participants employed self-management behaviours related to maintaining a psychological balance to address emotions (e.g. religious coping, relaxation, diverting attention and so forth). Perhaps, participants may benefit from psychological interventions that target both individual and collective factors to enhance these self-management strategies, the inclusion of which has been supported by a systematic synthesis of asthma self-management trials (Pinnock et al., 2017).

Studies on cultural hybridity[66] in UK born/raised generations with long term illnesses found religion was given precedence over traditional culture to self-manage illness (Moosavi et al., 2007; Robinson, 2009; Small et al., 2005). Lakhanpaul et al. (2017) found Bangladeshi, Indian, and Pakistani individuals used religious coping as part of self-management. Previous literature agree that in other cultures such as African Americans and American Indians also used religious coping as part of self-management of chronic or terminal illness (Castro et al., 2009; Kreuter et al., 2003, 2013). Attitudes towards medication in Ramadhan can be crucial as found in this study and there remains a gap in addressing Ramadhan concerns (in supported self-management and interventions) (Canino et al., 2009; Hawthorne et al., 2007; Leong et al., 2012; Small et al., 2005). Additionally, this study found cultural hybridity in using treatment and accessing services supporting the overlapping model of hybridity in healthcare proposed by Small et al. (2005) (see Figure 8; chapter 6). For example, the use of CAM alongside biomedicine can involve the fusion of beliefs and practices from two zones through negotiations and struggles e.g. recommendations or expectations from others (Small et al., 2005). Hence, even though a person may be medicalised from one zone (e.g. healthcare services) they may use CAM in another zone (e.g. home), implying that holistic understanding of self-management helps to break down and understand various facets involved in hybridity.

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[66] Cultural hybridity is the bi-cultural competence and negotiations of being a part of two or more cultures with a new sense of belonging (Hall, 1990, 2014)

In this study, most of the sample employed the integration strategy of acculturation where most participants identified themselves as 'British Bangladeshi'/'British Pakistani' or 'bicultural' (most first generation rated themselves as more orientated towards South Asian culture with a fair understanding of English). This means that there should be caution in generalising findings to other South Asians who may adopt different acculturation strategies e.g. all participants in this study could speak English (Sam & Berry, 2010). There have been many studies around acculturation and South Asian health but little has been conducted in asthma e.g. tobacco use (Mukherjea, Modayil, & Tong, 2018), breastfeeding practices (Choudhry & Wallace, 2012), and atherosclerosis (Bharmal et al., 2018; Volgman et al., 2018). Some of these previous studies have also found the presence of acculturative stress[67], e.g. interviews showed that women had conflict with their mother in-laws for infant feeding preferences (formula feeding compared to breastfeeding) (Choudhry & Wallace, 2012).

7.5.3 Strengths and weaknesses of the study

This research is one of the few studies exploring cultural changes in understanding asthma self-management behaviour in the Bangladeshi and Pakistani populations in the UK. Preferably, comprehension of cultural changes such as acculturation needs to be studied longitudinally e.g. before and after encountering another culture (Berry, 2005). Selected questions from the SL-ASIA scale were used to provide an indication of the acculturation in the sample (Iyer & Haslam, 2003; Suinn et al., 1987), however the scale was limited in providing a fuller picture of cultural diversity (e.g. questions only asked about linguistic abilities in either English or South Asian languages), but some participants who could speak other European and Middle-eastern languages e.g. one first-generation Bangladeshi could also speak fluently in Italian. Suggestively, super diversity may be important to consider due to the recent mass migration flow from European countries to the UK (Meissner & Vertovec, 2015).

I have only explored the perspective of Bangladeshi and Pakistani participants in this study. One of the reasons for this was that the Indian population was too diverse in terms of religion, language, caste system and so forth, which are all factors that would need to be

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[67] Acculturative stress is the reaction and experience of daily stress and degree of psychological/sociocultural adaptation challenges resulting from encountering a larger mainstream culture (Berry, 2005; Sam & Berry, 2010)

considered in a larger study (Bradby & Brand, 2015; Sinha, 2014). In addition, recruitment of participants represented a balance of primary (n=15) and secondary/tertiary care participants (n=13), from both ethnicities. However, caution should be exercised in generalising findings on subcultural differences and generations, as most first-generations were recruited from secondary care asthma clinics who may have more uncontrolled asthma (seven out of ten; representing all five Bangladeshi participants). There was also no representation of participants from secondary care in the third and fourth generation. Some recruitment strategies and methods (e.g. posters) were ineffective in this study. Effective recruitment strategies (e.g. GP invites/calls, HCP referrals and face-to-face approach in asthma clinics) may have influenced the diversity of participants to those who accessed healthcare services (Roosa et al., 2008). On the contrary, though face-to-face recruitment strategies may have been effective in this study and others (McLean & Campbell, 2003; Symonds et al., 2012), other studies have shown that face-to-face methodology are not necessary for enhancing recruitment of South Asian participants e.g. posters can be effective (see section 9.4.1 reflexivity of using language in research) (Stirland et al., 2011).

It may also be argued that the participants recruited were mainly English speakers, thereby representing that section of the population, while excluding non-English speakers who may have different asthma self-management behaviour or are less likely to consult NHS HCPs (Roosa et al., 2008). Language may be the door to participant insight and empowerment, arguably not accounting for difference in language may play on power dynamics between the researcher and the researched, since the voice of certain sections of the community are not reflected (Cameron et al., 2018; Lloyd et al., 2008b; Rooney et al., 2011). However, proactive plans were in place to accommodate for non-English speakers including recruitment of interpreters, presence of a bilingual researcher and face-to-face strategies for recruitment in community settings such as places of worship and community centres (Stirland et al., 2011), though time restrictions and practical barriers such as the reliability of interpreters/participants turning up to interviews was an issue (Lloyd et al., 2008b; Ochocka & Janzen, 2007; Stirland et al., 2011). More time and funding would mean measures could be in place to develop a relationship/trust with key people from the community and participants through series of meetings, shown to be important in some studies (MacNeill et al., 2013; Ochocka & Janzen, 2007; Rooney et al., 2011; Stirland et al., 2011). It would be further interesting to understand what culturally appealing recruitment strategies would be most effective in addressing barriers to participation e.g. strategies that are congruent with

cultural beliefs and values of the studied population such as accounting for stigma (Rooney et al., 2011; Roosa et al., 2008; Stirland et al., 2011), and how to ensure clinical diagnosis of asthma can be validated through such methodology (Roosa et al., 2008).

Although, participant recruitment in NHS facilities yielded English speakers in the final sample, there were expression of interests from potential participants who were recruited from the same settings who did not speak English (or spoke basic English). They did not make the final sample for various reasons listed in participant demographics of the results (see section 7.4.1). This may reflect that it is not easy to include every dimension of language in qualitative research that usually comprises of a small number of participants (see section 9.4.2 reflexivity on qualitative data interpretations) (Cameron et al., 2018; Lloyd et al., 2008b). Language has its own complexities that need consideration (Cameron et al., 2018). First generation participants in this study may have been able to speak some English, but perhaps their health literacy, written or reading English skills were not very good. One of the main factors that needed consideration was related to how certain people use oral languages e.g. being accustomed to using Sylheti may mean that a significant part of the first-generation Sylhetis may place more emphasis on learning other languages orally, hence participants who spoke in English may only know the verbal format compared to written format (Cameron et al., 2018; Lloyd et al., 2008). Materials were provided in this study to account for these factors, therefore helping participants with the research process e.g. the presence of a bilingual researcher who helped in matters related to reading and writing and the audio-recorded PIS and consent form (Lloyd et al., 2008a).

Allowing participants to express themselves in their native language in interviews (even though they may speak English), may have ensured that they were able to fully express themselves and encouraged in-depth discussions; this was important as literature has noted that most South Asians were typically unfamiliar with the research process and tended to provide short and simple answers (MacNeill et al., 2013; Stirland et al., 2011). Participants from the all generations were also able to use words/phrases to create meaningful cultural expressions that cannot be articulated in English (Jaspal, 2010). A further strength of the study was that the data transcription and analysis was conducted in the original language spoken by participants. This avoids criticisms of analysis conducted with back translations; translating language can often have subjective and arbitrary interpretations without objective consistency e.g. the lack of equitable terms in English such as asthma or wheeze

(Reiss, 2014), though this meant only bilingual researchers could analyse some of the data (seven out of 27 transcripts). Accessibility by other researchers was ensured when data were back translated for presentation purposes. In addition, the emic-etic approach to data (referring findings back to the participant), provided insider/outsider insights and verifications of cultural interpretations that validated lived experiences of participants (Punnett et al., 2017), though it can be argued that this approach may be challenging when considering acculturation (or other cultural shifts) in the study sample may or may not match the background of a specified participant involved in the interpretation (see section 9.4.2 reflexivity on qualitative data interpretations). Novel ways to incorporate the complexity of language in the research process needs further exploration and evaluation (Lloyd et al., 2008a; Lloyd et al., 2008b).

Nonetheless, the first generation only comprised a section of the population studied (ten out of 27 participants). Debatably, there may be a risk that framing the first generation Bangladeshi and Pakistani individuals in a manner that suggests that they all have low health literacy and/or English-speaking issues, stigmatises the community and creates stereotypes, since these issues are true for various communities in the UK such as the mainstream White population. But, the purpose of this study was to provide a deeper understanding of asthma self-management behaviour and the role of culture in these two subcultural groups in their own distinctive right, rather than comparing the two groups to other populations or even suggesting that a specific characteristic is true solely for these communities (Lloyd et al., 2008b).

On the other hand, a good number of participants were included in this study; achieving data saturation with respect to the research questions (i.e. when there was a comprehensive understanding of perspectives) (Saunders et al., 2017). Moreover, to ensure reliability of coding data, a second coder checked 11% of the transcripts (Susanna Dowrick), and a further 11% was group coded (Liz Steed, Hilary Pinnock). A strong point to this study was the representation of participants from all generations. Arguably, there are other ways of classifying generational status as opposed to the definition used in this study. Generation can be defined by social markers that generate a collective and shared persona such as age, life stage, living through similar events, political shifts or technological transformations. But these definitions are not entirely helpful due to factors such as globalisation and technological advances that renders generational commonalities across cultures and SES

difficult to pinpoint. Tapping into these resources, youth across the globe may be more knowledgeable or financially equipped than the former generation (McCrindle & Wolfinger, 2010).

7.5.4 Conclusions and implications for future research

This qualitative study explored the perspective of Bangladeshis and Pakistanis on their asthma self-management across generations (first to fourth) to understand the role of culture and what needs to be integrated as part of a holistic asthma self-management intervention:

- Understanding the Bangladeshi and Pakistani self in the UK context adds to building on the concept of holistic self-management (Schulman-Green et al., 2012; Sinha, 2014). There can be multiple selves (an ongoing process of transitions and shifts across situations) where self-management behaviour was tied to the body, society and social discourses.

- Cultural factors that need to be considered in interventions are acculturation, cultural hybridity, subcultural differences, generational status, language use (e.g. language appropriate study resources, code switching between languages and language-matching between HCPs/researchers), emotions (including acculturative stress), religion/Ramadhan, cultural expressions (e.g. metaphors), social norms and practices (e.g. gender norms), individual and collective cognitions and health beliefs (e.g. cleansing beliefs), and CAM use.

- Future interventions can consider targeting emotions (including acculturative and culture-specific stress that can worsen asthma) in a psychological intervention, confusion on religious ruling on medicine use during Ramadhan, religious coping, technology based education on new and credible information (e.g. service help points) or new updated treatment, consideration/addressing language use, raising consciousness of unconscious beliefs and improving access and diagnosis in primary care (and opportunities to speak to a specialist with no time constraints).

- There are distinct cultural health expressions and interpretations that should be understood in context e.g. metaphor use and illness construction. What is understood and expressed by different South Asian populations can differ to other cultures e.g. collective cognitions/meanings attributed to the body and self-efficacy (Michaels, Michaels, & Wulf, 2012).

- There were power dynamics between HCPs and participants; information from HCPs were dependent on disease management which shaped participant attitude and reliance on medical management and believing no further support was needed, therefore implying that knowledge provisions (e.g. medical knowledge) does not necessarily provide power to participants. The exploration of methods to empower Bangladeshi and Pakistani participants in doctor-patient contact needs more research (Joseph-Williams, Elwyn, & Edwards, 2014; McHoul, McHoul, & Grace, 2015).

- A variety of HCPs were identified as important in participant's asthma care. However, there was little relationship between most participants and HCPs for their asthma, therefore it would be interesting to explore what a good/ideal relationship would look like for Bangladeshis and Pakistanis.

- Interventions need to be collaboratively developed with individuals with asthma to account for relevant components of lived experiences (Lakhanpaul et al., 2014b).

This chapter explored the perspective of Bangladeshis and Pakistanis on their asthma self-management, to understand the role of culture and what needs to be considered to develop holistic asthma self-management interventions. The next chapter describes a qualitative study on the perspective of HCPs on how supported self-management was provided to these communities.

Chapter 8. Qualitative study: Exploring healthcare professional's perspective on providing supported self-management to Bangladeshis and Pakistanis with asthma

The last chapter explored the perspective of Bangladeshi and Pakistani individuals on their asthma self-management. This chapter describes the perspective of HCPs on Bangladeshi and Pakistani patients and the provision of supported asthma self-management given to these communities. Those HCPs who were described as the most important professional in the asthma care of Bangladeshi and Pakistani participants with asthma (see chapter 7), were recruited for a semi-structured interview.

8.1 Rationale for the qualitative research

Professional support of self-management for individuals with asthma (including structured education, action plans and professional reviews/follow-ups), can improve asthma outcomes and has been widely recommended in guidelines, yet poorly implemented in routine practice (Ahmed et al., 2018; Pinnock et al., 2015, 2017). Support for Bangladeshi and Pakistani patients may rely on what HCPs understand as supported self-management adequate for their cultural background (i.e. cultural realities) e.g. the role of social support and other social, cultural and economic capital (Dwarswaard et al., 2016; Morris, Kennedy, & Sanders, 2016). To understand this better, cultural relativism[68], ethnocentrism[69] and universalism[70] were applied in this study to understand these perspectives (see section 3.2.1). Both universalism and ethnocentrism can lead to cultural misinterpretations through generalisations, perception bias and stereotypes (Billet, 2016; Kagitcibasi, 2017; Yadav &

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[68] Cultural relativism is the belief that culture should be judged by its own merits rather than the culturally bounded values and standards of another, and cultural diversity should be recognised and respected (Billet, 2016; Kagitcibasi, 2017)

[69] Ethnocentrism is the practice of judging a culture compared to standards of another culture, where another culture is deemed as inferior to one's own culture that is judged as the better society due to the perception of keeping up with the progression of time (Billet, 2016; Rachels, 2007)

[70] Universalism is the belief that there are fixed universal cultural realities regardless of time (Billet, 2016; Kagitcibasi, 2017; Rachels, 2007)

Yadav, 2015). Arguably, cultural competence is the professional ability to try and be aware, understand and apply cultural knowledge, skills and resources in daily practice (Betancourt et al., 2016).

8.2 Aims for the qualitative research

The perspective of HCPs on supported self-management for Bangladeshi and Pakistani patients were explored. The primary aim of the qualitative study was to understand HCP's perspective on Bangladeshi and Pakistani patients (i.e. cultural realities) and the provision of supported self-management given to these communities. The secondary aim was to explore what type of asthma self-management interventions HCPs believe would be useful for Bangladeshi and Pakistani patients with asthma and for their future practice needs.

The research questions were:
1) What are HCP's perspective and challenges of providing supported self-management support to Bangladeshis and Pakistanis in the UK?
2) What type of interventions HCPs feel would be useful for Bangladeshis and Pakistanis with asthma in the UK and for their professional development?

8.3 Methodology for the qualitative research

8.3.1 Study design

This qualitative research involved one-to-one semi-structured interviews. The COREQ checklist for qualitative research for this study was reported in Appendix 14. Due to the purposeful sampling strategy used in this study for recruiting various professional occupations (GP, asthma consultant, primary care nurse, asthma nurse specialist and emergency medicine doctor), anticipated time constraints for HCPs and various recruitment sites; I decided that one-to-one interviews would be more ideal than focus groups (Krueger & Casey, 2014; Rooney et al., 2011). In addition, one-to-one interviews have the potential of gathering in-depth information on an individual compared to focus groups which are focussed on group level opinions (Krueger & Casey, 2014).

8.3.2 Participants

HCPs were sampled using purposeful sampling to ensure that the relevant professional groups who were described as the most important HCP in the asthma care of Bangladeshi and Pakistani participant interview data were recruited (see section 7.4.6). There was evidence that most HCPs either had more contact with the Bangladeshi or the Pakistani population depending on the area they were recruited from, hence where possible (in the professional categories of GPs and asthma consultants) efforts were made to include experts with varied contact with Bangladeshis and/or Pakistanis. In addition, I included two asthma consultants who had contributed to the research by helping recruit Bangladeshi and Pakistani participants for interviews from their clinics (see chapter 7).

8.3.3 Selection inclusion/exclusion criteria

The inclusion criteria for HCP were:
- HCP categories who were considered as important in the asthma care of Bangladeshi and Pakistani participants in the previous interview stage (see chapter 7), i.e. GP, asthma consultant, emergency medicine doctor, asthma specialist nurse and primary care nurse.
- HCPs who support asthma patients from the Bangladeshi or the Pakistani community.

HCPs were excluded if:
- The HCP category was not identified by participants in the previous interview stage (see chapter 7).

8.3.4 Interview schedule

The interview schedule consisted of main topic areas and several prompt questions (see Appendix 15):
- Experience of working with Bangladeshi and/or Pakistani individuals with asthma.
- Perspectives on asthma self-management in the Bangladeshi and Pakistani patients and what support HCPs provide.
- Description of relationship with Bangladeshi and/or Pakistani patients.
- Working relationships and experiences with other HCPs who provide supported self-management to these communities.

- Opinions, thoughts and suggestions for professional development needs and intervention/s for Bangladeshis and Pakistanis.

8.3.5 Study procedure

The study procedure consisted of the following:

1) Study participant information sheet were sent to relevant organisations to distribute amongst staff/professionals who were asked to respond with an expression of interest form, using either a prepaid envelope or by email (see Appendix 16 and 17). As detailed in chapter 7, selected questions from the SL-ASIA were placed in the expression of interest form to enable me to describe the degree of acculturation in the sample. To my knowledge, there are no generic acculturation scale that can be used for various ethnic backgrounds in a study (see Appendix 17) (Iyer & Haslam, 2003; Suinn et al., 1987).

2) I took informed consent to participate in a one-to-one audio recorded semi-structured interview (see Appendix 18 and 15).

3) I (the principal researcher; a female PhD student; BA Hons, PGDip, MSc) carried out one-to-one interviews, until data saturation was achieved with respect to the research questions (i.e. when there was a comprehensive understanding of perspectives) (Saunders et al., 2017). I had previous qualitative research experience. HCPs that fitted the inclusion/exclusion criteria were recruited and interviews were carried out at recruitment sites (GP surgeries and asthma clinics) and Queen Mary, University of London.

   - Primary care staff: Participating GP surgeries involved in the recruitment of Bangladeshi and Pakistani patients in a prior interview stage (see chapter 7) were given study information to disseminate to their staff (Addison Road Practice; East One Health; Jubilee Street Practice).

   - Secondary care staff: HCPs at asthma clinics (The Barts and the London; Whipps Cross Hospital) were emailed with study information and asked to participate in an interview. Two consultants who contributed to the research in this thesis by helping recruit Bangladeshi and Pakistani patients for interviews in a prior research phase were included in this study (see chapter 7), but they were not familiar with the interview schedule. To further reduce bias, another researcher (Shauna McKibben) interviewed a consultant as he had an existing/ongoing relationship with me while I was recruiting further Bangladeshi and Pakistani patients. In addition, study

information packs were disseminated to emergency medicine doctors and ambulance paramedics at the Royal London Hospital, London Air Ambulance, London Ambulance Service NHS trust and the Barts and the London NHS, promoted by email, Twitter or snowballing from word of mouth from relevant colleagues.

4) Reflexive notes in a research journal were taken by the researcher after each interview and supervisor and peer consultations were accessed if/and when necessary (some of which have been discussed in section 9.4).

8.3.6 Model underpinning this study

Berry's acculturation model (1997, 2005, 2010)

One method of understanding Bangladeshi and Pakistani culture in the UK can be framed around Berry's acculturation[71] model (Berry, 2005; Berry, 1997; Sam & Berry, 2010), that suggests it is helpful to compare the patient's culture to the larger mainstream culture in their nature of contact and interaction (see Figure 7; section 6.1) (Sam & Berry, 2010). The larger culture in this study was viewed as the degree of acculturation amongst HCPs in the healthcare service, and their ability to provide supported self-management to acculturated individuals. There are four ways acculturation occurs in the mainstream group, which are opposites of the four individual/group patient acculturation strategies (see Figure 7 and section 6.1) (Sam & Berry, 2010):

- Multiculturalism (equivalent to integration[72]) - when cultural diversity is fully supported as a feature of the mainstream society. The correct atmosphere needs to be in place for the integration strategy to be chosen and sustained.

- Melting pot (equivalent to assimilation[73]) - where the mainstream society is more dominant than the individual's own cultural group.

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[71] Acculturation is the cultural changes influenced by encountering another mainstream culture (Berry, 1997; 2005; Sam & Berry, 2010)

[72] Integration is an individual/group level acculturation strategy where individuals maintain their original culture and also integrate with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

[73] Assimilation is an individual/group level acculturation strategy where individuals disconnect from their original culture to fit in with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

- Segregation (equivalent to separation[74]) - where the mainstream society tries to force separation of the individual from their society.

- Exclusion (equivalent to marginalisation[75]) - when both mainstream society and the individuals cultural group force exclusion through various societal factors.

8.3.7 Data analysis and interpretation

The interviews were digitally recorded, transcribed and entered into QDA Miner for analysis. The data were analysed using thematic analysis guidelines suggested by Braun and Clarke (2006). Thematic analysis was chosen because it matches the aims of this study. The thematic analysis considered (Braun & Clarke, 2006):

- The theoretical framework of a contextualist method, where analysis combines two methods of thematic analysis: 1) essentialist which focusses on individual experiences, meanings and realities and, 2) constructionist – which focusses on patterns of socially produced events, realities, meanings, experiences arising from structural conditions and/or sociocultural contexts. The combination of both methods considers the individual perspective on the meanings of experiences, motivations and interactions and how this has an impact on the wider sociocultural influences on the production of these meanings and realities.

- Patterns or themes were identified with an inductive 'bottom-up' data driven approach; a strategy of data coding without fitting data into a pre-existing coding framework or analytical perception of the researcher, therefore it is an analysis which emphasises on and is driven by data.

- The level at which themes were identified were at a latent level, which describes the form and meaning of interview transcripts at the surface or explicit stages and further detects, examines and interprets the underlying ideologies, assumptions and concepts which were thought to shape these descriptions (Braun & Clarke, 2006).

Moreover, 33% of the interviews were independently coded by a second coder (Jessica Porter) for reliability and comparison. The codes and coding framework were checked by two

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[74] Separation is an individual/group level acculturation strategy where individuals hold on to their original culture and avoid any adaptation or contact with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

[75] Marginalisation is an individual/group level acculturation strategy where individuals lose maintenance and contact with both original and mainstream cultures (Berry, 2005; Sam & Berry, 2010)

other researchers (33%; Liz Steed, Hilary Pinnock). Participant quotations were presented to illustrate the findings. For anonymity, quotes had the HCP category and numerical codes.

8.3.8 Ethical approval

The study gained NHS ethical approval on 23rd January 2017 (IRAS ID 200955; REC reference 16/YH/0524). Governance approval 011599.

8.4 Results for the qualitative research

8.4.1 Participant characteristics

HCP demographics

There were 16 expressions of interest to participate in the study. Nine HCPs were recruited including GP doctors (n=3), asthma consultants (one with general medicine expertise; n=3), helicopter emergency medicine service (HEMS) doctor (with experience of general emergency medicine expertise; n=1), a community/secondary care asthma nurse specialist (n=1), and a primary care nurse (n=1). HCPs worked in the London Boroughs: Tower Hamlets (n=3), City of London (n=3), Newham (n=1) and Waltham Forest (n=2). Interview duration ranged from 20 minutes to one hour and fifteen minutes. There were five females and four males, between the ages of 34 to 58, from a range of ethnicities (Bangladeshi, Irish, Spanish, Korean and White Caucasian) (see Table 10). Seven participants who returned an expression of interest form were not recruited for various reasons: lack of response to researcher contact by a GP; time restrictions or being busy was reported by three GP/community nurses and a paramedic; the HCP category consultants were fully recruited, and a primary care nurse preferred that the interview was not recorded. All HCPs reported considerable experience with the Bangladeshi and/or Pakistani population (ranging over five to thirteen years).

Degree of acculturation in the sample

In response to the question; *'how do you identify yourself?'* - All HCPs identified themselves as 'British' (n=9). Alongside this, five HCPs identified themselves as belonging to another ethnicity e.g. British Bangladeshi, British Irish, British Spanish or British White Caucasian

(n=5). This may reflect that some of the HCPs in the mainstream healthcare service reflected the acculturation strategy melting pot[76] and some reflected multiculturalism[77] (see Table 10).

In response to the question; *'what languages can you speak?'* - Four HCPs could speak another language alongside English e.g. Spanish, Korean, Standard Bengali or Bengali Chittagong dialect showing an indication of multiculturalism. Five HCPs could only speak English showing the segregation[78] strategy of acculturation (see Table 10).

In response to the question; *'how would you rate yourself?'* - All HCPs identified themselves as westernised ('mostly westernised' n=5; 'very westernised' n=4), reflecting the melting pot strategy (see Table 10).

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[76] Melting pot is a mainstream acculturation strategy where the mainstream society is more dominant than the individual's own cultural group (Berry, 2005; Sam & Berry, 2010)

[77] Multiculturalism is a mainstream acculturation strategy when cultural diversity is fully supported as a feature of the mainstream society. The correct atmosphere needs to be in place for the integration strategy to be chosen and sustained (Berry, 2005; Sam & Berry, 2010)

[78] Segregation is a mainstream acculturation strategy where the mainstream society tries to force separation of the individual from their society (Berry, 2005; Sam & Berry, 2010)

Table 10. Participant characteristics (healthcare professionals)

Profession /Ethnicity	Selected SL-ASIA questions		
	How do you identify yourself?	What language/s can you speak?	How would you rate yourself?
GP doctor /Irish	British Irish	Only English	Other: very westernised & Irish
GP doctor /Spanish	British Spanish	Bilingual (English & Spanish)	Mostly westernised
GP doctor /Bangladeshi	British Bangladeshi	Bilingual (Standard Bengali)	Mostly westernised
Consultant /White Caucasian	British	Only English	Very westernised
Consultant /Bangladeshi	British Bangladeshi	Mostly English, some South Asian (Chittagong dialect)	Very westernised
Consultant /White Caucasian	British	Only English	Very westernised
HEMS doctor /Korean	British	Mostly English (some Korean)	Other: mostly westernised & Korean
Nurse specialist /Irish	British White Caucasian	Only English	Other: mostly westernised & Irish
Primary care nurse /White Caucasian	British	Only English	Other: mostly westernised & Irish

8.4.2 Summary of themes
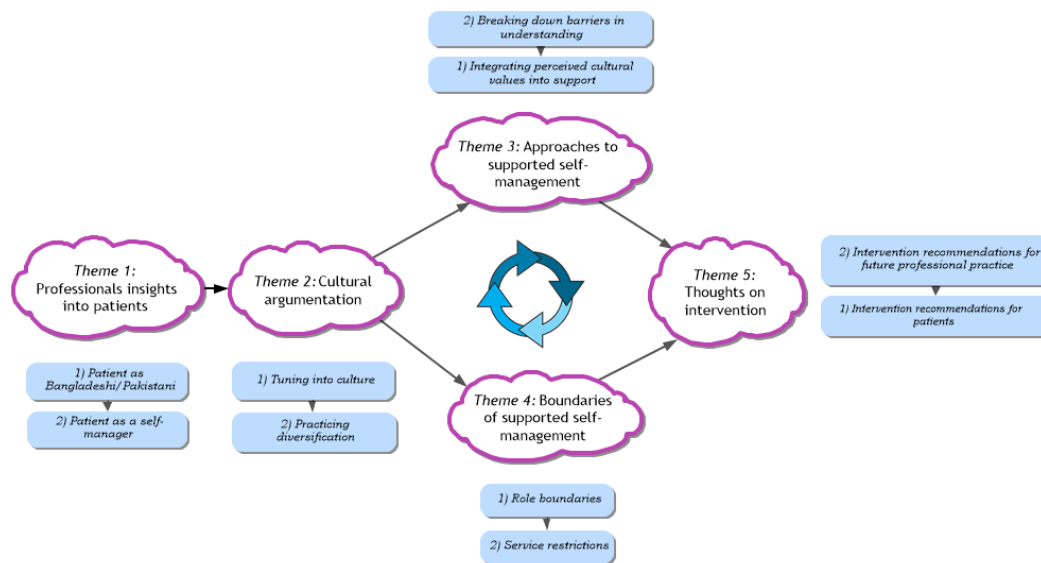
Figure 10. Thematic schema: Chain of reasoning behind providing supported self-management to Bangladeshi and Pakistani individuals with asthma

There was a chain of reasoning in providing supported self-management to Bangladeshi and Pakistani patients. Findings were organised under five interrelated themes to illustrate this (see Figure 10):

- Theme one - *Professional insights on patients:* What HCPs understand about the Bangladeshi and Pakistani culture and asthma self-management behaviour (both of which can be classed as cultural realities), *1) patient as Bangladeshi and Pakistani;* and, *2) patient as a self-manager*.

- Theme two - *Cultural argumentation:* The process of reasoning to support ideas around adapting supported self-management, where HCPs tried to systematically rationalise and contemplate on how to support these cultural realities by, *1) tuning into culture;* reflections on strategies to tune into culture and, *2) practicing diversification;* the wish to treat patients holistically.

- Theme three - *Approaches to supported self-management:* Where HCPs applied cultural realities based on insights of patients and cultural argumentations into action by, *1) integrating perceived cultural values into support* and, *2) breaking down barriers in understanding*.

- Theme four - *Boundaries of supported self-management:* The limits of understanding and implementing cultural realities in providing supported self-management through, *1) role boundaries* and, *2) service restrictions*.
- Theme five - *Thoughts on interventions: 1) intervention recommendations for patients* and, *2) intervention recommendations for future professional practice*.

8.4.3 Theme one: Professional insights on patients

This theme illustrates: 1) *patient as Bangladeshi and Pakistani;* how HCPs understand Bangladeshi and Pakistani culture and, 2) *patient as a self-manager;* how HCPs understand Bangladeshi and Pakistani patients as self-managers.

1) Patient as Bangladeshi and Pakistani

HCPs understood Bangladeshi and Pakistani culture to be mainly static (e.g. generational status, language spoken, family involvement, anxiety and resistance to change), and sometimes culture was treated as dynamic e.g. level of practicing religion.

"So, a couple of things within that I think, in culture, so in family is important, and they get influenced by family and relatives" (HEMS doctor, p9).

Generational status and language

There was widespread recognition of different generations of Bangladeshis/Pakistanis, however this was judged by age structures e.g. older patients were generally perceived to be the first generation (dismissing younger first-generation migrants in the UK). Most HCPs framed culture and self-management around thoughts of divisions; the section of the population who have problematic self-management (e.g. those who cannot speak English) and those who do not have problems with self-management (e.g. those who can speak English). Sometimes, HCPs used a classification strategy to frame this:

"I think that, the, the two Asian groups, of, people, in, this, cultural group we are talking about, and that ties into those who, speak English well, and those who do not speak English well. So, for the people who speak English well I think that, they are quite capable of using, the current information, guidelines, action plans and everything. For people who do not speak English very well... There is likelihood that they may have also, different alternative beliefs as

well, I think it's more unlikely than people who speak English very well, that they would be more likely to have beliefs in, other treatment systems etc." (GP, p1).

Although, a doctor described feeling uncomfortable with categorising culture in a static manner, but made similar comments later in the interview:

"You're asking me this question because you want me to get, put certain people within a box, and you know, what is my culture I feel, I'd tick the box of I'm both Asian and British, westernised and probably Bengali so, you know what culture are we talking about? Are we talking about my westernised culture? (GP, p3).

Language was thought of as a major service barrier to self-management using words such as *'biggest barrier'; 'a big, big, big bust';* and *'lost the big line'*. There was a sense that those who can speak English have better self-management and are easier to support/treat due to communication factors. Typically, the first generation were coined as those with language barriers (even if they had some understanding of English), that usually led to poorer understanding of asthma, its management, preventative treatments, PAAPs, appointment letters, use of monitoring equipment such as spirometry and peak flow, misinterpretations of religious beliefs and CAM beliefs (all perceived to be cultural problems). Often, there was talk around the patient's responsibility to bring family members into consultation for translating.

"There are lots of different generations of Bangladeshis, and I'm sure the younger ones would be able to explain how important it is and the, I'm guessing that over time there are less first-generation people and more second, third, fourth generation, so the numbers of people who don't necessarily get it, must be going down…' (Consultant, p5).

Some HCPs aligned the ability to speak English as a western value, and the channel that allows them insights into patient experiences, enabling them to achieve better communication and devise treatment strategies (this was also true for one HCP from the Bangladeshi ethnicity who was unable to speak Bengali fluently). In this regard, younger aged generations were understood to be more 'British' due to language ability (similar to White British patients), portraying ideas of changing cultural values in these generations e.g. independence, adherence to medication, smoking (especially in females who use this strategy for weight control), shisha and drug use. The latter three behaviours were perceived to be kept secret from family members.

"It is for the people who cannot communicate properly, I think for South Asian younger person whose British, there's clearly there's no problems but for the older ones…" (Consultant, p5).

Resistance to change

Some HCPs noted age was related to resistance to changing attitudes and behaviour towards self-management (especially in elderly patients), due to having fixated traditional ideas:

"Yeah, I think that there's a higher level of support required in terms of language probably, to make sure that everything is, fully understood. With older people, yes there's a higher level of understanding needed because, that person has their life experience, and, you're telling them something which is different from their life experience. And we know that the management of asthma has changed, in recent years... Which wasn't the case when they were younger people so, we're trying to tell older people, that may be what they were told in the past was wrong, and to believe us now and... Older people often think that you know... I've heard all this before; do I really believe something new?" (GP, p1).

Although, a nurse pointed out younger aged females who were involved in smoking and substance misuse (behaviours that were perceived to be culturally frowned upon for women), meant these female patients were secretive about their asthma and wanted to protect themselves from social embarrassment by resisting the acceptance of diagnosis and/or self-management. Acceptance may contribute to suspicions from others that asthma was caused by culturally disapproved behaviour such as smoking. However, Bangladeshis were mainly described as being more accepting of diagnosis since asthma was thought of as a well-known condition (comparable to other long-term illnesses).

"Then you try to give smoking advice, reducing smoking, stop smoking, furthermore, and… But they're like, 'Nah I, I just don't have asthma, I don't have it'. So, they're complete barrier, so they can understand English, and they can speak it and you can do a self-management plan, they'll take it home, they'll come back in a couple of weeks' time and say, 'I've stopped using it'; 'Did you stop smoking?'; 'No, that has no impact on my lifestyle and my health', so you're, on a full cycle again" (Nurse specialist, p7).

Additionally, most HCPs were uncertain whether stigma still exists in the UK context. There were also narratives around helping patients accept new ideas through ethnic-matching with staff members whom Bangladeshi and Pakistani patients can identify with (despite the professional background of the staff e.g. primary care receptionist). These staff members were thought of as insiders of the Bangladeshi and Pakistani culture with the innate ability

to provide insights to a problem and motivate patients. In contrast, most HCPs felt under-educated in culture and health:

> *"With this type of helping patients, it's the receptionist often know a lot more, about the factors that are causing problems, and motivating people and demotivating people, then the, clinicians themselves" (GP, p1).*

Family and the (influence of others)

Most HCPs provided consensus that family was an important part of culture e.g. big families mean more self-management support.

> *"I mean I have to say in a way, what, what, what is better about, what tends to be better about a lot of, patients from Indian Subcontinent is that they, usually come with family, more than Caucasian who don't, they come alone, usually. And so you know, especially sort of old, older people nearly always come, with the younger person from the family, and partly that is for, to translate. But at least you've got somebody there from family who's, helping, with that. And they tend to have more family support as well, so in a way, you know compliance should be better shouldn't it? Because they've actually got family around who can help them with, with inhalers and things like that and taking everything regularly" (Consultant, p6).*

HCPs preferred family as translators in consultations, but they felt undermined when patients were easily influenced by others around them e.g. dependency on others in seeking, *'answers'; 'gossiping', 'discussions'; 'advice'; 'instructions'* and *'reassurance'*. This form of reliance was perceived to be a cultural value (a form of communication where information is passed on throughout generations), particularly for the first generation:

> *"There are many patients who are good with their asthma so, I think there's a lot of discussion between, rather than just going away and taking your medication, they may well go back, and then there's a lot of discussion, around what they should do based on what other people tell them, there's a lot of gossiping, and that may be their main influence, rather than the professional" (Consultant, p5).*

Religion

A few HCPs described religion as part of culture (where people vary in degrees of spirituality), and these HCPs perceived religion to be a positive influence on self-management. They believed religion was something that encourages the behaviour of maintaining good health

and a potential solution for self-management. Therefore, professionals thought patients needed to become more responsible for their health by better following religious teachings:

> "I think with all religions there's, there are a lot of people signed up, and the question is how, deeply, the beliefs come through. I would think that most religions, would put a responsibility on individuals to look after themselves, and if whatever religion you take, if people were to follow it properly, then that would be a priority in their life. But the reality is, a number of people who have, useful, morally bound to their teachings, and when it comes to some of the hard parts like looking after yourself properly they, don't see it being as important, as other people would. So, so yes it would be a very easy way to, fix a lot of things if we said, 'Okay, if you're going to take this seriously, and take your religion seriously then you will, do what's best for yourself' (laughs)" (GP, p1).

Anxieties

There was widespread recognition of Bangladeshi and Pakistani patients (including family members) openly talking about having a lot of anxieties (including other psychological issues such as depression and anger), e.g. asthma specific anxieties such as coping in their daily lives and anxieties about seeing different HCPs in consultations who may not spend time listening to their concerns, acceptance of having asthma from others and difficulties around taking medication. Dealing with anxiety issues was perceived to be crucial. Anxiety can make asthma symptoms worse and hinder self-management e.g. following treatment instructions, accessing psychological services and hyperventilating. This was perceived to be a cultural problem and difficult to treat, especially in the first generation.

> "The understanding around the treatment, there was often a cultural problem because, they didn't, the people who were the more difficult ones to treat didn't have, Western knowledge of treatments, and were very anxious generally, and had so many anxieties that, it was difficult to give them instructions because, they often talk so much about their anxieties that, there wasn't enough time in the consultation to make you, feel convinced they really understood what you were asking them to do" (Consultant, p5).

2) Patient as a self-manager

Responsibility for own health

Most HCPs perceived Bangladeshis and Pakistanis as having little responsibility for their own health and if patients attained this they were described as *'ideal'* patient e.g. self-management was perceived to be part of religious beliefs; hence the '*ideal*' patient was

described as someone who engages and works towards following religious teachings properly and as a priority. Words to describe patient responsibility suggested a sense of obligation (e.g. *'You have.... '*), in performing activities for themselves e.g. attending appointments, carrying inhaler, conducting peak flow monitoring and proactively avoiding triggers. A few HCPs described patients frequently missed appointments (both from Bangladeshi and Pakistani backgrounds), particularly in relation to younger patients (and younger family members). The main reason mentioned for this was that HCPs believed there were competing interests in younger patient's lives e.g. managing roles and the timing of Ramadhan:

"And that's another thing about, patients from that community, Bengali and Pakistani communities tend to DNA more than, more than others I think…... I think they have better things to do, I think they have things to do you know. I mean sometimes that's going to work and things like that, that's genuine, worries about, losing time off work and things" (Consultant, p6).

The idea that patients should be responsible for their own health was linked to dependency (mainly prominent in first generations), e.g. reliance on the reliever inhaler as a short-term management strategy due to little understanding of preventative treatments, relying on family support (who may be children or grandchildren looking after their elders) and over relying on professional support. Hence, on one hand they described patients as not engaging properly for their health and on the other they were too dependent.

"Sometimes, they do what you tell them, and sometimes, they expect that advice, to follow that advice very carefully, maybe without trying to understand themselves, self-manage themselves so that part of responsibility in their own treatment, may be is missing a bit in that community I would say. I'm not sure if it's wrong but, instead of may be a bit more proactive, way of understanding your asthma. So maybe that's the, maybe in terms of how to manage your own asthma, because it's very much, you have to decide your own management depending on your symptoms, your triggers, so maybe that is, missing a bit, like the…" (GP, p2).

Therefore, the *'ideal'* patient was described as those who need to be less dependent and more proactive:

"So, you don't want them to build up a dependency on you, because I have one girl, she comes that every couple of months just because, I said, 'No, your fine, medically stable'. I said, 'I'm not your councillor. That's it'…" (Nurse specialist, p7).

Illness beliefs

Some self-management strategies were perceived to be related to cultural health beliefs, which some HCPs noted this may be reinforced by family. Most HCPs thought that patients believed that medication should be used for short term management and quick solutions, which may explain behaviours e.g. reliance on the reliever inhaler and difficulty in accepting the concept of preventative medication. A nurse described that asthma incidents (e.g. exacerbations), can act as a motivator for patients to adhere to medication but this is short lived:

> *"I think there is a group of Southeast Asian patients who are more, of a belief that there must be a cure out there and that maybe we are withholding it unless we… Unless they really persuade us to give it to them, which isn't the case" (Consultant, p4).*

Some HCPs noted that religious teachings can sometimes be misinterpreted, where the first-generation patients can become less proactive (due to the influence of others in the community), therefore HCPs felt helpless in dealing with these beliefs:

> *"Yeah because, like with other medicines, it's always going to go off to other medicines, the coating, of medication is 'erm, like for example flu jabs, they have this thing but when we say to them, 'Well, it's been approved by Allah, its gelatine', but then you, they don't want the flu jab but when they realise it's the coating of their normal medications that they take for blood pressure or something, it sort of has to be accepted because they've been doing that anyway. They must have this confliction in their mind, I shouldn't be doing this but it's best for my health. So, they're getting some health professionals to tell them that this is the right thing to do, and yet they've got a very strong belief which is understandable, then they need to, be careful that it's not, it's accepted with Allah and it's, it's within their culture it's the right thing to do for them as well. And their families often say that as well. God, you can't get that, even parents of flu jabs, we get a little asthma, children come in, with long-term conditions they've got to have their flu jabs. But then you get the mum and dad bringing them in but then they suddenly say, 'But it's got the gelatine in it', but actually it's all been accepted now, but they still, but we still struggle with that" (Primary care nurse, p8).*

Comprehension of asthma self-management

Most patients were perceived to have a lack of comprehension about asthma and its link to serious consequences such as death, though the diagnosis of asthma was perceived to be commonly known in the community. Patients were also perceived to have little understanding around self-management including asthma medication e.g. not understanding preventative treatment (perceived as a cultural problem) including reliance

on the reliever inhaler and little understanding around the idea of adjusting medicine dosage, treatment during diagnostic uncertainty, PAAP use, how devices work including performing inhaler technique, peak flow and spirometry:

> *"I think, I used to find a lot of problems with inhaler technique, the issue, if there were issues, it was things like difficulty around using the actual device, they just wouldn't get it, a lot of them and I don't know whether that's there wasn't enough time, translating how to use it or whether the concept of using inhaler would never quite sink in, where it was used more like a breath freshener, and also I suppose that was one, the actual physical taking" (Consultant, p5).*

Additionally, HCPs believed non-adherence was a real issue in the community. Most HCPs did not fully understand the reasons for the lack of knowledge and medicine adherence amongst patients, and HCPs recognised their own limitations that they may not be explaining information properly and expressed the need to seek out answers for this. HCPs also made various speculations on whether they were responsible for this e.g. not explaining what the inhalers are:

> *"I think when somebody's told they have asthma, they're given a Salbutamol, reliever, preventer, but they're never actually told what the condition is, and we rush in and say, 'These are two medications I want you to use', but we don't actually explain what each of the inhalers are, because if we are in the medical profession, we automatically assume everybody knows what the blue inhaler is. We also know what a preventer is, reliever, but we never say to them, 'This has to continue', then you find out when they come to clinic, they haven't renewed their prescription, because they think it's a one-off treatment and stops" (Nurse specialist, p7).*

HCPs also questioned whether non-adherence was linked to cultural, religious and linguistic factors e.g. whether medicine ingredients were compliant with religious rulings (such as alcohol-based inhalers) and that Bangladeshi patients have difficulties following instructions to use devices to monitor their asthma. HCPs speculated that one reason for non-adherence was that patients were confused around whether medicine can be taken during fasting hours in Ramadhan. Other reasons may be that patients are concerned about side-effects such as inhaler addiction and emotional issues (e.g. depression). Most narratives around non-adherence of medicine in younger aged generations was around the idea that patients had chaotic families who provided less support, or they indulged in behaviours such as smoking, drugs and shisha use, there was social embarrassment in using medicine and concern about gaining weight. The quote below illustrates this point and it also shows that HCPs were sometimes aware they were making assumptions:

> *"I think if you're a young girl, in the Asian, and this might be an assumption, but I met a lot, a lot of patients, they're afraid of weight gain, image conscious, and they're embarrassed" (Nurse specialist, p7).*

HCPs were also uncertain about whether patients can take medications while fasting in Ramadhan, what advice they can provide to them e.g. guessing what the Imam would advise but not being able to locate such instructions:

> *"And, such as during Ramadhan, so they would say, 'I'm not taking this inhaler because it's going into my lungs and absorbing into my bloodstream', and I would say, 'I think you can', but then where does the Imam say, 'Yes, they can, no they can't'…" (GP, p3).*

Poor understanding and engagement of patients was also reported with using PAAPs:

> *"I found action plans in this population to be very, poorly, followed and poorly understood, again this is more in the first and second-generation patients, or first generation who, aren't fluent in English. All our available asthma action plans are written documents in English, and therefore they don't really, come across very well and they're not really understood at all" (Consultant, p4).*

Attitudes towards HCPs

Patients were reported to have positive attitudes towards HCPs. Some HCPs reported Bangladeshi patients tend to trust doctors more than nurses, whereas doctors believed that nurse should be valued more than them because they knew more about self-management. The quote below illustrates this point and shows how HCPs were aware of making assumptions due to relying on experience:

> *"I think some Bangladeshis, and this is again stereotyping them, used to not value, a nurse, and to me I really think it's so important that we big up the nurses, because the nurses know more about inhalers, they have more time, and they understand a lot more about asthma than probably I do. But yet they would come to me and say, 'Oh doctor what should I do?' And I'd be, 'Why have you come to me and not the nurse' (laughs). So, I think that's the only thing is that they need to understand the value of the nurses and the pharmacist, to help and engage and empower them" (GP, p3).*

On the other hand, nurses reported they were not perceived as a medical HCPs, which meant less respect but also allowed patients to fully express themselves:

> *"I don't think I'm making an assumption for it because I do see it, and people, they do tell you what they are actually doing, and I think they open up a lot more to you, and they don't see a nurse as somebody in the medical profession, they don't see me as a… Doctor. Yeah, so they wouldn't respect me as much, so they'd open up and tell you your whole life story in 20 minutes when I think, I probably know more than I probably need to know. That girl last week, I know her whole story, from beginning to end, but it's how she'll take home the fact that she needs to use her inhalers. I think they'll tell you a lot more so they tell the consultant one thing, and she would have thought, 'Oh, that's not adding up', because you can see right through them if you say, 'Oh, do you smoke?', and I say, 'Oh, I think you do because your using polos and using chewing gum, and extra perfume, then like, so your parents are going to know you smoke', and they feel really stupid (laughs), so the little things, you have to relate to them though. You just have to yeah, get it"* (Nurse specialist, p7).

Some HCPs were frustrated with both Bangladeshi and Pakistani patients who travelled to South Asia and coming back with contradicting medical opinions on self-management:

> *"…When they travel, and they would travel to their home country and get the, get some help from the medical, people over there, and sometimes it wouldn't be necessarily, the management that we would've, advised. So, they would usually come and say, "My doctor in Bangladesh for example have told me to do this and that, or they have advised me to take another chest x-ray or get a CT scan and so on", so there are very varied, messages that they receive I think, yeah"* (HEMS doctor, p9).

8.4.4 Theme two: Cultural argumentation

This theme illustrates cultural argumentation; the process of reasoning to support ideas around adapting supported self-management. This was the stage where HCPs were tried to make sense how to adapt supported self-management by continually contemplating on their understanding of Bangladeshi and Pakistani culture and self-management behaviour: 1) *tuning into culture* - HCPs tended to tune into culture by reflecting on their supported self-management practices around culture and theorising reasons to make sense of self-management behaviour and, 2) *practicing diversification* - HCPs expressed the need to treat patients holistically e.g. accounting for co-morbidities and continually justified that they treat all patients the same regardless of ethnicity and illness.

1) Tuning into culture

Making sense of possible supported self-management needs

HCPs used their own personal/HCP identity and experience to reflect on the ideal supported self-management strategy for patients based on culture and this played out in various ways. For instance:

A doctor reflected on how she understood her own cultural identity being from a Bangladeshi ethnicity and living in the UK, and applying this to the diversity of patients and how they identify with her:

"However, if the patient I think, patients might look at me as an Asian doctor thinking, 'Oh, you understand, let me tell you more'. They might think that they get something more from me that they don't from a non-Bangladeshi doctor, but I don't believe that's the case. Oh, except say, by, talking in their own language sometimes they feel as if they can say what their own health beliefs are more, because they're not being translated" (GP, p3).

- HCPs recognised that their descriptions and ideas about culture were limited according to their experiences with cultural group in question and the locality the service was based in which may serve a certain community more than others, therefore acknowledging subcultural differences between Bangladeshis and Pakistanis. Experience with a cultural group was noted as a strategy to enhance cultural competence:

"I think it also depends on the hospital as well, if you have, a Bangladeshi person attending a hospital in say for example, (names hospital) or, you know I'm just naming a random hospital that's not, predominantly Bangladeshi, they get poorer health management? I'm not sure. I'd like to say no, because I believe that, not bias, not race biased, we're not racist. But yeah, I don't think that's the case. I think we are more culturally aware at the (names hospital), because we are exposed to the Bangladeshi, Bangladeshi population so much, I think, I think we are, better, at, understanding the culture better than other hospitals for example" (HEMS doctor, p9).

- Similarly, some HCPs pointed out that experience with Bangladeshi population (supported by other factors such as research) shaped their understanding around how the Bengali (Sylheti) language worked and reported their thoughts on filling in gaps in services:

"Yeah, I'm unsure at the moment, how we can make it adaptive to the Bengali speaking patients and I would not say, doing it in their own language, is the right way. Because I think a lot of literature, says it's not always helpful to translate into Bengali, and that's because the amount of money costs, time it takes to translate, then the back translation is not always perfect, and then people who can actually read Bengali often can read English, and also, if they can't their family members can, so…" (GP, p3).

- A few HCPs worked around cultural understanding of terms and phrases and reflected this back to patients to enhance mutual understanding e.g. providing clear explanations by using the terminology understood by patients:

> *"…'How many chest infections have you had?' They use the term chest infections where we know it's looking at asthma" (Nurse specialist, p7).*

- There were also some HCPs trying to balance religious beliefs with medical safety to increase medical adherence and reduce internal conflict for patients in treatment. HCPs also did not want to be perceived as a profession who prioritises medicine over patient beliefs:

> *"…Hopefully they realise that Ramadhan isn't meant to be about making them unwell, because actually when they are critically unwell or with long-term conditions that they need to have insulin, is actually acceptable, and that's the point we try and get across. We're not trying to stop the religion, we're trying to make sure, ensure that you're safe, but also that is safe to take it, with whatever you believe in" (Primary care nurse, p8).*

Theorisations about patient's self-management behaviour

All HCPs used the strategy of theorisation (or hypothesising) to make sense of a patient's self-management behaviour which was predominately perceived to be due to cultural and linguistic factors. Typically, HCPs would express their uncertainty on why patients behaved a certain way by using phrases such as; *'I am not sure'; 'I'm guessing'; 'I don't know'; 'Read it for reasons which are obscure'; 'I mean presumably'; 'I think';* then they made assumptions about various behaviours. One method of trying to understand self-management was basing assumptions on personal and professional experience with the population and making predictions based on this (e.g. working and/or living in Tower Hamlets an area with a lot of Bangladeshi residents). For instance:

- Speculations about Bangladeshi and Pakistani patients who were very anxious:

> *"Yeah, the sort of ones who can't speak English who are very anxious and, it will just be really useful to know what is it that would make them less anxious. And make them may be more, you know adherent to their treatment, because I'm, I've come up with all these theories, but I don't actually know" (GP, p2).*

- Speculations about patients who do not adhere to medication:

> *"And then, there are presumably cultural factors as well. I don't know what those are, I can only guess at those, this really, I don't know, which is presumably what you're investigating. There's, I think there is lower compliance, for whatever reason, because that is the crux of, when you look at most patients with difficult asthma whatever, what, whatever ethnicity they're from, one of the biggest problems to deal with is that, patients tend to be, less compliant. And, like you've said is you know we have a bigger proportion of, Asian subcon- Indian Subcontinent patients with difficult asthma. And compliance is an issue that is my impression from what I've seen. I don't know why that is though, but they tend to be less compliant people, for whatever language and cultural reasons there are, level of understanding I don't know"* (Consultant, p6).

- Speculations around medication advice in Ramadhan:

> *"But in terms of asthma, I have always said, 'Because it's going into lungs you're allowed', that's what I've said. But what does East London Mosque say? I think they say, 'If you can get away without it, maybe don't do it, but if you need it, then of course you have to have it'. Is your fast broken because you've done it? I think it's debatable. I think it's one of those you can wing it (laughs)"* (GP, p3).

2) Practising diversification

HCPs continually made comparisons to either i) other chronic illnesses (whether physical or mental) and/or ii) other ethnic populations; to justify that their support for Bangladeshi and Pakistani patients was part of a broader picture supporting patients as a whole (holistic supported self-management meant treating all co-morbidities (physical and mental health) and other physical problems such as pain, *'not just asthma'*.

> *"…Now if you're talking about specific to asthma you see, I don't believe, the new, system of GP should be focusing on disease-specific consultations. We should be looking at people generically, holistically, you know, it wouldn't be, 'Hello, I'm seeing you for your asthma today'. It would be, 'Hello, what can I do for you today?' You know, 'What's your best hope from this consultation?' I would like to, within that consultation say, 'Let's talk about your asthma', but it's unlikely that that's gonna be the patient's only agen… agend… agenda. So, I think somewhere, we need to incorporate the importance of asthma as a valuable, as valuable an illness as diabetes or their pain, or whatever, and I think that could be the focus of, if you get your asthma better, you'll feel better, then your mood will be better, than your pain might be better. That could be a more holistically way, of selling it"* (GP, p3).

HCPs also continuously justified that their relationship and support for Bangladeshi and Pakistani patients were the same for all patients (regardless of illness), articulating that self-management strategies such as using action plans are *'not just for asthma'*:

"And you might say how can we make this piece of paper more useful, to Bangladeshi patients. I think this is part of a broader picture that we are looking in general practice, which is we are being asked to do plans for everyone you know, COPD, diabetes, frailty, cancer, blood pressure, and asthma just happens to be one of them" (GP, p3).

Asthma was continually compared to diabetes e.g. when asked questions about asthma some HCPs used examples of diabetes instead:

"Yep because I like I said before, family, like say for example I'm not gonna go off asthma but diabetes. 'Well, my mum was on insulin and I, I don't want to be in the same thing'…" (Primary care nurse, p8).

In addition, all HCPs felt the need to compare Bangladeshi and Pakistani asthma patients to other ethnic groups with asthma (directly or indirectly), to emphasise they do not just provide supported self-management to Bangladeshi and Pakistani patients; *'not just South Asians'*. This may have also been a strategy to differentiate between what makes Bangladeshi and Pakistani patient's self-management behaviour unique and what does not. Main comparisons were made with White Caucasians:

"…'Erm maybe with children and mums, that there are, is a little bit of reluctance of using inhalers, if the child has asthma and they're worried if they keep using a brown inhaler if they gonna get addicted to it. But say that's possibly not any more different to one of my White Caucasian families" (GP, p3).

Except for narratives around language, where Bangladeshi and Pakistani patients were compared to Eastern Europeans, Italian, Spanish, Turkish or Polish communities:

"I don't know, I mean there's a language thing and that doesn't apply just to that, to that community obviously, you know I have patients from Eastern Europe and other places with, with very poor English patients who were born in Pakistan or Bangladesh or whatever. Especially who are elderly for example" (Consultant, p6).

8.4.5 Theme three: Approaches to supported self-management

This theme illustrates the application of HCPs insights on Bangladeshi and Pakistani patients and cultural argumentations (the process of reasoning to support ideas around adapting supported self-management) into practical strategies HCPs used to support Bangladeshi and Pakistani patients with their asthma self-management. HCPs used two main strategies to do this: *1) integrating perceived cultural values into support;* perceptions of culture influenced supported self-management and, *2) breaking down barriers in understanding;* supported self-management strategies used to enhance patient understanding of asthma self-management.

1) Integrating perceived cultural values into support

The way HCPs perceived and understood the culture of Bangladeshi and Pakistani patients influenced their choice of supported self-management approach e.g. family involvement, dealing with anxiety (and other psychological issues), supporting medicine adherence during Ramadhan and attitudes towards CAM use.

Encouraging family involvement

All HCPs tried to involve family into consultations, as either i) a strategy of encouraging continual support for self-management outside of the consultation, ii) as a means of helping patients to digest information and/or, iii) treated as a solution to enhance communication and language barriers that were present in the current services e.g. addressing translator costs. Language and communication barriers also existed for a doctor from the Bangladeshi ethnicity:

> *"I think what happens is, and this starts off, when they come into the hospital, so set in the hospital setting, if they don't have a family member, present with them, they can get a… Labelled, mislabelled asthma, just because they've reported the similar signs and symptoms, and then they could get, put on a load of medication but in actual fact, nobody's ever formally diagnosed them with asthma" (Nurse specialist, p7).*

Family involvement was sometimes perceived to be a part of routine assessment e.g. asking patients whether family members know about diagnosis or encouraging, reminding or requesting them to engage family members by using words/phrases that imply a sense of obligation/responsibility; *'Need to come with, someone'; 'You must have someone'; 'You must bring your family because it's no good'; 'Getting the whole a wife involved, the husband*

and family'; 'The family would have to support them'; 'They need family input'; 'You need to have somebody'; and 'You need to be honest and upfront':

> "And I think wherever possible (coughs) I'd rather encourage a patient to bring somebody with them because, you know it is quite a lot of money for so many health advocates so, if someone could always bring someone who's fluent in English with them, that would help" (Consultant, p5).

There were proactive accounts of family members helping patients of all ages (perceived by HCPs to be the 'Best scenario'; 'Big help'; 'The best thing'):

> "…But sometimes what I find if, 50, 60-year-old woman, who comes with their daughters, that's the best scenario, because normally they know about their conditions, they are well informed. They know everything and they can give that information to their families, you know to them. So that's a big help" (GP, p2).

Consent from family members was assumed by HCPs in most cases by family presence in consultations. The issue of consent and confidentiality was only touched on by one HCP:

> "By phoning their family, you've got to get consent, and sometimes that can be a barrier. How do you get consent, if they don't want their family to know? So, we lose out on both occasions" (Nurse specialist, p7).

Sometimes, the encouragement of HCPs to disclose information about asthma diagnosis to the patient's family created conflict for some younger aged patients due to fear around disclosure. These patients were described as having secretive behaviours e.g. hiding the fact that they smoke, use drugs or there was a need to protect themselves from new family members such as relationships through marriage:

> "She then got very upset in the fact that, she was getting married, how was she going to explain this to her future partner? Her husband, and his family, because they would have seen it as a stigma, and that she wouldn't be able to bare kids, and all of this, so we had to eh, so besides talking at the asthma, we had to do some psychology in that, it's a condition, it's well controlled, it's not an illness. It's not an illness, it's a condition that you can manage and you can get good control, and told her to take some steps back, as in to 'erh, get control, get an understanding, and use resources like Asthma UK, start by telling her family, and her friends, and her partner to be, that this is asthma, but I got control" (Nurse specialist, p7).

At the same time, most HCPs also pointed out limitations of involving family into asthma care. For example, it can exclude the patient from the conversation, inadequate translations

can lead to misinformation, patients can be influenced by others, patients be place responsibility for their health on others, and patient behaviour may change in the presence of family, for instance discussions around smoking behaviour.

> *"Sometimes I mean there's no problem having more people in the room that's fine, sometimes people, family members are dragged into the room who are not interested. They're sitting in the back, doing other things, that's very distracting for everyone. Sometimes the actual patient is very much, excluded from the conversation unfairly, that the family don't seem to want to involve them, and actually want to talk over them, and that I think is very problematic" (Consultant, p4).*

Dealing with emotions and providing psychological support

Most secondary care HCPs recognised that emotions (mainly anxiety) worsened asthma symptoms and hindered self-management in Bangladeshis and Pakistanis (hence they recognised the need for emotional management), but only a few accommodated this in different ways, including:

- Using physiotherapists in asthma clinics -

> *"…And what's very helpful is that we have a physiotherapist now, because, we found that a lot of people, anxiety makes them over, over breathe or hyperventilate, in addition to having asthma so we're not saying they don't have it, they might have both, just having her there, and being able to tell the patients, this is what's going on you're not imagining it. It's part of something else, and this is how you can deal with it, is really helpful. So, I think it, it plays a big role in all asthmatics not just South Asians, it's quite fascinating really" (Consultant, p5).*

- Where appropriate in HCPs signposted or referred patients for psychological support. Psychological services were also incorporated in one asthma clinic. However, some HCPs noted cultural barriers in accessing psychological services -

> *"So, depression and anxiety is a big thing, I think there's a cultural barrier to accessing help, for those things, and what I see in those communities is that those individuals, do not want to have, access counselling that we offer. And even though we have a, therapist in the clinic with us to help, but they don't want to, they don't want to, access that. In our clinic which is unusual I mean the vast majority of clinics don't have that, we have a psychotherapist, in clinic, who can see the patients and furthermore plug them into, more detailed assessment service. They, they, that then gets, they then decide whether or not that person is bad enough to want some of secondary care intervention like psychiatry, or whether they, would manage with just seeing a, with telephone counselling, or*

> *whether they'd have, should have group counselling or something like that. But in my view, there are cultural barriers to that, and I would say actually even, probably more often than not, patients from Indian Subcontinent do not want to, access counselling services even when they've got clearly high depression and anxiety scores, and they are suffering with that" (Consultant, p6).*

- Secondary care HCPs also allowed patients the space to express themselves while exploring and listening to their feelings -

> *"I think it's a case of allowing people within the time constraints to be able to air their anxieties as much as possible, and then I'll normally deal with all their points about what they're saying, and I will give my answer to what I think, their point is, and that's how I normally deal with it, just have a conversation" (Consultant, p5).*

Supporting medicine adherence during Ramadhan

Most HCPs thought colleagues need to increase awareness around medicine adherence during Ramadhan e.g. checking intentions for medication adjustments during this period.

> *"So, a lot of patients have dropped half their doses because of Ramadhan, because they've only taken it during the night period, and what I've tried to explain is that what they should just do is bunch their two doses much closer together, rather than dropping doses, but that hasn't been, a lot of the patients don't know that so they're dropping half their doses which is a big problem when they could quite safely just, bunch them together" (Consultant, p4).*

Some HCPs described that dealing with medication adherence during Ramadhan must be balanced by understanding of the importance of religious beliefs but also advising on good health and safety. Sometimes, this was a difficult approach for HCPs due to symbolically battling against family/peer influence who contradicted their advice:

> *"It depends on whether they are, compliant for their inhalers, or their tablets, and not just the younger generations but, age throughout the board, and during Ramadhan I think, you just have to educate them really, I think, to say that, 'Yes, it's Ramadhan, however your health, is also important', and I would tell them the, consequences of not having those medications, and versus having them, and just try to educate them really" (HEMS doctor, p9).*

A few HCPs thought that there was no need to treat patients differently during Ramadhan since the preventer (used either once or twice a day) can be easily adjusted into hours when patients do not fast, and the reliever should not be necessary. On one occasion, a GP assumed that patients can independently adapt to these changes.

> *"Even, you know in Ramadhan because lots of inhalers they are twice a day, that's the steroids, so that shouldn't be a problem, for asthma management" (GP, p2).*

Most HCPs guessed what the religious advice would be for breaking fasts or adapting medication to fasting hours. Often the advice involved referring the patient to the Imam:

> *"So, but so far, that's what I would advise, and I think Imams as well say if someone is unwell, if someone was short of breath, you know they would, it would be okay to use their inhalers. I suppose but I'm not, I haven't seen any documents about the advice about asthma, but that's what I would advise" (Consultant, p5).*

There was also limited guidance in helping professionals during Ramadhan for asthma compared to other illnesses such as diabetes:

> *"…Only during Ramadhan, where I think there's a debate as to whether they take their inhalers or not and I think whoever's, opportunist could say, 'I've seen that GPs find it helpful to give some guidelines on, during Ramadhan, what you like to do with your inhalers and your medication'. Because it matters in diabetes but there's nothing, not, I've seen on asthma" (GP, p3).*

Attitudes towards CAM use

HCPs divided CAM treatments into those that were complementary and those that were alternative forms. In the former, all HCPs were content with CAM use if this was used in addition to biomedical treatments, particularly if it made patients feel better. Generally, patients were left to decide whether they should use treatments or not, using phrases such as *'their own choice'; 'entirely up to them'; 'that's up to them'*. However, most HCPs were concerned about harm, cost, and patient beliefs that natural remedies were free from biomedical side-effects. Most HCPs did not have experience of talking about CAM in consultations, though a few described discussions that took place with other ethnic groups (including White Caucasian patients). Also, a few HCPs felt uncomfortable in addressing CAM use because they did not know enough about it and worked to address this gap in understanding e.g. a GP described being confronted with dry/wet cupping related to another illness and feeling concerned about not knowing enough about the treatment:

> *"I think that's a really interesting area that I don't think I know enough about. I think patients are using it. I think we should be asking more what are they using when, like the other day*

someone came in, they were a little elderly lady in a wheelchair, and a patient was using a bit less painkillers and I went, 'Oh what's making her do this?' And the, other patient's, the son said, 'She's done cupping', and it was, and I saw the cupping on her legs and I thought, 'Oh my God, I know nothing about this medicine', and she believed in it. So, with asthma, have I heard of anyone other than a bit of Chinese medicine which I don't even know where the people are and what it is, and sometimes they say, 'What do you think?' and I go, 'I know nothing about Chinese medicine, so please don't ask me however, if it cost you loads of money please don't do it. But if you believe in it and think ours are not working then, you go ahead, you're alright, but I'm not the right person to ask', because I'm not, and I wouldn't know (laughs), and there's so many different therapists" (GP, p3).

2) Breaking down barriers in understanding

HCPs practiced strategies to address issues around patient understanding of asthma self-management e.g. providing education, empathy, building a relationship, providing reassurance, repeating information and taking steps back and forth.

Providing education

Majority of HCPs described providing different forms of education e.g. simple advice, providing scenarios, teaching sessions, posters/leaflets and group activities. Additionally, a few HCPs provided audio-visual education by either using online resources or physical lung objects to overcome language barriers in understanding, for instance:

"I show them diagrams, so they can't actually go wrong which is from, it's not actually Asthma UK, it's called Right Breathe, and it's brilliant because it comes up with the asthma inhaler they're on and then it has a video of how to do it, there is no way, someone cannot understand somebody, watching the video because there is no language involved, it's just, basic... TV. …The barriers are down, like I say there may be a language barrier there, but if there's nobody with them, they've got the video" (Primary care nurse, p8).

Some HCPs questioned whether it was enough to just provide education without balancing this with checking patient understanding (e.g. concerns revolved around overwhelming patients with information and HCP's ability to transmit information adequately), and whether patients implemented what they learnt according to the variability of their asthma. For the latter, some HCPs described ongoing assessment of situations in follow-ups allowed them to provide appropriate support as the condition changed. They also recommended that coded safety nets on the system would be helpful to monitor this e.g. alerts that flagged up inhalers that contain alcohol during prescribing.

> *"So, definitely if a patient's, who don't speak English, even if they speak a bit but you are giving all that information and they look at you and you think they are understanding, I don't think you can be sure, you know because there are a lot of details, for you to understand it better, you need to do this inhaler twice a day, two in the morning, two in the evening. I don't think that would be a problem, of very general information but if you wanted them to know maybe about the triggers, maybe how to increase or reduce the steroid use. I guess that would be a problem, yeah with any patient with some language difficulty" (GP, p2).*

Most HCPs expressed thoughts around using different educational follow-up strategies or ideas outside the box on various issues e.g. planning a telephone asthma review protocol for patients who miss appointments, creating priority for reviewing patients who accessed unscheduled secondary care within 48 hours in the system, waiting room video lectures on inhaler technique, tailoring PAAPs according to the individual role and repeated online audio-visual education:

> *"Normally for asthma reviews you have quite a few patients that don't come for their reviews. So, here now for instance (names practice nurse) just did a protocol for telephone, asthma reviews. Only in few cases you know if they are not coming in, if they are in mild, stable, because if patients work, so we are trying to come with systems to make sure these patients don't miss appointments" (Consultant, p5).*

The empathic approach

Most HCPs used the strategy of being empathic to increase their understanding of what it must be like for the patients (including family members) to self-manage their asthma e.g. empathy towards cultural/religious beliefs, attitudes and values:

> *"Oh yeah! Yeah, yeah. Because they look at me and think you don't understand our values, so I'm not going to listen to you. So, if you chip it back and get an understanding, I know what you're thinking, and I know how to explore it. Because you need to understand that they, the family would have to support them. How do you get into the family's mind-set? How do you get into mum and dad's mind-set? How do you get into brothers and sisters mind-set? What are their values? Why do they not want to use it? Get a better understanding of the person. Don't see them as a patient, see them as a person, because there's a lot more going on in their head, then we know" (Nurse specialist, p7).*

Empathy was used to develop a better relationship/rapport with patients and this also helped patients become more open to receiving education:

> *"I think if someone gets used to seeing you they like seeing you again, often they get, we have multiple doctors in clinic, people often like to see the same doctor so they ask, and it's just having some continuity, I think just understanding anybody's life and where they're coming from, it's quite important" (Consultant, p5).*

Building a relationship

All HCPs reported having a good relationship with patients where trust meant ideally, *'building'* a relationship at first and over time to break down barriers (sometimes this also included building trust with family), e.g. making sure ongoing care was provided with the same HCP, helped *'break down barriers'* such as reduce patient anxieties. A few HCPs described ethnic-matching as an ideal way to developing rapport with patients.

> *"…I'm not a psychologist but I think if they build up a relationship with you, you've broken down so many barriers, and just getting to grips with it" (Nurse specialist, p7).*

Providing reassurance and repeating information

Another approach closely related to empathy was providing reassurance by trying to normalise the process of taking medicine (described by some HCPs):

> *"But also, sometimes we see patients relying a lot on their blue inhaler, and maybe they are a little reluctant on the steroids because they, you know these steroid works, they worry about side-effects or the steroid work. But then you, again you try to reassure them that you're giving them the right, minimum dose that controls their asthma, you know they shouldn't be having any side-effects and if they need a high dose. But if they need a high dose, they will need it because otherwise they will feel unwell, so I guess it's about explaining and giving information, try to reassure them" (Consultant, p5).*

Most HCPs hoped reinforcing or repeating information would break down barriers of understanding:

> *"Just repeating it a lot until hopefully patients understand and follow the plan" (Consultant, p4).*

Taking steps back and forth

Some HCPs described taking steps back and forth (e.g. going back to basics in education) in the hope that eventually this can help patients to digest information over time.

> *"…So, going back a couple of steps before I give them a self-management plan, get them to understand them and building up that relationship, just looking at them and thinking, what do you understand about asthma and if they, they don't understand then I have to go back a lot more steps before I come to the self-management plan"* (Nurse specialist, p7).

8.4.6 Theme four: Boundaries of supported self-management

This theme illustrates the challenges and boundaries that were present in the healthcare system which sets parameters in implementing supported self-management for patients; *1) role boundaries* - due to experience and structural barriers such as time and, *2) service limitations* - the way the healthcare service works, and the services provided to patients, and work across services.

1) Role boundaries

Level of exposure to Bangladeshi and Pakistani populations

All HCPs recognised that their perception and understanding of Bangladeshi and Pakistani patients were confined to the population that they have the most contact with, which were either the Bangladeshi, Pakistani or both communities; showing that they recognised subcultural differences). Most HCPs in the sample had more experience with Bangladeshi patients (due to the area the service was and sometimes HCPs were residents in the same borough), and some identified less experience with Pakistani patients (and vice versa):

> *"I've hardly had any Pakistani patients, and I know very little about them as a group, I've only got like, I think in this practice, I think I've only got like five families, so I wouldn't be able to judge, or say anything about them"* (Consultant, p6).

Dealing with time restrictions

Time constraints were typically cited by doctors as a restriction in their role and ability to do more. Doctor's perceived their main role was to diagnose and offer specialist advice on medicine and prescribing, and other team members should manage other aspects of the treatment e.g. often nurses were mentioned as valuable for dealing with self-management. Hence, the level of contact and insights for self-management strategies (e.g. PAAPs, follow-

ups and peak flow monitoring), were partial for doctors as opposed to nurses, therefore clinicians felt it was unclear whether certain aspects of self-management were implemented or embedded well in services.

"We don't really get time in the consultation to, do that as the doctor, we're very much more focused on the medication, if we're lucky enough to have a nurse specialist with us in clinic, and that's ideal to have one in every asthma clinic so that at least even if you're, if it's only for your new appointment, that they have more time to really go into the, person's daily life, and you know all of those things, often as the doctor in the clinic your role is to give specialist advice on the drugs and control of the asthma and the inflammation, and you look very much to your, rest of your team to help support the individual and that's standard across all diseases" (Consultant, p5).

Working outside the system

Even though, time was reported by nurses as a barrier, sometimes nurses were too involved with patients and occasionally had difficulty setting boundaries in involvement. Nurses often worked outside the system and role requirements. For example, this revolved around setting up follow-up appointments (in the service they work in and other services), and medications in primary care, exploring patient needs and helping patients digest information:

"Yeah so, I think I go in possibly too much. Instead of just drawing a line, because in a 15-minute consultation in clinics I'm thinking, we've only got 15 minutes, which ends up being 30 minutes, like girl last week, knew more she said. She told me a lot more than her family and best friends. But she learned a lot, going away, because we've explored about smoking, guys, lifestyle changes, compliance. So, the psychological part is, I think if you spend 20 minutes, I know you're not going to get it all in, but there is something that might trigger in that last five minutes of the take home, so if they only took home that smoking is bad for you and stopped it, then that's better than anything" (Nurse specialist, p7).

2) Service restrictions

Working with other professionals

There was little relationship between HCPs and other HCPs across different services to help implement asthma self-management. A few secondary/tertiary care HCPs reported that there was no need to refer to primary care professionals since they were the experts in asthma. Conversely, a primary care nurse sometimes disagreed with asthma consultants (e.g. the choice of inhaler prescription) but had to comply because consultants were the experts.

Most secondary care HCPs wanted better access and communication with GPs to improve ongoing supported self-management, particularly after discharge and during follow-ups.

> *"I suppose a good relationship with the GPs is, also, it also helps and, the discharge summary automatically get sent to the General Practice. If we can improve communication with the GPs, that would be helpful. Whenever you ring GP surgery to find out what's happened, with the person's medication regiment or anything like that, sometimes it's very difficult to get in touch with the GP. Or even the GP who, normally looks after the patient. They might be away, or the surgery might be closed, or then again you know it's, that's always been a problem... Tryna communicate with the GP. So, if we can improve our communication with the GP, to update them as to what happened, that will go a long way, in providing them with the, ongoing support. Yeah, because sometimes GP won't get our discharge letters or, we won't get what they said in the GP surgery or so on, so as long as we communicate, and, and make them aware, for what happened with their patient..." (HEMS doctor, p9).*

Previous and present examples of HCPs working together across services included holding joint committees, annual and spirometry update meetings, and consultants providing education in GP surgeries.

> *"Yeah we don't really, I think because we've got a highly specialised within the hospital, there isn't a, there isn't a lot of, joint working, when I first came here, there was a joint committee made up of some GPs from the PCT, who specialised in respiratory, we had a respiratory lead, and we used to have meetings I think once a month, for all the between some of the consultants and, these respiratory leads GPs, and we even, like four years ago, even up to then we had an asthma lead. I think she was the asthma lead or maybe she was the respiratory lead, and then a couple of years ago that was shelved by the CCG, and they made chronic disease leads, so the whole connection got lost, which is just such a shame because, we were beginning to work with this, respiratory lead really, really, some good work, looking at projects to try and reduce attendance at A&E, repeat attendances at A&E, how to follow up people when they go to A&E, and then we lost, because of reconfiguration we just didn't have anyone" (Consultant, p5).*

Access and patient pathways

There were mixed views from HCPs regarding whether there were organisational and structural barriers in services that hindered supported self-management. HCPs described barriers in service access and delays (e.g. follow-up in primary care for prescription and GP receptionists were blamed for the lack of access for booking appointments), and difficulties in attaining a diagnosis due to language barriers (e.g. patients were on asthma medications but received no diagnosis). There were also concerns around organisational finance to address language barriers (e.g. health advocates and written translation costs), and financials concerns for patients (e.g. prescription costs and CAM treatment). Additionally, there were

narratives around the idea that primary care should be more responsible for the patient's care. On the other hand, a GP doctor expressed conflict in referring patients to secondary care:

> "It is easy enough, but 'erm, there's a long wait for chest clinic appointments. So, that's the problem, it's easy to refer to them, in the meantime they're waiting to be seen. Paediatrics are a bit quicker. But, there is a bit of a difference in that, we're expected in the primary care to, manage asthma very well, am I allowed to refer people? Then say, 'Am I allowed to refer people? Why aren't you looking after this?' But sometimes diagnosis can be difficult. It is easy not to do, certainly, so the incentive of doing all of this, at times" (GP, p1).

All HCPs agreed that it was their job to adapt and keep up to date with guidelines. There were some suggestions to improve guidelines by suggesting strategies to reduce language barriers for services that provide care for ethnically diverse patients and signposting further information or help to support Bangladeshi and Pakistani patients:

> "I don't know, it might be that if you are having difficulties treating these people that there might be suggestions or signposts, of where you could get information and advice about how to deal with patients further, if you're working in an area like (names East London borough) you can probably access it or at least talk about it even if it doesn't happen, but if you're working in an area where your South Asians are very few, then nobody might even think of it, so I suppose it's just highlighting where you could get help" (Consultant, p5).

Using language intermediaries

Most HCPs thought there were gaps in the services for dealing with language barriers. The use of interpreters, leaflets/posters, health advocates and Language Line (a three-way telephone interpretation service), was described as strategies that provide low quality of interpreting, access and booking issues, time/delays and cost implications. Different interpreters also meant hindering the development of a relationship and trust with the patient.

> "The trust do, occasionally, pay for interpreters although we were told that they were going to stop paying for interpreters. There is Language Line which takes far too long to use, and the consultations ends up taking three times as long as it should, so it's very difficult to have a, you know, a conversation in 15 minutes, and use Language Line and get everything out you want to get out" (Consultant, p6).

Limited provisions for language had clinical implications for the quality of service:

"Oh yeah! Yeah. When you see them come into hospital and you think how does a doctor do an assessment when they don't even have an interpreter? How do you get to understand, what is, what they're feeling, so, even the elderly, come in and you think, you've just done an assessment, but how have you done a physical assessment? I've just stood and looked at you, the patient has gone, nodding her head but didn't understand. Is that agreement? Are they saying, 'Oh no, I don't have...', so it's very much, they need, I think they should be utilising interpreters a lot more" (Nurse specialist, p7).

On the other hand, a GP surgery had good and consistent presence of health advocates incorporated into their service for most languages e.g. stop smoking and teaching sessions.

Implementation difficulties with PAAPs

Most HCPs agreed that PAAPs were important to distribute but difficult to implement, hence they tried to work around what was currently in place.

"Felt that, I know a little bit about children so I think if do a plan as a doctor or a nurse, it's only as good as a piece of paper, what you need to do, is make sure that the school adopts it, that the child adopts it, that the family adopts it, that if you say, 'Does everyone know where the inhalers are kept? Do they have their own place?' So, all of that needs to go into the management plan, and you might say how can we make this piece of paper more useful, to Bangladeshi patients" (GP, p3).

Plans were usually perceived to be either very complicated (e.g. too much information), or irrelevant e.g. written language with back translation issues; hence family were typically consulted.

"I think, we don't do enough, basically, in that, the self-management plan we use at (names NHS trust) isn't great. I can't break it down any easier for them because I'm embarrassed to give it to them, but it's just for me personally I just try and ring a family member for consent afterwards. Just to go through that and say, 'Next time, would you mind coming with Mum, or Dad?' Because we've had three wasted journeys now, and the interpreters usually don't turn up. So, those are your barriers, so you might try really, really hard, but you know you're not going to get anywhere, but I do ring and say, 'Can you come the next time?' Just to make it easier" (Nurse specialist, p7).

Additionally, plans were not treated as part of routine treatment in some services e.g. in the emergency department and in one GP practice. A GP service described intentions to implement PAAPs and that it was part of their wish list due to time restraints and service limitations.

> *"It's a wish list. We tried several times to get it off the ground, but it is time-consuming to actually produce an asthma action plan for a patient 'erm.... But we know that it is, much better than, expecting them to, remember what we know, from a clinician's point of view, inside out, straight forward, sensible stuff, and we expect the patient to have the same, understanding of the logic of, this is your preventer, this is your reliever, this is so simple (laughs). And it is so simple once they understand it, we know from, from, a lot of studies that, that the patients do not necessarily found it as simple as, as we believe it to be, and that's why the written down plan has, proven to be, quite effective. But it's not, getting people, people to do it and it's not just me there's lots of, doctors here and there's a number of nurses, you know there's no point in one person, having a system. But it's more, nobody else, joining in because, you got a very fractured sort of service then very, only a few people get it, and the rest don't. So, we would have to have a practice it and implement it, and, put that amount of time" (GP, p1).*

8.4.7 Theme five: Thoughts on interventions

This theme illustrates HCP's thoughts on prospective interventions: *1) intervention recommendations for patients* and, *2) intervention recommendations for future professional practice*.

1) Intervention recommendations for patients

Most HCPs suggested Bangladeshi and Pakistani patients needed basic education in the form of workshops/open days, verbal education in audio-visual formats and leaflets on Ramadhan. This could be delivered in various settings e.g. primary care and mosques. A GP doctor and a primary care nurse recommended group meetings that build confidence in self-help groups in the community or social prescribing that involved befriending. Often, they recommended intervention ideas for patients with language difficulties rather than other Bangladeshis and Pakistanis who can speak English.

> *"I think, when I used to, my colleagues they work in Diabetics and Diabetics Association. They do a lot of education that has come from the community and where they drop into the, mosque, and they do a lot of education around asthma, not asthma you know diabetic 'erm, heart disease, and lifestyle changes. They do pop-up sessions and they invite different parts. This is generic invites so whoever turns up. So, it's ongoing education that can start locally, and where better than your mosque isn't it? Because they're not going to turn up to community centre because sometimes the woman don't like to mix with the men, so you gonna think how am I going to get sections in, and then community centres probably wouldn't be the best idea so you'd go locally to where the individual goes, I would think anyway. Because we've done some education and I worked in the community previously, we used to go to the mosque and do open days, we did a lot" (Nurse specialist, p7).*

Alongside these intervention ideas, most HCPs also thought patients should have appropriate PAAPs tailored to culture, religion and language incorporating the following ideas; non-textual, verbal, pictorial, simple, colourful, stickers and cultural icons and delivered on audio-visual formats (e.g. DVDs, YouTube and Bengali TV).

"I get that we're vaguely trying to plug but it's remarkably difficult, because I think they tried to plug it in TB, by translating it into Bengali and found a lot of people couldn't read, so therefore actually it need to be a verbal or, non-textual, asthma action plan and that we haven't yet got round to producing" (Consultant, p4).

2) Intervention recommendations for future professional practice needs

Relevant cultural training/information

All HCPs reported that they were not offered, or they did not receive any cultural training. They also described they had no awareness of any training offered and therefore had to rely on experience:

"There is no specific training anywhere within the NHS, I've never heard of, about cultural specific factors for any of our patients, occasionally you get a word wisdom from a consultant, whose training you about good phrases to use but... That would probably be in total across my twelve years of training about fifteen minutes of teaching moment" (Consultant, p4).

- Training content

All HCPs agreed that training in the area needs to address gaps in cultural knowledge (showing real willingness to learn). Most HCPs improve understanding of the patient's cultural and/or religious beliefs e.g. knowing what the correct Islamic teachings are for asthma, so they can advise the patient through education, attitudes, values, myths, self-management needs, concerns/barriers, expectations, communication strategies (e.g. words/phrases that work), explanations for self-management behaviour (e.g. non-adherence and the lack of understanding of spirometry and peak flow monitoring).

"Any, any sort of, ideas or myths if you like that they have, that might not be true and, if I known that, I can say to them, this, this isn't, this is not correct because of such and such, and end of discussion. Because I'm sure there's, not just Bangladeshi and Pakistani cultures, but

there are other cultures who, have their own beliefs, and they have old wives' tales, and so on" (HEMS doctor, p9).

Some HCPs thought patients should be involved in the training since it complements some supported self-management strategies they used e.g. empathy:

"I think you need to, you probably need get, go back to basics and see what their cultural beliefs are, and their understanding, and see where they're coming from, so you can give them a lot of, education but you need to understand what barriers you may be up against, and I think you need to walk in their shoes for a couple of days and experience what it is for them. But also, experience their cultural beliefs, and attitudes basically" (Nurse specialist, p7).

Two HCPs (a GP and nurse specialist) described the idea of patients telling stories of living with asthma and how this plays across settings from the hospital, community and to the home would be interesting to them (telling stories was perceived to be part of Bangladeshi and Pakistani culture), e.g. patient journeys on highlighting barriers they face, who they meet, how knowledge is passed on and stories of how beliefs vary across generations:

"I think I've understood it. I think people understand stories they like it, if you give positive stories you know, in Bengali it's 'golphor' (stories) you know, hearing the story about how positive stories came out of someone who, didn't think that they would benefit from an inhaler and then actually started taking their inhaler and then they took their prevention and then they had less hospital admissions. Somewhere there, that needs to be adopted into, how is it affecting their lives, which I think an asthma management plan tells you take your inhaler these times a day, look out for your triggers. Yeah, I'm unsure at the moment, how we can make it adaptive to the Bengali speaking patients" (GP, p3).

Other HCPs wanted to know the outcome of the interviews conducted with Bangladeshi and Pakistani patients in a prior stage (see chapter 7). A GP doctor felt any form of cultural training would be welcomed. Alongside these training needs, a few HCPs also conveyed that they wanted to know more about updated evidence on asthma outcomes amongst Bangladeshis and Pakistanis e.g. epidemiological data on asthma prevalence and unscheduled care, and what further self-management support they require due to this.

"At the moment, I would just be interested in a paper from you, with what sort of comments from the patients about? What is it that they feel they need, on asthma and are not getting at the moment?" (GP, p3).

These HCPs believed that it would provide them a deeper understanding of self-management behaviours (e.g. patient beliefs, needs, concerns/issues and non-adherence), especially when language can be a barrier into building insights on the first generation:

"It would be good to hear from, maybe if some patients were interviewed and there was a translation, hearing about what they're thinking" (Consultant, p5).

A GP doctor felt any form of cultural training would be welcomed. Alongside these training needs, a few HCPs also conveyed that they wanted to know more updated evidence on asthma outcomes amongst Bangladeshis and Pakistanis e.g. epidemiological data on asthma prevalence and unscheduled care, and what further self-management support they require due to this.

- Interacting with the researcher

Most HCPs described that the interview questions helped them realise and created an awareness of the way they see and provide supported self-management to their patients e.g. two GP doctors reflected on the need to be more aware (see researcher reflexivity notes in see section 9.4):

"No, it's just about, awareness… Now that you ask me all these questions I can think about different things. So, then maybe once you know about all that, if you are with a Bangladeshi family, you can actually, start asking about those things, instead of just giving information without sometimes knowing their concerns, because they might not say anything" (GP, p2).

- Training format

All HCPs wanted training in a face-to-face group format due to believing group discussions are useful to interact with others and help create a platform where one can bounce off ideas with other HCPs who may have different experiences coming from different fields, and therefore this can create a greater impact on their learning. The asthma nurse specialist wanted presentation slides and a couple of days of training with patients. However, the nurse preferred a small number of attendees to promote an atmosphere that allows attendees to express themselves. Alongside the group training, two doctors (GP and consultant) also wanted the option for an online format for convenience and time. Posters and leaflets were

also suggested as an alternative to face-to-face training. Some HCPs felt online training options hinder active involvement in training:

> *"Probably, ideally it would be some sort of a workshop with a group of people, with different, different experiences so, like me I'm oblivious, experience directly out the, cultural aspects"* (GP, p1).

- Delivery of training

Most HCPs agreed that the delivery of training should be by an HCP with asthma expertise (except one GP doctor who was unsure who the ideal provider would be). There were a range of professions recommended; doctor, nurse, researcher, health promotion specialist, respiratory technician, psychologist, health advocate, or a healthcare assistant. Although, alongside this a GP doctor and a nurse specialist believed that this person should not be a clinician or nurse due to restrictions in resource and time in their profession.

> *"If you had community asthmatic, asthma nurses then they would be ideal, but if you didn't then it should be a healthcare provider working in the area. Difficult to get a practice nurse out and doing it, but I think they should be running these events. It should be on someone in the healthcare profession that knows about asthma, health promotion and better understanding"* (Nurse specialist, p7).

There was an impression by two secondary care doctors (HEMS doctor and consultant) that their speciality/profession needs to match the provider's profession to enhance credibility and possibilities of understanding their lived experiences in their workplace:

> *"I think it would, be helpful, if it's a doctor, I'm just tryna think about whether, if it would make difference if it was a doctor or a nurse or, asthma specialist nurse, or from the community I'm just tryna think, who might be best, person. And it depends on the target audience as well, if you are educating someone, in an acute setting, like an A&E physician, A&E doctor then, I think, I think, an Asian doctor who works in that field, is important. So, it really depends on the audience actually, because if I were, were to attend the training, and I turn up, and it's not relevant to my specialty, I would lose interest. So, if I'd been invited to a training, and... If I'm, if I'm being trained by someone who, has no experiences in A&E, or any type of medicine at all, and who works in the community, although I would still respect that person but, I would still think about the credibility of that, particular teaching session. I would be thinking, I work in A&E, this doesn't apply to me, so why am I being taught by this person. Whereas if I had... A doctor who works in A&E, who is also from that background, who knows, understands... The challenges and barriers that the South Asians face, then I'll be slightly more intrigued into it, and vice versa if I was a GP, I would want an A&E doctor telling me about, you know management of asthma in the community and so on, so I think it's dependant on, the target audience"* (HEMS doctor, p9).

Additionally, most HCPs believed that the provider should be from a South Asian background due to the idea that they are insiders of culture and the healthcare profession who have *'a foot in two worlds'*:

> *"Well, I would like to know a lot more about cultural elements that are affecting the way they're, managing their condition, because I wouldn't say that I've got an expertise in that, personally. But I would say that, that healthcare workers form the Pakistani community would have a lot more information, inside info that they could share with me" (GP, p1).*

- Concerns about training

Although, some HCPs stated that they would not have any barriers in attending training, there were some concerns about time, length of training and resources/funding for training to be developed and delivered:

> *"Yeah are there resources? Would there be resources? Would there be resources though to do any of this? I don't know if we are trying to answer a question where, there aren't funds to even solve a problem, that's just my cynical, do know what I mean? We've got lots of problems, and we can talk about solutions but, is there any realistic prospects of funding the solutions?" (Consultant, p5).*

Primary care professionals reported training organised with the Clinical Commissions Group (an NHS body responsible for the planning and commissioning of primary care services in London) would be easier to attend. A barrier to attending training may be that the content (asthma self-management in Bangladeshi and Pakistani patients) may be too specific for doctors who deal with broader health issues:

> *"The other challenge I see, from this particular project, is that it's, its very niche and, and because I've had a chat about this with my colleagues yesterday, because I phoned you, I felt really guilty for not doing this meeting. They said, 'What's this meeting about?' I said, 'Helping South Asians manage their, having self-management in, with asthma', and they said, 'That's really specific, that's like super specific'. And so, I think that might be, that might be a bit of a challenge I think. Because if you had said, 'I want to educate you about the health beliefs, and clinical practices, in Asian culture, that may conflict with their management of chronic illnesses, or any illnesses', that'd be more, better received. But because it's so specific, they will think, 'You know, this is so specific, and so niche, why is this person coming in for half an hour of our teaching session to, tell me about this'. So, it might be difficult to convince the person who's organising the teaching, to say I wanna talk to them specifically about asthma, not just asthma but in Asian patients. I think that might be a bit of a hurdle, I think" (HEMS doctor, p9).*

8.5 Discussion for the qualitative research

8.5.1 Main findings

This study explored the perspective of nine HCPs (from a range of professions; asthma consultants, emergency medicine doctors; GP doctors, primary care nurse and asthma nurse specialist), on providing supported self-management to Bangladeshi and Pakistani patients with asthma. There was a chain of reasoning behind how HCPs provide supported self-management. Main findings related to the objectives were:

- *To understand HCP's perspective on Bangladeshi and Pakistani patients (i.e. cultural realities) and the provision of supported self-management given to these communities:* HCPs prioritised adapting supported self-management according to Bangladeshi and Pakistani culture, though they had a gap in knowledge; no HCP received any cultural training and there were organisational/service restrictions in implementing supported self-management. This may have led HCPs to rely on universalism[79] over cultural relativism[80] to understand and interpret culture and adapt supported self-management accordingly. Examples of universalistic perspectives include the assumption that family need to be a part of treatment for all patients, categorising language barriers and age with poor self-management and connecting fluency in English with younger aged patients who are better self-managers. Sometimes, HCPs used cultural relativism by relying on their personal/professional identity, experience and the use of some supported self-management strategies such as empathy. For instance, recognising that there were subcultural differences between Bangladeshis and Pakistanis, recognising individual differences in religion, identifying that there were cultural changes in the UK, attitudes towards CAM use, the recognition of oral South Asian languages e.g. Sylheti patients cannot always read standard Bengali, and acknowledging that patients are diverse and need to be treated holistically and in context but in doing so they limited

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[79] Universalism is the belief that there are fixed universal cultural realities regardless of time (Billet, 2016; Kagitcibasi, 2017; Rachels, 2007)
[80] Cultural relativism is the belief that culture should be judged by its own merits rather than the culturally bounded values and standards of another, and cultural diversity should be recognised and respected (Billet, 2016; Kagitcibasi, 2017)

holistic care to a disease management approach to co-morbidities. There was no ethnocentrism[81] strategies used.

- *To explore what type of asthma self-management interventions HCPs believe would be useful for Bangladeshi and Pakistani patients with asthma and for their future practice needs:* intervention recommendations for patients included basic education in various formats, group meetings (e.g. self-help groups and social prescribing), and culturally relevant PAAPs. Most HCPs suggested that they needed cultural training in group settings (of whom some wanted patients to be involved). Other HCPs wanted cultural knowledge in the form of information such as the publication/s from interviews conducted with Bangladeshis and Pakistanis (see chapter 7).

8.5.2 Interpretation of findings in relation to previously published literature

Medical anthropologists have widely considered that HCPs have their own professional or elite medical culture, considering its implications on supported self-management for Bangladeshis and Pakistanis may be interesting (Boutin-Foster, Foster, & Konopasek, 2008; Romero & Margolis, 2008; Taylor, 2003). Medical culture can consist of shared values, customs, norms, beliefs and communication styles generated from medical knowledge, training and role modelling of hierarchical professionals (e.g. what is acceptable professional behaviour in medicine), with the confidence in the truth of the medical approach and the underpinning assumption that HCPs have special authority to ease human suffering from illness and injury (Romero & Margolis, 2008; Taylor, 2003). In this respect, medical culture can be produced and reproduced from the professional members in a group, thus becoming timeless (Taylor, 2003). Each professional category may vary in their cultural characteristics and behaviour influenced by educational experiences of each group (Engum & Jeffries, 2012; Orchard, Curran, & Kabene, 2005). HCPs might not view themselves as belonging to the medical culture known as 'a culture of no cultures' (Taylor, 2003). The invisibility of being a part of the medical culture may deflect social opposition or criticisms of it, and therefore re-establishes itself as the mainstream and definitive truth. A reality that is assumed to be the truth and anything other than this is regarded as an alternative suggesting that medical culture may be one-sided. HCPs may apply a particular medical gaze that influences the care

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[81] Ethnocentrism is the practice of judging a culture compared to standards of another culture, where another culture is deemed as inferior to one's own culture that is judged as the better society due to the perception of keeping up with the progression of time (Billet, 2016; Rachels, 2007)

provided, hence power may be exerted over patients on what is medically important (Romero & Margolis, 2008; Taylor, 2003). For instance, HCPs may express themselves by using medical terminology and acronyms, language which can create misunderstandings for patients (Boutin-Foster, Foster, & Konopasek, 2008). Although, research in the area is scarce (Romero & Margolis, 2008; Taylor, 2003).

The conceptualisation and interpretation of HCPs and patients on asthma may be different (the explanatory models of illness). Medical culture (e.g. the medical environment, peers/mentors and curriculum) may be play a role in producing differences in explanatory models of illness, which HCPs need to be aware of to provide holistic supported self-management to patients (Boutin-Foster, Foster, & Konopasek, 2008). To grasp holistic supported self-management, there is a need to understand that cultural beliefs, practices and treatment are extrapolated from different domains in a individuals life e.g. individual, family, community and healthcare services (Leventhal, Benyamini, & Shafer, 2007; Small et al., 2005). The combination of knowledge and perceptions from different domains allow hybridity to occur in the healthcare service (Small et al., 2005). The cultural hybridity model by Small et al. (2005), suggests hybridity can be established (e.g. reflections, negotiations and refinements on the correct self-management behaviour), that guide appropriate actions. This can explain differences in beliefs, practices and treatment between the patient and the HCP (of which one of the areas HCPs may extrapolate from can be medical culture) (Boutin-Foster, Foster, & Konopasek, 2008). This also agrees with Leventhal's theory on illness representations that illness perception may differ in patients and HCPs (Leventhal, Benyamini, & Shafer, 2007).

Medical culture teaches learning techniques to HCPs such as studying medicine through case studies or psychosocial narratives of patients, where meanings and arguments are created with clinical reasonings and planned therapeutic treatments. Arguably, these accounts do not provide a holistic representation of the patients lived experiences but could be perceived as an edited version of the illness (Romero & Margolis, 2008; Taylor, 2003). Exploring patient stories may be perceived in the medical culture as subjective; unworthy of time, since it does not signify replicable facts (Boutin-Foster, Foster, & Konopasek, 2008). However, in this study some HCPs (Bangladeshi GP and asthma nurse specialist) suggested that the idea of telling asthma stories across trajectories in interventions could help gain a deeper understanding of Bangladeshi and Pakistani patient lives with asthma. The use of storytelling can provide

holistic insight to patient-centred care, since it allows patients to have a voice (Greenhalgh et al., 2015; Schwind et al., 2016). This has been emphasised in few recent narrative studies with South Asians e.g. diabetes in pregnancy (Greenhalgh et al., 2015), and heart condition in women (Schwind et al., 2016).

HCPs adapted supported self-management according to culture which prevailed over other factors. HCPs believed that Bangladeshi and Pakistani culture consisted of: telling stories, family involvement, defining generation based on age, and Bangladeshi and Pakistani patients were anxious people, whereas speaking English was perceived to be an English value. All professionals recognised that they were not experts in culture (some HCPs admitted that they were making assumptions) and needed cultural training to develop cultural competence, including both Bangladeshi doctors. The use of theorisations and inaccurate terms (e.g. one consultant referred to South Asians as 'Southeast Asians' throughout the interview), exemplified gaps in cultural knowledge. Although, HCPs were trying their best but potentially may also be getting it wrong. This suggests that HCPs need support from the organisation they work in. The absence culturally relevant training suggests the healthcare service is providing a system that employs the segregation[82] strategy of acculturation, e.g. through the lack of awareness and exclusion of relevant cultural training offered to HCPs, adequate language interpreters and PAAPs (Khambhaita et al., 2017; Wray & Bartholomew, 2010). On the other hand, the absence of ethnocentric approaches amongst HCPs may mean that the healthcare system in London does not adapt to segregation styles of health care (Kagitcibasi, 2017; Sam & Berry, 2010). Perhaps, better information is needed to influence gaps in services (Ramaswamy & Kelly, 2015). Previous qualitative studies have suggested that culture needs to be studied within its context; to tailor interventions and train professionals adequately, but the area of research has been currently underexplored (Castro et al., 2010; Liu et al., 2016; Yadav & Yadav, 2015).

HCPs often treated culture as static by making universal assumptions about culture and self-management needs, though some of these universal assumptions had some basis of truth ('evidence-based assumptions'). A previous qualitative research found that Indian and Pakistani individuals usually consult family members to manage exacerbations (Hussein & Partridge, 2002). Sometimes, HCPs were aware that they were making assumptions in the

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[82] Segregation is a mainstream acculturation strategy where the mainstream society tries to force separation of the individual from their society (Berry, 2005; Sam & Berry, 2010)

absence of adequate knowledge therefore they relied on their experiences (Castro, Barrera, & Steiker, 2010). This can lead to the risk of overgeneralisation. For instance, HCPs in this study perceived Bangladeshi and Pakistani culture as ingrained around big families with more support, despite knowing that younger aged patients prefer to keep asthma related issues to themselves due to smoking and so forth. It can be argued that this imposition of family involvement may exercise an unintentional form of conflictual power 'over'[83] the patient's choice, and acculturative stress[84], as it infers a struggle against traditional cultural expectations of HCPs (Sam & Berry, 2010; Storey, 2010). This may be an example of the power of medical culture or gaze that influences the provision of supported self-management (Romero & Margolis, 2008; Taylor, 2003). Family were often used as the preferred method of language translation and ongoing self-management support (sometimes without seeking the consent of the patient). However, HCPs did not account for the flexibility of social support over time e.g. breakdown in relationships (Morris, Kennedy, & Sanders, 2016). A qualitative synthesis (Dwarswaard et al., 2016) and a qualitative study (Morris, Kennedy, & Sanders, 2016), provide support that family are the most important source of social support. However, family support can vary; it could be practical such as helping with routine tasks (e.g. collecting prescriptions), or moral help involving intensive tasks e.g. performing exercise with the patient. Although, these studies were not specific to the South Asian population (Dwarswaard et al., 2016; Morris, Kennedy, & Sanders, 2016). Interviews with Bangladeshi and Pakistani participants showed that family support for asthma was limited to practical and moral support when they observed asthma symptoms (see chapter 7).

Another example of universalistic 'evidence-based assumptions' was the idea that self-management was poor in most first generations; defined by HCPs as those who were mostly elderly and had little English-speaking ability. This may be one reason why HCPs suggested that future interventions should focus on these patients by addressing language issues. Nurses used their own initiatives to try and overcome language barriers in the services e.g. using audio-visual educational strategies to improve understanding of asthma medications,

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[83] Power 'over' (also known as conflictual power) consists of the capability of individuals/groups/institutions to prevail over another in doing something that a person is resistant to, would not normally do and is not in their interest. This form of power is based on social relations (Haugaard, 2002)

[84] Acculturative stress is the reaction and experience of daily stress and degree of psychological/sociocultural adaptation challenges resulting from encountering a larger mainstream culture (Berry, 2005; Sam & Berry, 2010)

peak flow monitoring and spirometry. This may be an important strategy to address language for intervention development. The systematic review showed that audio-visual strategies used in a RCT had beneficial outcomes e.g. inhaler technique (see chapter 5) (Ahmed et al., 2018). According to previous literature, audio-visual materials/resources that present difficult information in the correct language/dialect can help patients with low literacy (despite ethnicity), e.g. illustrating asthma signs and symptoms such as different sounds of cough (croup or whooping cough) (Jones et al., 2014; Lakhanpaul et al., 2017; Neill et al., 2015). This may be extremely helpful for South Asians who have oral languages with no written form (Jones et al., 2014; Lakhanpaul et al., 2017). If signposting for audio-visual information/resources is used in future interventions, it is unclear how this would work e.g. the approach would require people to be IT literate (Neill et al., 2015). The lack of language facilitation in healthcare have been described in a UK based qualitative study for parents of children with asthma, which was speculated as the cause for differential supported self-management e.g. seeking help from HCPs who could speak the same language (Lakhanpaul et al., 2017). Arguably, poor language provisions in organisations may reflect institutional racism[85], though on the other hand it may be that the healthcare service is overburdened, in addition to cost limitations (Ramaswamy & Kelly, 2015). No doubt language opens the doors of communication and insight (Al-Azami, 2006; Jaspal, 2010). In saying this, a Cochrane systematic review has shown that solely relying on language modifications is not enough to produce positive asthma outcomes (Bailey et al., 2009).

Sometimes, HCPs expressed cultural relativism which reflected cultural competence in supported self-management (Betancourt et al., 2016). Religion was perceived to be part of culture, and HCPs recognised individual differences in this. But, there were assumptions made on religious advice and knowledge since HCPs had little understanding of the area. Although, there were some guidance on self-management in other chronic illnesses (e.g. diabetes and cardiovascular disease), a comprehensive overview in asthma was missing (Asthma UK, 2016d; Bukhari, 2016), and gaps in knowledge meant religious teachings were extrapolated from one illness and applied to asthma (Asthma UK, 2016d; NHS Choices, 2017). For instance, Ramadhan medication advice was often guesses or revolved around referrals to 'the Imam' as someone all patients would want or have access to (Asthma UK, 2016d; Bukhari, 2016). In qualitative interviews with Bangladeshi and Pakistani participants, they did

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[85] Institutional racism is the public institutions response of ignorance to the needs of ethnic minorities that is not directly obvious (Ramaswamy & Kelly, 2015)

not mention the Imam as someone who was important for their asthma care (see chapter 7). This may be complicated by individual differences in religion such as whether individuals identify with an Imam (Bukhari, 2016; Koenig & Shohaib, 2014). Cultural relativism would mean cohesively noting all these factors (Billet, 2016; Kagitcibasi, 2017).

Moreover, HCPs noted that there were subcultural differences amongst Bangladeshis and Pakistanis by repeatedly stating that their experiences were confined to one group over the other (due to the locality of services where one ethnicity may be more present than the other). One subcultural difference reported for Bangladeshis was the preference for doctors over nurses; but this has been reported for many cultures (Dwarswaard et al., 2016; Morris, Kennedy, & Sanders, 2016). Although, doctors described nurses are the ones that are more involved in supported self-management than themselves; their focus was on disease management of asthma (may be an example of the influence of the medical cultural gaze on the provision of treatment/intervention provided to patients) (Romero & Margolis, 2008; Taylor, 2003). This is supported by a qualitative research in primary care which showed that GPs had minimal involvement in supported self-management; they believed that this was the nurses job, particularly for implementing PAAPs (Morrow et al., 2017). Similarly, some HCPs proposed that patients need to be treated holistically in self-management, but the meaning of holistic self-management was different. HCPs believed holistic self-management meant considering the physical and mental co-morbidities of a patient (another example of the influence of the medical cultural gaze on patient care) (Romero & Margolis, 2008; Taylor, 2003). This supports other findings that users of the biomedical model can fragment supported self-management by relying on disease management (Morris et al., 2016; Schulman-Green et al., 2012), agreeing with interviews with Bangladeshis and Pakistanis who described HCPs promoted a disease management approach to supported self-management (see chapter 7). At the same time, some secondary care HCPs recognised that emotional role management played an important role in self-management (especially for anxiety) and tried accommodating support for this e.g. referrals to and incorporation of psychological services in asthma clinics. This was not reflected in interviews with Bangladeshis and Pakistanis (see chapter 7), perhaps this was due to the sample studied or as recognised by HCPs in this study there may be cultural barriers to acknowledging and accessing psychological services in the community (Arora, Metz, & Carlson, 2016; Loya, Reddy, & Hinshaw, 2010).

HCPs believed that Bangladeshi and Pakistani patients did not have a good understanding of asthma medication and described this as a cultural problem, however interviews with Bangladeshi and Pakistani participants has shown that they knew more about medication than about asthma (e.g. medicine dosage). This disagrees with previous studies (Griffiths et al., 2001; Hussein & Partridge, 2002; Moudgil & Honeybourne, 1998), including systematic reviews (Ahmed et al., 2018; Miles et al., 2017), that found various South Asian populations have difficulty understanding information around medications, suggesting that perhaps understanding of asthma medications are changing in the UK. Despite this, some Bangladeshis and Pakistanis had difficulty in understanding spirometry and peak flow meters, which aligns with the HCP perspective (see chapter 7).

Ethnic minority HCPs may face acculturative stress while training to be a HCP over what medical culture places value upon due to conflicting cultural identities e.g. being used as an interpreter (Roberts, Sanders, & Wass, 2008; Taylor, 2003). However, in this study both doctors with a Bangladeshi ethnic background (consultant and GP) also described gaps in their cultural knowledge; they may have reflected multiculturalism[86] and melting pot[87] strategies of acculturation at a mainstream healthcare level (Sam & Berry, 2010), disagreeing with the universal idea that the ethnic background of HCPs qualifies them as insiders of cultural knowledge, who may have better relationship or provide better service to the general South Asian community (Kagitcibasi, 2017; Samples et al., 2014). Perhaps, habitus[88] plays a role, where studying culture may be necessary for deep cultural knowledge. The strategy of the current healthcare system or culture is to propose ethnic-matching of professionals and patients, but one of the things this approach does not recognise is the variation of South Asian languages and dialects and that some professionals do not speak any South Asian languages at all (Culley, Hudson, & Rapport, 2007; Griffiths et al., 2001). The notion itself employs the assumption that there is harmony within cultures with natural/innate understanding and abilities, in addition to implying that all cultures need

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[86] Multiculturalism is a mainstream acculturation strategy when cultural diversity is fully supported as a feature of the mainstream society. The correct atmosphere needs to be in place for the integration strategy to be chosen and sustained (Berry, 2005; Sam & Berry, 2010)

[87] Melting pot is a mainstream acculturation strategy where the mainstream society is more dominant than the individual's own cultural group (Berry, 2005; Sam & Berry, 2010)

[88] Habitus is the internalised dispositions of second nature social rules and categorisations on perceptions, thoughts and behaviours predicted by past experiences, and social, cultural and economic capital (Bourdieu, 2017, 2018)

ethnic-matching other than the White Caucasian culture (Samples et al., 2014; Wray & Bartholomew, 2010).

Notably, there is a distinction between ethnic and language matching (Colucci et al., 2015; Hoong Sin, 2007). The latter is used in interventions to enhance access to patient education and so forth, but not necessarily restricted to ethnicity, whereas ethnic-matching entails the matching of HCPs and patients based on ethnicity (Colucci et al., 2015; Culley et al., 2013; Mucic, Hilty, & Yellowlees, 2016). The idea of ethnic-matching was re-iterated by HCPs in this study. Most HCPs felt that interventions need to be delivered by an 'insider' to culture (a South Asian HCP). The assumption that ethnic and language matching were the same, essentially 'ethnic matching'; was presented as a complete solution to improve self-management for Bangladeshi and Pakistani patients. Arguably, the ethnic-matching approach in healthcare services may be regarded as a melting pot strategy to acculturation, since it can reduce the ethnicity of HCPs to a methodological approach of matching professionals with patients without prioritising the skills or qualities that HCPs bring to their profession (Sam & Berry, 2010; Samples et al., 2014). In addition, there may be an intentional form of conflictual power at an institutional level, when factors such as language provisions are not catered for, even though HCPs widely recognised this limitation. HCPs in this study used certain supported self-management strategies (e.g. empathy), which may perhaps be an alternative to ethnic-matching and needs further exploration. In addition, it is questionable why ethnic-matching takes priority over other demographic factors e.g. age, gender, technical and interpersonal skills (Khambhaita et al., 2017).

8.5.3 Strengths and weaknesses of the study

To my knowledge, this was one of the first studies to apply cultural relativism, universalism and ethnocentrism in understanding perspectives of supported asthma self-management. Cultural relativism has been used in various health related research e.g. mental health (Sweetland et al., 2016), palliative care (Cherny et al., 2015), developing cultural competence in HCPs e.g. nursing (Rohrbach Viadas, 2015), and issues that cause health concerns e.g. female circumcision (Chung, 2018; Kagitcibasi, 2017). Some moral critics argue that cultural relativism can protect cultures from being criticised on perceived harmful practices, essentially also robbing people of the ability to resolve disagreements within a culture itself, though this viewpoint may suggest that good health and treatment of illness are universal

(Billet, 2016; Kagitcibasi, 2017; Lukes, 2016). In this study, cultural relativism was used as an approach to improve discussions around the understanding of supported asthma self-management for Bangladeshi and Pakistani patients in a way that allowed the researcher to enter into the world and the perspective of HCPs. The approach here was not about medical ethics rather how beliefs were played out (Van der Geest, 2014).

Arguably, it can be tentative whether we can fully obtain an objective viewpoint of the Bangladeshi and Pakistani culture, and perhaps it would be elusive to assume this could be achieved, particularly since culture is dynamic and changes over time (Billet, 2016; Castro, Barrera, & Steiker, 2010; Kagitcibasi, 2017). Although, I recognised that Bangladeshi HCPs were judging their own culture, rather than an outsider assessing another's culture. However, it can be debated whether they were judging culture based on their own acculturation strategy. In addition, the acculturation of HCPs may be individual/group level acculturation but since the healthcare service was treated as the mainstream society from the acculturation model in this study, the acculturation strategy of the HCP was taken to represent the healthcare service (Sam & Berry, 2010). No doubt, HCPs from various cultures (including ethnic minorities) can be part of the healthcare service. Attributing the acculturation style of HCPs to the mainstream healthcare society (which may not be a true reflection of the healthcare service), has the potential to blame HCPs for their personal acculturation strategy they adopted. I also recognise that staff from different cultural backgrounds may be less at bureaucratic levels (Ramaswamy & Kelly, 2015; Sam & Berry, 2010).

Most HCPs had more contact with the Bangladeshi individuals than Pakistani patients with asthma (e.g. both nurses), therefore caution should be taken in generalising findings. Where possible for participants in the same professional category (e.g. consultants and GPs), those with contact with either Pakistanis and/or Bangladeshis were included. Moreover, two HCPs with Bangladeshi ethnicities were represented, who identified themselves as 'westernised'/'British Bangladeshi' (from the multiculturalism and melting pot acculturation strategies), findings may differ with South Asian HCPs from other acculturation strategies. Another difficulty with this study was the use of selected questions from the SL-ASIA scale to describe the level of acculturation in the sample who have varied ethnic backgrounds e.g. the scale included the assessment of South Asian languages (Hsueh et al., 2015; Suinn et al., 1987). Accounts of cultural realities may also be restricted to the type of service in question

e.g. hospital asthma clinics often had patients with uncontrolled asthma. I recognise that there are different ways to categorise generations. HCPs in this study classified generation based on age structures, however this approach may overshadow needs of younger migrants who may be classed as second or third generations (McCrindle & Wolfinger, 2010).

Ambulance paramedics, online forum professionals/users and the study researcher were identified by some Bangladeshis and Pakistanis as categories of HCPs who were the most important in their asthma care, but they were not represented due to difficulty in recruitment and time limitations (see chapter 7). Some categories of HCPs interviewed were few in number (e.g. GP nurse, emergency medicine doctor and asthma nurse specialist). Other professional categories were not chosen, who may potentially also be important in asthma care for this community, due to the methodology chosen in interviews with Bangladeshis and Pakistanis (see chapter 7), where they were asked which HCP was important in their care and those HCP categories were interviewed. For example, pharmacists have been found to be important references for South Asian children and their parents/guardians, particularly for non-English speakers (Lakhanpaul et al., 2014), though the study itself had a selective sample and this study included adults (with basic English speaking abilities), who may have had different preferences. Insights from other HCPs could have provided interesting grounds of understanding supported self-management from other perspectives. However, a good number of HCPs from a range of backgrounds were included in this study and data saturation was achieved with respect to the research questions (i.e. when there was a comprehensive understanding of perspectives) (Saunders et al., 2017). To ensure reliability of coding data, a second coder checked 33% of the transcripts (Jessica Porter), and to ensure codes in the data were not missed a further 33% were group coded for reliability (Liz Steed; Hilary Pinnock).

8.5.4 Conclusions and implications for future research

This qualitative study explored the perspective of HCPs on supported self-management provided to Bangladeshis and Pakistanis with asthma, to understand how this can inform holistic asthma self-management interventions:

- Medical culture to a degree may influence supported self-management for Bangladeshi and Pakistani, which suggests a sense of power (Romero & Margolis, 2008; Taylor, 2003), e.g. promoting disease management of asthma and defining co-morbidities with a

medical understanding. However, the awareness and research on medical culture may be limited (Romero & Margolis, 2008; Taylor, 2003). On the other hand, medical culture may not have influenced other aspects of supported self-management (Romero & Margolis, 2008; Taylor, 2003), e.g. some HCPs wanted to know patient stories on self-management.

- HCPs prioritised culture in adapting supported self-management. HCPs did not receive cultural training and were not aware of any services that offer training. This meant that HCPs used universal approaches to categorise culture and supported self-management that was needed, without fully accounting for cultural changes in the UK.

- HCPs also expressed cultural relativism which may be viewed as a step further towards developing cultural competence e.g. they recognised differences in subcultures, oral languages with no written form and individual difference in practising religion.

- Doctors believed that their roles mainly revolved around supporting disease management, therefore they were not really providing supported self-management. Nurses were described as those who provide a more comprehensive self-management support (e.g. medical, role and emotional). This can imply a shift in responsibility for supported self-management to nurses. In addition, further insights from nurses may be interesting due to this.

- There may be an unintentional exercise of conflictual power between HCPs and patients, when HCPs expect patients to comply with their cultural expectations (e.g. the involvement of family). This may also cause acculturative stress. In addition, there may be an intentional form of conflictual power at an institutional level, when factors such as language provisions are not catered for, even though HCPs widely recognised this limitation.

- It needs to be assessed whether cultural training and culturally relevant materials can have a meaningful impact in the healthcare service e.g. PAAPs, matching providers and patients from various acculturated strategies or other demographic factors such as gender, age, technical or interpersonal skills rather than ethnicity, better language provisions and signposting further cultural information in guidelines (Khambhaita et al., 2017).

- In view of these findings, it would be interesting to ponder on the classification of supported self-management in guidelines e.g. since HCPs were reliant on family members for language translation.

This chapter explored the HCP's perspective on providing supported asthma self-management to Bangladeshi and Pakistani patients. The next chapter discusses the findings from the research in this thesis.

Chapter 9. Discussion

The last chapter explored the perspective of HCPs on supported self-management for Bangladeshis and Pakistanis with asthma. This chapter discusses the findings of the research in this thesis; discussions on methodologies used in the research (particularly emphasising on language and reflexivity).

9.1 Summary of main findings

This thesis has used a holistic lens to capture the dynamic features of asthma, self-management and the Bangladeshi and Pakistani sociocultural context (Schulman-Green et al., 2012; Trappenburg et al., 2013; Udlis, 2011). One method of doing this was to consider the perspective and expertise of Bangladeshi and Pakistani individuals with asthma and relevant HCPs, but the growth of research has not been substantial and/or robust e.g. exploring the South Asian self[89] (Sinha, 2014; Triandis, 2018). The systematic review looked at what was included and has worked/not worked in previous interventions in the South Asian and Black populations, revealing that sociocultural context was important for self-management (including whether individuals are from a minority or indigenous population) (see chapter 5). Therefore, the perspective of Bangladeshis and Pakistanis with asthma in the UK were explored in qualitative interviews, which showed that understanding the Bangladeshi and Pakistani self in self-management helped to represent and piece together the dynamic role of asthma, self-management and culture. For Bangladeshis and Pakistanis, self-management was tied to; i) the body (e.g. balancing emotions in the body), ii) context (e.g. acculturative or culture-specific stress) and, iii) the distribution of knowledge and social discourses e.g. selective information from HCPs shaped understanding self-management as disease management (see chapter 7). Finally, qualitative interviews with HCPs showed that they prioritised the adaptation of supported self-management according to culture. In the absence of appropriate training, most of the time HCPs overgeneralised the support they provided. Nonetheless, HCPs had a real willingness to learn about culture and welcomed the idea of cultural training/information. Additionally, some HCPs emphasised on disease management of asthma in self-management, but some secondary care HCPs also recognised

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[89] The self can be broadly defined as direct or indirect statements that comprise of the self referring to *'I', 'me', 'mine', 'myself'* (Triandis, 2018), in social motivations, attitudes, beliefs, intentions, norms, roles and values (Cooley, 2017; Triandis, 2018)

the importance of emotional self-management in Bangladeshi and Pakistani patients (see chapter 8).

9.2 Interpretation of findings of the thesis

The overarching aim of this thesis was to understand the role of UK Bangladeshi and Pakistani culture on asthma self-management behaviour, which can help set the foundations for developing holistic bottom-up interventions detailed in this section (which has been explicitly recommended in asthma clinical guidelines) (NICE, 2013; SIGN, 2016).

9.2.1 Findings in relation to the role of culture on asthma self-management behaviour

Considering the role of the approach to culture

There is no standard definition of culture and different disciplines may adopt various interpretations (Bhopal & Sheikh, 2009; Castro et al., 2010). Some research treats culture as a static entity (using proxy terms such as ethnicity), while some research treats culture as dynamic (see section 3.2 for more details) (Bhopal & Sheikh, 2009; Castro et al., 2010). This project has found that culture is dynamic and changes according to context e.g. generational differences in self-management (see chapter 7). Research on the migrant paradox such as the healthy immigrant effect refute the static view and implementation of culture by that suggesting that individuals are more likely to be healthy in South Asia compared to those resident in the UK, therefore suggesting that the norms of the dominant group may not reflect the ideal health for other cultures (Falicov, 2009; Kennedy et al., 2015; Roura, 2017).

The area of providing culturally competent supported self-management to Bangladeshi and Pakistani patients has been underexplored (Castro et al., 2010; Liu et al., 2016; Yadav & Yadav, 2015). The qualitative study with Bangladeshis and Pakistanis with asthma has been one of the few studies that have asked participants who was the most important HCP for their asthma. The choice in HCPs varied from; GP doctors, primary care nurses, the emergency department secondary care asthma clinic, asthma consultant, severe asthma clinic, study researcher, ambulance paramedics, online forum doctors, and in some case no HCP was chosen. Most Bangladeshi and Pakistani participants described that they choose

their GP doctor due to inexperience with and access to other HCPs. These preferences were taken into consideration in the purposeful sampling of HCPs in the next phase of the qualitative study (see chapter 8). HCP interviews showed a logical chain of reasoning behind how HCPs prioritised understanding of culture over other factors in adapting supported self-management. For instance, integrating perceived cultural values into support e.g. family involvement and breaking down barriers in understanding through building a relationship. However, there was a gap in cultural knowledge; no HCP received or was aware of any training, and there were organisational/service restrictions in providing supported self-management. For instance, there was little exploration of CAM in consultations. Some HCPs were concerned about their confidence level in discussing this due to the lack of knowledge.

Interviews revealed that limitations in HCP's cultural knowledge meant that they often treated culture as static (fixed); relying on overgeneralised assumptions and theories based on experience to understand Bangladeshi and Pakistani patients better. The social identity theory suggests that to identify and understand a culture, strategies (e.g. social categorisation) may be used (see section 2.2.4) (Tajfel & Turner, 2004). HCPs can treat patients from other cultural backgrounds as objects in society that need to be categorised (Michie et al., 2014; Tajfel & Turner, 2004). For example, HCPs assumed that family needed to be a part of self-management for all patients. Sometimes, HCPs were aware that they were making assumptions in the absence of adequate knowledge and tried to avoid it. Self-management problems were mainly perceived to be located with the first generation (those who are elderly with language barriers), rather than differences that arise from the context of self-management behaviours. Thereby, overshadowing young migrants or older patients who may or may not have language difficulties. Therefore, HCPs mainly recommended that interventions should be developed for the first generation e.g. resolving language issues. In contrast, they associated the fluency of English in younger aged patients to those patients who were perceived to have better self-management.

Family (especially extended family) may be a part of traditional Bangladeshi and Pakistani culture, but this may not always be the case in the UK. The social capital of family support can be lost during migration, in addition to the feasibility of living with extended family members who provide support and there may be changes in relationships over time (Kagitcibasi, 2017; Kennedy et al., 2015; Morris, Kennedy, & Sanders, 2016). But, HCPs still expected patients to gain family support in their asthma self-management as part of routine

care, despite knowing that some younger aged patients prefer to keep asthma related issues to themselves due to smoking behaviour and so forth. In the case of patients with language differences, the need for family involvement may be perceived as a form of reliance in HCPs, especially for language translation. The traditional cultural expectations of HCPs (e.g. need for family involvement) in self-management may infer an unintentional form of conflictual power[90] in the struggle of acculturative stress[91] (construct[92] from the acculturation model) between HCPs and patients. This can cause stress to individuals who want their asthma to be private (Sam & Berry, 2010; Storey, 2010). Interviews with Bangladeshi and Pakistani participants showed that most individuals did not feel that they needed/wanted extra support (beyond practical and moral support) or thought of their family as the first point of access for issues related to their asthma, compared to other illnesses such as diabetes. Therefore, family support may not always be the best form of supported self-management (see chapter 7). Conversely, previous literature has documented that elders in a family are respected in both Bangladeshi and Pakistani culture, which has an impact on addressing health concerns e.g. collective decision-making or decision-making by male elders (Perera & Chang, 2018; Triandis, 2018). Additionally, UK based trials for South Asian adults have not incorporated family into an intervention. It may be interesting to explore the impact of this (Ahmed et al., 2018).

Medical anthropologists have stipulated that HCPs have their own professional or elite medical culture[93] (e.g. the medical environment, peers/mentors and curriculum), which may influence supported self-management for Bangladeshis and Pakistanis, though research in the area is scarce (Boutin-Foster, Foster, & Konopasek, 2008; Romero & Margolis, 2008; Taylor, 2003). Although, since HCPs may not view themselves as belonging to a medical

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[90] Power 'over' (also known as conflictual power) consists of the capability of individuals/groups/institutions to prevail over another in doing something that a person is resistant to, would not normally do and is not in their interest. This form of power is based on social relations (Haugaard, 2002)

[91] Acculturative stress is the reaction and experience of daily stress and degree of psychological/sociocultural adaptation challenges resulting from encountering a larger mainstream culture (Berry, 2005; Sam & Berry, 2010)

[92] Constructs are key concepts related to behaviour that interventions are based on (Michie & Prestwich, 2010)

[93] Medical culture is a dynamic entity of shared professional values, customs, norms, beliefs and communication styles generated from medical knowledge, training and role modelling of hierarchical professionals; there is full confidence in the truth of the medical approach and that HCPs have special authority to ease human suffering from illness and injury (Romero & Margolis, 2008; Taylor, 2003).

culture (Taylor, 2003), it can deflect any visible social oppositions or criticisms of their approach to supported self-management. Arguably, those HCPs who apply a medical lens in supported self-management may be exerting power over patients on what they feel is medically important (Romero & Margolis, 2008; Taylor, 2003). For example, promoting the disease management of asthma as self-management and defining co-morbidities with a medical understanding.

Differences in the explanatory models of illness between HCPs and patients with asthma may be due to medical culture, which needs to be recognised to ensure holistic supported self-management is provided (Boutin-Foster, Foster, & Konopasek, 2008). In addition to understanding cultural beliefs, practices and treatment in the daily lives of patients e.g. from individual, family, community and healthcare levels (Leventhal, Benyamini, & Shafer, 2007; Small et al., 2005). This agrees with Leventhal's theory on cognitive and emotional illness representations that illness perception may differ in patients and HCPs (Leventhal, Benyamini, & Shafer, 2007), e.g. views on breathlessness may vary (that refer to rules of norms to make sense of the threat of illness) (Marks et al., 2015; Sidora-Arcoleo et al., 2012). The theory suggests that illness representations and common-sense beliefs are formulated from associating interactions between the individual, social and professional realms, which guide appropriate or inappropriate coping behaviour (Marks et al., 2015; Morrison & Bennett, 2009). Knowledge and perceptions drawn from different domains (that overlap e.g. popular/community, healthcare/professional and folk zones) allows a better and holistic understanding of cultural hybridity[94] (e.g. illness negotiations) in a healthcare service (Small et al., 2005). This cultural hybridity model at healthcare level was suggested by Small et al. (2005), which states that hybridity guides appropriate behaviour e.g. reflections on choices, negotiations and refinements on the correct self-management behaviour. This can explain differences in beliefs, practices and treatment between the patient and the HCP (of which one of the areas HCPs may extrapolate from is the medical culture) (Boutin-Foster, Foster, & Konopasek, 2008). This highlights the need for researchers to understand the importance and implications of hybrid domains (e.g. accessing treatment), which can allow healthcare services to respond to numerous cultural milieus (Small et al., 2005). On the other hand, as agreed by some HCPs (Bangladeshi GP and asthma nurse specialist), storytelling may be a method of holistically understanding patient lives with asthma (Boutin-Foster, Foster, &

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[94] Cultural hybridity is the bi-cultural competence and negotiations of being a part of two or more cultures with a new sense of belonging (Hall, 1990, 2014)

Konopasek, 2008; Greenhalgh et al., 2015; Schwind et al., 2016), though medical culture may dictate that storytelling is non-scientific and subjective (Boutin-Foster, Foster, & Konopasek, 2008). Storytelling has been emphasised in few recent narrative studies with South Asians e.g. diabetes in pregnancy (Greenhalgh et al., 2015), and heart condition in women (Schwind et al., 2016).

When culture is treated as an dynamic entity, it suggests that people are active learners and decision-makers of culture (Barrera et al., 2013; Castro et al., 2010; Fortun et al., 2014; Yadav & Yadav, 2015). Culture in this thesis was understood as a subjective reality of an individual, which can be framed as a mosaic[95] (an identifiable structure of tiles). Each tile can comprise of one identity (e.g. ethnicity), and therefore individuals may identify different factors as part of their cultural mosaic reflecting the complexity of culture (Chao & Moon, 2005; Triandis, 2018). This helps avoid assumptions made by researchers on a community when participants are asked what their culture consists of and avoids any conflictual power 'over' defining cultural terms by treating culture as static (Ahmad & Bradby, 2008; 2007; Castro, Barrera, & Steiker, 2010). For a deeper understanding, the social identity theory suggests that collective identity is derived from one's own knowledge of a membership in a social group/s (e.g. values, relationships and social roles) and emotional significance attached to membership. This is ensured by two processes that enhance perceived belongingness: social categorisations (a reflexive approach to labelling oneself and the place in the social world), and social comparisons (comparing oneself to those who are similar) (Tajfel & Turner, 2004).

Interviews showed that on a few occasions, cultural relativism[96] was used by some HCPs by relying on their own personal/professional identity, experience and using supported self-management strategies such as empathy, which are all dynamic attributes of cultural competence (Betancourt et al., 2016). For instance, HCPs recognised individuality in religion such as whether Bangladeshi and Pakistani individuals practiced Islam or not varied, but at the same time they made universalistic[97] theories and assumptions due to lack of knowledge e.g. generic advice was given during Ramadhan based on information on other illnesses.

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[95] Cultural mosaic consists of tiles and a structural framework of a collage of factors that contribute to an individual's sociocultural identity (Chao & Moon, 2005)
[96] Cultural relativism is the belief that culture should be judged by its own merits rather than the culturally bounded values and standards of another, and cultural diversity should be recognised and respected (Billet, 2016; Kagitcibasi, 2017)
[97] Universalism is the belief that there are fixed universal cultural realities regardless of time (Billet, 2016; Kagitcibasi, 2017; Rachels, 2007)

Although, HCPs identified that there was a need for further guidance on Ramadhan and that this information needs to catch up with other conditions such as diabetes and cardiovascular disease (Asthma UK, 2016d; Bukhari, 2016). Bangladeshi and Pakistani participant interviews also acknowledged this (see chapter 7). Moreover, some HCPs recognised the unhelpful nature of materials/resources translated into the nearest language/dialect for people who speak oral languages with no written form.

Considering the role of various sociocultural contexts and subcultural similarities/differences

The systematic review adds to the few studies that have synthesised the effectiveness of asthma self-management interventions for South Asians (and African Americans). Harvest plots revealed that interventions based in developed countries (UK, Canada and USA) (Blixen et al., 2001; Fisher et al., 2004, 2009; Ford et al., 1997; Griffiths et al., 2004, 2016; Kelso et al., 1995, 1996; Moudgil, Marshall, & Honeybourne, 2000; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005), were not consistently effective on asthma outcomes compared to those in South Asia, though the latter trials were at a high risk of bias and based in tertiary care settings where it may be easier to show health benefits (Agrawal et al., 2005; Behera et al., 2006; Ghosh et al., 1998; Shanmugam et al., 2012). More robust interventions in the UK are needed focussing on the sociocultural context and capital in the UK (Ahmed et al., 2018). Most indigenous trials developed interventions according to recommendations made in Western programmes and/or generic international guidelines (e.g. GINA), rather than customising interventions to their own population (Agrawal et al., 2005; Ghosh et al., 1998; GINA, 2016; Shanmugam et al., 2012). This is crucial since sociocultural contexts in developing countries may focus on communicable illnesses rather than long-term conditions for which there may be little healthcare resources, training and staff. Therefore, interventions in developing countries may need to adapt to existing resources and healthcare systems (Asbroek et al., 2005; WHO, 2007; Yorgancioglu et al., 2016). Limited descriptions of other contextual factors (e.g. SES and urban/rural areas), where interventions were conducted could not be examined further in the review. It was unclear whether culture or the minority-status of an ethnic group influenced the variance in self-management outcomes and whether poor study fidelity had an impact on delivering these cultural interventions, since only two studies reported that they assessed fidelity (Griffiths et al., 2016; Velsor-Friedrich et al., 2012).

The systematic review has also added to the few existing systematic reviews (e.g. Lakhanpaul et al., 2014a) that have identified barriers and facilitators of implementing asthma self-management behaviour for South Asians (and African Americans), across different sociocultural contexts. Identified barriers and facilitators can inform understanding of self-management behaviour according to context; whether they were generic, related to minority-status or culture-specific (Bhopal & Sheikh, 2009). Identified barriers to self-management were:

- The lack of knowledge (a generic barrier of self-management in all populations) (Behera et al., 2006; Ford et al., 1997; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012). To further support this barrier, Bangladeshi and Pakistani participants (and HCP experiences) revealed that they had little asthma and self-management awareness.

- Differences in learning styles was a minority-status barrier (Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012), e.g. age/cognitive decline (Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012).

- Culturally specific stressors (e.g. neighbourhood violence) was a barrier specific to African Americans (Velsor-Friedrich et al., 2012).

Identified facilitators to self-management included:

- Providing education and self-management support (a generic facilitator of self-management in all populations) (Behera et al., 2006; Ghosh et al., 1998; Kelso et al., 1995, 1996; Poureslami et al., 2012; Velsor-Friedrich et al., 2012).

- Culturally and linguistically appropriate education (a specific facilitator for South Asians despite country of residence) (Behera et al., 2006; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012).

- Education adapting to individual learning styles (a minority-status facilitator) (Velsor-Friedrich et al., 2012).

- Addressing daily stressors/social support (a specific facilitator of self-management for African Americans) (Blixen et al., 2001; Fisher et al., 2009; Velsor-Friedrich et al., 2012).

- General self-management strategies e.g. practising self-management, PAAPs and written reinforcements (facilitators related to indigenous South Asians) (Agrawal et al., 2005; Behera et al., 2006; Ghosh et al., 1998).

The qualitative study demonstrated the complexity of the Bangladeshi and Pakistani sociocultural context in the UK (Sharif, 2012). For instance, place of residence may be important where identifications or references may be formed with the majority ethnicity in

a London locality e.g. Pakistanis who lived in urban areas where there were a lot of Bangladeshis considered themselves as part of that community. This highlights the flexible nature and the diverse influence of the sociocultural context in the UK. Understanding this may be helpful when considering subcultural similarities and differences in asthma self-management, important for developing future asthma interventions (Sharif, 2012). Examples of subcultural differences found in the qualitative study was that some Bangladeshis may have cleansing asthma beliefs about impurities inside the body (e.g. sweating and purifying the body), maintaining masculinity (e.g. social visibility of strength, lack of vulnerability and good control), and some first-generation Bangladeshis were given inhalers but struggled with obtaining an asthma diagnosis important for initiating self-management. According to the common sense self-regulatory model, an asthma identity is needed to initiate appropriate self-management (Leventhal, Benyamini, & Shafer, 2007). Another qualitative study found that there were also problems attaining asthma diagnosis for other South Asian subcultures (Lakhanpaul et al., 2014b). In contrast, Pakistanis used homeopathic medications and some Pakistanis had little acceptance of asthma. Although, there should be caution in generalising findings on subcultural similarities and differences, since the participants only represented a small proportion of the population (see reflexivity on generalisation in section 9.4). In addition, HCPs also recognised that there were subcultural differences between Bangladeshis and Pakistanis, by realising that their experiences were confined to one group (Bangladeshis) over the other (Pakistanis), due to the locality of services where contact with one ethnicity may be more prevalent than the other. These findings fill in a gap in literature; the systematic review showed that subcultural differences were not usually considered in previous research and the perspective of HCPs add to understanding this further (see chapter 5) (Ahmed et al., 2018).

Considering the role of cultural beliefs and norms

The systematic review (see chapter 5) found that it was unclear whether the use of theory and theoretical intervention components had an impact on asthma outcomes. The review also showed that future interventions may benefit from targeting health beliefs. The theoretical component 'knowledge' presented in interventions may need to resonate with the recipients to address barriers and facilitators of self-management e.g. targeting beliefs to account for the way information is learnt, processed and is meaningful for a cultural group (Castro, Barrera, & Steiker, 2010; Resnicow et al., 1999). 'Beliefs about capabilities' and

'beliefs about consequences' (can be perceived as a form of deep structure learning) may need to be targeted to enhance comprehension and processing of knowledge (an identified barrier) and address individual learning styles (an identified barrier and facilitator), and ensuring education is culturally and linguistically appropriate (an identified facilitator) (Behera et al., 2006; Ford et al., 1997; Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012). Health beliefs about asthma have been found to be important for medicine adherence (Horne et al., 2013). This agrees with a previous study (Moudgil & Honeybourne, 1998), and systematic reviews (Lakhanpaul et al., 2014a; Miles et al., 2017), which have reported that South Asians find it difficult to understand information on medicine/treatment. The cultural hybridity model at a healthcare level suggests that health beliefs are mainly drawn and defined from the popular sector (e.g. family and community) and then healthcare services (professional sector) and folk services (traditional sector) are accessed for treatment (Small et al., 2005).

Bangladeshi and Pakistani participants believed that self-management meant control and discipline over activities, which agrees with previous literature in other cultures (Kralik, Paterson, & Coates, 2010). Adding to existing literature, participants believed that good control and discipline meant that there was an absence of feeling of asthma. Participants described the belief that asthma was caused by natural and supernatural world causes (e.g. stress, cold and/or God), and asthma was perceived to be a cold illness. Attribution of cause to God's will (for Muslim South Asians) and Karma (for Hindu South Asians) were found in another qualitative study, but White British families did not cite destiny or religious health beliefs (Lakhanpaul et al., 2017). Hence, there may be shared religious health beliefs amongst Muslims and Hindus that illness are fate destined by God and therefore individuals should console each other for patience (Haleem & Smart, 2013). Sometimes, beliefs about predestination can be negatively interpreted by many researchers as 'fatalism'; a term that has negative connotations that devalues religious beliefs and creates a selective picture, without considering the broader perspective. For instance, Islamic belief in God's will may also mean that individuals have responsibility for their own health, need to use available resources for treatment and it can help with the degree of illness acceptance (Ahmad & Bradby, 2008; Yadav & Yadav, 2015), agreeing with previous literature where Indian, Bangladeshi, Pakistani and Nepalese individuals believed diabetes was caused by God's will and also genetic predisposition (Patel et al., 2015).

Some characteristics of self-management of the internal regulation around the body has been reported in previous studies for various cultures such as the hot or cold beliefs, however there were some differences e.g. what was considered as hot or cold varied (Ahmed et al., 2017; Helman, 2014; Patel et al., 2015; Patel & Iliffe, 2017). Bangladeshi and Pakistani participants made various attributions to hot and cold beliefs. For instance, hot remedies was found to include dressing up warm and using the heater, and cold food was found to include yoghurt and ginger. I co-authored a letter to a journal (Ahmed et al., 2017), highlighting the potential cultural perceptions of the blue reliever inhaler based on the hot and cold beliefs. The colour blue can represent cold, questioning whether cold inhalers can be effective in balancing cold illnesses such as asthma. Colours representing hot such as orange may be unconsciously acceptable to certain populations (see Appendix 19). Additionally, cleansing beliefs were relevant for some Bangladeshis (from the first generation), which has been a novel finding in asthma research for this population. This belief has been reported in previous diabetes literature in various South Asian subgroups e.g. the belief that diabetes can be caused by food entering the body and it needs to be secreted through sweat, urine and blood. Therefore, sweating out asthma when visiting South Asian countries during hot weather was perceived to be beneficial (Patel et al., 2016; Patel & Iliffe, 2017).

Interviews with Bangladeshi and Pakistani participants may reflect the existence of habitus[98] in collective health beliefs (e.g. hot and cold beliefs), where individuals described these beliefs and implemented them in self-management, but the rationale behind them were often largely unknown (Bourdieu, 2017, 2018). Often, most of these beliefs were not reported when prompted in interviews, however participants described related scenarios during unprompted questions. This suggested that active behavioural intention (explicit decisions to behave in a certain way) may not always needed for behaviour change (Burke et al., 2009a). Intentions may also have various meanings, where 'yes' in some cultures may mean 'no' such as Filipina and Latina culture (e.g. agreement or consent may be made to avoid conflict with others such as disrespecting instructions from elders but in reality there was no intention to screen for cancer) (Pasick et al., 2009b), and intentions of others may be

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[98] Habitus is the internalised dispositions of second nature social rules and categorisations on perceptions, thoughts and behaviours predicted by past experiences, and social, cultural and economic capital (Bourdieu, 2017, 2018)

more prominent then the intentions of the individual e.g. during safe sexual behaviour in Indian sex workers (Evans & Lambert, 2008).

In a way, beliefs related to habitus can be targeted in interventions to raise consciousness of its existence (Marteau, Hollands, & Fletcher, 2012). Arguably, behaviour change theories need to consider the sociocultural context of a population and they may need to accommodate for raising consciousness of health beliefs (Marteau, Hollands, & Fletcher, 2012; Triandis, 2018). Interviews showed that one way to raise consciousness may be to use the symbolic gaze of others e.g. asthma symptoms can become normalised for a person resulting in overlooking symptoms, until others who are perceiving these symptoms prompt the person for self-management. Additionally, since cold constructs such as the winter allowed individuals to become more attentive to asthma self-management around the body (or develop the feeling of becoming a person with a asthma identity), it may be feasible to assume that interventions may work better when the self[99] was more conscious that self-management or support was needed (Marteau, Hollands, & Fletcher, 2012). On the other hand, some cultural beliefs (e.g. avoiding cold food) may be explained by conscious and unconscious habits; automatic mental responses triggered by daily environmental and contextual cues and past/repeated experiences that influence frequency of automatic health behaviours (Gardner, 2012). However, the explanatory factor of habits is mainly individually conditioned or is the effortful repeated responses to habits rather than collective behaviours between social groups which are more difficult to withdraw from (Bourdieu, 2017, 2018; Crossley, 2013). Targeting unconsciousness in interventions can relate to habits, but not all unconscious behaviours are habits and not all habits are unconscious. Unconscious behaviours are also not always dependent on environmental cues (Marteau, Hollands, & Fletcher, 2012).

Moreover, previous literature does not report beliefs around asthma as feelings that come and go. It was unclear if this belief was specific to just the Bangladeshi and Pakistani participants (Harver & Kotses, 2010; Holland, 2017). Some studies have highlighted that this belief may be due to the perceived short term nature of asthma and its treatment (Bedi, 2007; Hussein & Partridge, 2002; Shendge, Deka, & Kotwani, 2012). This finding was

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[99] The self can be broadly defined as direct or indirect statements that comprise of the self referring to *'I', 'me', 'mine', 'myself'* in social motivations, attitudes, beliefs, intentions, norms, roles and values (Cooley, 2017; Triandis, 2018).

reinforced by HCP interviews (see chapter 8), who experienced and interpreted that some Bangladeshi and Pakistani patients believed in short term reliever management and quick solutions for managing their asthma. However, even though Bangladeshi and Pakistani participants in this study believed that feeling asthma inside the body meant that asthma was present and not feeling asthma in the body meant that asthma was absent; it does not necessarily mean that they do not know asthma was a chronic illness. This demonstrates that cultural interpretations of data was important to avoid misinterpretations (Kralik et al., 2010).

It may be useful to frame cultural beliefs (e.g. causation, beliefs around body function and short-term nature of asthma/treatment) using the common sense self-regulatory model of illness representations. The cognitive representation of asthma threat suggests that there are five factors (cure, cause, consequence, identity and timeline) that predict whether adaptive or maladaptive coping responses are selected. For instance, perceived causes of the illness e.g. adequately identifying the cause of asthma predicts adaptive coping that is positively appraised and thereafter repeated (Leventhal, Benyamini, & Shafer, 2007). Whether individuals believed in supernatural or natural causes does not negate beliefs about existing biological causes (Patel et al., 2015). Perception of cure, consequences (e.g. belief that breathless would immediately lead to an asthma attack) and timeline may play a part in perceiving asthma symptoms as short-term due to its variability, therefore they are more likely to adopt a self-management response to complement this; avoiding a long-term treatment approach and reinforcing short term medication use. Representation of identity can determine which combination of cultural health beliefs are selected e.g. medical education may help refine health beliefs accordingly and therefore influencing self-management and/or an asthma diagnosis/identity may help initiate self-management (Leventhal, Benyamini, & Shafer, 2007).

Current behaviour change theories such as the common sense model of self-regulation may help researchers understand some health beliefs better in some populations (Leventhal, Benyamini, & Shafer, 2007), though it can be argued that it provides little context for cultural beliefs which may be both based on individual and collective cognitions (Marks et al., 2015; Triandis, 2018). The common sense model of self-regulation may also indirectly suggest that beliefs need to change according to expected 'assumed norms' of ideal health standardised on the majority/middle-class populations, but not all beliefs are harmful (Marks et al., 2015).

Bangladeshi and Pakistani participants established norms using the perspective of others e.g. social gaze, social reactions and social comparisons. Arguably, the perception of oneself may be greater in the presence of God for those who are more religious; found to enhance behaviours such as social awareness, monitoring, accountability and behaving desirably (Gervais & Norenzayan, 2012). Similarly, a qualitative study with Mexican and Filipina communities found that subjective norms (perceived social pressure to perform or not to perform a behaviour) may be important for behaviour change, but the construct did not consider the role of others in support outside of the immediate social circle e.g. support from other cancer survivors (Washington et al., 2009).

The systematic review (chapter 5) showed that addressing 'beliefs about capabilities' was linked to self-efficacy[100] in three trials (a recognised theoretical construct important for enhancing self-management behaviour; Bandura, 1977), but this was not beneficial (Ford et al., 1997; Griffiths et al., 2016; Velsor-Friedrich et al., 2012). The social cognitive theory used in two trials in this review did not have beneficial outcomes (Griffiths et al., 2016; Velsor-Friedrich et al., 2012). This suggests that in this context it may not be enough to change self-efficacy outcomes (Burke et al., 2009b). Perhaps, self-efficacy has different meanings for different cultural groups and needs to be explored further (Burke et al., 2009b). Bangladeshi and Pakistani participants revealed that self-efficacy beliefs were sometimes based on external social capital such as social comparisons with others (e.g. who has better asthma control), which can be threatening (e.g. growing older or through acculturative stress), though it may be enhanced through experiences e.g. the provision of knowledge and increase in familiarity due to normalisation amongst familiar others. The social identity theory stipulates that social comparisons are used as a strategy to identify, conceptualise and understand one's own collective identity in culture, in comparison to those who are similar (e.g. those with an asthma identity), increasing the sense of perceived belongingness (Tajfel & Turner, 2004).

Self-efficacy has been found to operate differently according to context, agreeing with previous studies (Klassen, 2008; Evans & Lambert, 2008; Pasick et al., 2009a). Previous studies reviewing the effectiveness of theory in the South Asian population suggest that they

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[100] Self-efficacy is the belief that one has the ability to complete a task (Bandura, 1977)

partially explain health behaviours based on individual[101] cognitions rather than collective[102] cognitions and largely ignore the population's sociocultural context (Evans & Lambert, 2008; Pasick et al., 2009a). For instance, compared to the White population, Klassen (2008) found Asians had low self-efficacy since measurements did not account for their collective essence of self-efficacy e.g. they had modesty bias and collective functioning was praised more than individual self-efficacy. A mammogram screening study found that Latino and Filipino women had high self-efficacy from collective means (e.g. having stable relationships with others) compared to individual means (Burke et al., 2009b; Triandis, 2018). Similarly, self-efficacy for safe sexual behaviours in Indian sex workers was dependent on wider occupational context of practice, where sex workers autonomy and negotiation in encounters can involve up to four people including customers, madams, pimps and other power structures, and norms specific to Indian brothels (Evans & Lambert, 2008). Most participants believed that they had good self-efficacy, regardless of having basic knowledge on asthma and self-management. This questions whether it is necessary to fully inform a person with the knowledge of asthma to achieve good self-efficacy or whether the understanding of self-efficacy is completely applicable to various cultural contexts (see chapter 7) (Griffiths et al., 2001; Kralik et al., 2010).

Interviews have shown that some Bangladeshi first generations struggled to received asthma diagnosis even though they were given inhalers which may have implications for self-efficacy. Previous studies suggest that self-efficacy in various cultures can be dependent on social capital such as the availability and access to resources in a country (Burke et al., 2009b; Thompson, 2009). The social cognitive theory in cultural context (Bandura, 2002), recognises the collective essence of self-efficacy, however treats all collective cultures as homogenous groups, thus what self-efficacy means in one population may be different to another community (Burke et al., 2009b). Further exploration of theoretical constructs using qualitative research may be beneficial to inform understanding for the Bangladeshi and Pakistani community (Burke et al., 2009a; Thompson, 2009).

Considering the role of psychological issues

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[101] Collective cultures tend to cognitively convert situations using collective settings (and therefore prioritise collective perceptions and goals (Triandis, 2018)

[102] Individualistic cultures tend to cognitively convert situations using individual settings and therefore prioritise individual perceptions and goals (Triandis, 2018)

Bangladeshi and Pakistani participants learnt from adapting self-management into their lives; they used psychological strategies to address imbalances in the body from asthma including emotions such as stress (e.g. religious coping such as prayer, relaxation, taking breaks, diverting attention and changing ones environment), which have not been documented in previous asthma research for any South Asian subcultural groups. Worrying or fear about the future while ageing with asthma was something specific in the first generation e.g. losing control. In India, the self has been shown to be consistent with values of peace of mind and freedom from stress in religions such as Hinduism and Buddhism in various outdated studies (Roland, 1991; Sinha & Tripathi, 1994; Sinha, 1988). Interviews revealed that this was relevant today and a part of Islam suggesting that a psychological intervention combining and enhancing these learnt self-management strategies may be helpful (Pinnock et al., 2017). Some evidence has suggested that yoga may be helpful with stress (Nagarathna & Nagendra, 2010). To support this, interviews with secondary care HCPs (see chapter 8) revealed that they experienced Bangladeshi and Pakistani patients had a high level of psychological issues, particularly anxiety that worsened asthma. Some HCPs coped with this by either signposting patients to psychological services, incorporating psychological support into secondary care asthma clinics, using physiotherapists and listening to patients air their concerns, but cultural barriers were noted in accessing these services, agreeing with another study (Nagarathna & Nagendra, 2010). This implies that secondary care HCPs were not entirely focussed on disease management of asthma as suggested by Bangladeshi and Pakistani participant interviews. Although, most participants were recruited from primary care services.

According to the common sense self-regulatory model of illness representations, alongside cognitive representation of illness, emotional response to asthma threat also predicts whether adaptive or maladaptive coping responses are adopted. For instance, the imbalance of emotions in the body or anxiety could either predict positive or negative self-management strategies (Leventhal, Benyamini, & Shafer, 2007). However, a mixed methods study found that the theory did not fully describe emotional illness beliefs for Indian, Bangladeshi, Pakistani and Nepalese individuals self-managing their diabetes, since they were mainly based on individual level explanations and the relevant role of others (larger social networks) were not considered. For example, emotional distress of a person was reduced by others in social spaces; the greater the social support, the less emotionally distressed people were about their diabetes (Patel et al., 2015).

Considering the role of language and cultural expressions

Often, ethnic-matching can be presented as a solution to resolve differences in culture, without considering contextual factors such as acculturation[103], subcultural differences and different languages/dialects, which can absorb responsibility of healthcare services in tailoring services (Ahmad & Bradby, 2008; Wray & Bartholomew, 2010). The ethnicity of a professional/researcher does not mean that they are a specialist in culture. Habitus explains that a person who studies and is aware of culture can be more in the position of expertise than someone who belongs to a cultural group (Bourdieu, 2017, 2018). HCPs in this study believed that South Asian HCPs were insiders of Bangladeshi and Pakistani culture and that the medical field should deliver future training interventions. Some HCPs (from various ethnic backgrounds) also believed that to build an ongoing relationship with patients, providers need to be from the same ethnic background. The two doctors from a Bangladeshi cultural background made universalistic assumptions about culture. They also acknowledged that they were not experts; this can be due to acculturation and/or perhaps habitus (Sam & Berry, 2010). This suggests that matching patients and HCPs may be more complex (Khambhaita et al., 2017). Conceivably, some HCPs from the Bangladeshi background either did not speak any South Asian languages at all or spoke one dialect out of several dialects (Kagitcibasi, 2017; Samples et al., 2014). First generation Bangladeshi and Pakistani participants showed that they preferred HCPs who could speak their language rather than the ethnicity of a HCP (see chapter 7). Ethnic-matching may also overshadow other skills a HCP can bring to a profession and organisation, which needs to be recognised (Samples et al., 2014). Future matching of providers and patients may need to explore acculturation-matching, gender-matching or matching cultural characteristic based on other demographic factors (Khambhaita et al., 2017; Sam & Berry, 2010).

A RCT found improvements for Turkish participants with poor English and irregular computer experience in inhaler technique and knowledge, after they received a translated information pack and a multimedia touch screen system that used video clips and language instructions of practical demonstrations (Goodyer, Savage & Dikmen, 2006). Perhaps, these video were specific to cultural norms such as gestures that target deep learning structures (Poureslami

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[103] Acculturation is the cultural changes influenced by encountering another mainstream culture (Berry, 1997; 2005; Sam & Berry, 2010)

et al., 2012; Resnicow et al., 1999). Building on this, in the absence of adequate language provisions in healthcare services, nurses suggested the use of an audio-visual materials to improve understanding of inhaler technique, peak flow monitoring and spirometry, particularly for dealing oral language. Supporting this, the systematic review showed that audio-visual strategies used in a RCT with Punjabi Indians had beneficial outcomes (e.g. inhaler technique; see chapter 5) (Ahmed et al., 2018; Poureslami et al., 2012), and previous literature showed that audio-visual materials/resources can help patients with low literacy (despite ethnicity) (Jones et al., 2014; Lakhanpaul et al., 2017; Neill et al., 2015). This may be an area of research that needs to be explored further (Goodyer, Savage, & Dikmen, 2006; Poureslami et al., 2012).

Bangladeshi and Pakistani participants used various forms of cultural expressions. For instance, the interpretation of asthma around the body was articulated using metaphors to create imagery that described the challenges and struggles around health and illness e.g. describing asthma as a phantom, battling/fighting against asthma and comparing good health to the physical strength of powerful animals. These expressions were also used to describe emotions that caused an imbalance in the body and the impact of inhaler on the body e.g. the blue reliever was described as a fire extinguisher. Highlighting that may be the use of metaphors are a part of the Bangladeshi and Pakistani culture, hence intervention need to consider language use and the way individuals normally talk and express themselves around health and illness are not universal (Billet, 2016; Kagitcibasi, 2017).

Considering the role of social discourses

The way Bangladeshi and Pakistani participants spoke about asthma and the information they received about asthma influenced self-management. Social and community awareness and talk/support about asthma was sparse. Social observability of asthma symptoms encouraged practical and moral support from family (but not other forms of support such as emotional aid), in comparison to diabetes for which family/peers provided more support. This agrees with other asthma studies (Griffiths et al., 2001; Hussein & Partridge, 2002; Sharif, 2012). Talking about asthma was not a social norm; asthma was a private condition (sometimes kept secret due to perceived fear of stigma), compared to other chronic illnesses such as diabetes. However, UK born/raised generations spoke about their asthma, if they had a close asthma connection with another person (someone else with asthma), or other

people appeared to have credible medical knowledge about asthma due to their profession or area of study. This study adds to existing literature by identifying that some Bangladeshi and Pakistani participants in the UK still have 'perceived' fear of stigma. This may overlap with preserving a essence of masculinity for Bangladeshi men with asthma e.g. male participants did not want to be seen as vulnerable or in need of protection due to their asthma (Goffman, 2009). One explanation may be that in Bangladeshi and Pakistani culture men are obliged to financially support their families, therefore they need to be perceived as strong (Harry, 2012).

The way medical information was promoted determined the type of self-management that was employed. Bangladeshi and Pakistani participants described receiving disease management information on asthma from HCPs e.g. knowledge on how and when to take asthma medication and monitor asthma. Therefore, most Bangladeshi and Pakistani participants relied on the disease management approach to asthma. Hence, most participants may have become medicalised by the provision of selective information, rendering them to believe that no further support was needed as part of their self-management. To my knowledge, the qualitative study with Bangladeshi and Pakistani participants was the first to disagree with existing literature (including systematic reviews), which have reported that most South Asians find it difficult to understand information related to asthma medication (Ahmed et al., 2018; Lakhanpaul et al., 2014b; Miles et al., 2017), and the experiences of HCPs who expressed concerns about widespread non-adherence (see chapter 8). I found that UK born/raised generations (and some first generations) had a good level of knowledge about asthma medications e.g. they knew the difference between a reliever and preventer inhaler and they were aware of medical terminologies for inhalers. In addition, all participants across generations had knowledge of when and how to take their medications e.g. medication dosage. Most Bangladeshi and Pakistani participants were good at adhering to their medications. On the other hand, both Bangladeshi and Pakistani and HCP participants described difficulties in the population around how asthma monitoring devices work (e.g. using the peak flow meter and spirometry), which may be a potential area for intervention development, though my sample was only a small representative (see chapter 7 and 8).

Additionally, there were different levels of medicalised selves across generations (see Table 9; chapter 7). For instance, the elder first generations were more medicalised; adhered

strictly to medication and on time, though they were less active in seeking medical/social aid and preferred to struggle with asthma in isolation; whilst the younger first generations sometimes forgot medication and sought medical help when needed. Conversely, if Bangladeshi and Pakistani participants accessed other forms of information, they were more resistant towards listening to the medicalised advice given by HCPs, who were described as professionals that overgeneralise asthma support and individual differences were not considered e.g. all people do not need a spacer for their inhaler. Some HCP interviews agreed with Bangladeshi and Pakistani participants experiences of medicalisation, where clinicians described their role as predominately based on providing medical aspect of self-management (compared to nurses). Although, some secondary care HCPs recognised that Bangladeshi and Pakistani patients also needed emotional support and integrated this into their asthma clinics (see chapter 8).

A previous systematic review has shown that the inclusion of supported self-management shaped the meaning of self-management for people. Individuals also want to be guided by HCPs to try other self-management strategies that they were not accustomed to (Dwarswaard et al., 2016). The medicalisation of self-management may play on the conflictual power dynamics between doctors and patients, where limited access to scientific knowledge (production, distribution, and legitimisation) created by those in authority can be a form of control for their preferred disease management strategy of asthma that can be difficult to object by patients due to limited awareness. Education on asthma could be informative and can transform attitudes towards self-management. Likewise, awareness of and questioning medicalisation may be an important part of taking responsibility for self-management (Hashem & Merritt, 2018; McHoul, McHoul, & Grace, 2015).

Considering the role of other chronic illnesses and asthma

Often, diabetes was prioritised above asthma for Bangladeshi and Pakistani individuals in various ways. Perhaps, asthma variability influenced the perception that asthma was different to other long-term conditions, therefore perceived self-management may be expected to be different (Pearce et al., 2016). In addition, diabetes may be labelled as a 'South Asian' illness compared to asthma (BBC, 2010; Shah & Kanaya, 2014). HCP interviews also compared asthma to other illnesses (physical or mental), but with the viewpoint that patients need to be treated holistically by considering other co-morbidities by emphasising

on diabetes (see chapter 8). The meaning of holistic care elaborates on the disease management approach to self-management, which was evident in interviews with some HCPs in this study, who believed nurses were better suited to help patients with 'non-medical' forms of supported self-management. Previous literature agrees with this; that doctors were not really doing much to support asthma but shifted this responsibility to nurses (Hashem & Merritt, 2018; Morrow et al., 2017; Schulman-Green et al., 2012). Additionally, some Bangladeshi participants showed that they trusted doctors over nurses; that seem to be universal to most cultures, agreeing with previous literature (Morris et al., 2016; Morrow et al., 2017). HCP's emphasis on diabetes (and other illnesses e.g. cardiovascular disease), compared to asthma may have deeper implications for healthcare services. Current Ramadhan guidance, advice and resources at organisational level (healthcare, charity and research) stresses on other illnesses rather than asthma. Limited available resources on asthma may mean shifting of responsibility by signposting patients to the Imam, without recognising the significance of and access to an Imam or what role they play in an individual's life with asthma (Asthma UK, 2016d; Bukhari, 2016). No Bangladeshi and Pakistani participant described the Imam as an important source of support for their asthma.

Considering the role of generational status

Generational differences; a part of culture, where cultural knowledge learnt or is transmitted across generations sets the basis for meaningful identifications, boundaries and relationships to occur (that adapts during acculturation). For instance, observable behaviours (e.g. avoiding food that can worsen asthma), or cognitive processes (e.g. shared hot and cold beliefs) pave the way for unique cultural expressions of asthma such as the use of metaphors and feeling asthma in the body. Generational differences have hardly been focussed on in asthma research with the general South Asian population (Kreuter et al., 2003, 2013; Yadav & Yadav, 2015). Age in the Bangladeshi and Pakistani first generation participants was important to consider e.g. how they learned information and attitudes towards medicine adherence from Bangladesh or Pakistan. The strategy to categorise generations in this study (according to migration status and upbringing) differed to how HCPs categorised generation as related to age structures (e.g. the elderly status of a patient meant that they were categorised as the first generation), which may be one of the collective methods of looking at populations who have numerous generations that have grown up in the UK. However, this

approach does not consider changes in social capital e.g. resources such as technology sharing platforms and globalisation that make it difficult to draw comparisons for different cultures (McCrindle & Wolfinger, 2010). Most Bangladeshi and Pakistani participants and HCPs referred to the first generation as those that needed more asthma self-management support. It was unclear why they were perceived as the most vulnerable section of the population, but it may explain why most existing interventions are targeted at the first generation with language modifications (Ahmed et al., 2018). This was interesting since the number of first generations are smaller than other generations in the UK, and younger migrants can also be perceived as the first generation according to some definitions (Ahmed et al., 2018; Davidson, Lui, & Sheikh, 2010).

Considering the role of acculturation, acculturative stress and culture-specific stressors

The qualitative study has been the first to explore acculturation in asthma self-management in Bangladeshis and Pakistanis. Most acculturation research around South Asians are in other health topics e.g. tobacco use (Mukherjea, Modayil, & Tong, 2018). South Asian culture can be both tight and loose in the UK (Gelfand et al., 2011; Triandis, 2018). The looseness of culture on some aspects allows acculturation to take place easily which may be different to other cultures. Berry's acculturation model suggests that individuals/groups can freely adapt to a new/mainstream environment in various ways over time, generations, and a given situation (Berry, 2005; Sam & Berry, 2010). Existing evidence suggests that integration[104] in the acculturation model (Berry, 2005; Sam & Berry, 2010) is the preferred method to enhance asthma as it predicts less acculturative stress and better adaptation; indirectly suggesting that the integration strategy needs to be imposed upon individuals for better health outcomes. This infers that there may be an underlying power imbalance, where other acculturation strategies may be blamed for poor asthma outcomes due to the lack of integration with the mainstream society. Additionally, if the integration strategy is the preferred strategy for encouraging good health, the influence of the mainstream group should cannot be ignored (Ahmad & Bradby, 2008; Sam & Berry, 2010). Multiculturalism[105]

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[104] Integration is an individual/group level acculturation strategy where individuals maintain their original culture and also integrate with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

[105] Multiculturalism is a mainstream acculturation strategy when cultural diversity is fully supported as a feature of the mainstream society. The correct atmosphere needs to be in place for the integration strategy to be chosen and sustained (Berry, 2005; Sam & Berry, 2010)

(equivalent to integration) in the acculturation model (Berry, 2005; Sam & Berry, 2010) at a healthcare level accommodates for cultural diversity for the integration process to occur at an individual/group level e.g. historically racism in the UK was more apparent during 1980s and 1990s, possibly pushing the first generation towards other acculturation strategies such as separation[106] (Ahmad & Bradby, 2008; Sam & Berry, 2010). Evidence around the migrant paradox suggests that acculturation may be bad for you (e.g. losing established social capital), creating an impasse (Kennedy et al., 2015; Roura, 2017). In addition, some HCP (see chapter 8) believed that acculturation (integration and assimilation[107]) was bad for asthma (e.g. young females who smoked), though this perception may be dependent on what they believed was not part of a culture such as smoking.

First generation participants reported specific acculturative stress (a construct in the acculturation model), related to adjustments to the UK environment that made their asthma worse e.g. poor lifestyle factors (see chapter 7) (Sam & Berry, 2010). The acculturation model suggests that the more acculturative stress a person experiences, the less positive attitudes there will be towards the mainstream culture (Ali, 2008; Sam & Berry, 2010). Arguably, a solution to manage this stress may be to learn culture specific behavioural skills (e.g. learning the mainstream language), but this may not be enough if society renders it difficult to acculturate (Sam & Berry, 2010). Questionably, what does integration mean in the context of cultural hybridity (Hall, 2014; Sam & Berry, 2010), where some Bangladeshis/Pakistanis may show integration characteristics in certain social situations, but in family circumstances they can employ another acculturation strategy e.g. separation strategy aligned with more traditional Bangladeshi and Pakistani cultural attitudes (Hall, 2014; Sam & Berry, 2010; Trinh et al., 2009). This transition between different social context can be explained by acculturative stress (Sam & Berry, 2010). If the integration strategy was shown in a family that was more inclined towards the separation strategy, there may be negative consequences (e.g. disapproval, shame, guilt, obligation for duty and a sense of disrespect for elder authority figures), suggesting that perhaps the acculturation strategy of the family

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[106] Separation is an individual/group level acculturation strategy where individuals hold on to their original culture and avoid any adaptation or contact with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

[107] Assimilation is an individual/group level acculturation strategy where individuals disconnect from their original culture to fit in with the mainstream culture (Berry, 2005; Sam & Berry, 2010)

also needs to be considered in interventions (Hawthorne et al., 2007; Sam & Berry, 2010; Trinh et al., 2009).

As mentioned before, some HCPs reported that some younger female patients hide from their family that they smoke and are diagnosed with asthma, implying that social support for asthma can vary due to this (see chapter 8). Acculturative stress in second generations revolved around struggling with expectations of older generations on the imposition of traditional social norms that compromise the adoption of appropriate asthma self-management strategies e.g. conflict created from the expectations of others that women should prioritise domestic chores that can worsen asthma. This can involve a series of negotiations and assessments on which aspect of one's identity may be more important while struggling against these expectations (Sam & Berry, 2010), agreeing with previous literature e.g. Pakistani females are generally perceived to be responsible for domestic duties (Harry, 2012). Acculturative stress in the third and fourth generations involved the imposition of traditional values of elders when they were children e.g. CAM use (Sam & Berry, 2010).

Alongside generation-specific acculturative stress, there was also evidence of culture-specific stressors within the Bangladeshi and Pakistani culture itself (e.g. family responsibilities; see chapter 7), that hindered focus on self-management. HCPs (see chapter 8) who supported Bangladeshi and Pakistani patients have identified this, signifying the importance of studying the lived experiences of both HCPs and Bangladeshi and Pakistani individuals with asthma. Literature informing what constituted as the Indian self suggested that cultural values such as family are a part of the self (including the stress of looking after the family) (Gupta, 1999). However, this study is outdated (Gupta, 1999), although its findings seem to be applicable to the UK context for Bangladeshis and Pakistanis. The systematic review (see chapter 5) showed that there were culture-specific stress for African Americans e.g. violence in the neighbourhood (Ahmed et al., 2018). Therefore, culture-specific stress may be something common in ethnic minorities (both African-Americans and Bangladeshis and Pakistanis), and that the boundaries of the identified barriers and facilitators in the review may be dependent on available evidence and should not be taken at face value.

Considering the role of cultural hybridity

Qualitative interviews revealed that there were various forms of cultural hybridity in asthma self-management involving learning to negotiate, experiment, trial and error and exploring cultural boundaries; reinforced by positive reinforcements such as stepping away from medicalised self-management; therefore adding to literature on what is known about cultural hybridity in asthma self-management (Canino, McQuaid, & Rand, 2009; Leong, Ramsey, & Celedón, 2012). This aligns with the cultural hybridity theory that suggests a person belonging to two or more cultures are more likely to be bi-culturally competent, and mix identities according to different situations, available resources and level of significance attached to an identity (Hall, 1990, 2014). Examples of hybridity found in Bangladeshi and Pakistani participants were that some individuals struggled with acculturative stress, cultural/social norms and expectations (e.g. female gender norms), and prioritised Islam over traditions cultural interpretations of religion in Bangladeshi and Pakistani culture in self-management (Hall, 2014; Small et al., 2005; Tambiah, 2017). Both Bangladeshi and Pakistani cultures can practice some cultural versions of Islam (e.g. conversions of Hindu people to Islam in Bangladesh can mean that some aspects of Hindu practices may still exist that may not be identified without attaining education in Islam), demonstrating the complexity of cultural influences that needs to be understood better (Rassool, 2015).

Hybridity is an aspect of culture that has no particular form such as society, politics, boundaries or country (it is an almost fictional or an imagined orbit of identity) (Tambiah, 2017). The practice of filtering out the correct Islamic practices agrees with another qualitative study looking at Indian, Bangladeshi and Pakistani families, where religious solutions were used for asthma e.g. CAM use based on perceived religious teachings (Lakhanpaul et al., 2017). In addition, HCPs revealed that they believed religion was a good influence on self-management and the ideal patient should follow it properly, rather than interpret and practice religion erroneously. They also acknowledged that there were individual differences in the orientation and practice of Islam; which adds to existing literature., implying that the incorporation of religion in interventions may be beneficial.

Considering the role of religion

Most participants with asthma identified religion as a significant part of their culture except for three participants who were passive members of Islam (Mishra et al., 2017). For those participants who perceived Islam as part of their identity and actively practised it, their

religious identity shaped behaviour towards asthma and self-management, agreeing with previous literature (Graafland, 2017; Mishra et al., 2017; Perera & Chang, 2018). This suggests that individuals who do not identify themselves with religion may not benefit from interventions that target religion (Cragun et al., 2016). It should be noted that people can become more active in religion during certain time periods such as stressful situations and Ramadhan and express religion differently (Cragun et al., 2016; Graafland, 2017; Mishra et al., 2017). Bangladeshi and Pakistani participants used religious coping such as movements in prayer to self-manage their asthma, agreeing with previous literature that suggests prayer can be a form of physical and mental relaxation, since it involves a conversation with a higher entity, meditation and mindfulness resulting in better physical and psychological health outcomes (e.g. breathing and enhancing awareness of emotions) (Mishra et al., 2017; Perera & Chang, 2018). All Muslims in this study were Sunni Muslims and findings may differ with different sects of Islam and this complexity needs to be considered in future studies (Abbas, 2010; Koenig & Shohaib, 2014; Rassool, 2015; Tarlo, 2010).

Ramadhan played an important part in medicine adherence. Participants were confused about whether medication use during fasting hours was permissible according to Islamic rulings. Most HCPs were also concerned about medication use during Ramadhan and described that they did not have enough knowledge on Islam (and Ramadhan), and asthma to feel confident enough to be able to advise accordingly. Hence, speculations and guesses were made around the role of the Imam (see chapter 8). Often, on the internet existing information on Ramadhan refers individuals with asthma to other sources that recommend consulting the Imam without recognising the significance and usefulness of the Imam to an individual's life (whether individuals actively or passively practice Islam) (Asthma UK, 2016d; Bukhari, 2016). It should be noted that the definition of who is a knowledgeable religious leader may be extremely subjective. An Imam may or may not be a religious leader depending on how it is defined. A basic definition of an Imam is someone who leads congregational prayer, who may or may not have additional duties or religious knowledge beyond reciting the Qur'an (Padela et al., 2011). There seems to be more Ramadhan self-management interventions for conditions such as diabetes and cardiovascular disease than asthma (Bukhari, 2016; Niazi & Niazi, 2012). HCPs thought perhaps annual checks before Ramadhan may be helpful to ensure health and safety. Additionally, a few HCPs had other concerns around Islam and medication use such as the inclusion of alcohol-based inhalers (see chapter 8).

9.2.2 Findings in relation to informing future asthma self-management interventions

The role of Bangladeshi and Pakistani culture in asthma self-management behaviour and exploration of some intervention characteristics can help provide the foundational work for developing holistic and culturally relevant interventions, the latter detailed in this section.

This has been one of the few studies that have asked Bangladeshi and Pakistani participants with asthma and HCPs in semi-structured interviews (see chapter 7 and 8), what they thought prospective interventions should consist of (though the sample was a selected representative of the population):

- Preferences for interventions that may be helpful for the community: An overwhelming majority of Bangladeshi and Pakistani participants highlighted the need for basic asthma awareness in the community (in relevant languages). First generations were perceived as the group most in need of an intervention. Other participants described the need to confront traditional cultural norms and expectations that can hinder self-management (e.g. traditional gender norms), and improvements for primary care services e.g. asthma diagnosis.

- Preferences for interventions that may be helpful for Bangladeshi and Pakistani individuals with asthma: The first-generation participants described needing various types of interventions in appropriate languages, even if they were fluent in English e.g. education. UK born/raised generations (some second generations and all third generations), described the idea of 'newness' or 'freshness' needed in interventions to add value to the information that they already know on technological platforms. They also suggested ideas in line with this e.g. help points based on locations on apps/leaflets to improve access to services. Participants with mild asthma or asthma since childhood believed interventions (and action plans) were not needed because they felt qualified through experience that they had adequate self-management skills. Establishing credible information was important throughout generations. On occasions, this was true even if knowledge was provided by HCPs due to the perceived recognition that some professionals do not truly account for the variability in asthma amongst individuals. Other interventions recommended by UK born/raised generations included education, lay information in inhaler boxes, psychological breathing techniques and service

improvements. Most participants wanted education in a group setting; they felt sharing ideas, thoughts and experience would be beneficial. Asthma experts were preferred by all participants as deliverers of an intervention (ethnicity was not important, but language-matching was). Most Bangladeshi and Pakistani participants had not been given and did not own an action plan. Implementation of action plans were missing for most first generations (except one Bangladeshi), which agrees with various studies that PAAPs are not implemented well for this population (Foster et al., 2005; Griffiths et al., 2001; Hussein & Partridge, 2002).

- HCPs recommended that Bangladeshi and Pakistani participants may benefit from various interventions including:

    i. Basic education on various formats such as workshops/open days, verbal education in audio-visual formats, reviews and Ramadhan leaflets.

    ii. Group meetings that involve befriending (e.g. self-help groups and social prescribing).

    iii. Culturally appropriate PAAPs.

    iv. Addressing language by non-textual and audio-visual means e.g. DVDs, YouTube and Bengali TV.

- HCP preferences for interventions that would suit future professional practice needs: There was a need for cultural training in a face-to-face group settings and cultural information from interviews with Bangladeshi and Pakistani participants (see chapter 7). Sometimes, HCPs wanted patients to be involved in training e.g. storytelling. Experts in asthma from various professions were preferred as the best person to deliver the intervention. Most HCPs suggested that the expert should be from a South Asian background. Barriers in attending professional training may include time, concerns for resources, length of training and whether the content of training was too broad.

- Going forward, one or more intervention ideas can be chosen and developed further from this project (see section 9.6.2 for a list of ideas).

The systematic review found 15 culturally modified[108] interventions, showing that there was a small growing evidence in this area but most interventions were not robust (Ahmed et al., 2018). Sometimes, modifying interventions may be the easiest option with little work needed, related to funding limitations or organisational requirements (Bailey et al., 2009;

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[108] Culturally modified interventions are developed for a majority population but modified to apply to other ethnic groups using various strategies (Bailey et al., 2009; Falicov, 2009)

Barrera et al., 2013; Castro, Barrera, & Steiker, 2010). Arguably, culturally modified interventions have a 'one size fits all' approach and therefore it is argued that it may not fulfil the requirements of cultural competence (Barrera et al., 2013). Therefore, it can be claimed that the culturally modified approach fails to acknowledge that people have different ways of thinking about illness and healing, and that individuals are able to acculturate to different cultures (Castro, Barrera, & Steiker, 2010; Sam & Berry, 2010). Debatably, this can be related to institutional racism[109], and the melting pot[110] strategy of acculturation due to the response of ignorance or insignificance attached to understanding culture. Notably, at some level finance in the healthcare system may be limited and services may be overburdened (Ramaswamy & Kelly, 2015; Sam & Berry, 2010). On the other hand, culturally modified interventions may meet certain cultural competence requirements according to healthcare services e.g. using a bilingual provider accommodating for language adaptations of intervention content (Leong, Ramsey, & Celedón, 2012).

The systematic review showed that there were two culturally targeted[111] interventions, and that there were no culturally tailored[112] interventions (Behera et al., 2006; Kreuter et al., 2003, 2013; Poureslami et al., 2012), agreeing with an earlier Cochrane systematic review by Bailey et al. (2009), that evidence on bottom-up cultural interventions for asthma are limited with little progress in research (more research on its advancement is needed). Perhaps, this may be due to the amount of time required to develop bottom-up interventions which may also be expensive compared to modified trials (Bailey et al., 2009; McManus & Savage, 2010). A feature used in culturally targeted trials was the collaborative development of interventions with patients and significant others that aimed at deep structure learning in processing cultural and linguistic information reflecting the holistic perspectives and experience of self-management in the community (Behera et al., 2006; Castro, Barrera, & Steiker, 2010; Poureslami et al., 2012; Resnicow et al., 1999). Collaboratively developed interventions may need to be piloted in focus groups/interviews for clarity, relevance and acceptability, and refined before implementation and evaluation (Behera et al., 2006;

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[109] Institutional racism is the public institutions response of ignorance to the needs of ethnic minorities that is not directly obvious (Ramaswamy & Kelly, 2015)
[110] Melting pot is a mainstream acculturation strategy where the mainstream society is more dominant than the individual's own cultural group (Berry, 2005; Sam & Berry, 2010)
[111] Culturally targeted interventions are bottom-up interventions that account for the shared characteristics of a cultural group during development (Kreuter et al., 2003)
[112] Culturally tailored interventions are bottom-up interventions that consider cultural dimensions unique to individuals within a group (Kreuter et al., 2003)

Poureslami et al., 2012). Equally, culturally targeted interventions may also include some modified features e.g. language modification on proven self-management strategies such as PAAPs. Therefore, the distinction between targeted, tailored or modified interventions is not absolute (Ahmed et al., 2018; Liu et al., 2012).

The systematic review found over half the trials did not use theory (Agrawal et al., 2005; Behera et al., 2006; Blixen et al., 2001; Fisher et al., 2004; Ford et al., 1997; Kelso et al., 1995, 1996; Shanmugam et al., 2012). Those trials that used theory including two models (Fisher et al., 2009; Griffiths et al., 2004), mainly used them to inform intervention-relevant constructs or predictors[113] of self-management behaviour. However, theory use did not tailor/deliver theory selection or intervention techniques according to intervention population that are likely to benefit from it (Fisher et al., 2009; Ghosh et al., 1998; Griffiths et al., 2004, 2016; Poureslami et al., 2012; Velsor-Friedrich et al., 2012; Velsor-Friedrich, Pigott, & Louloudes, 2004; Velsor-Friedrich, Pigott, & Srof, 2005). Therefore, it was unclear which behaviour change theory would be beneficial for intervention development for Bangladeshis/Pakistanis and/or whether it should be supplemented with theories from other disciplines applicable to health. Little author descriptions were given for providers that delivered the interventions. Therefore, intervention development recommendations for providers were difficult to pinpoint.

The option between whether an intervention needs to be culturally targeted or tailored warrants justification, depending on what the intervention focusses on and the suitability of each approach (Barrera et al., 2013; Castro, Barrera, & Steiker, 2010; Kreuter et al., 2003, 2013). The systematic review and qualitative studies in this thesis justify that future asthma self-management interventions may either need to be culturally targeted where group characteristics can be targeted such as family, language (depending on how language was used), or religion (Castro, Barrera, & Steiker, 2010; Kreuter et al., 2003, 2013), and/or culturally tailored where choices or tailored messages are provided (Kreuter et al., 2003, 2013). Both these approaches are aimed at deep structures that aid receptivity of information as well as behaviour change (Resnicow et al., 1999). Cultural training for HCP would ideally be culturally targeted at a group level. A useful strategy to help understand cultural targeting in interventions may be population segmentation, the extent that the

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[113] Predictors are a construct that is targeted in interventions to predict/correlate with/causes behaviour change (Michie & Prestwich, 2010)

target group has been segmented into various homogeneous group values rather than their ethnicity e.g. collective messages for religion, gender or generation (Castro, Barrera, & Steiker, 2010; Hawkins et al., 2008).

9.3 Reflections on dealing with the intricacies of language

Research needs to consider language provisions for Bangladeshi and Pakistani individuals with asthma. This section describes researcher reflections on language provisions provided in the qualitative research for Bangladeshi and Pakistani participants in this thesis.

9.3.1 Reflecting on language provisions

Language can be a vital part of the research process, but it can also be neglected if only English-speaking participants are recruited (intentional or unintentional), due to difficulties in recruitment, the lengthy process of language translation, funding limitations and inappropriately translated measurement instruments. In the qualitative study with Bangladeshi and Pakistani participants, there were various language accommodations in place to help with participants with language difficulties and low literacy. Some of which followed published procedures recommended by Lloyd et al. (2008a) (see chapter 7):

- Bangladeshi and Pakistani participants who were not able to read, write or speak in English were given an audio recorded translation of the PIS on a CD or audio format in the languages; Sylheti/English or Urdu/English (see Appendix 10 for PIS form and see Appendix 11 for the audio-recorded PIS in different languages). This was an ideal strategy to fully inform participants who speak in oral languages with no written form, as well as for participants who have low health literacy (Lloyd et al., 2008a). Some Bangladeshi and Pakistani participants described the content of the PIS in interviews (e.g. reiterating the information in PIS), reflecting that they gained a good understanding of the purpose and concepts used in the study (see reflexivity note in section 9.4).

- All Bangladeshi and Pakistani participants in the qualitative study could speak varying levels of English and therefore provided a written signature on the consent form; however, I (as a bilingual researcher) had plans in place for verbal consent to be audio recorded after listening to a audio-recorded consent form, to fully inform the participant (see Appendix 11) (Lloyd et al., 2008a). This has also been recommended in previous asthma literature for this population (Symonds et al., 2012).

Strategies used to address language difficulties or health literacy in this study has reaffirmed findings from Lloyds et al. (2008a), that showed it was a useful methodology in need of further attention in future studies. In addition, the audio-recorded PIS and consent form coincidently resonate with the findings of this thesis that audio-visual means in educating Bangladeshi and Pakistani patients can be helpful to address language barriers (reported by nurse interviews; see chapter 8) and can be linguistically more effective (reported in the systematic review; see chapter 5). This also agrees with previous studies (Goodyer, Savage, & Dikmen, 2006; Lakhanpaul et al., 2014b; Poureslami et al., 2012). In addition, interviews with Bangladeshi and Pakistani participants found that the first generation wanted interventions delivered in the appropriate language even though they could speak English, which illustrates that language provisions are needed despite proficiency in English (see chapter 7).

Recruitment posters written in English, Standard Bengali and Urdu were also placed in a variety of settings e.g. online social media/university student society groups, community halls, sixth form colleges and healthcare facilities (see Appendix 6). However, the potential of these posters in recruitment had little value. None of the participants were recruited through advertising posters, despite insistence of the ethics board and recommendations in previous literature, e.g. a systematic review by Ibrahim & Sidani (2014) and a qualitative asthma recruitment study by Stirland et al. (2011). On the other hand, posters, leaflets and newspaper adverts were found to be less effective and perceived to be formal or distant in other studies (McLean & Campbell, 2003; Symonds et al., 2012). Synonymous to the recruitment experiences in the qualitative study in this thesis, the interpersonal contact (e.g. telephone and face to face strategy) worked better in achieving recruitment targets. Other literature has found that personal invitations from HCPs and community/faith leaders worked better for the South Asian community (Liu, Davidson, & Sheikh, 2011; Rooney et al., 2011). Strikingly, when these posters were translated from English to another language, the language presented was similar to textbook languages, therefore they were more literal, as opposed to conversational. This is a widely recognised issue in the field of back translation of language resources (Colucci et al., 2015; Reiss, 2014).

9.3.2 Reflecting on language transcription and interpretation

Translation can be considered to be an art form (Reiss, 2014), but there may be many issues with back translation of languages e.g. grammatical, conceptual and contextual differences that are reliant on subjective, literal and arbitrary interpretations that reduce reliability. Verbatim translation to English can be near to impossible such as translating South Asian concepts that have no equivalent terms in English e.g. asthma and wheeze (Reiss, 2014; Suh, Kagan, & Strumpf, 2009). There are underlying assumptions that there are universal definitions of terms (rather than being relative) (Jaspal, 2010). Inequivalent use of concepts is like comparing apples to oranges (Reiss, 2014; Suh, Kagan, & Strumpf, 2009). Hence, relevant interviews in this project were transcribed and analysed in languages spoken by Bangladeshis and Pakistanis; using the 'Bengalish' and 'Urlish/Roman numerals' strategy by bilingual researchers (the mixing of two languages that retains the pronunciation in the South Asian language, but the words are written using the English Alphabet), by bilingual transcribers that helped retain the original cultural and linguistic meanings and interpretations intended by participants. Analysis for seven out of 27 transcripts therefore could only be analysed, though illustrative quotes were presented in both languages (South Asian and English) in the qualitative chapter in case there were discrepancies, and this also allowed others to read the original language used (see chapter 7). Hence, the source language does not always have to be English. There are innovative strategies that can be used and needs further exploration. Back translations may be viewed as the imbalance of power since it treats English as the preferred language of understanding and analysing transcripts or language appropriate resources (Punnett et al., 2017; Reiss, 2014; Storey, 2010).

Transcribing and analysing data in the original language was a good method for accounting for oral languages with no written form (e.g. Sylheti), and when participants switched language codes[114] from English to South Asian languages for words/phrases that cannot be fully articulated or expressed in English (or vice versa), e.g. the use of metaphors and use of humour. To my knowledge, this has not been commonly used in research before, but has been widely used on social media formats and corpus linguistics (a system of language coding based on statistical methods); therefore adding a unique angle to research (Ahmed & Tinny, 2013; Chandra, Kundu, & Choudhury, 2013). Typically, interviews in oral languages are transcribed to its nearest language first (e.g. Sylheti written in Standard Bengali), before

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[114] Code switching is the switching between two languages in a sentence, phrase, conversation and so forth (Rampton, 2014)

being translated to English, losing a great deal of cultural and linguistic specific meanings, expressions, traditions and concepts, and an important part of describing the perspective and lived experiences of Bangladeshi and Pakistani individuals in this study (Liu, Davidson, & Sheikh, 2011; Lloyd et al., 2008a; Suh, Kagan, & Strumpf, 2009). On the other hand, analysing transcripts with different languages took substantially longer than transcripts that were written in English, perhaps due to my limited practice (Chandra, Kundu, & Choudhury, 2013; Sultana, 2014).

Cultural expressions are important to understand differences in interpretations of health and illness behaviours, that are not always universal and therefore can differ to western understandings e.g. the contextual meanings attributed to feeling asthma in the body compared to the biological perspective of asthma (Michaels et al., 2012). One technique of capturing cultural expressions was to use the emic (outsider cultural perspective) and etic (insider cultural perspective) to data, where a participant in the research were referred back to (Punnett et al., 2017). Interviews with Bangladeshi and Pakistani participants showed that they believed in asthma coming and going, which may be perceived as if they do not know that asthma is a chronic illness, when in fact some participants had this belief but knew asthma was a long term illness (Bedi, 2007; Halm et al., 2006; Rand & Apter, 2008). Another example from previous literature suggests belief in God's will in the attribution of illness that can be negatively labelled as 'fatalism' when interpreted in isolation. However, this belief may suggest a positive undertone of the contentment and acceptance of having an illness if this belief was placed in context (Ahmad & Bradby, 2008; Koenig & Shohaib, 2014; Yucel, 2010). Therefore, the emic-etic approach may be perceived as an avenue to redistribute power to participants (Punnett et al., 2017). Although, there may be certain challenges to this approach since acculturation in the study sample may not match the background of a specified participant involved in the interpretation (Haugaard, 2002; Punnett et al., 2017; Sam & Berry, 2010).

Interviews with Bangladeshi and Pakistani participants demonstrated the use of code switching in language (but this was less in the first generation), whether that meant switching from English to South Asian languages or vice versa. For instance, for certain words or phrases that could only be expressed in certain languages (such as cultural expressions of humour that creates certain meaning, even though most of the interviews were conducted in English. Arguably, the expression of these words/phrases would be limited if these

participants did not have an interviewer who was able to understand the same language (Suh, Kagan, & Strumpf, 2009). Interestingly, most of the first-generation participants who could speak English choose to express themselves in their mother-tongue (Standard Bengali, Sylheti and Urdu). Accommodating for language gave them the space for fully expressing themselves and encouraged in-depth discussions and stories, which they may not be able to articulate in English. This was important since previous literature suggests that for some South Asians research experience may be a novel and they may provide short and simple answers in interviews (MacNeill et al., 2013; Stirland et al., 2011; Suh, Kagan, & Strumpf, 2009). In this study, almost all first-generation participants showed signs that they were learning from the interview process. For instance, they were very particular about understanding the process of participating in the interviews e.g. some first generations read the consent form out aloud and expected the researcher to correct them if they misunderstood (see chapter 7).

9.4 Researcher reflexivity on qualitative research

Language provisions are important to ensure research rigour, in addition to researcher reflexivity on the qualitative research to safeguard the quality of research (Beebeejaun et al., 2015; Berger, 2015).

9.4.1 Introducing reflexivity in research

Reflexivity is the process where researcher attention is directed back to one self, when generating knowledge in research (on an ongoing basis from beginning to the end). This has been proposed as a strategy to maintain quality control in qualitative research (Beebeejaun et al., 2015; Berger, 2015). The position of the researcher's background (e.g. age, gender, ethnicity, emotional responses and political/professional beliefs), can be points of reflexive thinking, practice and evaluation that question the influence of researcher position on the research such as ethics such as power dynamics, biases, beliefs, emotions, personal experiences, research agendas and ramifications on outcomes (Berger, 2015; Probst, 2015). Some have argued that to be reflexive, individuals need to be aware of the existence of something and those factors that a person is unaware of are missed, therefore reflexivity does not always ensure research rigour (Probst, 2015). Reflexivity is different from reflections on research. The latter is the ability to look back on a situation that needs to be

reflected on, therefore helping individuals learn from experience, search for reasoning, and challenge assumptions and biases.

9.4.2 Procedures in place for reflexivity

For the qualitative studies in this thesis, I kept a research diary and I had supervisor and peer briefings. Both these strategies, helped me as a researcher become more aware of my own reactions and guard against imposing my ideas during the research process and the researched (Berger, 2015). In addition, the COREQ checklist for reporting qualitative research was used to report findings from interviews and maintain credibility (Appendix 5 and 14). The emic-etic (insider/outsider) cultural perspective where interpretations of interviews with Bangladeshis and Pakistanis were referred back to the participant for accuracy, can be perceived as allowing power to be redistributed (Punnett et al., 2017). This could be considered as a form of consensual power[115], since it involves finite power given to participants through the loss of power from the researcher, funding bodies and so forth. Other reflexive strategies such as repeated interviews were not suitable in this project due to time restrictions and the length of the process (Berger, 2015).

9.4.3 Reflexivity on researcher position: insider (familiarity) and outsider (unfamiliarity) roles

There are no guidelines for reflexivity, however one way of presenting this was framing reflexivity around the insider and outsider roles (Probst, 2015; Zempi, 2016). A researcher's position can move from an outsider position (unfamiliar factors between the researcher and the researched), to an insider position (familiar factors between the researcher and the researched) (Fletcher, 2010). It is presumed that insider researchers have privileged information compared to outsider researchers (Fletcher, 2010; Zempi, 2016). At the same time, outsider researchers may claim that they are in a better position to be objective (Zempi, 2016). However, the differences between the researcher and the participant can be so great that often it is not obvious who is the insider/outsider (Fletcher, 2010).

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[115] Power 'to' (also known as consensual power) consists of the general ability of individuals/groups/institutions to allow something to occur. This form of power is based on material and/or social action; often entailing finite power that is not produced but acquired from another who loses power (Haugaard, 2002)

Academic/HCP expertise and setting: moving back and forth from becoming an insider and outsider

Recruitment of Bangladeshi and Pakistani participants from secondary care asthma clinics (12 participants) sometimes took place while shadowing the asthma consultant during consultations or outside of the consultation room and interviews also took place in healthcare service settings (e.g. GP surgery). I could not help but wonder whether this positioned me as an insider to the HCPs field as an expert in asthma, and an outsider to the participants (Berger, 2015). If participants perceived me as part of the HCP team, interviews may have been influenced in several ways. For instance, the influence of setting can be an indirect form of power. Generally, it can be argued that an interviewer and interviewee may have asymmetrical consensual power shifting back and forth in the way knowledge is created or throughout the research process. The interviewer has power to shape the questions in the interview, but the main form of power may be that the interviewee has the power to choose what to disclose in interviews (Anyan, 2013).

Even if there are counter balances in place to address power imbalances in conversations, participants can make assumptions about the researcher's background (e.g. SES, education, gender, ethnicity and professional background), that suggest the interviewer has greater power (a form of conflictual power[116]) (Anyan, 2013). For instance, throughout one interview I could sense that a first-generation participant was being very tough and expressed a strong vocal presence directed at me (I felt his energy pushing against me with his words without provocation), by continually making the point that HCPs should not overgeneralise. After the interview, he also urged me to stop generalising people's asthma, therefore I assumed that the participant had classed me as an HCP, may be due to the interview taking place at the GP surgery or due to study invitations sent out from the surgery. Initially, I believed that he did not trust HCPs. But, when I placed this data in the context of other data; I realised that he was talking about not wanting to be medicalised by HCPs and each patient deserved to be treated on an individual basis. Arguably, the participant was exercising a form of power over me to emphasise his point of view (Anyan, 2013).

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[116] Power 'over' (also known as conflictual power) consists of the capability of individuals/groups/institutions to prevail over another in doing something that a person is resistant to, would not normally do and is not in their interest. This form of power is based on social relations (Haugaard, 2002)

In another example, a participant mentioned CAM use; ruqyah, but immediately stopped talking about it. After prompting, he stated that he did not think there was a section for this in the interview and took a peak at my interview schedule. Perhaps, this was due to classing me (the researcher) as an HCP, or due to the interview taking place in an academic setting (Queen Mary, University of London though study invitations were also distributed from a GP surgery). Perhaps, maybe he believed that there was no point in talking about CAM use in an academic/medical research. Ruqyah well known in Muslims and Bangladeshis in the UK (Eneborg, 2013), and the participant knew I was Muslim but it made little difference. Arguably, the perception as an insider academic/HCP overshadowed my religious/ethnic background. Possibly, some participants may have withheld non-medical information due to this (Berger, 2015). However, as the researcher I prompted an explanation to what he was involved in during the ruqyah treatment with the intention to reassure him that it was acceptable to speak about this and differentiate what type of ruqyah this was (permissible or prohibited in Islam), but this may have seen as a form of conflictual power, where researcher emphasis on prompts may be perceived as a form of control on what is being emphasised on in interviews (Anyan, 2013).

Similarly, audio-recording; an interviewers tool, can be a form of indirect conflictual power in the interview setting (Anyan, 2013). Recorded knowledge may also be a strategy to legitimise information that cannot be retracted e.g. prior to an interview one Bangladeshi participant spoke at length about how expectations from in-laws in domestic chores hindered her self-management, but when prompted in interviews she refrained from mentioning it. Ultimately, the participant had the consensual power to decide what was disclosed in the interview (Anyan, 2013). This suggests that audio-recording may have deterred some participants in mentioning other sensitive information (Berger, 2015). In addition, since I was interviewing HCPs on supported asthma self-management for Bangladeshi and Pakistani patients, I felt that many HCPs were overselling the fact that they treated all Bangladeshi and Pakistani patients the same as any other patient (there was continual emphasis on this). I assumed perhaps this was due to the perception that I, as researcher (someone outside their profession) can hold them to account in the form of a written publication or perhaps it was because the interviews were audio-recorded. In addition, I wondered how much the study materials influenced HCPs centralising culture in their responses to interview questions for social desirability purposes (see chapter 8).

In contrast, many Bangladeshi and Pakistani participants described the need to talk to someone, but they perceived that their HCPs were not have available time to listen to them. Sometimes, the opportunity to talk to the researcher was described as a motivation to attend the interview, particularly for some first-generation participants who reported that they attended the interview to ask questions (e.g. about their asthma medication), even though they knew I did not have a clinical background. Surprisingly, one participant described me ('the researcher') as the most important HCP in their asthma care, even though there were only three contacts between me and the participant (the initial meeting for recruitment, telephone contact to set up an interview date and the interview). Additionally, during the interview, another participant described how my presence helped him during the initial recruitment meeting because I spent a few minutes talking to him about his asthma. Time for emotional support (e.g. active listening) was also described in interviews; which sometimes meant interview lengths were longer. To support this, previous literature has shown that interviews can offer the space for sharing stories, information and experiences which can be therapeutic for participants since it may involve an emotional release (Rossetto, 2014).

In addition, an atmosphere in a qualitative interview has been suggested to raise participant consciousness and self-awareness (Rossetto, 2014). This was also true for interviews with both Bangladeshis/Pakistanis and HCPs, where some participants reported that they did not realise what they did as part of self-management (or supported self-management) until they reflected on this in the interview (see chapter 7 and 8). This can be related to habitus[117], were factors that occur in everyday lives are assumed to be logical reasoning, but can become more apparent through thoughtful reflection or interview prompts (Bourdieu, 2017, 2018). For instance, it was clear that when prompted in interviews some participants replied in the negative (e.g. whether food has an influence on self-management), but when unprompted in other questions they reported hot and cold beliefs about food. Reaffirming my interpretation that norms may be described but the rationale behind this may be missing (Burke et al., 2009a). The value for time may have made me more approachable than their actual HCPs and an immediate relationship may have developed. Despite this, I had to learn

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[117] Habitus is the internalised dispositions of second nature social rules and categorisations on perceptions, thoughts and behaviours predicted by past experiences, and social, cultural and economic capital (Bourdieu, 2017, 2018)

to maintain a professional researcher boundary which was at time difficult e.g. four first generation participants asked for my personal number to stay in touch with them and/or insisted that I should provide answers to their clinical questions. In my mind, it was clear that participants needed support from HCPs, which were not being addressed. Saying no felt a bit emotional since my purpose was to gain their insight into their self-management and knowing that they left the interview needing more help. On one occasion I was able to feed back to a consultant with generic statements to protect the anonymity of the participants.

Cultural characteristics between the researcher and participant: moving back and forth from becoming an insider and outsider

Arguably, researchers who share similar cultural characteristics as the participant (e.g. ethnicity and gender), are in a better position to extrapolate ideas, perspectives and opinions. This echoes what HCPs believed that HCPs with a South Asian background are insiders of South Asian culture and the HCP field. This argument suggests that insiders have privileged knowledge (Fletcher, 2010). However, an insider role or familiarity can blur boundaries e.g. participants can withhold information due to assuming knowledge is already known to a researcher (Berger, 2015). I have experienced this while recruiting participants who I already met before interview appointments. Often, in interviews expressed how they have previously told me an experience they had during the initial meeting did not elaborate on this. Therefore, I had to ensure that they were prompted further on what they had told me prior to the audio-recorded interview.

I was uncertain whether my Bangladeshi ethnic background had an impact on interviews with Bangladeshi and Pakistani participants, and tried to safeguard against imposing my own cultural views about Bangladeshi and Pakistani culture e.g. I asked Bangladeshi, Pakistani and HCPs participants what they believed their culture consists of (Berger, 2015). But, I did recognise that language was a gateway that allowed participants the consensual power to articulate what they wanted to share (Anyan, 2013; Berger, 2015), therefore may be participants perceived me to be an insider since I could speak the same language (Berger, 2015; Krzywoszynska, 2015). There were important examples in data that supported this e.g. use of metaphors and code switching in languages. Perhaps, being a researcher from a multilingual background allowed me to reach stories or perspectives, particularly for the first generation (Rossetto, 2014). I also become more aware of cultural and linguistic expressions

and meanings when I was transcribing some of the interviews. I sensed that some first generations were struggling to speak about their experiences in English, but since other participants also switched between languages I do not feel this influenced findings in the data (Krzywoszynska, 2015).

Building an interview atmosphere that was language friendly may have started with listening to audio-recorded PIS for some first-generations (Lloyd et al., 2008a). Perhaps, the audio PIS may have increased participant knowledge on the topic and had some influence on the findings. Participants were reiterating the same understanding of what self-management is and that participating in the study would not directly benefit the participant. At some level, this might have influenced answers to the question on the meaning of self-management, perhaps at the same time suggesting that the audio PIS was beneficial for increasing understanding. But, this was similar to written PIS information participants received. In addition, I had experienced six first-generation participants reading out the consent form with me to ensure that they had understood what was written on the form before signing it and/or they also wanted me to correct their English, which may show that they were enthusiastic about being able to fully understand the interview process (see chapter 7) (Lloyd et al., 2008a).

Additionally, I may have been perceived as an insider to participant religion; Islam, or an outsider when information may have been withheld on behaviour that Islam disapproves of (Berger, 2015). I realised that may be my appearance which display physical religious symbols could potentially cause a small differential influence on the findings (Berger, 2015; Zempi, 2016). On one occasion, I noticed that a participant omitted information on the fact that he used to smoke and drink alcohol at the beginning of the interview and then he later admitted this; perhaps non-judgemental rapport was built as the interview progressed. In contrast, one participant revealed that she smoked, used drugs, had a relationship with a male friend outside of marriage but was also cheating on him. It seemed that she was comfortable enough to openly speak to me. I thought perhaps that this was due to providing the space and opportunity to talk to someone about her asthma in the interview (Rossetto, 2014).

An insider role of a researcher based on cultural characteristics can sometimes be problematic, when researchers used their own experiences in data interpretation and this takes the participant's perspective for guarantee. In this study, I used the emic-etic

(insider/outsider) cultural perspective to reduce this. I may have been an outsider in terms of the unfamiliarity with or in experience with asthma or self-management of a chronic condition, though this was not visually obvious to the participant (Berger, 2015). To reduce gaps between researcher and the participant, I familiarised myself with asthma and self-management by studying previous literature and shadowing the asthma consultant in clinics. On the other hand, I may have been an insider in data interpretation due to my cultural background as a Bangladeshi. PPI colleagues were also used to ensure study materials and interview schedule were suitable (Zempi, 2016). In addition, I experienced that previous literature may have shaped my expectations (Berger, 2015). I expected that there would be difficulty in recruiting first generation participants from reading literature that suggested they are difficult to recruit due to language barriers and the novelty of research for the population (MacNeill et al., 2013; Rooney et al., 2011; Stirland et al., 2011). However, as an outsider (to the first generation and an academic researcher), I was challenged by my own stereotypes when I experienced that they were the most enthusiastic participants out of the whole sample.

9.4.4 Reflexivity on researcher position: the interpretation of qualitative data

Qualitative data does not speak for itself in analysis compared to quantitative data or literature such as poems. Researchers need to both analyse and interpret the data to create a depth of understanding by adding value, hence analysis consistently involves varying degrees of interpretations and these interpretations are much more than the product of analysis (Willig, 2012), e.g. semantic (surface level) and latent (surface and explicit levels) (Braun & Clarke, 2006; Willig, 2012). Data interpretations can be liberating and helpful to the people studied or the people interpretations are generally applied too, therefore it can be argued that there are ethical risks in not interpreting data. For example, elaboration and amplification of meaning in data, by making connections of patterns and relationships (e.g. the use of metaphors) allows interpretations to be patient-centred where an understanding is developed from their perspective (Flick, 2013).

On the other hand, there may be ethical risks and considerations that need to be in place to ensure quality in interpretations (e.g. to minimise the impact of people who are studied or those whom the findings can be generalised to), and internal validity of interpretations e.g.

holistic and meaningful reflection of human behaviour (Merriam & Tisdell, 2015). For instance (Merriam & Tisdell, 2015; Willig, 2012):

- Researcher reflexivity (as noted in section 9.4).

- Awareness of interpretation limitations e.g. remaining open to other explanations.

- The contextualisation of data so the reader is aware of the setting of interpretation (and if suitable can generalise appropriately from this).

- Ensuring that the participant's voice is reflected in the interpretation but recognising that the interview transcript in its own right holds the true voice of the participant and consideration of the language used.

- Ensuring interpretations answer the research questions.

In the qualitative research in this thesis, the theoretical standpoint I used was the thematic analysis guidelines from Braun & Clarke (2006), which provided a consistent approach to contextualise interpretation and enhanced credibility (a filter to which data can be examined without compromising the quality of analysis) (Crowe, Inder, & Porter, 2015; Sutton & Austin, 2015).

Qualitative work is not about the attribution of frequencies. The nature of qualitative work means that the number of participants studied are small and the findings are detailed descriptions of the data. Hence, this study was a representational view of a phenomena driven by those participants in it and there should be careful consideration of assuming applicability without recognising contextualisation (Atieno, 2009). In quantitative research, there is a certain level of confidence that can be applied to the generalisation of findings. However, external validity or generalisability is not highly regarded in qualitative research, since the purpose is to provide a rich and in depth understanding of a selected few participants within their context, whether that holds meaning or transferability to others or not, in a similar context. Hence, context needs to be adequately described for readers to draw from transferability and any generalisations need to be congruent to the philosophical purpose of qualitative research (Crowe, Inder, & Porter, 2015; Merriam & Tisdell, 2015). In the qualitative research in this thesis, I used triangulation, where multiple researchers were used to confirm coding of emerging data (including peer discussions) and participant validation of data interpretations, where either there was a suggestion to refine or better capture the true voice of the participants (Merriam & Tisdell, 2015). I could have involved more participants in this triangulation process, though this was restricted due to time restrictions (Crowe, Inder, & Porter, 2015; Merriam & Tisdell, 2015). In addition, data

saturation with respect to the research questions (i.e. when there was a comprehensive understanding of perspectives) (Saunders et al., 2017), indicated that there were no more emerging findings (Merriam & Tisdell, 2015; Sutton & Austin, 2015).

9.5 Strengths and limitations of studies in this thesis

This project brought together evidence on developing culturally relevant asthma self-management interventions for Bangladeshi and Pakistani individuals with asthma in the UK. To my knowledge, it is one of the few studies to explore the effectiveness of existing interventions, cultural shifts in the UK (representing generational status, acculturation, cultural hybridity and so forth) in understanding asthma self-management behaviour and using cultural relativism to understand supported self-management behaviour in HCPs. However, South Asian asthma self-management interventions are scarce, data synthesis of RCTs for the systematic review were difficult to conduct since studies were often small and included unpowered subgroup analysis (Bhopal & Sheikh, 2009). Deprivation and SES could not be explored further due to discrepancies in data and did not seem to be important in Bangladeshi and Pakistani or HCP interviews (Forno & Celedón, 2009).

The systematic review had a good number of RCT interventions. The review incorporated interventions for another culture (African Americans) that helped identify barriers and facilitators of self-management and effectiveness of interventions according to whether they were generic, related to minority status or culture-specific. Likewise, the qualitative studies with individuals with asthma and HCPs had a good number of participants. This study was limited to Bangladeshi and Pakistani individuals. The largest South Asian subculture in the UK; Indians (Census, 2015), were not represented in the interviews due to the diverse nature of India (religion, language, districts and so forth), and time restrictions of studying three subcultures. Perhaps, there would have been more interesting and distinct subcultural differences (Nazroo, 2006). In addition, all Bangladeshi and Pakistani participants in the qualitative study were Muslims. It would have been interesting to explore the impact of other religions. Therefore, caution should be applied in overgeneralising results (e.g. findings related to subcultural differences), since culture is dynamic and participants (Bangladeshi, Pakistani and HCPs) were from one region in the UK (Castro, Barrera, & Steiker, 2010). Similarly, the study did not explore children with asthma or their proxies (parents/guardians/carers). In the former, studying children would have meant carrying out

age friendly qualitative research rather the using a semi-structured interview schedule e.g. ethnographic research involving drawings of asthma and how they look after their asthma would be interesting. But, studying children cannot occur in isolation to their parents/carers, which would have meant adjusting the study questions and a larger qualitative study. In HCP interviews, it would have been interesting to have varied representations of HCPs from different acculturation strategies.

There was evidence on culturally targeted interventions, but there were no evidence for culturally tailored interventions, therefore more research is needed (Ahmed et al., 2018). Further research on implementing ideas from this project need to be developed and tested in interventions. It is worth noting that overemphasising on cultural factors in research may lead to stereotyping or oversimplification (Lakhanpaul et al., 2014b); culture should not be treated as a cause and solution for intervention development (Ahmad & Bradby, 2008). Arguably, the more you delve into culture the infinite the possibilities of research that can be applied to interventions. This closely aligns with the idea that culture can be a mosaic (an identifiable structural framework of a collage of factors that contribute to an individual's sociocultural identity in the form of tiles), that reflect the complexity of culture in its context (Chao & Moon, 2005).

In terms of methodology, harvest plots (Ogilvie et al., 2008), TCS (Michie & Prestwich, 2010), and TDFs were used (Cane et al., 2012), which were all good and reliable strategies for studying the data presented in the systematic review. A strength in the interviews was providing the space for individuals to express themselves using the language they felt more confident with, encouraging deep conversations (in first to fourth generations), which may have not been the case if individual's spoke in English (having a multilingual researcher helped achieve this). Transcription and analysis was also in the original language spoken by individuals with the emic and etic approach (insider/outsider cultural perspective), therefore reducing subjectivity in cultural interpretations, especially when concepts and cultural expressions are difficult to translate (Punnett et al., 2017; Reiss, 2014), though, maybe a standardised method of transcribing, or guidelines on this needs to be developed in health research (Baker et al., 2000). In addition to this, all findings (from the systematic review and qualitative studies) were independently second reviewed or coded to reduce subjectivity in interpretations.

There are several criticisms of the acculturation model (Ali, 2008; Schwartz & Zamboanga, 2008). It does not fully acknowledge cultural hybridity[118], or peer importance (e.g. gang assimilation) (Ali, 2008; Miller et al., 2013; Schwartz & Zamboanga, 2008). Ideas around the migrant paradox suggest mental and physical health can be poor after acculturating to mainstream society or during global events that create hostility and stressors for ethnic minorities (Roura, 2017; Sam et al., 2008). Migrants should be placed into context; there are English speakers from European, American and other Western countries who may experience less stress, whereas asylum seekers or refugees may be more likely to suffer from trauma and little social support (Meissner & Vertovec, 2015; Vertovec, 2007). In addition, the possibility to acculturate through the separation[119] strategy may be higher in rural areas, mainstream society norms and rules may be less compared to urban areas where there are more ethnic minority residents (Triandis, 2018). The validity of the acculturation adaptation strategy marginalisation[120] has been questioned, since it is not clear how individuals develop a cultural identity without drawing upon their original or mainstream culture and whether they suffer acculturative stress from both cultures, though I did not find any examples of marginalisation in my research (Ali, 2008; Miller et al., 2013; Schwartz & Zamboanga, 2008). Acculturation research and measurements have been also underexplored in the general South Asian populations in the UK (Choudhry & Wallace, 2012; Kalra et al., 2004; Palmer et al., 2007; Iyer & Haslam, 2003).

9.6 Implications of findings

This section describes the implications of the research from this thesis on; Bangladeshi and Pakistani culture, intervention development and at organisational level (research, healthcare service and charity). There may need to be a whole systems approach to promote asthma self-management in the Bangladeshi and Pakistani population (Pinnock et al., 2015; Taylor et al., 2014).

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[118] Cultural hybridity is the bi-cultural competence and negotiations of being a part of two or more cultures with a new sense of belonging (Hall, 1990, 2014)
[119] Separation is an individual/group level acculturation strategy where individuals hold on to their original culture and avoid any adaptation or contact with the mainstream culture (Berry, 2005; Sam & Berry, 2010)
[120] Marginalisation is an individual/group level acculturation strategy where individuals lose maintenance and contact with both original and mainstream cultures (Berry, 2005; Sam & Berry, 2010)

9.6.1 Implications for Bangladeshi and Pakistani culture

Implications: the importance of conceptualising culture

The definition of culture is broad and dynamic; people actively learn cultural patterns and perceptions, therefore this needs to be studied over time (Barrera et al., 2013; Castro, Barrera, & Steiker, 2010; Fortun et al., 2014). Defining Bangladeshi and Pakistani culture and its core values (largely ignored or assumed by previous research) can help identify deep structures relevant to the community and should be the starting point for developing bottom-up cultural interventions (Castro, Barrera, & Steiker, 2010; Resnicow et al., 1999). Culture can be thought of as a mosaic[121] consisting of tiles related to each identity (Chao & Moon, 2005). One way of capturing what culture consists of in a mosaic was to ask participants themselves in interviews; those who are part of the Bangladeshi and Pakistani culture and those who observe and interact with it (Bhopal & Sheikh, 2009; Castro et al., 2010). Therefore, focussing on specific populations may be a way forward in incorporating all the complexities of culture and how it influences health, and tailoring healthcare interventions so these complexities do not get lost (Castro, Barrera, & Steiker, 2010). Conceptualising culture adequately may mean that homogenous groups of people may become harder to recruit (Castro, Barrera, & Steiker, 2010; Perera & Chang, 2018). Considerably, attaining a true viewpoint of culture may be elusive (Billet, 2016; Kagitcibasi, 2017).

Bangladeshi and Pakistani participants described their culture as (see chapter 7):

* Smoking amongst men.
* Family involvement.
* Cultural norms and expectations around gender e.g. domestic chores and staying at home to raise children were perceived to be a female duty such as cooking fresh curries every day and speaking about asthma was not a norm.
* Food habits (e.g. rice for Bangladeshis/biryani for Pakistanis and curry), or food that worsen asthma (e.g. specific Bangladeshi fish, Bangladeshi cooking style that emits fumes, aubergine and red meat).
* Community accountability for disapproved behaviours and the lack of privacy.

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[121] Cultural mosaic consists of tiles and a structural framework of a collage of factors that contribute to an individual's sociocultural identity (Chao & Moon, 2005)

- High value for medicine rather than seeking medical help as a solution to resolve asthma in older first generations.

- CAM use.

- Religious identity e.g. respect for oneself and their body.

- Exercise was described as something alien in Pakistani first generation.

Additionally, Bangladeshi and Pakistani culture in the UK maybe loose, rendering norms to become flexible and allowing acculturation[122] to occur (Sam & Berry, 2010; Triandis, 2018). This project reaffirms that Bangladeshi and Pakistani culture can be both individualistic[123] and collective[124] (Triandis, 2018).

Observers of culture (HCPs who may make universalistic[125] and relativistic[126] assumptions); including some HCPs from the Bangladeshi backgrounds who described Bangladeshi and Pakistani culture as consisting of (see chapter 8):

- Telling stories.

- Family involvement and influence of others e.g. gossiping.

- Defining generation based on age.

- Anxiety and cultural barriers in accessing psychological services.

- Speaking fluently in English was perceived to be an English value. Language barriers caused comprehension and communication issues e.g. understanding PAAPs.

- Religion may be a part of culture, but the first generations may misinterpret orthodox religious beliefs. Recognising individual differences in religiosity

- Understanding of asthma medication (e.g. preventer inhaler), and difficulty in understanding asthma monitoring devices e.g. peak flow meter.

- Psychological issues that make symptoms worse (e.g. anxiety).

- Perceived resistance in changing traditional health attitudes in older aged patients and resistance in changing health attitudes in younger aged patients e.g. smoking.

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[122] Acculturation is the cultural changes influenced by encountering another mainstream culture (Berry, 1997; 2005; Sam & Berry, 2010)
[123] Individualistic cultures tend to cognitively convert situations using individual settings and therefore prioritise individual perceptions and goals (Triandis, 2018)
[124] Collective cultures tend to cognitively convert situations using collective settings (and therefore prioritise collective perceptions and goals (Triandis, 2018)
[125] Universalism is the belief that there are fixed universal cultural realities regardless of time (Billet, 2016; Kagitcibasi, 2017; Rachels, 2007)
[126] Cultural relativism is the belief that culture should be judged by its own merits rather than the culturally bounded values and standards of another, and cultural diversity should be recognised and respected (Billet, 2016; Kagitcibasi, 2017)

HCPs may also have their own culture; medical culture[127]. Medical culture may be hard to define due to its widespread invisibility amongst HCPs (Taylor, 2003). However, its impact on supported self-management may be crucial e.g. differences in the explanatory models of illness between HCPs and patients with asthma (Boutin-Foster, Foster, & Konopasek, 2008).

Implications: the importance of sociocultural contexts and subcultural similarities/differences

Studies that improve understanding of sociocultural contexts allow a deeper appreciation for developing bottom-up cultural interventions (Ahmed et al., 2018), e.g. the influence of acculturation on self-management though this research area may suffer from limited descriptions on study settings e.g. SES. Therefore, caution is required when extrapolating findings from one context to another, though sparse research may mean literature from different countries may be the only source when building a firm evidence-base (Bhopal & Sheikh, 2009; Lakhanpaul et al., 2014a; Liu et al., 2016). London may be more diverse than other UK cities, which may mean that one subcultural group may identify with the other on some health behaviours, though not all. These findings fill in a gap in literature; since subcultural differences are largely ignored in previous research (Ahmed et al., 2018). Although, there should be caution in generalising findings on similarities and differences since the participants only represent a small proportion of the population (Crowe, Inder, & Porter, 2015; Sutton & Austin, 2015).

Implications: considering cultural shifts in the UK

Research needs to consider the cultural shifts that take place in the UK. Bangladeshi and Pakistani culture in the UK maybe more distinct than the culture in South Asia (this was recognised by Bangladeshi and Pakistani participants in this thesis). Important cultural shifts to consider are:

- Looseness of culture allowed acculturation to occur easily (Sam & Berry, 2010). Acculturation may also be flexible according to the context a person with asthma finds themselves in e.g. integration may be more apparent in peer contexts while separation

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[127] Medical culture is a dynamic entity of shared professional values, customs, norms, beliefs and communication styles generated from medical knowledge, training and role modelling of hierarchical professionals; there is full confidence in the truth of the medical approach and that HCPs have special authority to ease human suffering from illness and injury (Romero & Margolis, 2008; Taylor, 2003).

may be employed in family settings aligned with more traditional Bangladeshi and Pakistani cultural attitudes, suggesting that the family acculturation strategy is also important (Hall, 2014; Sam & Berry, 2010; Trinh et al., 2009).

- Acculturative stress[128] can differ across generations (Sam & Berry, 2010).

- Culture-specific stressors within the Bangladeshi and Pakistani culture (e.g. cultural problem-solving methods caused anxiety), hindered focus on self-management. Prevalence of anxiety was also recognised by HCPs. Culture-specific stress has been identified for African-Americans, therefore perhaps this particular stressor may be something that is typical in ethnic minorities (Ahmed et al., 2018).

- Generational status is a part of culture where cultural knowledge is learnt or transmitted across generations that sets the basis for meaningful identifications, boundaries and relationships to occur (this adapts during acculturation) (McCrindle & Wolfinger, 2010), e.g. observable behaviours (e.g. avoiding food that can worsen asthma), or cognitive processes (e.g. shared hot and cold beliefs; attitudes towards medicine) allow unique cultural expressions of asthma to occur such as the use of metaphors and feeling asthma in the body. Defining generations can vary according to researcher methodology, HCPs and people with asthma e.g. according to age structures or migration history (McCrindle & Wolfinger, 2010).

- There are individual differences in practising religion which may become a part of one's culture that can shape behaviour towards asthma, illness and treatment (Castro, Barrera, & Steiker, 2010; Kreuter et al., 2003, 2013), hence these individuals may benefit from an intervention revolving around religious messages (Cragun et al., 2016). Religiosity can also be flexible. Individuals can become more religiously active during certain time periods e.g. stressful situations or Ramadhan (Cragun et al., 2016; Graafland, 2017; Mishra et al., 2017).

- Ramadhan plays an important role in medicine adherence. Confusion (from patients and HCPs) on whether medication can be used during fasting hours according to Islamic rulings can influence adherence. Referrals to the Imam has been commonly adopted without recognising the significance and usefulness of the Imam to the lives of Bangladeshis and Pakistanis (whether individuals actively and/or passively practice Islam) (Asthma UK, 2016d; Bukhari, 2016).

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[128] Acculturative stress is the reaction and experience of daily stress and degree of psychological/sociocultural adaptation challenges resulting from encountering a larger mainstream culture (Berry, 2005; Sam & Berry, 2010)

- Cultural hybridity[129] influences asthma self-management behaviour (Hall, 2014), e.g. seeking out correct Islamic practices may predict solutions employed for self-management.

- Health beliefs are important part of culture and health. For instance, beliefs in the short term nature of treatment did not necessarily mean that asthma was not perceived as a chronic illness. Self-efficacy[130] beliefs were not based on knowledge of asthma but based on individual and collective factors such as social comparisons with others (e.g. who has better asthma control) and through experiences e.g. the provision of knowledge and familiarity that enhances the process of normalisation (Burke et al., 2009b; Thompson, 2009). Habitus[131] may exist in collective beliefs (e.g. hot and cold beliefs), where individuals described these beliefs and implemented them in self-management, but the rationale behind them were largely unknown (Bourdieu, 2017, 2018).

- Social factors were a crucial factor in culture. For instance, the establishment norms using the perspective of others e.g. symbolic social/cultural gaze, social reactions and social comparisons. Gender norms and practices were also apparent e.g. struggling with traditional expectation of others over self-managing asthma adequately. Social discourses influenced talk of asthma to and from others since asthma was perceived as a private condition (in comparison to other illnesses). Often, the significance of asthma was overshadowed by other chronic illnesses perceived to be common in the community e.g. diabetes. This may be related to the variable nature of asthma, which means that self-management may be unique (Pearce et al., 2016).

- Subcultural differences in urban areas (see the point above) (Sharif, 2012).

- CAM use e.g. homeopathic treatment was common in Pakistanis (Micozzi, 2014).

- Language use e.g. cultural expressions and bilingualism/multilingualism (see the point below) (Jaspal, 2010).

Implications: language and cultural interpretations

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[129] Cultural hybridity is the bi-cultural competence and negotiations of being a part of two or more cultures with a new sense of belonging (Hall, 1990, 2014)

[130] Self-efficacy is the belief that one has the ability to complete a task (Bandura, 1977)

[131] Habitus is the internalised dispositions of second nature social rules and categorisations on perceptions, thoughts and behaviours predicted by past experiences, and social, cultural and economic capital (Bourdieu, 2017, 2018)

Language is an important part of culture and language provisions should be provided in the research process and at organisational levels (Jaspal, 2010). Culturally and linguistically appropriate education can enhance self-management (Ahmed et al., 2018). Language provisions in consultations (for patients and the family) are more important than the ethnicity of HCPs (see chapter 7). However, HCPs expressed how language provisions were poor in healthcare services (except for one GP surgery), therefore there was a lot of reliance on family members to interpret. Audio-visual education formats may be a good way forward in addressing language barriers for difficult information (see chapter 8). Audio PIS used for interviews in this thesis seemed to beneficial, accounting for oral languages with no written form (see chapter 7; Appendix 11). The practical implementation of this strategy needs to be considered such as funding to cover costs of equipment, person/filming time and plans for incorporating user feedback (Roland et al., 2011). However, there are pre-existing resources online e.g. Right Breathe online and on smartphone apps (Right Breathe, 2018). Signposting to these resources may be difficult for low IT literate patients and may need to be facilitated by HCPs (Neill et al., 2015). Accuracy of language translation is also crucial, to avoid providing study material that are less conversational and imitated textbook style of translating. The recruitment posters translated for this project were similar to textbook writing (see Appendix 6). The differential impact created by written Standard Bengali indiscriminately used for Sylheti speakers were recognised by some HCPs and needs to be recognised further (see chapter 8).

Cultural/linguistic expressions and interpretations on self-management behaviour is crucial (Reiss, 2014; Suh et al., 2009). Cultural expressions such as illness construction and meaning applied to behaviour change constructs[132] (e.g. self-efficacy), may not be universal (Burke et al., 2009b). Addressing language in research methodology can help ensure expressions and interpretations are adequately represented e.g. using the emic/insider and etic/outsider cultural perspective. Transcribing interview data using bilingual strategies such as 'Bengalish' is possible (Al-Azami, 2006; Punnett et al., 2017), and may fill in gaps left by back translations (Reiss, 2014). There may be contextual differences between cultures such as the way Bangladeshis and Pakistanis speak, and apply meanings and experiences attributed to the body, emotions or asthma (e.g. asthma was perceived to be a cold illness). The use of metaphors to illustrate struggling with health and illness, and code-switching between

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[132] Constructs are key concepts related to behaviour that interventions are based on (Michie & Prestwich, 2010)

languages for bilinguals may be culturally important (Michaels et al., 2012). Perhaps, interventions should consider incorporating cultural expressions to allow information to become relevant to the population (Castro, Barrera, & Steiker, 2010).

9.6.2 Implications for developing future bottom-up culturally relevant interventions

Implications: the field of holistic asthma self-management interventions for Bangladeshis and Pakistanis

Asthma, self-management and South Asian culture are all dynamic which can be fully appreciated in holistic interventions (Dwarswaard et al., 2016; Udlis, 2011). Holistic approaches to self-management consider the individual as the expert of their own condition, however the implementation of this has not progressed for most South Asian groups with asthma (Michaels, Michaels, & Wulf, 2012; Tirodkar et al., 2011). Research in this thesis has explored part of the Bangladeshi and Pakistani self that is applied to self-management, adding to the understanding of holistic self-management in this population e.g. self-management around body regulation and balance (see chapter 7). Similarly, exploring the perspective of HCPs helped add to the understanding of holistic supported self-management for Bangladeshis and Pakistanis (Bodenheimer, MacGregor, & Sharifi, 2005; Dwarswaard et al., 2016; Trappenburg et al., 2013), e.g. adapting for culture was the main strategy to provide support (see chapter 8).

Some HCP insights (e.g. they experienced Bangladeshi and Pakistani patients had a lot of emotional issues that worsened asthma), which align with findings from interviews with Bangladeshi and Pakistani participants (see chapter 7), have not been previously reported in literature (see chapter 8). Adding to this, HCPs also believed that holistic self-management meant looking at all aspects of disease management such as co-morbidities in various people with asthma, although some secondary care HCPs also recognised the need for emotional management (see chapter 8). This showed that the definition of holistic care varies between HCPs and individuals with asthma (Kralik et al., 2004; Schulman-Green et al., 2012; Small et al., 2005). Interestingly, it can be questioned whether equally respecting both perspectives (the individual with asthma and HCPs) are warranted, since some HCPs focused on disease management and Bangladeshis/Pakistanis with asthma may focus on other forms of self-

management e.g. CAM use. This suggests that those interventions solely focused on collaborative development with HCPs may not fully reflect the priorities of Bangladeshis and Pakistanis with asthma and may led to low engagement (Manikam et al., 2016). Arguably, the perspective of Bangladeshis and Pakistanis with asthma should be prioritised, since it is their world HCPs are tapping in to provide support (Michaels, Michaels, & Wulf, 2012; Tirodkar et al., 2011). The systematic review showed that most interventions used HCPs to deliver interventions, but there was a paucity of descriptions on this in existing research. Therefore, there is a need to know more about the involvement of HCPs in interventions.

Implications: feature and content of future culturally relevant interventions

This thesis has reviewed most definitions applied to culturally relevant interventions and categorised them into three categories; i) culturally modified[133], ii) culturally targeted[134] and, iii) culturally tailored[135]. Other labels that were considered were culturally attuned, adapted and so forth (see chapter 3). There is a growing evidence base for culturally modified interventions, and little but strong evidence for culturally targeted/tailored interventions (see chapter 5). Research need to justify reason for choosing culturally tailored interventions has been chosen or is suitable over culturally targeted interventions, especially due to the paucity of evidence on cost-effectiveness (Barrera et al., 2013; Castro, Barrera, & Steiker, 2010; Kreuter et al., 2003, 2013). The importance of interventions recognising the diversity of culture has been supported by interviews with Bangladeshi and Pakistani participants that found cultural factors such as acculturation, was important to account for (see chapter 7).

To ensure effectiveness of future interventions, the systematic review and qualitative studies in this thesis suggest that self-management interventions may need to be aimed at deep structures e.g. core values such as beliefs and norms (Resnicow et al., 1999). Therefore, depending on the focus of future interventions, culturally targeted interventions may be needed aimed at group characteristics e.g. family, language (depending on how language is used), or religion (Castro, Barrera, & Steiker, 2010; Kreuter et al., 2003, 2013). Culturally

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[133] Culturally modified interventions are developed for a majority population but modified to apply to other ethnic groups using various strategies (Bailey et al., 2009; Falicov, 2009)
[134] Culturally targeted interventions are bottom-up interventions that account for the shared characteristics of a cultural group during development (Kreuter et al., 2003)
[135] Culturally tailored interventions are bottom-up interventions that consider cultural dimensions unique to individuals within a group (Kreuter et al., 2003)

tailored interventions may be needed aimed at individual characteristics in a group e.g. where may be a choice can be provided to suit the individual, tailored messages, or problem-solving options (Kreuter et al., 2003, 2013). Culturally targeted interventions may benefit from using the population segmentation; the extent the target group has been segmented into more homogeneous group values e.g. collective messages for religion, gender or generation (Castro, Barrera, & Steiker, 2010; Hawkins et al., 2008). Notably, interventions that are culturally targeted or tailored may also have some modified aspects e.g. evidence-based plans in different languages (Liu et al., 2012), or may need to be adapted to social capital e.g. resources and healthcare system in a country (Ahmed et al., 2018; Castro et al., 2009; Kreuter et al., 2003, 2013).

Going forward, one or more intervention ideas can be chosen and developed further from this project (Lakhanpaul et al., 2014b):

- Ramadhan e.g. medicine adherence or annual Ramadhan checks.
- Religiosity incorporated in interventions e.g. prayer movements or speaking to God.
- Psychological imbalances e.g. emotions, religious coping, relaxation, diverting attention and cultural/acculturative stress.
- Basic asthma education that was credible information e.g. under the umbrella of the NHS.
- Beliefs and raise self-consciousness of habitus e.g. the belief that self-management means control and discipline (Kralik, Paterson, & Coates, 2010), beliefs around body functions such as hot and cold and cleansing beliefs (Harver & Kotses, 2010; Helman, 2014; Holland, 2017), beliefs about causation, CAM use, beliefs about medication such as addiction, religious beliefs and stigma (Holland, 2017; Wray & Bartholomew, 2010).
- Addressing individual learning styles to allow information to be relevant e.g. educational level and gender (Moudgil, Marshall, & Honeybourne, 2000; Poureslami et al., 2012; Velsor-Friedrich et al., 2012).
- Addressing traditional cultural norms and expectations e.g. masculine and feminine gender norms.
- The use of appropriate language, even if participants in the first generation can speak in English e.g. the use of audio-visual formats in interventions.
- New/fresh interventions that add value to avoid normalisation (e.g. new information, research, case studies, tips or updates), on technological platforms e.g. text messages, emails and smartphone apps. Other participant ideas included adding novelty to asthma

reviews, disguising inhaler devices as nicotine patches/vapes and help points based on locations to improve access to services.

- Improvements in primary care services e.g. patient-centred communication, ongoing follow-up reminder/support, better diagnosis of asthma, helping with asthma acceptance, consultation time, language provisions, inclusion of triage nurses in primary care, referral for lung function tests and access to speak to specialists without time restrictions.

- PAAP design improvements (e.g. accommodating for oral languages such as audio-visual formats), and PAAP implementation in routine practice.

- Cultural training/information for HCPs delivered by experts in asthma.

- Signposting further information for HCPs to other resources in guidelines.

- It would also be interesting to know whether interventions based on social support are beneficial (e.g. considering acculturation of the family), particularly for cultures which can be loose and both individualistic and collective (Sam & Berry, 2010; Triandis, 2018).

Interviews with Bangladeshi and Pakistani participants showed that they had poor asthma awareness (including the community), and they acknowledged the need for education with credible information (see chapter 7). Previous reviews suggest that South Asians find it difficult to understand medical information, contrary to this thesis that found there was better knowledge on medication rather other information on asthma (Ahmed et al., 2018; Lakhanpaul et al., 2014b; Miles et al., 2017). The systematic review showed current interventions included education but understanding in participants was missing and therefore beliefs need to be targeted (see chapter 5). Health beliefs are an important part of culture (Hussein & Partridge, 2002; Patel et al., 2015). But, how beliefs are applied in interventions may need to be reconsidered due to the existence of habitus, that lead to individuals having logical/common-sense individualistic and collectivist practices that they are not completely aware of (Bourdieu, 2017, 2018). Therefore, raising consciousness of beliefs (physical or symbolic) may be important for initiating asthma self-management and may allow interventions to work better during self-consciousness (Marteau, Hollands & Fletcher, 2012), e.g. feeling asthma in the cold can make a person more conscious of having asthma symptoms or becoming aware that other people are observing/reacting to one's asthma symptoms can help prompt self-management.

Better research and guidance on collaboratively developing interventions for South Asians are needed (Castro et al., 2010; Liu et al., 2016; Netto et al., 2010). The systematic review showed that there was less evidence for culturally tailored compared to targeted interventions (see chapter 5). There also seems to be inadequate guides for developing tailored interventions, and even less in the field of asthma in the UK context. Most existing guidance on culturally tailored interventions are for non-South Asian populations based on individual articles. Hence, researchers can usually pick and choose which approach to adopt in interventions (Bailey et al., 2009; Castro, Barrera, & Steiker, 2010; Liu et al., 2016; Netto et al., 2010).

Implications: the relevance of standard behaviour change theories in interventions

Evidence on the application of behaviour change theories to asthma self-management in most South Asian subgroups has been sparse (Pasick et al., 2009a). It was unclear if standard behaviour change theories were effective for ethnic minorities (South Asians and African Americans; see chapter 5). Therefore, which behaviour change theory would be beneficial for future intervention development in this population and for providers remains unclear. Perhaps, theories need to be selected, described and implemented appropriately by authors. Previous literature suggests that theory is not always helpful e.g. for common-sense behaviours. Theories may also be standardised according to norms of the majority population's sociocultural and historical contexts of practicing health behaviours (e.g. White, middle-class backgrounds in developed countries) (Burke et al., 2009a; Michie & Prestwich, 2010), who arguably mainly have individualistic culture and cognitions (though some recognise social factors) (Cohen, Wu, & Miller, 2016; Triandis, 2018). Therefore, its applicability to other populations may be questionable, especially for populations who have collective cultures (Burke et al., 2009a; Fortun et al., 2014; Michie & Prestwich, 2010; Pasick et al., 2009a), influencing the meaning and interpretation of theoretical constructs (Burke et al., 2009b).

Knowledge provisions may need to be complimented by considering beliefs to ensure information is relevant and processed easily for a cultural group (Castro, Barrera, & Steiker, 2010; Resnicow et al., 1999). Illness representations (e.g. cold represents asthma) and cultural meanings attributed to self-efficacy may be partly based on collective values such as social comparisons with others and norms of the ability to successfully complete a task with

little asthma knowledge (see chapter 7) (Burke et al., 2009b; Klassen, 2008; Triandis, 2018). To some extent vicarious experience and social/verbal persuasion in the social cognitive theory may be slightly more aligned with collective cultures (Klassen, 2008; Triandis, 2018). This gap may be why Bandura (2002) refined the social cognitive theory for cultural contexts, where collective self-efficacy considers access to sociocultural capital loss and gain, although the theory does not consider the meaning of culture or cross-cultural variations and tends to homogenously applying its constructs (Burke et al., 2009b). Self-efficacy can also be relevant if sociocultural capital (e.g. the body, resources, significant relationships, prestige, social honour and preventative strategies), are in place in a sociocultural context e.g. access to inhalers (Burke et al., 2009b; Thompson, 2009).

Similarly, the social identity theory can help comprehension of collective strategies used to identify culture through social categorisation and comparison. The former useful in understanding people categorise the identity of others (e.g. patients), and the latter useful for understanding how individuals compare asthma identities (Tajfel & Turner, 2004). However, the theory is generic and there remains a gap in holistic understanding identity changes such as acculturation and hybridity (Hall, 2014; Sam & Berry, 2010). In addition, health behaviours that people may be unaware of also need further consideration (Bourdieu, 2017, 2018). Intention and beliefs may not have to be deliberate (Burke et al., 2009a). Self-management behaviours can be associated with habitus influenced by sociocultural factors that are based common-sense routines due to past and traditional influences (Bourdieu, 2017, 2018). Questionably, thinking needs to be applied on how to target habitus-related constructs (e.g. intention and beliefs), if individuals themselves are not fully aware of the rationale behind them (Bourdieu, 2017, 2018; Burke et al., 2009a).

Moving forward, the use of cross-cultural health psychology theories (e.g. the acculturation model and the cultural hybridity theory used in this thesis) may helped clarify and delve deeper into the role of culture in self-management in the UK (Hall, 2014; Sam & Berry, 2010). For instance, 'acculturative stress' helped provide insight into the sociocultural specific stress and dilemmas that individuals with asthma face when trying to self-manage their asthma, and the need for acculturation-matching of HCPs and patients as opposed the generically ethnic-matching (Sam & Berry, 2010). Additionally, the cultural hybridity model at healthcare level explained differences in explanatory models of illness between HCPs and patients, though this can also be explained by the common-sense self-regulatory theory (Leventhal,

Benyamini, & Shafer, 2007), and the existence of medical culture (Boutin-Foster, Foster, & Konopasek, 2008).

Emotional response (e.g. the imbalance of emotions in the body during asthma symptoms) in the common sense self-regulatory model helped understand self-management (see chapter 7), though found to partially explain emotional response to diabetes self-management in South Asians in another study (Patel et al., 2015). Cognitive illness representations of asthma beliefs and adaptive or maladaptive self-management from the common-sense self-regulatory theory were useful to some extent (Leventhal, Benyamini, & Shafer, 2007). For instance, cure, cause, consequence, identity and timeline were helpful for relating to various scenarios e.g. causation beliefs about predestination by God, developing an asthma identity from attaining a diagnosis, and the short-term nature of asthma/treatment (Leventhal, Benyamini, & Shafer, 2007).

Perhaps, other theories (e.g. the common sense self-regulatory model) (Leventhal, Benyamini, & Shafer, 2007; Patel et al., 2015), need to consider cultural revisions including standardisation, contextualisation and re-evaluation for different South Asian subcultures (Burke et al., 2009a; Evans & Lambert, 2008; Pasick et al., 2009a), following the footsteps of Bandura (2002) but also considering cross-cultural variations and so forth. For further research, it would be interesting to nail down which specific theories have been standardised on what population, whether theories have been tested in another population for relevance and effectiveness (Burke et al., 2009a; Pasick, Burke, & Joseph, 2009). However, research developments have been sluggish, though relatively growing in cancer screening research for ethnic minorities in America (e.g. Joseph et al., 2009; Pasick et al., 2009b; Pasick & Burke, 2008; Washington, et al., 2009). Better qualitative research may also add to revisions of standard theories by considering a population's sociocultural context (Hay & Lee, 2009; Pasick, Burke, & Joseph, 2009; Shelton, Griffith, & Kegler, 2017; Washington et al., 2009).

9.6.3 Implications for health organisations (research, charity and healthcare service)

Implications: seeking asthma treatment in South Asia

Interviews Bangladeshi and Pakistani participants showed that there was some dissatisfaction with healthcare services, particularly primary care. A few first generations were vulnerable in struggling to attain an asthma diagnosis in primary care. This may have implications for the first generations who may believe that better care can be received in South Asia with the right HCP (see chapter 7). This can be a concern for HCPs due to contradicting medical opinions from South Asia (see chapter 8). Hot weather in South Asia was also believed to be better for asthma (see chapter 7).

Implications: support provided for Ramadhan

Current Ramadhan asthma self-management advice and resources at an organisational level for both Bangladeshis/Pakistanis with asthma and HCPs warrants improvement, and needs to catch up to other fields of research e.g. diabetes and cardiovascular disease (Asthma UK, 2016d; Bukhari, 2016). Bangladeshi, Pakistani and HCP interviews showed that there are confusions around whether medication can be used during fasting hours (see chapter 7 and 8). The role of the Imam in chronic healthcare needs rethinking. Generally, the Imam is someone who leads congregational prayer with knowledge of reciting the Qur'an, who may or may not have additional Islamic knowledge on religious ruling (Padela et al., 2011). The definition of who is a knowledgeable religious leader can be subjective (Padela et al., 2011). It could be perceived as the shift of responsibility by organisations dissolving themselves of responsibility to provide support. People are also different e.g. Imam may not be an important part of a person's life and access to Imams differ (Asthma UK, 2016d; Bukhari, 2016).

Implications: revisiting values of ethnic-matching and language-matching

Organisational policies may need to revisit the classification of cultural competence (Betancourt et al., 2016). Current policies may generally involve ethnic or language-matching between providers and patients. However, this implies and reinforces the assumption that there is harmony within cultures of which people have innate and natural abilities of understanding their own culture and that all cultures need ethnic-matching other than White cultures. For instance, ethnic-matching of South Asian HCPs and patients do not automatically mean building good rapport nor does it symbolise cultural expertise (Samples et al., 2014; Wray & Bartholomew, 2010). Due to habitus (Bourdieu, 2017, 2018), and

different acculturation strategies, it may mean some people with asthma or HCPs from South Asian background do not speak any South Asian languages at all and some can speak a variation of South Asian languages and dialects, where matching languages may be difficult (Culley, Hudson, & Rapport, 2007; Sam & Berry, 2010).

It would be interesting to explore the nature of acculturation-matching and the impact this can have on supported self-management in asthma (Ahmad & Bradby, 2008; Wray & Bartholomew, 2010). This perspective may add to recognising cultural diversity for both Bangladeshis/Pakistanis with asthma and HCPs from a South Asian background. This approach can also help avoid the reduction of the ethnicity of HCPs to a methodological approach of matching rather than acknowledging their skills/qualities brought to their profession (Sam & Berry, 2010; Samples et al., 2014). Additionally, most HCPs in interviews showed that language provisions in healthcare were poor (see chapter 8). One reason for this may be budget concerns and availability of staff (Leong, Ramsey, & Celedón, 2012). However, at an organisational level ignoring cultural diversity may be regarded as institutional racism[136] (Ramaswamy & Kelly, 2015).

Implications: organisational support for HCPs

Service limitations prevented HCPs from fully performing supported self-management, particularly for clinicians e.g. time restrictions (see chapter 8). But, some Bangladeshi and Pakistani participants wanted the opportunity to speak to a specialist without time restrictions (see chapter 7). Despite this, there was a real sense that HCPs were trying to understand Bangladeshi and Pakistani culture and adapted supported self-management around this, even though there was a gap in cultural knowledge (see chapter 8). Given that supported self-management is important (Ahmed et al., 2018; Pinnock et al., 2017), ongoing cultural training or information is an avenue of improving supported self-management and building on cultural competence (Betancourt et al., 2016). For instance, it may help HCPs recognise that self-management is not the same as disease management of asthma, especially clinicians who were found to shift the responsibility of self-management to nurses (Hashem & Merritt, 2018; Morrow et al., 2017; Schulman-Green et al., 2012). Interviews with Bangladeshi and Pakistani participants have shown that reinforcing the disease management

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[136] Institutional racism is the public institutions response of ignorance to the needs of ethnic minorities that is not directly obvious (Ramaswamy & Kelly, 2015)

approach to asthma with selective medical information had a powerful influence on medicalising Bangladeshi and Pakistani participants (they become reliant on asthma medication and monitoring as part of self-management; see chapter 7). Additionally, HCPs can create acculturative stress due to insufficient training (e.g. persisting that family need to be involved in treatment), as it infers a struggle against traditional cultural expectations from HCPs (Sam & Berry, 2010). Most Bangladeshi and Pakistani participants did not have ongoing relationship with HCPs for their asthma, therefore it would be interesting to explore what a good relationship may look like and whether there may have cultural meaning attached to this (see chapter 7) (Morris et al., 2016; Morrow et al., 2017).

Asthma guidelines provide generic advice (GINA, 2016; SIGN, 2016). Perhaps, signposting further information for the Bangladeshi and Pakistani population can be beneficial for HCPs e.g. providing links to online resources (see chapter 8). Evidence on the usefulness of signposting information may need to be assessed (Manna et al., 2003). Most language provisions were poor e.g. use of interpreters, leaflets/posters, health advocates and Language Line (three-way telephone interpretation). Audio-visual language adaptations may be a way forward e.g. on inhaler technique, PIS, consent forms and so forth (see chapter 8) (Goodyer et al., 2006; Lloyd et al., 2008a; Poureslami et al., 2012). Even if Bangladeshi and Pakistani participants could speak English, they preferred interactions and expressing themselves in their mother-tongue (see chapter 7). Therefore, even if cultural training is provided, organisational support to fully implement supported self-management is needed (Betancourt et al., 2016).

Implications: power dynamics underlying research and healthcare services

There may be implicit/abstract conflictual power implications in every aspect of cultural research and clinical/organisational healthcare delivery (Ramaswamy & Kelly, 2015; Storey, 2010). Hierarchical entities[137] have the power to define the world using words/concepts that create boundaries and regulate knowledge/meaning through authority and legitimate channels e.g. what is normal health beliefs and behaviours (Storey, 2010). Hence, the power to define, create boundaries and blame cultures for not conforming to the norms of others (Ahmad & Bradby, 2008; Singer, 2012). In the latter, blaming cultures for health problems

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[137] Hierarchical entities can be defined as dominant elites/classes who have access to resources (Haugaard, 2002; Zoller & Dutta, 2009)

can dissolve the responsibility of healthcare services by providing an illusion that adequate is being provided for a diverse population (Matsumoto & Juang, 2016).

Researchers, HCPs and healthcare services need to be aware of power dynamics to ensure that power is deconstructed and there are safeguards to reduce this (Anyan, 2013; Holmes, Hughes, & Morrison, 2014). For instance:

- Definitions of hierarchical entities can be adopted in research and services (and even by people) and applied indiscriminately e.g. treating culture as static in epidemiological research or developing and testing behaviour change theories on a selective population and applying them to other populations (Joseph et al., 2009; Pasick et al., 2009b; Washington, et al., 2009).

- The setting where research takes place may indirectly influence the way the researcher is perceived and the answers to interview questions (Anyan, 2013). The participant can have consensual power[138] to decide whether they disclose or withhold information and may be conscious of audio-recording (Anyan, 2013; Berger, 2015).

- Providing participants with adequate language provisions during research (e.g. audio-recorded PIS and allowing participants the option to speak in their mother-tongue), can help redistribute consensual power to articulate what they wanted to share (Anyan, 2013; Berger, 2015).

- Back translations of understanding and analysing interviews conducted in different languages can imply that English is treated as a superior language, even though this process may lose cultural and linguistic meanings. However, back translations may sometimes be the only strategy available to some researchers. The research in this thesis has shown that there are other innovative ways of transcribing interview data e.g. Bengalish (Punnett et al., 2017; Reiss, 2014; Storey, 2010). The emic-etic approach (insider/outsider cultural perspective) such as involving participants in verifying data interpretation can readdress power imbalance that researchers and funding bodies have in presenting findings (Punnett et al., 2017).

- Collaboratively developing interventions may mean providing an atmosphere where participants are not obliged to explain something or have the pressure to represent their community. In addition, the process needs to both create knowledge and social change

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[138] Power 'to' (also known as consensual power) consists of the general ability of individuals/groups/institutions to allow something to occur. This form of power is based on material and/or social action; often entailing finite power that is not produced but acquired from another who loses power (Haugaard, 2002)

to challenge hierarchical entities. There needs to be a sense that the research process reflects the value of the community and not research agendas e.g. non-textual formats may be one option (Beebeejaun et al., 2013; Bombak & Hanson, 2017).

- There may be conflictual power dynamic between HCPs and patients. HCPs who make universalistic assumptions and integrate it into supported self-management can impose unintentional power on patients who do not act according to their expectations e.g. the belief that family need to be involved in asthma support (Storey, 2010). Access to discourses (production, distribution and legitimisation) can imply power imbalances. The knowledge distributed by HCPs can have the power to shape some patients, if selective information is provided on disease management e.g. providing information on taking medication without explaining the reasons for this. Patients can sometimes resist becoming medicalised and this form of power needs to be recognised (McHoul, McHoul, & Grace, 2015).

There may be some ethical implications of power, for instance patient-centred care may suggest that it may not be ethically correct to encourage discussions about asthma if this is not the norm of a community and challenge patient beliefs and experiences e.g. a person can believe they have good asthma control, even though medical measurements suggest otherwise, or the usefulness of PAAPs for individuals who believe they do not need it due to having mild asthma (Kralik, Paterson, & Coates, 2010; Yahav, 2016).

9.7 Conclusion

Cultural complexities illustrate that South Asians are not a homogenous group, therefore specific features of diverse cultures and subcultural need consideration. Focusing on the complexity of culture meant that there needed to be a in depth exploration of certain South Asian subcultural groups; the UK Bangladeshi and Pakistani populations (Nazroo, 2006). The role of UK Bangladeshi and Pakistani culture on asthma self-management behaviour were explored, which can help set the foundations for developing holistic bottom-up interventions. In addition to recognising the importance of different sociocultural contexts (whether individuals with asthma are from a minority or indigenous population). The paucity of research suggests further evidence in the field is needed.

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Appendices

Appendix 1. Publication from the thesis (one). Interventions to enhance the adoption of asthma self-management behaviour in the South Asian and African American population: a systematic review

https://doi.org/10.1038/s41533-017-0070-6

REVIEW ARTICLE   OPEN

Interventions to enhance the adoption of asthma self-management behaviour in the South Asian and African American population: a systematic review

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South Asian and other minority communities suffer poorer asthma outcomes, have a higher rate of unscheduled care and benefit less from most existing self-management interventions when compared to the majority population. Possible reasons for these differences include failure to implement asthma self-management strategies, or that strategies implemented were inappropriate for their needs; alternatively, they may relate to the minority and/or lower socioeconomic status of these populations. We aimed to synthesise evidence from randomised controlled trials for asthma self-management in South Asian and Black populations from different sociocultural contexts, and identify barriers and facilitators to implementing self-management. We systematically searched eight electronic databases, and research registers, and manually searched relevant journals and reference lists of reviews. Seventeen trials met the inclusion criteria and were analysed narratively. We found two culturally targeted interventions compared to fifteen culturally modified interventions. Interventions used diverse self-management strategies; education formed a central component. Interventions in South Asian and African-American minority communities were less effective than interventions delivered in indigenous populations in South Asia, though the latter trials were at higher risk of bias. Education, with continuous professional support, was common to most interventions. Facilitators to asthma self-management included: ensuring culturally/ linguistically appropriate education, adapting to learning styles, addressing daily stressors/social support and generic self-management strategies. In conclusion, when developing and evaluating self-management interventions aimed at different cultures, the influence of sociocultural contexts (including whether patients are from a minority or indigenous population) can be important for the conceptualisation of culture and customisation of self-management strategies.

npj Primary Care Respiratory Medicine (2018)28:5 ; doi:10.1038/s41533-017-0070-6

INTRODUCTION

South Asian communities, along with other minority populations, have poorer asthma outcomes, higher rates of hospital admission, greater risk of rehospitalisation and a higher death rate compared to majority white populations.[1–3] Asthma self-management, consisting of education, written Personalised Asthma Action Plans (PAAPs) and regular reviews (supported self-management) is known to improve health outcomes, and is recommended in national and international guidelines.[4–6] Despite hopes that self-management offers a potential solution to address preventable health inequalities,[1,5,7] there are concerns that asthma self-management interventions have produced little or no positive improvements on health outcomes for South Asians or other minority populations, further widening the gap of asthma inequalities.[7–10] Possible explanations for these variations include differences in health-seeking behaviours related to health beliefs and attitudes to mainstream medicine,[1,7,11] environmental or lifestyle factors,[1,5,11,12] poor healthcare access and the quality of asthma care provided to these communities.[13] These factors may be driven by cultural diversity, by the experience of being a minority and/or by socioeconomic status (SES). Thus, the way in which self-management is accessed and delivered to these various populations, need to be explored, and self-management strategies

may need to be developed for the target population's culture, ethnicity, SES or other needs.[1,5,7]

There are distinctions between the way interventions can be made relevant to a population (see Table 1). 'Culturally modified/ adapted' interventions, are developed for a majority population and then modified for use in other ethnic groups; the core content, however, is the same. 'Culturally targeted' interventions are developed from a bottom-up process that considers the shared characteristics and context of a cultural group before developing an intervention. Finally, bottom-up interventions that assess and are aimed at the unique cultural characteristics and dimensions of individuals within a cultural group, with individualised intervention delivery are known as 'culturally tailored'.[14,15] Culturally targeted or tailored interventions are generally suggested to be more effective than culturally modified interventions, though the evidence for this has focussed mainly on children,[14,16,17] is limited or out-dated.[5,14,17–19]

Studies and clinical practice guidelines often indiscriminately apply findings from a majority population in a South Asian country, as relevant and applicable to South Asian minorities and majorities in other countries, despite differences in time and space of lived experiences and cultural shifts.[20,21] Not only are the South Asian and Black population heterogeneous groups, but culture is

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Table 1. Definition of terms

Term	Definition	Examples
Culturally modified/adapted interventions[14]	Pre-existing generic interventions modified for the intention of being relevant to ethnic groups using various strategies, though the content is primarily the same	Language translation, and use of images and bilingual educators from a similar ethnicity as the target population
Culturally targeted interventions[15]	A bottom-up process which considers the shared characteristics and dimensions of collective individuals of a culture before developing an intervention, aimed at a group level	Religion
Culturally tailored interventions[15]	A bottom-up process which considers the unique cultural characteristics and dimensions of individuals within a cultural group before developing an intervention, aimed at individuals within a group	Level of religious identification or spirituality
'Majority' South Asians	Interventions from South Asian countries where the population forms a majority	South Asians in India
'Minority' South Asians; 'Minority' African Americans	Interventions from countries where the population forms a minority	South Asians in the UK or Canada; African Americans in the USA

fluid and continuously being shaped and reshaped across time and place, depending on an individual's interaction with, and ability to respond to, the variability in their environment. Overlooking this 'contextualisation' may hinder adoption of self-management behaviour. Conversely, education aimed at cultural context enhances meaning, receptivity, relevance and processing of information by patients.[20,22,23] Comprehension of a patient's contextual realm offers a deeper understanding of the dynamic nature of cultural influences on self-management behaviour e.g., collective perceptions of asthma, familiarity with self-management and availability of, or access to, resources. This raises the question of whether poor asthma outcomes in ethnic minorities can be explained by their minority-status and/or by their relative social deprivation.[6,16,19,24–28] These differences within a cultural group can influence the level of organisational and structural asthma inequalities faced by patients.[29]

This systematic review aims, in South Asian and Black communities (majority and minority populations), to (1) describe features of culturally relevant asthma self-management interventions, (2) synthesise the evidence for the effectiveness of interventions in different sociocultural contexts, and (3) identify barriers and facilitators to asthma self-management behaviour. We included interventions from South Asian countries where the population forms a majority ('majority' South Asian), and interventions from countries where the population forms a minority ('minority' South Asian; 'minority' African American) (see Table 1). We included studies of Black minority populations because our scoping work suggested that there was important literature, especially in African-American communities. This also allowed exploration of both the role of South Asian ethnicity, specifically versus the impact of minority/majority status on self-management outcomes.

RESULTS

Characteristics of included trials

From a total of 3174 citations, we included 17 papers (reporting 16 trials) (see Fig. 1). The randomised control trials (RCTs) were conducted between 1995 and 2016; four South Asian trials were from India (labelled 'majority' South Asian)[30–33] four South Asian trials were from the UK[34–36] and one from Canada[37] (labelled 'minority' South Asian), and nine African-American trials were from the USA (labelled 'minority' African American)[26–34] (see Table 2). The overall risk of bias within trials was uncertain,[30,33,37–41] or high.[31,32,36,42–45] Three trials had low risk.[34,35,46] (see Table 3).

Participant characteristics: The 'majority' population in the South Asian trials comprised of Indians,[30–33] whereas 'minority' South Asian trials included Indians,[37] and mixed subcultures (e.g.,

Bangladeshi, Pakistani, Indian or Sri Lankan).[34–36] All Black population trials studied the African-American minority population in the USA.[38–46] Most trials (fourteen studies) did not define ethnicity; only three 'minority' South Asian trials defined ethnicity according to self-identification or language spoken.[34,35,37] All trials aimed interventions at asthma patients (whether this was children, adolescents, adults or elders).[30–46] In addition, some trials also targeted parents,[30,32,38,46] trained African-American coaches and/ or residents,[38,46] or healthcare professionals (clinicians and nurses).[30,32,34–46]

Study setting: All 'majority' South Asian trials were based in tertiary care hospitals.[30–33] In contrast, 'minority' South Asian trials were conducted in primary care,[35,36] or a combination of community, primary care and hospital (secondary/tertiary) settings.[34,37] Similarly, the African-American trials were conducted in various settings: primary or secondary schools,[40,41,45] tertiary care hospitals,[39,42] emergency department[43] and three trials used a combination of settings; community, school and hospital (secondary/tertiary).[38,44,46]

Geographical area and socioeconomic status: Among the 'minority' trials that specified the demographic location of patients, these were described as urban in six trials[34–36,40,41,46], and one African-American trial was conducted in mixed urban and rural areas.[43] Eight trials were described as from economically deprived or low-income areas,[34,35,38–41,45,46] and two 'minority' trials (South Asian and African American) were conducted in low/ middle-class areas.[36,44]

Intervention characteristics: Table 2 describes intervention characteristics. All interventions included patient education, though the approach, method of delivery and content varied. Examples included education-sessions or classes,[30,32,33,35,36,38–46] training for patients,[30,32,34–36,38,46] and healthcare professionals, coaches or residents,[30,32,34–36,38,46] education in written,[31–33,35,39,43,44] or video format,[35,37,42] education in the form of social support,[46] or a local education/promotional campaign.[38] Twelve out of 17 interventions were delivered by healthcare professionals,[30,32,34–36,38–46] five of whom were specifically trained for the project.[30,32,35,42,43] Three interventions from minority countries were delivered in South Asian languages by healthcare professionals or research facilitators,[35–37] two 'majority' South Asian trials had written materials in Hindi or Tamil,[30,33] and two USA interventions were delivered by trained African American lay people or university staff who were residents in the community.[38,46] Intervention duration ranged from 40 minutes to 1 year and follow-up lengths ranged from 1 month to 3 years (see Table 3 for details on the latter).

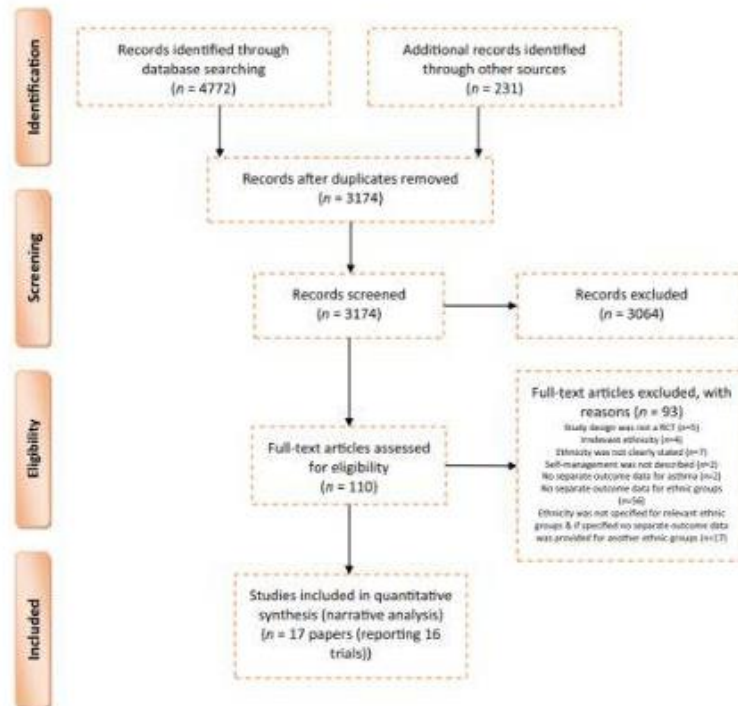Strategies for reinforcing knowledge or self-management behaviours included follow-up classes,[36,45] nurse

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Fig. 1 PRISMA flow diagram

clinics[34,35,39,41,44,45] and written materials.[42,43] Most trials described other intervention characteristics used alongside education,[30,32–46] including the use of written PAAPs in all South Asian trials (majority and minority)[30–37] and some African-American trials,[41,45,46] provision of emergency oral corticosteroid courses,[34] asthma medication/therapy,[30,32,34,36,39,42,44,45] placebo inhalers to practice technique,[43] asthma diary/workbook,[30,32,33,42] peak flow monitoring,[30,34,36,37,39,41,42,44,45] medication counselling[33] and access to free asthma organisation helplines.[42] In seven trials, intervention strategies were based on specific guidelines, e.g., National Institutes of Health, National Heart Lung and Blood Institute, Global Initiative for Asthma (GINA) and Scottish Intercollegiate Guideline Network (SIGN).[33–36,39,44,46] Usual care for the control groups varied,[30–36,39–44,46] including illustrative leaflets,[37] routine education classes,[45] and recruiting similar neighbourhood areas to the intervention sites.[38]

(1) Features of culturally relevant interventions. In line with our definition and that in previous literature,[14,15] we did not find any culturally tailored interventions, and only two of seventeen trials evaluated culturally targeted interventions.[31,37] Behera et al.[31] ('majority' South Asian trial at high risk of bias) provided a targeted written self-care booklet in Hindi (including a PAAP) developed collaboratively from patient knowledge, relevant literature and expert advice. Poureslami et al.[37] ('minority' South Asian trial at unclear risk of bias) developed educational videos in collaboration with community members and healthcare professionals. The educational videos included three intervention possibilities (i.e., scientific knowledge, community opinions/narratives or a combination of both), that incorporated cultural beliefs and attitudes, e.g., cultural gestures, humour, storytelling and social interaction

styles appropriate for Punjabi Indians. The aim was to facilitate patients' trust in the community member and/or clinician who delivered the intervention.[37] Both interventions were piloted in focus groups to improve clarity, relevance and acceptability and were refined before evaluation. These trials were not classified as culturally tailored because they were delivered to the specified cultural group without distinguishing or measuring individual cultural differences within that group.[31,37]

Both trials significantly improved knowledge. Poureslami et al.[37] improved adherence to physician instructions on medication and inhaler use, and Behera et al.[31] reported reduced symptoms, hospital admissions and use of breathing exercises during acute attacks. Although, the former trial achieved significant findings on all outcomes for Punjabi Indians, the Chinese population (who were studied as a parallel group with their own culturally targeted intervention) performed even better. The authors considered that this may be related to participant demographics; the Punjabi Indians were older and less educated than the Chinese community.[37]

In contrast, 15 out of 17 interventions were found to be culturally modified.[30,32–36,38–46] They used strategies such as adapting existing interventions or materials for the target ethnic group,[32,15,39,44] e.g., an African-American training video was re-recorded with South Asian actors,[35] and ethnically relevant images were used such as African-American celebrities.[34,35,42] Other studies applied interventions to several ethnic groups without considering cultural differences; thus, providing written or oral education (e.g., classes, PAAPs and workbooks) translated from English to the target participant language or using bilingual educators, without adjusting intervention content.[33–36] However,

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Table 2. Overview of study characteristics of included trials

Study, Country	Population characteristics		Study setting; SES/area	Intervention characteristics				
	Aim	Ethnicity; Participants; Sample age; Sample size (I/C)		Intervention description/length	Control /other group descriptions	Delivery (ethnicity; language)	Mode of delivery	Modified; Targeted; Tailored
'Majority' South Asian trials								
Agrawal[30] India	Evaluated efficacy of PAAPs for asthma control	Indian; Patients; parents; 2–12; 60 (32/28)	Tertiary (university clinic)	Education; sessions, training including on asthma symptom diary and peak flow measurements / PAAPs / Asthma therapy/not stated	No PAAP standard asthma therapy and education	Trained physician; social scientist (-)	Individual; Written material	Modified
Behera[31] India	Assessed patient knowledge of self-care needs and develop/evaluate a self-care manual	Indian / Patients; 18–60; 523 (260/263)	Tertiary (outpatient university clinic) / –	Education-booklet in Hindi (included a PAAP) / Booklet evaluation/not stated	No specific instructions/pilot study used to develop booklet in Hindi (n = 45)	Not stated (Hindi)	Written material / Other methods not stated	Targeted
Ghosh[32] India	Assessed the impact of self-management education and training on health status and resource use	Indian / Patients; Parents; 10–45; 276 (140/136)	Tertiary (university clinic) / –	Education; sessions, training, written instructions, audio-visual aids, role models, group/scenario discussions / Daily diary (included symptom assessment and financial workbook) / Asthma therapy / PAAPs/four 2 hour sessions	Regular care e.g. drug administration	Trained social scientist (-)	Group; / Written material	Modified
'Minority' South Asians trials								
Shanmugam[33] India	Provided pharmaceutical care through partnership of pharmacists and patients for good asthma control	Indian / Patients Age: ~; 66 (33/33)	Tertiary (university hospital) / –	Education; sessions, asthma care diary in English and Tamil (including leaflet). PAAP and symptom log sheet / Medication counselling/not stated	No pharmaceutical care	Not stated (English and Tamil)	Written material; / Other methods not stated	Modified
Griffiths[34] UK	Tested whether specialist nurses across ethnically diverse and deprived areas reduce unscheduled care	South Asians (mostly Bangladeshi) White Caucasians, Other (Black/African Caribbean/Other)	Primary/secondary (out-of-hours GP service/hospital)	Education; training based on guidelines, nurse review with advice / PAAP explained in English and Sylheti	Usual care; single nurse visits to discuss asthma guidelines and check inhaler technique	Trained nurse specialists (partially; PAAPs explained in Sylheti)	Individual; / Written material;	Modified

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Table 2 continued

Study, Country	Population characteristics		Study setting; SES/area	Intervention characteristics				Modified; Targeted; Tailored
	Aim	Ethnicity; Participants; Sample age; Sample size (I/C)		Intervention description/length	Control /other group descriptions	Delivery (ethnicity; language)	Mode of delivery	
		Patients; 4–60: 164 (95/69)	Deprived/urban	Ongoing clinical support for professionals on computer prompts; Peak flow meters provided; Oral corticosteroids/2 one hour visits for GP practices; 194 days			Telephone	
Griffiths[35] UK	Tested whether culturally specific education programmes adapted from USA interventions reduce unscheduled care	South Asians (Bangladeshi, Pakistani, Indian, Sri Lankan) Patients; Primary/secondary care clinicians; 3 and above; 375 (183/192)	Primary (GP); Deprived/urban	Education session including PAAP, nurse follow-ups to book appointments (CDSMP), research training with video based on guidelines, South Asian actors and manualised programme (PACE/CDSMP; 2-hour session PACE; two seminars;	Usual care; nurse delivered standardised consultation. No PAAP/follow-up appointments provided	PACE; Nurse specialists, Academic GP's CDSMP: Trained nurse specialists (South Asians)	Group; Video/DVD; Written material	Modified
Moudgil[36] UK	Tested whether bilingual education of treatment optimisation and follow-up reduce urgent healthcare and improve quality of life	South Asian (mainly Indian and Pakistani), White European; Patients; GP; 11–59; 344 (171/173)	Primary (GP); Low or medium deprivation/urban	Education; community sessions delivered in South Asian languages including written literature, education follow-up; Booklet including PAAP (based on BTS guidelines) and peak flow measurements; GP trained on prescribing, optimal treatment, knowledge and medication; Peak flow meter provided; Asthma therapy/40 minutes	Usual asthma care follow-up	Trained GP (South Asian)	Individual; Written material	Modified
Pouredam[37] Canada	Explored the effectiveness of different culturally relevant information	South Asians (Indian Punjabi), Chinese	Other/tertiary (home, university clinic)-	Education; videos (physician-led, community and physician-led/	Pictorial pamphlet in either Mandarin, Cantonese or Punjabi	Research facilitators (South Asian)	Group/video	Targeted

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Table 2 continued

Study, Country	Population characteristics		Study setting: SES/area	Intervention characteristics		Delivery (ethnicity; language)	Mode of delivery	Modified; Targeted; Tailored
	Aim	Ethnicity; Participants; Sample size (N; age; Sample size (N; Q)		Intervention description/length	Control /other group descriptions			
	formats and impact on self-management	Patients; 21 and above; 45 (33/12)		community combination) Peak flow meter PAAPs/1 month	/Co-development of intervention (n = 35); focus group sessions (n = 40)			
'Minority' African American trials								
Blixen[42] USA	Tested feasibility of a culturally appropriate in-patient education programme for hospitalisation	African Americans	Tertiary (hospital)	Education; sessions and video, asthma workbook using African-American images, references to famous celebrities, written education posted as follow-up	Received usual care	Trained nurse (Not stated)	Individual;	Modified
		Patients; 8–50; 28 (14/14)	–	Peak flow meter; MDI spacer provided Toll free numbers for asthma organisations/ Three 1-hour sessions			Video/DVD; Written material	
Fisher[36] USA	Tested community-based intervention to improve asthma awareness, attitudes, management practices and reduce acute care	African Americans, White Caucasians, Others; Patients; parents 5–14; 249 (100/149)	Other (community, school) Low income	Education; promotion campaigns, sessions, training residents to support patients in school and community/ 12 months	Four areas in the same location with similar SES characteristics	Trained university staff/residents (African American)	Group; Individual	Modified
Fisher[46] USA	Tested whether community health workers can reach low-income parents of hospitalised children and to reduce rehospitalisation	Parents; African-American Coaches; 2–8; 191 (97/94)	Other/secondary (community, hospital) Low income/ urban	Education; sessions by asthma coach based on guidelines and parental support contacts/ meetings for readiness to change; training for asthma coaches (including PAAPs)/2 years	Usual care; inpatient education and discharge planning with PAAP, a suggested follow-up primary care within 1 week of discharge	Nurse, psychologist, three trained coaches (African American)	Individual; Group; Telephone	Modified
Ford[43] USA	Reanalysed an education programme that assessed the effects on asthma outcomes	African Americans; Patients; 18–70; 241 (119/122)	Secondary (emergency department) Urban and rural	Education; sessions and follow-ups, handout, mailed sessions for non-attenders Visual medical card	Received no intervention	Trained healthcare professionals and nurses (not stated)	Group; Written material	Modified

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Table 2 continued

Study, Country	Population characteristics		Intervention characteristics					
	Aim	Ethnicity; Participants; Sample age; Sample size I/ C	Study setting; SES/area	Intervention description/length	Control /other group descriptions	Delivery (ethnicity; language)	Mode of delivery	Modified; Targeted; Tailored
Keslo[39] USA	Provided major long-term therapeutic intervention and intensive education	African Americans; Patients; 18 and above; 52 (30/22)	Secondary /tertiary (emergency department/ university clinic); Low; deprived	Wallet sized card (with medication list, dose, frequency) Placebo inhaler to practice/3 sessions; Education; sessions based on NIH guidelines, Follow-up clinics; Education booklet (including diary card for measurements and 1-page summary of asthma prevention, medications, triggers and peak flow meter product literature); Asthma therapy for ICS; Peak flow meter (colour-coded stickers), inhaled b-agonist and aero chamber provided/1-hour session	Usual care	Pharmacy researcher, pulmonologist (not stated)	Individual; Telephone; Written material	Modified
Keslo[44] USA	Tested if a long-term management programme (emphasising ICS and patient education), would improve outcomes	African Americans; Patients; 18 and above; 39 (21/18)	Tertiary (university based clinic); Low; working and middle-class college students	Education; session; Educational booklet Written instructions on asthma crisis management; Asthma therapy and peak flow meter (colour-coded stickers), MDI and other medications; Follow-up clinics (including diary)/2 years	Usual care from local physicians	Pharmacy researcher (not stated)	Individual; Group; Written material	Modified
Velsor-Friedrich[40] USA	Tested the effect of a school-based education programme (Open Airways) on the psychosocial outcomes	African Americans; Patients; 8–13; 102 (40/62)	Other; (Eight public primary school)	Education; sessions/ 2 weeks, six 45 minute sessions per week	Usual care; participated in the Open Airways programme after intervention	Academic professor, nurse (-)	Group	Modified

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Table 2 continued

Study; Country	Population characteristics			Intervention characteristics				
	Aim	Ethnicity; Participants; Sample age; Sample size (// ♀)	Study setting; SES/area	Intervention description/length	Control /other group descriptions	Delivery (ethnicity; language)	Mode of delivery	Modified; Targeted; Tailored
Velsor-Friedrich[41] USA	An extension of the study above (Velsor-Friedrich 2004); tested a two-part school-based education programme	African Americans Patients; 8–13; 52 (28/24)	Other (eight public primary schools with nurse clinics) with nurse clinics) Low/Urban Low/urban	Education-sessions (as above) A further 5-month visit with nurse where education information was reinforced, a packet of asthma information reviewed if needed, PAAPs adjusted, clinical assessment on medication and peak flow monitoring/ 7 weeks, 45 minute sessions, once per week	As above and all students received a PAAP	Academic professor, academic nurse(-)	Individual; Written material	Modified
Velsor-Friedrich[45] USA	Evaluated efficacy of a school-based asthma education program on psychosocial & health outcomes	African Americans Patients; 13–19; 137 (74/63)	Other (5 secondary schools) Low	Education, sessions, coping skills training including role-playing & technology use (with a booster session as follow-up) Nurse practitioner reinforcement & clinic visit Provided MDI, hydro fluoroalkane & static free chamber Peak flow diary PAAP/Six 45 minute sessions over 6 weeks	Routine education	Clinician, nurse, clinical psychologist trained doctoral student (-)	Individual; Group	Modified

Note: Missing data obtained from authors is noted in italic in the table

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Table 3. All included paper findings as reported and the decisions underpinning the harvest plots

Citation design, sample group/size and risk of bias score	Outcome categories, FU	Reported outcomes values for intervention (I)/control (C) ("indicates the primary outcome (if stated)	Researcher's interpretation for the harvest plot
Agrawal[30] n = 60 children FU: 4 m Overall risk of bias: Unclear	Clinical-unscheduled care, 4 m	Compared to controls, children in the intervention group had: Fewer acute asthma events: I: 0.50 (SD 0.71) vs. 1.0 (SD 0.61); p = 0.02	Illustrated as a consistent significant positive effect
	Clinical-asthma control, 4 m	Compared to controls, children in the intervention group had: Improved symptom score: (from the symptom diary) I: 21.9 (SD 14.4) vs. C: 33.7 (SD 10.9); p = 0.0006 Fewer nocturnal awakenings: I: 1.75 nights/month (SD 1.30) vs. C: 3.25 (SD 1.20); p = 0.001 Reduced school absenteeism: I: 1.5 days/month (SD 1.4) vs. C: 2.54 (SD 1.79); p = 0.015	Illustrated as a consistent significant positive effect
	Process	Not assessed	–
	Behavioural	Not assessed	–
Behera[31] CCT n = 523 adults FU: 2 wks, 6 m, 1 yr Overall risk of bias: high	Clinical-unscheduled care, 1 yr	A reduction in hospital admissions is illustrated graphically (the authors state that there was a significant decrease in hospital admissions in the intervention group at FU compared to the control group)	Illustrated as a consistent significant positive effect
	Clinical-asthma control, 2 wks, 6 m, 1 yr	Symptom scores decreased in both groups I: Baseline: 18.14 (SD 41.23) vs. FU 1 yr: 12.61 (SD 28.66) C: Baseline 18.76 (SD 42.64) vs. FU 1 yr: 10.69 (SD 24.30) Logistic regression: compared to the control group, more intervention group patients showed a significant improvement in symptom scores at 2 w, 6 m and 1 yr (p < 0.001)	Illustrated as a consistent significant positive effect
	Process, 2 wks, 6 m, 1 yr	Knowledge scores increased significantly in the intervention group and fell in the control group: I: Baseline: 13.04 (SD 4.06) vs. FU 1 yr: 28.13 (SD 15.70); p = <0.001 C: Baseline 11.44 (SD 4.0) vs. FU 1 yr: 9.47 (SD 2.89); p = <0.001 Logistic regression: Compared to the control group, more intervention group patients showed a significant increase in knowledge scores at 2 wks, 6 m and 1 yr (p < 0.001)	Illustrated as a consistent significant positive effect
	Behavioural, 2 wks, 6 m, 1 yr	Reported self-care in acute attacks showed no change in attitudes in either group, but significantly more patients in the intervention group adopted the recommended position (sitting, leaning forward) and practiced breathing exercises during an acute attack as compared to control patients	Illustrated as a significant positive effect but hatched to show inconsistency
Ghosh[32] n = 276 adult, adolescent, children/parent	Clinical-unscheduled care, 1 yr (assessed by diary in months 4, 8 and 12)	Fewer total number of ED visits, but no between group difference in proportion with ED visit Number of ED visits in the 3-month diary: I: 11.6 (SD 16.2) vs. C: 21.8 (SD 25.0); p = 0.002 Proportion with ED visits in the 3-month diary: I: 42.9 vs. C: 50.0% (p = 0.117) Number and duration of hospitalisations were both significantly reduced Hospital days in the three diary months: I: 5.8 (SD 10.7) vs. 12.5 (SD 19.8); p = 0.016 Proportion hospitalised in the three diary months: I: 27.1 vs. C: 36.8%; p = 0.043	Illustrated as positive but hatched to indicate inconsistency
FU: 4 m, 8 m, 1 yr Overall risk of bias: high		Fewer productive days lost in the intervention group during the three diary months	Illustrated as a consistent significant positive effect

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Table 3 continued

Citation design, sample group/size and risk of bias score	Outcome categories, FU	Reported outcomes-values for intervention (I)/control (C) [a] indicates the primary outcome (if stated)	Researcher's interpretation for the harvest plot
	Clinical-asthma control, 1 yr (assessed by diary in months 4, 8 and 12)	Day lost: 17.6 (SD = 24.2)/34.1 (SD = 38.8); $p = 0.003$ PEFR was significantly improved in the intervention group relative to the control group; Mean PEFR from diary cards I: 332 (SD 50.78) vs. 290 (SD 77.69); $p = < 0.001$	
	Process	Not assessed	–
	Behavioural	Not assessed	–
Shanmugam[33] CCT $n = 66$ FU: 29 days Overall risk of bias: unclear	Clinical-unscheduled care	Not assessed	–
	Clinical-asthma control, 29th day	Asthma control improved in the intervention group compared to the control group. Mean ACT score for each question was greater in the intervention group at FU: $p < 0.05$ (Overall mean ACT scores are not reported) Lung function showed a greater increase in the intervention group compared with control PEFR (L/min): Baseline: I: 282 (SD 95) vs. C: 265 (SD 93); FU: I: 336 (SD 88) vs. C: 268 (SD 85); $p = < 0.05$	Illustrated as a consistent significant positive effect
	Process	Not assessed	–
	Behavioural	Not assessed	–
Griffiths[34] $n = 44$ practices/324 – [South Asians I: 95 C: 69 $n = 164$], adults, adolescents, children	Clinical-unscheduled care, 1 yr	[Note: these data are an *a priori* sub-group analysis] "Time to first unscheduled care effect on South Asians was not significant between intervention and control; South Asians HR 0.72, 0.48 to 1.09 "Proportion attending unscheduled asthma care: no between group differences in whole population. No data for South Asian sub-group, but authors state that 'intervention effect was non-significant for other sub-group analysis'	Illustrated as a consistent no effect
FU: 2 m, 9 m, 1 yr Overall risk of bias: low	Clinical-asthma control, 2 m, 1 yr	[Note: these data are an *a priori* sub-group analysis] Symptoms: no between group differences in whole population. No data for South Asian sub-group, but authors state that 'intervention effect was not significant for other sub-group analysis'	Illustrated as a consistent no effect
	Process	[Note: these data are an *a priori* sub-group analysis]	–
	Behavioural, 2 m, 1 yr	Self-management behaviour: no between group differences in whole population. No data for South Asian sub-group, but authors state that 'intervention effect was not significant for other sub-group analysis'	Illustrated as a consistent no effect
Griffiths[35] $n = 84$ practices/375 elders, adults, adolescents, children, primary and secondary care clinicians	Clinical-unscheduled care: 171 days/C: 189 days/I: 72 days/ C: 339 days/1 yr	Unscheduled care: there was no between group difference in healthcare use "Time to first unscheduled contact FU: HR = 1.19 (0.92 to 1.53); $p = 0.185$ Proportion without unscheduled care FU: OR = 0.72 (0.45 to 1.16); $p = 0.175$ Time to first unscheduled primary care contact FU: HR = 1.20, 0.92 to 1.57 $p = 0.177$ Time to first routine review in primary care FU: HR = 2.22, 1.67 to 2.95 $p = < 0.001$	Illustrated as a consistent no effect

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Table 3 continued

Citation design, sample group/size and risk of bias score	Outcome categories, FU	Reported outcomes values for intervention (I)/control (C) *indicates the primary outcome (if stated)	Researcher's interpretation for the harvest plot
FU: 3 m, 1 yr Overall risk of bias: low	Clinical-asthma control, 3 m, 1 yr	Corticosteroid prescriptions: There was no between group difference in steroid prescriptions Steroids FU: I: 1.16 vs. 0.98 Adjusted incidence rate ratio: 1.14 (0.87–1.49) Asthma control: there was no between group difference in symptom score	Illustrated as a consistent no effect
	Process, 3 m, 1 yr	Symptom score FU 1 yr: 9.9 (SD 5.0) vs. C: 10.1 (SD 4.2) AHR: −0.04 (−1.16 to 1.09); p = 0.949	Illustrated as a consistent no effect. Another bar plotted to illustrate the 3 m finding—as a consistent significant positive effect
		Self-efficacy was improved at 3 m but not at 1 yr follow-up: At 3 months: I: 6.7 (2.1) vs. C: 6.3 (1.9) AHR: 0.44 (0.05 to 0.82); p = 0.027 At 12 months: I: 6.4 (1.8) vs. C: 6.3 (1.6) AHR: 0.25 (−0.13 to 0.63); p = 0.188	
	Behavioural	Not assessed	-
Moudgil[36] n = 689 (White Europeans 345, Indian subcontinent 344); adults, adolescents, children	Clinical-unscheduled care, not stated ISC: n = 294 (I: 151 C: 143)	[Note: these data are an a priori sub-group analysis] Number of asthma events/episodes for South Asians: no between group differences	Illustrated as a consistent no effect
		*Proportion with an admission: I: 5.3 vs. C: 6.3% OR 0.83 (0.28 to 2.44); p = 0.9081	
		Proportion with an A&E attendance: I: 1.4 vs. C: 4.0% OR 2.92 (0.52 to 21.2); p = 0.3184	
		Proportion with out-of-hours primary care. I: 2.8 vs. C: 2.6% FU: OR 0.95 (0.19 to 4.60); p = 1	
		Proportion with a GP consultation. I: 55.9 vs. 50.3%. OR 0.80 (0.49 to −1.30); p = 0.3971	
		Proportion with a steroid course. I: 20.3 vs. 19.9%. OR 0.97 (0.53 to 1.79); p = 1	
FU: 4 m, 8 m, 1 yr Overall risk of bias: High	Clinical-asthma control, 1 yr ISC: n = 280	[Note: these data are an a priori sub-group analysis] Quality of life in South Asians was significantly better in the intervention group	Illustrated as a consistent significant positive effect
		Change in AQLQ FU: I: 0.11 vs. −0.15. Between group mean difference 0.26 (0.17–0.36); p = < 0.001	
	Process	Not assessed	-
	Behavioural	Not assessed	-
Poureslami[37] n = 92 (47 Chinese, 45 Punjabi); Adults	Process, 3 m, 6 m Punjabi n = 43	[Note: these data are an a priori sub-group analysis] *Knowledge: no comparison data for intervention and control groups	Insufficient data
FU: 3 m, 6 m; 1 telephone survey interview Overall risk of bias: unclear	Behavioural, 3 m, 6 m Punjabi n = 43	[Note: these data are an a priori sub-group analysis] Understanding physician instructions; on *medication and proper inhaler use skills: no comparison data for intervention and control groups	Insufficient data
Blixen[42] n = 28, Adults	Clinical-unscheduled care, 3 m, 6 m	Healthcare use: no data provided, though stated as no significant between group differences	Illustrated as a consistent no effect
	Clinical-asthma control, 3 m, 6 m	Quality of life: There was no significant between group differences Overall AQOL score. FU 6 m: I: 4.59 (SD 1.48) vs. C: 4.43 (SD 1.52); p = 0.12	Illustrated as a consistent no effect
FU: 3 m, 6 m Overall risk of bias: high	Process	Not assessed	-

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Citation design, sample group/size and risk of bias score	Outcome categories, FU	Reported outcomes-values for intervention (I)/control (C) *indicates the primary outcome (if stated)	Researcher's interpretation for the harvest plot
Fisher[38] n = 249 Adolescents, children, parents	Behavioural, 3 m, 6 m	Self-management behaviours: no data, though stated as no-significant between group differences	Illustrated as a consistent no effect
	Clinical-unscheduled care, Quarterly for 3 yrs	*Acute care: no data given (results illustrated graphically), though authors stated no significant between group differences in acute care (hospitalisations and ED attendances p = 0.35)	Illustrated as a consistent no effect
FU: 3, 6, 9, 12, 16, 20, 24, 28, 32, 36 m Overall risk of bias: unclear	Clinical-asthma control	Not assessed	–
	Process	Not assessed	–
	Behavioural, Every quarterly until 3 yrs	*Asthma management: no significant between group differences in the non-validated assessment of parent's reported attitude about asthma and asthma management	Illustrated as a consistent no effect
		Attitudes about asthma FU: I: 2.34 vs. C: 2.24 (p = 0.35)	
		Appropriate thresholds for seeking help Baseline: I: 30 vs. C: 47%; FU: I: 51 vs. C: 53% p = 0.77	
Fisher[46] n = 191/parents, coaches	Clinical-unscheduled care, 1 yr, 2 yr	*Hospitalisation Compared to controls, the intervention group had fewer hospitalisations;	Illustrated as a consistent significant positive effect
		Hospitalised at least once FU: I: n = 35/96 (36.5%), 55 vs. C: 55/93 (59.1%); 95% CI (0.11–0.34); p = .002	
FU: 6, 12, 18, 24 m Overall risk of bias: low	Clinical-asthma control	Not assessed	–
	Process	Not assessed	–
	Behavioural	Not assessed	–
Ford[43] n = 241 (African American = 163, Caucasian = 78)	Clinical-unscheduled care, 4 m, 8 m, 1 yr	*ED visits No impact (Note: these data are an a priori sub-group analysis) ED visits/year I: Baseline: 5.0 (SD 3.6) vs. FU 2.7 (SD 3.3); C: Baseline: 6.7 (SD 8.4) vs. FU: 4.8 (SD 6.8)	Illustrated as a consistent no effect
		No between group comparisons reported	
	Clinical-asthma control, 4 m, 8 m, 1 yr	Limited days of activity No impact (Note: these data are an a priori sub-group analysis)	
		Days/person: I: Baseline: 20.6 (SD 25.4); FU: 18.7 (SD 36.8) C: Baseline: 27.8 (SD 33.4); FU: 27.9 (SD 55.7); no between group differences reported	
FU: 4 m, 8 m, 1 yr Overall risk of bias: high	Process, 1 yr	*Knowledge and beliefs: no effect (Note: these data are an a priori sub-group analysis)	Illustrated consistently no effect
		Mean scores I: Baseline: 14.1 (SD 2.9); FU: 14.6 (SD 3.2) C: Baseline: 14.3 (SD 2.3); FU: 14.7 (SD 2.3)	
		No between group differences reported	
	Behavioural	Not assessed	–
Kesto[39] n = 52 adults	Clinical-unscheduled care, 1 yr	*Unscheduled care: compared to controls, the intervention reduced ED visits but not hospitalisations	Illustrated as a significant positive effect but hatched to show inconsistency
		*Change in ED visits Baseline: I: 4.4 (SD 2.7) vs. C: 3.4 (SD 2.6); FU: I: 2.6 (SD 2.6 vs. C: 3.5 (SD 2.7) Between group difference p = < 0.01	
		Change in hospitalisations Baseline: I: 1.3 (SD 1.3) vs. C: 1.0 (SD 1.2); FU: ± 0.5 (SD 0.8) vs. C: 0.5 (SD 0.9) Between group difference p = 0.37	
FU: 1 yr, telephone every 2 wks to every 6 m Overall risk of bias: unclear	Clinical-asthma control	Not assessed	–
	Process, After intervention	No data reported for knowledge	Insufficient data
		No data reported for medicine treatments	

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Table 3 continued

Citation design, sample group/size and risk of bias score	Outcome categories, FU	Reported outcomes-values for intervention (I)/control (C) a indicates the primary outcome (if stated)	Researcher's interpretation for the harvest plot
Kesio[44] n = 39, adults	Behavioural Clinical-unscheduled care, 1 yr, 2 yr	Not assessed. Unscheduled care: Intervention group had a greater reduction in hospitalisations and ED visits. "Change in ED visits: Median (IQR) visits 2 years, I: 0 (0, 0) vs. C: 2 (1.5, 2); p = <0.05. "Change in hospitalisations. Median (IQR) hospitalisations, I: 0 (0, 0) vs. C: 0.5 (0, 1); p = <0.05	Illustrated as a consistent significant positive effect
FU: every month then every 2–3 m. Overall risk of bias: High	Clinical-asthma control 6 m, 1 yr, 18, 2 yr	No control group data reported for quality of life, asthma bother or peak flows	Insufficient data
	Process, before and after intervention	No control group data reported for Knowledge control group. No control group data reported for medicine treatments control group	Insufficient data
	Behavioural	Not assessed	–
Velsor-Friedrich[40] CCT n = 102, children	Clinical-unscheduled care, 2 wks, 5 m, 1 yr	Unscheduled care: the intervention group had significantly more unscheduled visits at 5 m and 1 yr. Medical visits at 5 m. Mean (SE) I: 0.12 (0.05) vs. C: 0.02 (0.04). Medical visits at 1 yr. Mean (SE) I: 0.07 (0.03) vs. C: 0.00 (SD 0.02); p = 0.01	Illustrated as a consistent significant negative effect
FU: 2 wks, 5 m, 1 yr Overall risk of bias: unclear	Clinical-asthma control, 2 wks, 5 m, 1 yr	Symptom days: greater reduction in days with symptoms in intervention compared to control. Symptom days at 5 m. Mean (SE) I: 2.15 (SE 0.30) vs. C: 1.42 (SE 0.21). Symptom days at 1 yr. Mean (SE) I: 1.26 (SE 0.33) vs. C: 1.49 (SE 0.23); p = 0.047. PEFR: intervention group had greater increase in PEFR at both FU time-points. % increase in PEFR at 5 m. I: 2.9% (SE 2.0%) vs. C: 2.9% (SE 1.0%). % increase in PEFR at 1 yr. I: 7.5% (2.0%) vs. C: 2.9% (SE 1.2%); p = 0.046. School absences: no between group difference in days absent from school. Days absent at 1 yr. I: 9.03 vs. C: 14.4 days	Illustrated as a consistent positive effect but hatched to show inconsistency
	Process, 2 wks, 5 m, 1 yr	Knowledge, self-efficacy and self-esteem/motivation: no significant between group differences. Asthma knowledge test at 5 m. I: 14.05 (SE 0.55) vs. C: 13.35 (SE 0.38). Asthma belief survey at 5 m. I: 4.23 (SE 0.10) vs. C: 4.15 (SE 0.08). Self-perception inventory at 5 m. I: 2.80 (SE 0.08) vs. C: 2.85 (SE 0.05)	Illustrated as a consistent no effect
	Behavioural, 2 wks, 5 ms	Self-practice/asthma self-care: No significant between group differences. Denyes self-care agency instrument at 5 m: 72.03 (SE 2.46) vs. 70.57 (SE 1.68)	Illustrated as a consistent no effect
Velsor-Friedrich[41] CCT n = 52, children	Clinical-unscheduled care, 2 wks, 5 m, 1 yr	Asthma self-care instrument at 5 m: 68.67 (SE 2.89) vs. C:70.41 (SE 2.00). Urgent medical visits (and medications): no significant between group differences at any time point. Urgent doctor visits at 12 m. I: n = 4 (14%) vs. C: n = 5 (20%)	Illustrated as a consistent no effect
FU: 2 wks, 5m, 1 yr, 2 yr Overall risk of bias: unclear	Clinical-asthma control, 2 wks, 5 m, 1 yr, 2 yr	No data: some data on medicine use was provided. Symptoms, PEFR and school absences: no significant between group differences at any time point	Illustrated as a consistent no effect

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Citation design, sample group/size and risk of bias score	Outcome categories, FU	Reported outcomes-values for intervention (I)/control (C) *indicates the primary outcome (if stated)	Researcher's interpretation for the harvest plot
	Process, 2 wk, 5 m, 12 m	Proportion with > 1 day with symptoms/2 wks at 1 yr: I: 14 (50%) vs. C: 13 (54%) % increase in PEFR from baseline at 1 yr: I: 26.21% (SD 0.22) vs. C: 27.80% (SD 0.31)	Illustrated as a consistent positive effect but hatched to show inconsistency
		Average days absent from school. I: 9.03 vs. C: 14.4	
		Knowledge and self-efficacy: Intervention group had higher scores at all time-points, but neither group improved over time	
		Asthma Knowledge: test at 1 yr. Adjusted mean I: 14.28 (SE 0.80) vs. C 11.88 (SE 0.87); p = 0.03	
		Asthma belief scale at 1 yr. Adjusted mean I: 4.09 (SE 0.14) vs. C: 3.82 (SE 0.15); p = 0.01	
		Self-esteem: no significance between group differences at any time point	
		Self-perception inventory at 1 yr. Adjusted mean I: 2.71 (SE 0.08) vs. C: 2.78 (SE 0.10)	
	Behavioural, 2 wks, 5 m, 1 yr	Asthma self-care practice/general self-care: intervention group had higher scores at all time-points, but neither group improved over time	Illustrated as a consistent positive effect
		Denyes self-care agency instrument: I: 75.55 (SE 2.60) vs. 67.41 (SE 2.82); p = 0.01	
		General self-care: I: adjusted mean I: 72.99 (SE 3.26) vs. C: 63.75 (SE 3.53); p = 0.2	
Velsor-Friedrich[45] RCT n = 137, adolescents	Clinical-Unscheduled care, 6 m, 12 m	Hospital visits: no significance between group differences p > 0.05 (no other data provided)	Illustrated as a consistent no effect
FU: 2 m, 6 m, 1 yr Overall risk of bias: high	Clinical-asthma control, 6 m, 1 yr	Symptoms reduced in both groups: no significant between group differences	Symptom takes priority. Illustrated as a consistent no effect
		PEFR: no significance between group differences	
		School absences reduced in both groups, no significant between group differences	
	Process, 6 m, 1 yr	Knowledge, self-efficacy improved in both groups: no significant between group differences	Illustrated as a consistent no effect
		Coping frequency/efficacy, no significance between group differences	
	Behavioural, 6 m, 1 yr	Self-care practice, no significance between group differences	Illustrated as a consistent no effect

For conflicting outcomes within a category, the decision process was dependent upon priority of evidence including
• Defined primary outcomes in an adequately powered sample/sub-group analysis (for the latter we will consider a prior sub-group analysis)
• Outcomes measured using a validated instrument (as opposed to non-validated instruments)
• Outcomes that were clinically and statistically significant (e.g. achieved minimum clinically important difference)
• If doubts remain, the author's interpretation was considered to provide context for the final decision

Note:
• For quality of life outcomes, we will use the overall score. If no overall score is stated the outcome will not be plotted
• Asthma related quality of life scales will be given priority (e.g. AQLQ) over generic quality of life scales (e.g. EQ5D)
• For the clinical-asthma control category, symptoms will be a priority over other outcomes in the same category as it is a better indicator of asthma control

Abbreviations; FU follow-up, wks weeks, m month, yr year, RCT randomised control trial, CCT clinical control trial, ED emergency department visits, I intervention, C control, CI confidence interval, AQLQ quality of life questionnaire, AQ20 the airways questionnaire 20, ACT asthma control test, F F statistics, AHR adjusted hazard ratio, HR hazard ratio, OR odds ratio, EES estimated effect size, PEFR peak expiratory flow rate, SD standard deviation, SE standard error, DF degree of freedom, p p-values

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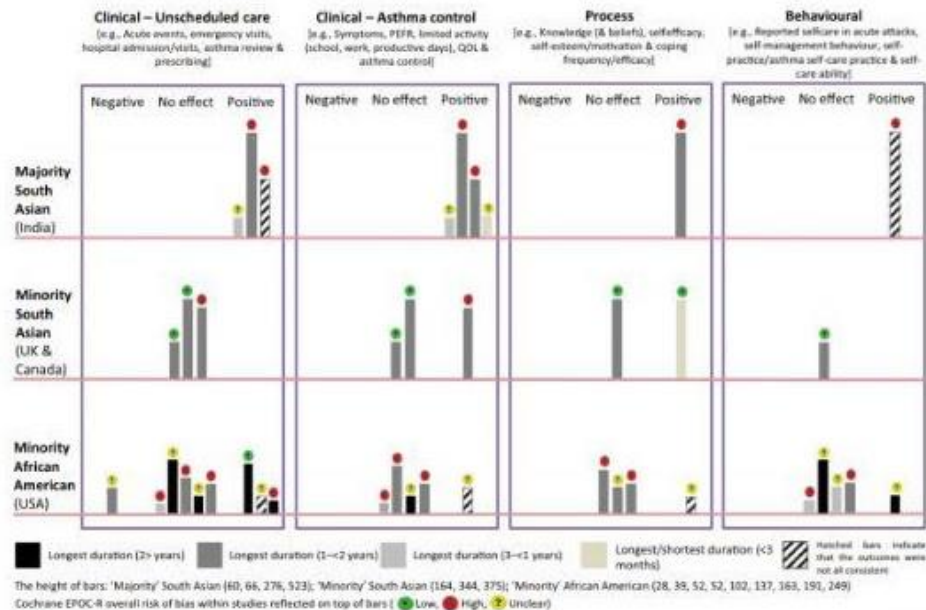Interventions to enhance the adoption of asthma
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Fig. 2 Harvest plots illustrating the effectiveness on clinical, process and behavioural outcomes of self-management interventions across different ethnic groups and social contexts. To determine the overall effectiveness of trials, plots were placed under each category (unscheduled care, asthma control, process or behavioural), according to whether findings were positive (i.e., interventions, which were significantly effective in the intervention group), negative (i.e., interventions, which were significantly effective in the control group), or outcomes that had no impact between groups. The colours of the plots in the graph represent the study length (long and/or short), the height of the bars represent the sample size and the icon on the top of the bars represent the overall risk of bias within studies

the distinction between modified, tailored and targeted interventions is not clear-cut. Both culturally targeted interventions also incorporated some modified components,[21,37] e.g., adaptation of language in PAAPs to meet the target population needs.[31]

(2) Effectiveness of interventions in different sociocultural contexts. In the harvest plot (Fig. 2 and Table 3), the four outcome categories (i.e., unscheduled care, asthma control, process and behavioural), are plotted for the three ethnic groups, 'majority' South Asian, 'minority' South Asian and 'minority' African American.[47] The harvest plots show that the interventions in the 'majority' South Asian trials were effective, though notably they were all based in tertiary care settings potentially serving a relatively severe asthma population (thus with greater potential for improvement).[30-33] In addition, risk of bias, was either high,[31,32] or unclear,[30,33] and two of these trials had short follow-up periods (1 and 4 months).[30,33]

In contrast, trial outcomes from studies involving both 'minority' communities were inconsistent, though more trials were at a low risk of bias,[34,35,46] in contrast to 'majority' trials. In the 'minority' South Asian trials, most of the outcomes did not show significant benefit.[34-36] The exceptions were improved quality of life in a trial at high risk of bias,[36] and in another study improved self-efficacy at 3 months, which was not sustained at 12 months.[35] Similarly, in 'minority' African-American trials (all but one were at high or unclear risk of bias),[46] most interventions were ineffective,[38,40-43,45] or inconsistent.[39-41] In addition, one trial at unclear risk of bias had a *negative* impact on unscheduled care.[45] Three trials had

positive outcomes (unscheduled care and behavioural),[41,44,46] of which one trial was at a low risk of bias.[46]

(3) Identified barriers and facilitators to self-management in included trials. A range of barriers and facilitators to asthma self-management were identified and differentiated according to ethnicity and sociocultural context (illustrated in Fig. 3). Key findings were that:

- Across both ethnic groups and all social contexts, barriers included insufficient knowledge and understanding of asthma and related factors[31,36,37,43]; facilitators included providing self-management education,[21,32,37,39,44,45] and support from healthcare professionals (with continuity of care).[31,32,37,41,44]
- In 'minority' trials, even though language barriers were accounted for,[36,37] a barrier identified for South Asians, was insufficient consideration of individual learning styles related to age,[36,37] gender[36,37] and level of education.[37] In a 'minority' African-American trial, culturally/age specific self-management strategies (e.g., gaming) were identified as a facilitator.[45]
- A facilitator that occurred frequently in studies involving South Asians across both majority and minority settings was providing culturally and linguistically appropriate educational materials. Language barriers were not an issue for 'minority' African Americans.[31,36,37]
- Some barriers and facilitators were specific to one of the two ethnic groups or social context. For instance, facilitators for 'majority' South Asian trials included generic self-management strategies,[30-32] e.g., use of PAAPs,[30] written reinforcement,[31]

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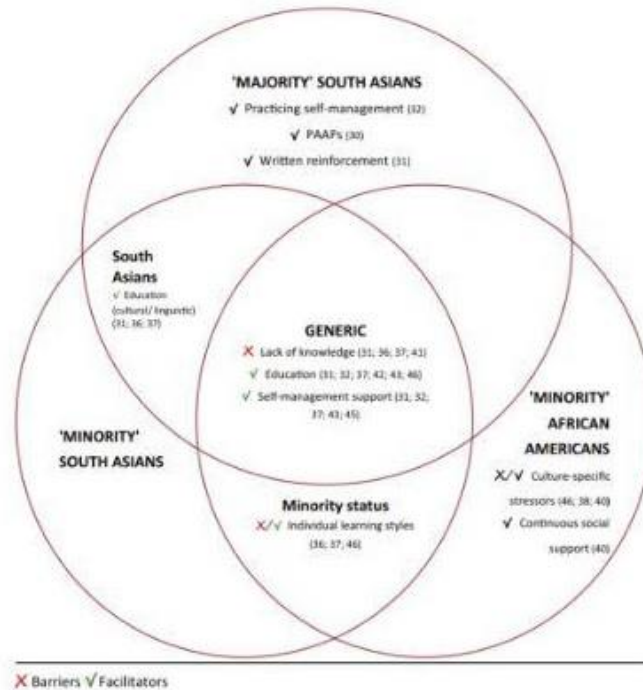Interventions to enhance the adoption of asthma
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Fig. 3 Summary of identified barriers and facilitators to asthma self-management in interventions across different groups

and practising preventative behaviour.[32] One African-American trial observed that stressors (e.g., neighbourhood violence), interfered with generic self-management strategies such as relaxation and breathing exercises in adolescents.[45] Similarly, three African American trials incorporated discussions of managing common stressors in daily African American lives as a facilitator, because this allowed individuals to focus on asthma.[42,45,46] Another African-American trial identified social support as a facilitator.[46]

DISCUSSION

Main findings

We identified seventeen RCTs, most at unclear or high risk of bias, which tested asthma self-management interventions for South Asian or African-American communities. Education was a component of all interventions, but content, mode of delivery and additional strategies varied.[30–46] Only two interventions were culturally targeted,[31,37] in contrast to 15 culturally modified interventions,[30,32–36,38–46] and no culturally tailored interventions. Trials based in South Asian countries,[30–33] appeared to be more effective than those delivered to minority populations (for both South Asians and African Americans),[34–36,38–46] though with the caveat that none of the 'majority' population trials were at low risk of bias and targeted populations were from tertiary care hospitals (in whom it may have been easier to demonstrate health benefits due to more severe asthma).[34,35,46] Hence, it is unclear whether culture or minority-status of an ethnic group influences the variance in self-management outcomes. Education with on-going professional support was identified as a facilitator to asthma self-management in all groups.[31,32,37,39,44,45] Other facilitators included focussing on individual learning styles in minority communities,[45] culturally and linguistically appropriate education for minority and indigenous South Asians,[31,36,37] generic self-management strategies in 'majority' South Asian communities,[30–32] and strategies for dealing with stress and social support in African-American populations.[42,45,46]

Interpretation of findings in relation to previously published literature

A previous systematic review[14] concluded that a culturally targeted intervention[48] (in line with the definitions of this review) was more effective than generic programmes in improving asthma outcomes, and revealed that most interventions were culturally modified. We found only two culturally targeted interventions,[31,37] suggesting that this recommendation has not been adopted, hence progress in this area of research has not advanced. This may be due to the expensive and lengthy nature of developing targeted or tailored interventions compared to the ease of adapting or re-testing modified interventions,[14,17] however, in the long-term culturally targeted or tailored interventions may be more cost-effective. Trials have typically considered ethnic groups as homogenous, e.g., they do not consider variation among smaller subcultural groups of South Asians or African Americans, or the influence of acculturation in minority communities, potentially important for designing interventions.[34–36,38–46]

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The two culturally targeted trials also included some modified characteristics, e.g., language adaptation for PAAPs, so the distinctions between culturally relevant interventions is not absolute. This is supported by a previous systematic review,[19] which found interventions labelled as targeted or tailored also incorporated modified features, e.g., community/participatory approach to smoking cessation. It may be that modification of certain proven asthma self-management strategies, e.g., PAAPs, together with customising by culturally specific elements is an optimal approach.

Targeted trials customise the development of interventions to a cultural group rather than just adjusting the content. For instance, interventions developed collaboratively with target groups helped existing self-management strategies to be linguistically and culturally relevant.[7,16,31,37] This can be further understood as aiming at deep structures, e.g., cultural beliefs, norms, lifestyles, environmental and social contexts, which aid receptivity of information and behaviour change. The Person-Based Approach[49] to intervention development suggests that comprehension of user perspectives and contexts based on qualitative studies at every stage of development is central to customisation. In contrast, modifying surface structures to observable traits, e.g., language, ethnicity, food and clothing, may influence information processing but not behaviour change (a common characteristic of modified interventions).[23] For instance, two 'minority' South Asian trials modified interventions according to language with mostly ineffective outcomes, suggesting merely focussing on language modifications is insufficient for their needs.[35,36] However, more rigorous trials are needed, as both targeted interventions had either high or unclear risk of bias.[31,37]

Similarly, some 'majority' South Asian interventions were modified from generic programmes rather than developed for their own community.[30,32,33] For example, Ghosh et al.[32] a trial from India, adapted self-management strategies from an intervention from Colorado, USA.[50,51] Trials from diverse sociocultural contexts and different cultural groups demonstrate the potential pitfalls of extrapolating findings from one context and applying it to another.[16,20,21] A possible explanation for 'majority' South Asian trials incorporating culturally modified strategies may be that international clinical guidelines for respiratory diseases,[30-32] e.g., GINA,[6] promote a generic model of self-management interventions with evidence and examples from high-income populations and recommendation of adaption to low or middle-income countries (LMICs).[27] While remaining true to the core evidence-based features of supported self-management presented in guidelines, intervention developers also need to deliberate on the principles of cultural relevance to the targeted local community, rather than depending on translation.[52] For LMICs, this may be challenging due to the lack of resources, training and manpower, as well as public health priorities and models of care focusing on communicable rather than long-term conditions.[27,28,53] GINA guidelines acknowledge these difficulties, but do not offer specific guidance on providing targeted or tailored self-management;[54] in contrast to the advice about cost-effective options for diagnosis and treatment in LMICs.[6,28]

Conceptualising culture with its interaction with context offers new avenues of comprehending the role of culture in health. Apart from better outcomes in 'majority' South Asian trials based in tertiary care settings compared to 'minority' communities,[30-33] poor reporting with limited descriptions of SES,[30-33,37-39,42,44,45] and diversity of trial settings,[34-41,45-46] meant we were unable to draw conclusions about associations between outcomes and contextual data. This is an important point as variations in SES within a culture has been suggested to determine health outcomes, e.g., restrictions in accessing services.[29] In LMICs such as India, tertiary care may currently be the only practical setting for delivering asthma self-management interventions due to lack of community-based clinical and research expertise, as well as

social and financial barriers that result in under-diagnosis, under-treatment and limited treatment availability. In the absence of adequately resourced primary care, it is common for individuals in these populations (particularly for children) to only access healthcare during exacerbations, rather than receiving preventative care.[28,53]

Strengths and limitations of this study

To our knowledge, this review is one of few studies analysing the effectiveness of South Asian or African-American asthma self-management interventions. By identifying barriers and facilitators across two different ethnic groups and sociocultural contexts, our review can inform the customisation of interventions.[21,52,53] We included seventeen trials, though the exclusion criteria of requiring separate outcome data for the specific groups of interest may have restricted the number of articles included in the final analysis; identification of more culturally targeted and even some tailored trials would have been informative. Limited resources precluded duplicate selection of papers, but we undertook a ten percent reliability check of the selection process. Risk of bias assessment was duplicated and data extraction was fully checked by a second reviewer.

Further, limited descriptions of the studies made it difficult to know how the interventions were developed or on what they were based on, particularly in the 'majority' South Asian trials.[30,32,33] In addition, few authors responded to our request for further information. This meant that one of the targeted trials was excluded from the harvest plot analysis because data on between group differences were missing.[37] Additionally, some harvest plot decisions relied upon sub-group analyses, which reduce study power and thereby could have increased the potential for null findings.[34,36,43] However, primary outcomes were prioritised and, for clarity, inconsistent findings were indicated by hatched bars to limit over interpretation.[35,39] Subjectivity in assessing the outcomes for the harvest plot was minimised by specifying predefined criteria that were replicable, and all the judgements were checked by at least two reviewers. Additionally, even though harvest plots are a good technique of illustrating heterogeneous findings and can be personalised to the requirements of the review, they may neglect some important outcomes that cannot be reported in the plots and overemphasise others.[4,55]

Conclusions and implications for future research, policy and practice

Asthma self-management interventions delivered in South Asian and African-American minority communities were less effective than interventions delivered in indigenous populations in South Asia, though the design/conduct of the latter studies meant that they were at greater risk of bias. Additionally, most trials from India are not designing interventions to their community, instead they are following guideline recommendations from studies in high-income countries. Studies that improve understanding of sociocultural contexts, allow a deeper appreciation of customising interventions and how to prevent inequalities in self-management behaviour, both are needed to inform international asthma guidelines. Targeted or tailored intervention development does not exclusively include collaboratively developed components customised to beliefs and needs of the target ethnic group, but may also include adaption of existing resources. Intergroup subcultural heterogeneities, cultural changes over generations (due to acculturation) and individual learning styles, add to the complexity of self-management behaviour and all need to be explored further. Rigorous trials of culturally targeted or tailored interventions are needed. Moreover, there needs to be standard recommendations on how trials verify participant ethnicity/culture, as only three 'minority' South Asian trials defined ethnicity according to self-identification or language spoken and culture

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Table 4. Search strategy terms

Asthma	Self-management	Population search
Asthma	Self management OR asthma control OR self care	South Asians
	Barriers OR facilitators	Bengali OR Bangladeshi OR Bangladesh
	Beliefs OR attitudes	Indian OR India
	Knowledge OR asthma education	Pakistani OR Pakistan
		Black OR African OR Afro Caribbean
		Ethnic OR ethnicity

Table 5. PICO search strategy

PICO	Criteria
Population	South Asian communities (Indian, Pakistani, Bangladeshi etc.), or Black populations (African, Caribbean or Other) asthma patients, their parents/carers, healthcare or lay professionals. The search considered all population ages and countries
Intervention	Asthma self-management interventions in any healthcare, community or remote settings. We used the self-management definition of the US Institute of Medicine: *"The tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their conditions"*[40]
Comparator	Asthma patients, parents/carers of children with asthma, healthcare or lay professionals supporting asthma patients, who did not receive asthma self-management intervention
Outcomes	Outcomes of interest were: 1. Clinical outcomes: (i) current asthma control was defined as the degree to which different asthma manifestations were reduced/eliminated by treatment. Here, main categories include clinical-asthma control level (ii) future risk of adverse events and unscheduled healthcare utilisation. All clinical outcomes are aligned with the American Thoracic Society/European Respiratory Society Task Force standardised definitions[57] 2. Process outcomes: any outcome that occurred because of certain steps in a process, e.g., knowledge and self-efficacy 3. Behavioural outcomes: outcomes related to behaviour, e.g., medicine adherence and inhaler technique
Exclusion	1. All studies that did not explicitly specify population were excluded e.g., trials that did not provide details on which ethnic group they are referring to when they used broad terms such as 'West Indians' or 'Asians' 2. Studies of multiple ethnic populations that did not provide outcome data separately for the South Asian and the Black ethnic groups or subgroups were excluded 3. Trials studying multiple illnesses but did not provide separate outcome data for asthma were excluded

was not considered and/or perceived to be synonymous to ethnicity.[34,35,57]

METHODS

The review protocol is registered with the PROSPERO database (registration number CRD42015020174). We followed the procedures described in the Cochrane handbook for systematic review of interventions.[56]

Search strategy

Our key search terms were 'asthma' 'AND' 'self-management' 'AND' 'population' (including terms for South Asian and Black communities as summarised in Table 4 (detailed in Supplementary Appendix 1). We searched for RCTs on eight electronic databases (*Medline, EMBASE, Web of Science, PsycINFO, Scopus, Elsevier Science Direct, Cochrane Library including Cochrane Airways Group Register of Trials and Google Scholar*), three research registers in [February 2015] (*PROSPERO, The University of York's Centre for Reviews and Dissemination, and the Clinical Trials Database*), manually searched relevant journals (*Patient Education and Counselling, Health Psychology and Ethnicity and Health*), and searched reference lists of identified systematic reviews. The search was not confined by publication year or language.

Inclusion and exclusion criteria

We included RCTs evaluating self-management interventions delivered to South Asian or Black asthma patients, the parents/carers of children with asthma, lay or healthcare professionals who care for people with asthma from these communities. The search

included populations of all ages and in any country. Black African Americans, were included because they are from another well-studied minority population, with experience of socioeconomic deprivation, and our scoping of literature suggested there was a relatively large evidence base. Outcomes of interest were clinical (e.g., unscheduled care and asthma control),[57] process, behavioural (e.g., knowledge and medicine adherence). We excluded studies that did not specify their population (e.g., trials using broad terms when describing their population such as 'West Indians' and 'Asians'), and trials of multiple ethnic populations that did not provide separate asthma outcome data for the ethnic groups of interest (see Fig. 1; The PICO strategy is summarised in Table 5).

Study selection

A PRISMA diagram was used to report the number of studies identified, the screening process and the final list of included studies (see Fig. 1). All titles, abstracts and full texts were screened by one reviewer (S.A.), and a random 10% by two other reviewers (L.S., H.P.). Disagreements were resolved by discussion and the inclusion/exclusion criteria clarified as necessary.

Data extraction and risk of bias

A standardised Cochrane data extraction sheet was modified for this study.[58] All data extraction was completed by one reviewer (S. A.) and independently checked by a second reviewer (K.H.). Discrepancies were resolved by discussions between reviewers and the wider team (L.S., H.P.), until consensus was achieved. Trial authors were contacted by email to clarify any missing, unclear or additional data required. If contact with the author failed, the uncertainty was noted on the data extraction form. The Cochrane

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EPOC Risk of Bias Assessment Checklist,[59] was used to evaluate bias in included studies. This was independently coded by two researchers (S.A., K.H.), and any discrepancies were resolved by another researcher (L.S.).

Analysis

We anticipated that studies would be too heterogeneous for meta-analysis and, therefore, used a narrative synthesis, illustrating key findings on trial effectiveness with a harvest plot.[55] Harvest plots allow visual representation of the findings of a narrative synthesis (comparable to Forrest plots in a meta-analysis), facilitating comparison across studies.[55] They enable identification of interesting patterns among varying outcomes, and may highlight the strongest or most inconsistent evidence, areas of possible concern, and gaps in the research. If there were various outcomes in one category (e.g., the asthma control category might include symptom scores, symptom-free days, or days off work/school with a range of significant and non-significant results), the overarching outcome was determined according to predefined criteria (see note to Table 3), applied and agreed by three researchers (S.A., H.P. and/or L.S.).[55] Sizes of lines and colour hatchings were used to illustrate features of the trial according to a defined convention (see summary in footnote to Fig. 2 and detailed description in Table 3). Barriers and facilitators were identified from data and/or interpretations of study authors.

Data availability

All included papers are published; no further data are available. Requests for further information should be addressed to the corresponding author.

Disclaimer

The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

AUTHOR CONTRIBUTIONS

Development of concept and design of the work (S.A., L.S., H.P., S.J.C.T.), data collection (S.A., L.S.), screening and second reviewing titles, abstracts and full texts (S.A., L.S., H.P.), data extraction (S.A., K.H.), data analysis and interpretation (S.A., L.S., H.P.), second review of harvest plots analysis table (H.P.), third review of harvest plots analysis table (L.S.), initial draft of the manuscript (S.A.), critical revision of the article (S.A., H.P., L.S., S.J.C.T.), and final approval of the version to be published (S.A., H.P., L.S., S.J.C.T., K.H.). Salina Ahmed (S.A.); Hilary Pinnock (H.P.); Liz Steed (L.S.); Stephanie JC Taylor (S.J.C.T.); Katherine Harris (K.H.).

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Appendix 2. Detailed search strategy

Basic search strategy: Asthma search term AND Self-management terms AND Population search terms NOT Genetics NOT Qualitative OR Observational OR Cross-sectional OR Case control OR Cohort study (FILTERS: Humans; English). All searches in (title/abstract). Exemplar of search strategy on Medline database (Date searched: 18/02/15).

Search	Query	Items found
#1	Asthma	148124
#2	(Self management OR Self care OR Asthma control OR Barriers OR Facilitators OR Beliefs OR Attitudes OR Knowledge OR Asthma education)	1607427
#3	South Asians	4385
#4	(Bengali OR Bangladeshi OR Bangladesh OR Indian OR India OR Pakistani OR Pakistan)	462725
#5	Black	159599
#6	(African OR Afro Caribbean)	143933
#7	(Ethnic OR Ethnicity)	243317
#8	(Asthma) AND ((Self management OR Self care OR Asthma control OR Barriers OR Facilitators OR Beliefs OR Attitudes OR Knowledge OR Asthma education))	40018
#9	((((South Asians) OR ((Bengali OR Bangladeshi OR Bangladesh OR Indian OR India OR Pakistani OR Pakistan))) OR Black) OR ((African OR Afro Caribbean))) OR ((Ethnic OR Ethnicity))	849047
#10	(((Asthma) AND ((Self management OR Self care OR Asthma control OR Barriers OR Facilitators OR Beliefs OR Attitudes OR Knowledge OR Asthma education)))) AND (((((South Asians) OR ((Bengali OR Bangladeshi OR Bangladesh OR Indian OR India OR Pakistani OR Pakistan))) OR Black) OR ((African OR Afro Caribbean))) OR ((Ethnic OR Ethnicity)))	2706
#11	Genetics	2769758
#12	((((((Asthma) AND ((Self management OR Self care OR Asthma control OR Barriers OR Facilitators OR Beliefs OR Attitudes OR Knowledge OR Asthma education)))) AND (((((South Asians) OR ((Bengali OR Bangladeshi OR Bangladesh OR Indian OR India OR Pakistani OR Pakistan))) OR Black) OR ((African OR Afro Caribbean))) OR ((Ethnic OR Ethnicity)))))) NOT Genetics	2366
#13	(Qualitative OR Observational OR Cross-sectional OR Case control OR Cohort Study)	1128116
#14	(((((((Asthma) AND ((Self management OR Self care OR Asthma control OR Barriers OR Facilitators OR Beliefs OR Attitudes OR Knowledge OR Asthma education)))) AND (((((South Asians) OR ((Bengali OR Bangladeshi OR Bangladesh OR Indian OR India OR Pakistani OR Pakistan))) OR Black) OR ((African OR Afro Caribbean))) OR ((Ethnic OR Ethnicity)))))) NOT Genetics)) NOT ((Qualitative OR Observational OR Cross-sectional OR Case control OR Cohort study))	1622
#15	(((((((Asthma) AND ((Self management OR Self care OR Asthma control OR Barriers OR Facilitators OR Beliefs OR Attitudes OR Knowledge OR Asthma education)))) AND (((((South Asians) OR ((Bengali OR Bangladeshi OR Bangladesh OR Indian OR India OR Pakistani OR Pakistan))) OR Black) OR ((African OR Afro Caribbean))) OR ((Ethnic OR Ethnicity)))))) NOT Genetics)) NOT ((Qualitative OR Observational OR Cross-sectional OR Case control OR Cohort study)) Filters: Humans	1359
#16	(((((((Asthma) AND ((Self management OR Self care OR Asthma control OR Barriers OR Facilitators OR Beliefs OR Attitudes OR Knowledge OR Asthma education)))) AND (((((South Asians) OR ((Bengali OR Bangladeshi OR Bangladesh OR Indian OR India OR Pakistani OR Pakistan))) OR Black) OR ((African OR Afro Caribbean))) OR ((Ethnic OR Ethnicity)))))) NOT Genetics)) NOT ((Qualitative OR Observational OR Cross-sectional OR Case control OR Cohort study)) Filters: Humans; English	1339

Appendix 3. PRISMA checklist for systematic reviews

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	88
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	n/a for thesis
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	88-89
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	91-92
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	90
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	90-94
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	92-94
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Appendix 2
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	93-95
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	93-95
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	91-92

Appendix 3 continued			
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	93-94
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	Table 5
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	95-98

Appendix 4. Characteristics of excluded studies

	Citations	Reason/s for exclusion
1	Allen et al. (1995). Randomised trial of an asthma self-management programme for adults. *Thorax*, 50(7): 731-738.	Unspecified ethnicity (i.e. Australian born)
2	Al-sheyab et al. (2012). Peer-led education for adolescents with asthma in Jordan: A cluster-randomized controlled trial. *Pediatrics,* 129(1): E106-E112.	Irrelevant ethnicity (i.e. Arabic/Ethiopian)
3	Apter et al. (2013). Feasibility, acceptability and preliminary effectiveness of patient advocates for improving asthma outcomes in adults. *Journal of Asthma,* 50(8): 850-860.	No separate subgroup analysis for African-American/Black
4	Apter et al. (2011). Problem solving to improve adherence and asthma outcomes in urban adults with moderate or severe asthma: A randomized controlled trial. *Journal of Allergy and Clinical Immunology,* 128(3): 516-U122.	No separate subgroup analysis for African-American/Black
5	Bailey et al. (1990). A randomized trial to improve self-management practices of adults with asthma. *Archives of Internal Medicine,* 150(8): 1664-1668.	No separate subgroup analysis for Blacks
6	Bailey et al. (1999). Asthma self-management: Do patient education programs always have an impact? *Archives of Internal Medicine*, *159*(20), 2422-2428.	Reports only baseline outcomes for African-Americans
7	Barbanel et al. (2003). Can a self-management programme delivered by a community pharmacist improve asthma control? A randomised trial. *Thorax*, 58(10): 851-854.	Unspecified ethnicity (only mentions ethnic minority group)
8	Baren et al. (2001). A randomized, controlled trial of a simple emergency department intervention to improve the rate of primary care follow-up for patients with acute asthma exacerbations. *Annals of Emergency Medicine*, 38(2): 115-122.	Does not specify what is meant by the ethnic group 'Asian'; Not self-management
9	Bartholomew et al. (2000). Watch, Discover, Think, and Act: Evaluation of computer-assisted instruction to improve asthma self-management in inner-city children. *Patient Education and Counseling,* 39(2-3): 269-280.	No separate subgroup analysis for African-Americans (outcome data only on choice of character & coach) (N.B. This study is part of multiple studies i.e. no. 8, 9 & 82)
10	Bartholomew et al. (2006). Partners in school asthma management: Evaluation of a self-management program for children with asthma. *Journal of School Health*, 76(6): 283-290.	Does not specify what is meant by the ethnic group 'Asian American'; No separate subgroup analysis for African-Americans & Caribbean Americans (N.B. This study is part of multiple studies i.e. no. 8, 9 & 82)
11	Bell et al. (2010). Electronic health record–based decision support to improve asthma care: A cluster-randomized trial. *Pediatrics*, 125(4): e770-e777.	No separate subgroup analysis for Blacks
12	Bellin et al. (2014). The influence of community violence and protective factors on asthma morbidity and healthcare utilization in high-risk children. *Journal of Urban Health-Bulletin of the New York Academy of Medicine,* 91(4): 677-689.	This study is a secondary analysis of data from another RCT study; No separate subgroup analysis for 96% African-Americans

	Appendix 4 continued	
13	Bonner et al. (2002). An individualized intervention to improve asthma management among urban Latino and African-American families. *Journal of Asthma*, 39(2): 167-179.	No separate subgroup analysis for African-Americans
14	Brown, J. V. et al. (2002). Home-based asthma education of young low-income children and their families. *Journal of Pediatric Psychology,* 27(8): 677-688.	No separate subgroup analysis for African-Americans
15	Brown et al. (2006). Randomized trial of a comprehensive asthma education program after an emergency department visit. *Annals of Allergy Asthma & Immunology,* 97(1): 44-51.	No separate subgroup analysis for African-Americans
16	Brown et al. (2004). Physician asthma education program improves outcomes for children of low-income families. *Chest,* 126(2): 369-374.	No separate subgroup analysis for African-Americans
17	Bruzzese et al. (2011). Feasibility and preliminary outcomes of a school-based intervention for inner-city, ethnic minority adolescents with undiagnosed asthma. *Patient Education and Counseling,* 85(2): 290-294.	No separate subgroup analysis for African-Americans (N.B. This study is part of multiple studies i.e. no. 16 & 17)
18	Bruzzese et al. (2011). Effects of a school-based intervention for urban adolescents with asthma: A controlled trial. *American Journal of Respiratory and Critical Care Medicine*, 183(8): 998-1006.	Does not specify what is meant by the ethnic group 'Asian American'; No separate subgroup analysis for African-Americans & Caribbean-Americans (N.B. This study is part of multiple studies i.e. no. 16 & 17)
19	Bruzzese et al. (2008). Feasibility and impact of a school-based intervention for families of urban adolescents with asthma: Results from a randomized pilot trial. *Family process*, 47(1): 95-113.	No separate subgroup analysis for African-Americans
20	Bryant-Stephens et al. (2009). Impact of a household environmental intervention delivered by lay health workers on asthma symptom control in urban, disadvantaged children with asthma. *American Journal of Public Health,* 99 S3: S657-665.	No separate subgroup analysis for 94% Black non-Hispanics
21	Bryant-Stephens & Li (2008). Outcomes of a home-based environmental remediation for urban children with asthma. *Journal of the National Medical Association*, *100*(3): 306-316.	No separate subgroup analysis for African-Americans
22	Butz et al. (2010). Influence of caregiver and provider communication on symptom days and medication use for inner-city children with asthma. *Journal of Asthma, 47*(4): 478-485.	No separate subgroup analysis for African-Americans (N.B. This study is part of multiple studies i.e. no. 21 & 22)
23	Butz et al. (2012). Factors associated with completion of a behavioral intervention for caregivers of urban children with asthma. *Journal of Asthma, 49*(9): 977-988.	No separate subgroup analysis for African-Americans (N.B. This study is part of multiple studies i.e. no. 21 & 22)
24	Butz et al. (2005). Home-based asthma self-management education for inner city children. *Public Health Nursing, 22*(3): 189-199.	This study is a secondary cross-sectional analysis of an RCT study

	Appendix 4 continued	
25	Castro et al. (2003). Asthma intervention program prevents readmissions in high healthcare users. *American Journal of Respiratory and Critical Care Medicine*, *168*(9): 1095-1099.	No separate subgroup analysis for 'predominantly African-Americans'
26	Catov et al. (2005). Asthma home teaching: Two evaluation approaches. *Disease management,* 8(3): 178-187.	This study is a secondary analysis of two RCT studies; It compromises of a non-randomised design since the control group were those who declined the intervention; No separate subgroup analysis for 'predominately African-Americans'
27	Celan et al. (2012). Home-based family intervention for low-income children with asthma: A randomized controlled pilot study. *Journal of Family Psychology*, 26(2): 171-178.	No separate subgroup analysis for 98% African-Americans
28	Clark et al. (2010). From the female perspective: Long-term effects on quality of life of a program for women with asthma. *Gender Medicine,* 7(2): 125-136.	Unspecified ethnicity (i.e. it is not mentioned)
29	Clark et al. (2010). An evaluation of asthma interventions for preteen students. *Journal of School Health, 80*(2): 80-87.	Does not specify what is meant by the ethnic group 'Asian'; No separate subgroup analysis for African-Americans
30	De Oliveira et al. (1999). Evaluation of an educational programme for socially deprived asthma patients. *European Respiratory Journal, 14*(4): 908-914.	Unspecified ethnicity (i.e. it is not mentioned)
31	Eakin et al. (2012). Asthma in Head Start children: Effects of the Breathmobile program and family communication on asthma outcomes. *Journal of Allergy and Clinical Immunology,* 129(3): 664-670.	No separate subgroup analysis for 97% African-Americans
32	Evans et al. (1997). Improving care for minority children with asthma: Professional education in public health clinics. *Pediatrics, 99*(2): 157-164.	No separate subgroup analysis for African-Americans
33	Evans et al. (1999). A randomized clinical trial to reduce asthma morbidity among inner-city children: Results of the National Cooperative Inner-city asthma study. *The Journal of Pediatrics*, *135*(3): 332-338.	No separate subgroup analysis for Blacks
34	Flores et al. (2009). Improving asthma outcomes in minority children: A randomized, controlled trial of parent mentors. *Pediatrics, 124*(6): 1522-1532.	No separate subgroup analysis for African-Americans
35	Garrett et al. (1994). Prospective controlled evaluation of the effect of a community based asthma education centre in a multiracial working class neighbourhood. *Thorax,* 49(10): 976-983.	Irrelevant ethnicity (i.e. European, Maori, Pacific Islander & Not known)
36	George et al. (1999). A comprehensive educational program improves clinical outcome measures in inner-city patients with asthma. *Archives of Internal Medicine, 159*(15): 1710-1716.	No separate subgroup analysis for 'particularly African-Americans'
37	Gerald et al. (2009). Increasing adherence to inhaled steroid therapy among schoolchildren: Randomized, controlled trial of school-based supervised asthma therapy. *Pediatrics, 123*(2): 466-474.	The intervention is not really self-management but rather a trial of directly observed treatment (i.e. the intervention children were observed taking their preventer medication at school); No separate subgroup

	Appendix 4 continued	
		analysis for 91% Blacks
38	Gerald et al. (2006). Outcomes for a comprehensive school-based asthma management program. *Journal of School Health, 76*(6): 291-296.	No separate subgroup analysis for 98% Black African-Americans
39	Goeman et al. (2013). Educational intervention for older people with asthma: A randomised controlled trial. *Patient Education and Counseling, 93*(3): 586-595.	Does not specify what is meant by the country 'Asia'; No separate subgroup analysis for Indians & Sri Lankans
40	Gorelick et al. (2006). Emergency department allies: A controlled trial of two emergency department-based follow-up interventions to improve asthma outcomes in children. *Pediatrics*, *117*(4): S127-S134.	No separate subgroup analysis for Blacks
41	Greineder et al. (1999). A randomized controlled trial of a paediatric asthma outreach program. *Journal of Allergy and Clinical Immunology, 103*(3): 436-440.	Does not specify what is meant by the ethnic group 'Asian'; No separate subgroup analysis for Blacks
42	Griffiths et al. (2005). Randomised controlled trial of a lay-led self-management programme for Bangladeshi patients with chronic disease. *British Journal of General Practice, 55*(520): 831-837.	No separate outcome data for asthma (only mentions the rate of compliance with the intervention)
43	Griffiths et al. (2005). Expert Bangladeshi patients? *British Journal of General Practice*, 55: 000-000.	No separate outcome data for asthma
44	Guendelman et al. (2002). Improving asthma outcomes and self-management behaviors of inner-city children: A randomized trial of the Health Buddy interactive device and an asthma diary. *Archives of Pediatrics & Adolescent Medicine, 156*(2): 114-120.	No separate subgroup analysis for African-Americans
45	Gustafson et al. (2012). The effects of combining web-based eHealth with telephone nurse case management for paediatric asthma control: A randomized controlled trial. *Journal of Medical Internet Research*, *14*(4): 41-59.	No separate subgroup analysis for African-Americans
46	Halterman et al. (2014). Prompting asthma intervention in Rochester-uniting parents and providers (PAIR-UP) a randomized trial. *Jama Pediatrics*, *168*(10).	No separate subgroup analysis for Blacks
47	Homer, S. D. (2004). Effect of education on school-age children's and parents' asthma management. *Journal for Specialist Pediatric Nurse, 9*(3): 95-102.	No separate subgroup analysis for African-Americans
48	Horner, S. D. (2006). Home visiting for intervention delivery to improve rural family asthma management. *Journal of Community Health Nursing*, *23*(4): 213-223.	No separate subgroup analysis for African-Americans
49	Horner, S. D. & Fouladi, R. T. (2008). Improvement of rural children's asthma self-management by lay health educators. *Journal of School Health*, *78*(9): 506-513.	No separate subgroup analysis for African-Americans
50	Horner, S. D. & Brown, A. (2014). Evaluating the effect of an asthma self-management intervention for rural families. *Journal of Asthma*, *51*(2), 168-177.	Reports only baseline outcomes for African-Americans
51	Huss et al. (2003). Computer game for inner-city children does not improve asthma outcomes. *Journal of Pediatric Health Care, 17*(2): 72-78.	No separate subgroup analysis for non-Hispanic Blacks
52	Janevic et al. (2012). Study protocol for women of color and asthma control: A randomized controlled trial of an asthma-management intervention for African American women. *BMC Public Health*, 12.	No separate subgroup analysis for African-Americans

53	Janson et al. (2009). Individualized asthma self-management improves medication adherence and markers of asthma control. *Journal of Allergy and Clinical Immunology*, *123*(4): 840-846.	Does not specify what is meant by the ethnic group 'Asian'; No separate subgroup analysis for Blacks
54	Joseph et al. (2010). Factors associated with nonresponse to a computer-tailored asthma management program for urban adolescents with asthma. *Journal of Asthma*, *47*(6): 667-673.	No separate subgroup analysis for 98% African-Americans (NB. this study is part of multiple studies i.e. no. 52, 53 & 54)
55	Joseph et al. (2013). Evaluation of a web-based asthma management intervention program for urban teenagers: Reaching the hard to reach. *Journal of Adolescent Health, 52*(4): 419-426.	No separate subgroup analysis for 98% African-Americans (N.B. this study is part of multiple studies i.e. no. 52, 53 & 54)
56	Joseph et al. (2007). A web-based, tailored asthma management program for urban African-American high school students. *American Journal of Respiratory and Critical Care Medicine, 175*(9): 888-895.	No separate subgroup analysis for 98% African-Americans (N.B. this study is part of multiple studies i.e. no. 52, 53 & 54)
57	Karnick et al. (2007). The paediatric asthma intervention: A comprehensive cost-effective approach to asthma management in a disadvantaged inner-city community. *Journal of Asthma*, *44*(1): 39-44.	No separate subgroup analysis for African-Americans
58	Kercsmar et al. (2006). Reduction in asthma morbidity in children as a result of home remediation aimed at moisture sources. *Environmental Health Perspectives*, *114*(10): 1574-1580.	No separate subgroup analysis for Blacks ('mostly African/Americans')
59	Kintner & Sikorskii (2009). Randomized clinical trial of a school-based academic and counselling program for older school-age students. *Nursing Research*, *58*(5): 321-331.	No separate subgroup analysis for Blacks/African-Americans & Biracial (Black & White)
60	Klinnert et al. (2007). Outcome of a randomized multifaceted intervention with low-income families of wheezing infants. *Archives of Pediatrics & Adolescent Medicine*, *161*(8): 783-790.	Does not mention what is meant by the ethnic group 'Asian'; No separate subgroup analysis for African-Americans
61	Krieger et al. (2015). Community health worker home visits for adults with uncontrolled asthma the HomeBASE trial randomized clinical trial. *JAMA Internal Medicine, 175*(1): 109-117.	Does not specify what is meant by the ethnic group 'Other Asian'; No separate subgroup analysis for African-Americans
62	Krieger et al. (2009). A randomized controlled trial of asthma self-management support comparing clinic-based nurses and in-home community health workers: The Seattle–King County Healthy Homes II Project. *Archives of Pediatrics & Adolescent Medicine, 163*(2): 141-149.	Does not specify what is meant by the ethnic group 'Asian'; No separate subgroup analysis for African-Americans
63	Krieger et al. (2002). The Seattle-King County Healthy Homes Project: Implementation of a comprehensive approach to improving indoor environmental quality for low-income children with asthma. *Environmental Health Perspectives, 110*(Suppl 2): 311.	Does not specify what is meant by the ethnic group 'Asian'; No separate subgroup analysis for African-Americans
64	Kritikos et al. (2007). Interactive small-group asthma education in the community pharmacy setting: A pilot study. *Journal of Asthma, 44*(1): 57-64.	Unspecified ethnicity (i.e. not mentioned)

	Appendix 4 continued	
65	La Roche et al. (2006). A culturally competent asthma management intervention: A randomized controlled pilot study. *Annals of Allergy Asthma & Immunology, 96*(1): 80-85.	No separate subgroup analysis for African-Americans (only mentions no differences were found between African-Americans & Hispanics in any asthma management variables)
66	Levy et al. (2006). The efficacy of asthma case management in an urban school district in reducing school absences and hospitalizations for asthma. *Journal of School Health*, *76*(6): 320-324.	No separate subgroup analysis for African-Americans
67	Lewis et al. (1984). A randomized trial of ACT (asthma care training) for kids. *Pediatrics, 74*(4): 478-486.	Does not specify what is meant by the ethnic group 'Asian'; No separate subgroup analysis for Blacks
68	Liao et al. (2006). The Breathmobile (TM): A novel comprehensive school-based mobile asthma care clinic for urban underprivileged children. *Journal of School Health*, *76*(6): 313-319.	Irrelevant ethnicity (i.e. Hispanic/Latino, Other)
69	Magzamen et al. (2008). Kickin' asthma: School-based asthma education in an urban community. *Journal of School Health,* 78(12): 655-665.	Does not specify what is meant by the ethnic group 'Asians'; No separate subgroup analysis for African-Americans
70	Martin et al. (2009). Improving asthma self-efficacy: Developing and testing a pilot community-based asthma intervention for African American adults. *Journal of Allergy and Clinical Immunology*, *123*(1), 153-159.	No separate subgroup analysis for 'predominantly African-Americans'
71	Mayo et al. (1990). Results of a program to reduce admissions for adult asthma. *Annals of Internal Medicine*, *112*(11): 864-871.	No separate subgroup analysis for Blacks
72	Millard et al. (2003). A randomized controlled trial using the school for anti-inflammatory therapy in asthma. *Journal of Asthma, 40*(7): 769-776.	No separate subgroup analysis for 'predominately African-Americans'
73	Morgan et al. (2004). Results of a home-based environmental intervention among urban children with asthma. *New England Journal of Medicine, 351*(11): 1068-1080.	No separate subgroup analysis for Blacks
74	Mosnaim et al. (2013). The impact of peer support and mp3 messaging on adherence to inhaled corticosteroids in minority adolescents with asthma: a randomized, controlled trial. *Journal Allergy and Clinical Immunology Practice, 1*(5): 485-493.	No separate subgroup analysis for African-Americans (N.B. This study is part of multiple studies i.e. no. 71 & 72)
75	Mosnaim et al. (2008). Use of MP3 players to increase asthma knowledge in inner-city African-American adolescents. *International Journal Behavioural Medicine, 15*(4): 341-346.	No separate subgroup analysis for 'Primarily African-Americans' (N.B. this study is part of multiple studies i.e. no. 71 & 72)
76	Nelson et al. (2011). A randomized controlled trial of parental asthma coaching to improve outcomes among urban minority children. *Archives of Pediatrics & Adolescent Medicine*, *165*(6): 520-526.	No separate subgroup analysis for African-Americans
77	Otsuki et al. (2009). Adherence feedback to improve asthma outcomes among inner-city children: A randomized trial. *Pediatrics*, *124*(6): 1513-1521.	No separate subgroup analysis for Blacks
78	Parcel et al. (1980). A health education program for children with asthma. *Journal of Developmental & Behavioral*	No separate subgroup analysis for Blacks (only mentions

Appendix 4 continued

	Pediatrics, *1*(3): 128-132.		findings for health locus of control); Evaluation design is a semi-crossover method
79	Patel et al. (2014). Study protocol for improving asthma outcomes through cross-cultural communication training for physicians: A randomized trial of physician training. *BMC Medical Education*, 14.		This is a study protocol (ongoing study) therefore no outcome data
80	Pauley et al. (1995). Pharmacist-managed, physician-directed asthma management program reduces emergency department visits. *The Annals of pharmacotherapy*, *29*(1): 5-9.		No separate subgroup analysis for Blacks; It compromises of a non-randomised design since patients served as their own controls
81	Persaud et al. (1996). An asthma self-management program for children, including instruction in peak flow monitoring by school nurses. *Journal of Asthma, 33*(1): 37-43.		No separate subgroup analysis for 69% African-Americans
82	Seid et al. (2012). The in vivo adherence intervention for at risk adolescents with asthma: Report of a randomized pilot trial. *Journal of Pediatric Psychology, 37*(4): 390-403.		No separate subgroup analysis for African-Americans
83	Shackelford & Bachman (2009). A comparison of an individually tailored and a standardized asthma self-management education. *American Journal of Health Education, 40*(1): 23-29.		Does not specify what is meant by the ethnic group 'Asian'; No separate subgroup analysis for Blacks
84	Shames et al. (2004). Effectiveness of a multicomponent self-management program in at-risk, school-aged children with asthma. *Annals of Allergy, Asthma & Immunology, 92*(6): 611-618.		No separate subgroup analysis for African-Americans
85	Shegog et al. (2001). Impact of a computer-assisted education program on factors related to asthma self-management behavior. *Journal of the American Medical Informatics Association*, *8*(1): 49-61.		Does not specify what is meant by the ethnic group 'Asian'; No separate subgroup analysis for African-Americans (Blacks) (NB. This study is part of multiple studies i.e. no. 8, 9 & 82)
86	Shields et al. (1990). The effect of a patient education-program on emergency room use for inner-city children with asthma. *American Journal of Public Health, 80*(1): 36-38.		No separate subgroup analysis for Blacks
87	Sockrider et al. (2006). Delivering tailored asthma family education in a paediatric emergency department setting: A pilot study. *Pediatrics,* 117(S2): S135-S144.		No separate subgroup analysis for Blacks
88	Stevens et al. (2002). Parental education and guided self-management of asthma and wheezing in the pre-school child: A randomised controlled trial. *Thorax*, *57*(1): 39-44.		Does not specify what is meant by the ethnic group 'Asian/West Indian'
89	Tinkelman & Schwartz (2004). School-based asthma disease management. *Journal of Asthma, 41*(4): 455-462.		Irrelevant ethnicity (i.e. mostly Hispanic)
91	Walders et al. (2006). An interdisciplinary intervention for undertreated paediatric asthma. *Chest Journal*, *129*(2): 292-299.		Does not specify what is meant by the ethnic group 'Asians'; No separate subgroup analysis for African-Americans
92	Wilson et al. (2010). Does shared decision-making improve adherence in asthma. *American Journal of Respiratory and Critical Care Medicine, 181*(6), 566-577.		Does not specify what is meant by the ethnic group 'Asians'; No separate subgroup analysis for African-Americans

Appendix 4 continued		
93	Wilson et al. (2001). A controlled trial of an environmental tobacco smoke reduction intervention in low-income children with asthma. *Chest,* 120(5): 1709-1722.	Does not specify what is meant by the ethnic group 'Asians Other'; No separate subgroup analysis for African-Americans

Appendix 5. COREQ checklist for qualitative research (Bangladeshis and Pakistanis with asthma)

Domain 1: Research team and reflexivity	Guide questions/description	Reported on Page #
Personal characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	176
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	176
3. Occupation	What was their occupation at the time of the study?	176
4. Gender	Was the researcher male or female?	176
5. Experience and training	What experience or training did the researcher have?	176
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	171-172; 177
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Appendix 10; 11
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Appendix 10; 11
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	179
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	172
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	171-172
12. Sample size	How many participants were in the study?	180
13. Non-participation	How many people refused to participate or dropped out? Reasons?	180
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	177
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	177
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	180-183; Table 8
Data collection		

Appendix 5 continued

17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	175; Appendix 9
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	176
20. Field notes	Were field notes made during and/or after the interview or focus group?	Yes 177
21. Duration	What was the duration of the inter views or focus group?	180
22. Data saturation	Was data saturation discussed?	177
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	179-180
Data analysis		
24. Number of data coders	How many data coders coded the data?	180
25. Description of the coding tree	Did authors provide a description of the coding tree?	No
26. Derivation of themes	Were themes identified in advance or derived from the data?	No 179-180
27. Software	What software, if applicable, was used to manage the data?	179
28. Participant checking	Did participants provide feedback on the findings?	179-180
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	180
30. Data and findings consistent	Was there consistency between the data presented and the findings?	180-225
31. Clarity of major themes	Were major themes clearly presented in the findings?	180-225
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	225-241

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

আপনার হাঁপানি রোগ হওয়ার পর আপনি কি ভাবে নিজের পরিচর্য্যা করছেন? আপনার অনুভূতি আমাকে বলুন!

আপনার কি হাঁপানি রোগ আছে?
আপনি কি বাংলাদেশী অথবা বৃটিশ বাংলাদেশী?
বয়স কি ১৬ অথবা তার ওপরে?

আপনি সাক্ষাৎকারে আমন্ত্রিত আপনার অনুভূতি জানানোর জন্য!

- দক্ষিণ এশিয়ায় হাঁপানি রোগের স্বাস্থ্যগত মান তুলনামুলক ভাবে অন্য জাতির মানুষের তুলনায় নগন্য। বিভিন্ন মানুষ বিভিন্ন ভাবে অসুস্থতার পরিচর্য্যা করে। আমি দক্ষিন এশিয়ার মানুষের অভিজ্ঞতা শুনতে আগ্রহী।

- আমি শুনতে চাই আপনি কি ভাবে আপনার হাঁপানি রোগের পরিচর্য্যা করছেন এবং কি এটাকে প্রাভাবিত করছে?

- আপনি যা বলবেন তা আমি ব্যবহার করব সাংস্কৃতিকভাবে প্রাসঙ্গিক হাঁপানি সেবা বিকাশের ক্ষেত্রে, যা উন্নয়ন ঘটাবে দক্ষিণ এশিয়ার হাঁপানি রোগের স্বাস্থ্যগত মানের । (বাংলাদেশী এবং পাকিস্তানী)

কি ভাব এর সাথে জড়িত হবেন?

আপনার অংশগ্রহনের আগ্রহ জানিয়ে যোগাযোগ করুন প্রধান গবেষকের সাথে - সালিনা আহমেদ প্রধান গবেষক ০২০৭৮৮২২৫১৪ / salina.ahmed@qmul.ac.uk

Patient Recruitment Poster v1 11.06.16

آپ اپنے دمہ کی بیماری کی دیکھ بھال کس طرح کرتے ہیں؟ مجھے اپنی کہانی بتائیں

کیا آپ کو دمہ کی بیماری ہے؟

کیا آپ بنگلہ دیشی/ برطانوی نژاد بنگلہ دیشی یا پاکستانی/برطانوی نژاد پاکستانی ہیں؟

کیا آپ کی عمر 16 سال یا اس سے زیادہ ہے؟

ہے آپ کو اپنی کہانی بتانے کےلئے انٹرویو کی دعوت دی جاتی ہے

- جنوبی ایشیائی لوگوں کی صحت دمہ کے باعث دوسری نسلوں کے مقابلے میں زیادہ خراب ہوتی ہے۔ مختلف لوگوں کے پاس بیماری کی دیکھ بھال کرنے کے مختلف طریقے ہوتے ہیں۔ مجھے جنوبی ایشیائی آوازیں سننے میں دلچسپی ہے۔

- میں آپ سے سننا پسند کروں گی کہ آپ اپنے دمہ کی بیماری کی دیکھ بھال کس طرح کرتے ہیں اور اس کو کیا متاثر کرتا ہے۔

- میں آپ کی بتائی ہوئی باتوں کے استعمال سے ثقافت سے متعلقہ ایک سروس بناؤں گی جو کہ دمہ کے مریض جنوبی ایشیائی (بنگلہ دیشی اور پاکستانی) لوگوں کی صحت بہتر کرے گی۔

آپ کیسے شامل ہو سکتے ہیں؟

براۓ مہربانی پرنسپل محقق سے رابطہ کریں اور شریک ہونے میں دلچسپی کا اظہار کریں۔

سلینا احمد، پرنسپل محقق

020 7882 2514/salina.ahmed@qmul.ac.uk

Appendix 7. Patient study invitation letter

Exploring the Role of Bangladeshi & Pakistani Culture on Asthma Self-Management Behaviour

QUALITATIVE RESEARCH INTERVIEW

Date: XX XX XX

Dear XX,

I am writing to ask if you would be willing to take part in an interview study that is being carried out for my PhD at Queen Mary University of London. The aim of this study is to explore the role of culture in asthma self-management (i.e. how you look after your own asthma), and what influences this. We are particularly interested in the views of Bangladeshi and Pakistani individuals with asthma. By being involved in a face to face interview I would like to hear what you think about asthma management, the things you find helpful and things that you don't, and how we might improve health services that are provided to you.

Please find enclosed:

- An information sheet about the study, which contains the researchers contact details.
- If you cannot speak, read or write English, a translated CD or an emailed audio recorded version of the patient information sheet can be requested by contacting the researcher on the details below.
- A form to return, to let me know if you are happy to be contacted for the interview. Please return this in the pre-paid envelope provided (The envelope does not need a stamp).

If you require any further information on the study or require help with filling in the form, please contact the principal researcher, Salina Ahmed on 020 7882 2514 or salina.ahmed@qmul.ac.uk.

Thank you for your time.

Yours sincerely,

Salina Ahmed

Principal Researcher/Trainee Health Psychologist

Appendix 8. Patient expression of interest form

Exploring the Role of Bangladeshi & Pakistani Culture on Asthma Self-Management Behaviour

If after reading and/or listening to the enclosed Patient Information Sheet you are interested in helping with our study, please return this form so a researcher can contact you and explain more about the study.

Contact Information

Name:	
Address:	
Telephone number:	Best time to contact you
Email address:	
Preferred method of contact:	☐ Phone ☐ Email ☐ Post

About You and Your Asthma (We will only use this information to ensure interviews are held with a wide range of people).

Gender	☐ Female ☐ Male
Age	☐ 16-25 ☐ 26-45 ☐ 46-65 ☐ 65 or older
How do you identify yourself?	☐ South Asian: Bangladeshi/Pakistani/Indian ☐ British South Asian ☐ British Bangladeshi, British Pakistani, British Indian etc. ☐ British ☐ Other, specify:
What language/s can you speak?	☐ South Asian only (e.g., Bengali, Sylheti Urdu, Hindi, Punjabi, Kashmiri, Mirpuri etc...). ☐ Mostly South Asian, some English. ☐ South Asian and English about equally well (bilingual). ☐ Mostly English, some South Asian. ☐ Only English. Please specify which South Asian languages you can speak: ☐ Standard Bengali ☐ Sylheti ☐ Urdu ☐ Punjabi ☐ Kashmiri ☐ Mirpuri ☐ Other _____
How would you rate yourself?	☐ Very South Asian ☐ Mostly South Asian ☐ Bicultural (i.e. being a part of two or more cultures whether this is nations or ethnic groups) ☐ Mostly Westernized ☐ Very Westernized
How long have you had asthma?	

Once completed, please return in the stamped addressed envelope provided. Thank You.

Appendix 9. Patient interview schedule

Questions	*Prompts*
1. Opening Question: Tell me about your asthma?	*Diagnosis, meaning of asthma, symptoms and triggers*
2. What does asthma self-management mean to you? What do you do to look after your asthma?	*N.B. If a participant did not know about self-management a brief explanation was given and opinions regarding this were noted*
3. Tell me about your confidence in looking after your asthma?	*Self-efficacy*
4. What influences the way you look after your asthma?	*Culture, religion, identity, employment, education Understanding of asthma medication*
5. In general, what do you think is the view of people in your community on asthma? How asthma is managed?	*Relationships with those with or without asthma, family/peers, opinions on self-management of others*
6. Who is your first point of contact for problems related to your asthma?	*Most important HCP in asthma care and relationship healthcare professional*
7. What can healthcare/other professional services do to build a stronger relationship with Bangladeshi/Pakistani people with asthma?	*Thoughts on intervention: content, mode of delivery, format Improvements on PAAPs (N.B. all participants were shown a PAAP as an example to discuss its usefulness and how it can be adapted/tailored for them)*
8. Is there anything else you would like to share?	

Appendix 10. Patient information sheet

PATIENT INFORMATION SHEET: An invitation to take part in asthma research

Exploring the Role of Bangladeshi & Pakistani Culture on Asthma Self-Management Behaviour.

Salina Ahmed, Principal Researcher, 020 7882 2514, salina.ahmed@qmul.ac.uk

Can you help me by taking part in an interview

- First you need to understand what is involved & why the interview is being held.
- Please read the following information & discuss it with others if you wish.
- Do ask me if things are not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

Background of the study

- I want to look at the role of your culture on asthma self-management (i.e. practical ways you look after your asthma) & what influences this.
- South Asians have poorer asthma health & go into hospital more often than the general White population with asthma. Different people have different ways in looking after their illness. I am interested in South Asian voices.
- Taking part will help me understand asthma self-management in South Asians, particularly how culture affects self-management practices.
- This study will help develop or improve asthma services that are suitable for South Asian needs.

What is involved if I decide to take part?

- You do not need to take part in this study. But, if you decide to take part, you will be asked to sign (or verbally agree if you cannot write/read English) a consent form.
- I will interview you, which will last no longer then one hour & it will be audio recorded.
- You are free to withdraw from this study at any time without any explanation.
- Whether you take part in this study will not make a difference to the asthma care you receive.

- It is possible that some of the questions asked in the interview may cause some distress or if poor asthma control is identified, the researcher will pause/stop the interview and advise you to seek help from your GP.
- All collected information will be confidential (e.g. audio recording of interviews) will be stored in a locked filling cabinet & protected computer folder, kept securely at Queen Mary University of London.
- If you are aged between 16-18, it is not necessary to disclose any confidential information to your parent/guardian. However, if the researcher identifies potential asthma health concerns, this will be discussed with you and you will be encouraged to disclose this information with your parent/guardian.
- After the end of the study, the findings will be presented at conferences, published in a journal & as part of a PhD thesis. Any data collected including direct interview quotes will remain confidential, anonymous & will be stored safely.
- The research study will be expected to end on September 2017. Data will only be accessed by the researcher & the research team, until it is no longer required, when it will be safely shredded or erased.
- This study has gained ethical approval from NHS ethics.

What are the benefits/risks of taking part?

- Taking part in this research will not benefit you personally, however being involved in the study will contribute to the development/improvement of healthcare services for South Asian patients with asthma.
- Your treatment will not be affected. We are only asking for your opinion.

If you would like to complain you can contact the Patient Advice & Liaison Service by email/telephone pals@bartshealth.nhs.uk /020 3594 2040.

Please complete the enclosed forms, sign it & return it in the prepaid reply envelope.

This project is funded by Asthma UK Centre for Applied Research.

Patient information sheet v2 01.01.17 IRAS ID 200955

Appendix 11. Illustrative material one. Audio-recorded patient information sheets and consent forms (English; Sylheti; Urdu)

A CD containing the audio PIS and consent forms in English, Sylheti and Urdu have been placed at the back of the thesis. In addition, the audios can be found online in the Dropbox folder link:

https://www.dropbox.com/sh/sj97snomtrklc6i/AAAgOMGeOOqecC4dfdmjpWFha?dl=0

Participant Identification Number		

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research

QUALITATIVE STUDY CONSENT FORM

Exploring the Role of Bangladeshi & Pakistani Culture on Asthma Self-Management Behaviour

Salina Ahmed, *Principal Researcher, 020 7882 2514, salina.ahmed@qmul.ac.uk*

		Please initial each box
1.	I confirm that I have read and understood the attached information sheet for the above study *(v1 11.07.16)* and I have had the opportunity to ask questions.	
2.	I consent to take part in an interview for the above study.	
3.	I understand that my participation is voluntary, and I am free to withdraw at any time without giving any reason (Whether you take part in this study will not make a difference to the asthma care you receive).	
4.	I understand for this interview will be audio recorded and give consent to this.	
5.	I give permission for my age, gender and other non-identifiable background details to be used in the analysis of the results.	
6.	I understand my interview data/notes to be looked at by the research team and give consent for this.	

Name _____   Date ___/___/____

Signature _____

Or audio recorded verbal consent taken?   ☐ Yes   ☐ No   ☐ N/A

Name of person taking consent _____   Date ___/___/____

Signature _____

Appendix 13. Ethics approval for qualitative research

NHS

Health Research Authority

Miss Salina Ahmed
Centre for Primary Care & Public Health
Yvonne Carter Building, 58 Turner Street
London
E1 2AB

Email: hra.approval@nhs.net

23 January 2017

Dear Miss Ahmed

Letter of HRA Approval

Study title:	Exploring the role of Bangladeshi and Pakistani culture on asthma self-management behaviour: Patient and healthcare perspectives (Qualitative and intervention development study).
IRAS project ID:	200955
Protocol number:	1
REC reference:	16/YH/0524
Sponsor	Queen Mary University of London

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

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

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

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

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the After Ethical Review document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

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User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **200955**. Please quote this on all correspondence.

Yours sincerely

Rekha Keshvara
Assessor

Email: hra.approval@nhs.net

Copy to: Ms Sally Burtles
             Ms Elizabeth Clough, Barts Health NHS Trust
             NIHR CRN Portfolio Applications Team

Appendix 14. COREQ checklist for qualitative research (healthcare professionals)

Domain 1: Research team and reflexivity	Guide questions/description	Reported on Page #
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	245
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	245
3. Occupation	What was their occupation at the time of the study?	245
4. Gender	Was the researcher male or female?	245
5. Experience and training	What experience or training did the researcher have?	245
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	244 -245
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Appendix 16
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Appendix 16
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	247
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	244
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	245
12. Sample size	How many participants were in the study?	248
13. Non-participation	How many people refused to participate or dropped out? Reasons?	248
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	245-246
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	245-246
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	248-249; Table 10
Data collection		

Appendix 14 continued

17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	244-245 Yes; Appendix 15
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	245
20. Field notes	Were field notes made during and/or after the interview or focus group?	Yes 246
21. Duration	What was the duration of the inter views or focus group?	248
22. Data saturation	Was data saturation discussed?	250
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Data analysis		
24. Number of data coders	How many data coders coded the data?	247-248
25. Description of the coding tree	Did authors provide a description of the coding tree?	No
26. Derivation of themes	Were themes identified in advance or derived from the data?	247
27. Software	What software, if applicable, was used to manage the data?	247
28. Participant checking	Did participants provide feedback on the findings?	No
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	248
30. Data and findings consistent	Was there consistency between the data presented and the findings?	248-285
31. Clarity of major themes	Were major themes clearly presented in the findings?	248-285
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	285-297

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

Appendix 15. Healthcare professional interview schedule

Questions	Prompts
1. Tell me about your profession?	*Experience working with Bangladeshis or Pakistanis, training attended*
2. Tell me about your views on how Bangladeshi/Pakistani patients manage their asthma?	*Type of support provided* *Ramadhan, experience or opinions on using PAAPs, CAM use*
3. Do you use asthma guidelines in supporting Bangladeshi/Pakistani patients with their self-management?	*Awareness, usefulness, suggestions for improvements*
4. Tell me about what your relationship is like with Bangladeshi/Pakistani patients?	*Thoughts on family*
5. Which other professionals do you work with in partnership to provide asthma self-management support to these patients?	*Patient pathways: working with others*
6. Tell me about any ideas or suggestions you may have on how to better support these patients with their asthma self-management?	*Thoughts on intervention for professional practice and patients (content, delivery and format)*

Appendix 16. Healthcare professional information sheet

HEALTHCARE PROFESSIONAL INFORMATION SHEET: An invitation to take part in asthma research

Exploring the Role of Bangladeshi & Pakistani Culture on Asthma Self-Management Behaviour.

Salina Ahmed, Principal Researcher, 020 7882 2514, salina.ahmed@qmul.ac.uk

aukcar.ac.uk @aukcar

Can you help me by taking part in an interview

- This is an invitation for professionals who help support asthma patients from the Bangladeshi/Pakistani community with their illness (including doctors & nurses from primary or secondary care & so forth), to take part in an asthma research interview.
- Before you decide to take part, it is important for you to understand why the research is being done & what it will involve. First, I will explain the background to the study, then how the study will be conducted & what will happen if you decide to take part.
- Please take your time to read the following information carefully & discuss it with others if you wish. If anything remains unclear, please contact me directly on the details provided on the top of the page.

Background to the study

- South Asians suffer poorer asthma outcomes & have a higher hospital admissions rate compared to the majority White population with asthma. Supportive self-management of asthma by healthcare professionals is found to be effective, however it is not often provided as efficiently as possible.
- This qualitative study aims to explore key perspectives, professional challenges & discuss strategies to enhance self-management support from healthcare professionals to South Asian patients with asthma.

The purpose of the study

I would like to hear your views on your current practice & recommendations of enhancing supported self-management for South Asian (Bangladeshi/Pakistani) patients, the things you find helpful & things that you don't. I would value your thoughts on how to improve current asthma self-management practices in this community.

What will this interview involve if I decide to take part?

- You can participate in the study by being involved in a one-to-one audio recorded interview. The discussion will ask about asthma self-management support for Bangladeshi & Pakistani patients including your current practice, experiences & practical ideas to overcome barriers in self-management support.
- Taking part in this study is voluntary & you can change your mind to participate in the study at any time without giving a reason.
- All collected information will be confidential (e.g. audio recording of interviews) will be stored in a locked filling cabinet & protected computer folder, kept securely at Queen Mary University of London.
- After the completion of the study, the findings will be presented at conferences & published in a journal. Any data collected including direct interview quotes will remain confidential, anonymous & will be stored safely.
- I will use the findings to inform the implementation of a culturally tailored asthma self-management intervention for South Asians & make recommendations for good practice in supportive self-management as part of my PhD.
- This study has gained NHS ethical approval.

How will I choose who to invite?

I will use the information on the enclosed Expression of Interest Form to ensure that I recruit a range of healthcare professionals. I will contact you to answer any questions you may have & make arrangements for you to attend an interview at a time & place that suits you.

If you would like to complain you can contact the Patient Advice & Liaison Service by email/telephone pals@bartshealth.nhs.uk /020 3594 2040.

Please complete the enclosed forms, sign it & return it in the reply prepaid envelope.

This project is funded by Asthma UK Centre for Applied Research.

Professional information sheet v1 11.06.16 IRAS ID 200955

Appendix 17. Healthcare professional expression of interest form

Exploring the Role of Bangladeshi & Pakistani Culture on Asthma Self-Management Behaviour

Expression of Interest Form

If after reading the enclosed Information Sheet you are interested in helping with our study, please complete this form which asks for some background information about you. We will use this information to ensure that we recruit professionals with different experiences in the healthcare service.

Contact Information

Name:	
Occupation:	Organisation/Address
Telephone number:	Best time to contact you
Email address:	
Preferred method of contact:	☐ Phone ☐ Email ☐ Post

About You

Gender:	☐ Female ☐ Male
Age:	☐ 18-25 ☐ 26-45 ☐ 46-65 ☐ 65 or older
Ethnicity:	☐ White Caucasian ☐ White European, specify: ☐ South Asian, specify: ☐ Black African ☐ Black Caribbean ☐ Other, specify:
How do you identify yourself?	☐ South Asian: Bangladeshi/Pakistani/Indian ☐ British South Asian ☐ British Bangladeshi, British Pakistani, British Indian etc. ☐ British ☐ Other, specify:
What language/s can you speak?	☐ South Asian only (e.g., Bengali, Sylheti Urdu, Hindi, Punjabi, Kashmiri, Mirpuri etc...). ☐ Mostly South Asian, some English. ☐ South Asian and English about equally well (bilingual). ☐ Mostly English, some South Asian. ☐ Only English. Please specify which South Asian languages you can speak: ☐ Bengali, which dialect? _____ ☐ Pakistani, which dialect? _____ ☐ Other _____
How would you rate yourself?	☐ Very South Asian ☐ Mostly South Asian ☐ Bicultural (i.e. being a part of two or more cultures whether this is nations or ethnic groups) ☐ Mostly Westernized ☐ Very Westernized ☐ Other, specify:

Once completed, please return in the stamped addressed envelope provided. Thank You.

Appendix 18. Healthcare professional consent form

Participant Identification Number		

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research

QUALITATIVE STUDY CONSENT FORM

Exploring the Role of Bangladeshi & Pakistani Culture on Asthma Self-Management Behaviour

Salina Ahmed, *Principal Researcher, 020 7882 2514,* salina.ahmed@qmul.ac.uk

		Please initial each box
1.	I confirm that I have read and understood the attached information sheet for the above study *(v1 11.07.16)* and I have had the opportunity to ask questions.	
2.	I consent to take part in an interview for the above study.	
3.	I understand that my participation is voluntary, and I am free to withdraw at any time without giving any reason (Whether you take part in this study will not make a difference to the asthma care you receive).	
4.	I understand for this interview will be audio recorded and give consent to this.	
5.	I give permission for my age, gender and other non-identifiable background details to be used in the analysis of the results.	
6.	I understand my interview data/notes to be looked at by the research team and give consent for this.	

Name _____   Date ___/___/____
Signature _____

Name of person taking consent _____   Date ___/___/____
Signature _____

Appendix 19. Publication from the thesis (two). Correspondence letter - Blue inhalers: blowing hot and cold

https://doi.org/10.1038/s41533-016-0008-4

CORRESPONDENCE OPEN

Blue inhalers: blowing hot and cold

We read with interest the study reported by Fletcher et al.[1] published recently in this journal. Whilst we understand the benefits of uniformity in colour and acknowledge that in the UK 'blue inhalers' have become synonymous with reliever medication, we would like to highlight alternative meanings that colour may have amongst various ethnic groups, e.g. South/Southeast Asians, Puerto Ricans etc.[2-4]

These ethnic communities tend to explain illnesses and their treatments based on hot and cold health beliefs,[2-4] which refer to the representative and symbolic power found in hot and cold constructs, rather than physical temperature itself, e.g. in food, weather, colour, medicine, and emotions. Most respiratory diseases, e.g. asthma, are perceived to be cold illnesses triggered by exposure to cold elements, causing an imbalance of hot and cold energies, thus requiring hot treatment in order to restore the original balance.[2,3]

Blue represents cold, raising questions of whether blue 'cold' inhalers may be perceived as less effective medications in the context of these beliefs. This is important because medication beliefs are shown to be powerful predictors of adherence behaviour.[2,3,5] Additionally, this increases the likelihood of some patients using alternative medical treatments (e.g. rubbing hot chest massage ointment for night symptoms).[2,3] It has been speculated that colours representing heat, e.g. orange inhalers, may be more acceptable in these populations.[2] Moreover, these beliefs may be strengthened by the feeling of coldness, when inhaled medication touches the back of the throat, which may influence preferences for oral or dry powder devices instead of aerosol medication. One suggested strategy to overcome this is to complement inhaler use with exposure to hot constructs, e.g. tea.[4]

These communal perceptions are further reinforced by their deep historical presence, e.g. Asian health experts who learn these beliefs in childhood and endorse them.[2] Exploration of the implications of hot and cold beliefs in respiratory medicines could provide useful insight into barriers to adherence/acceptance of inhalers amongst ethnic groups and recognising cross-cultural mindsets can contribute to improving patient care and asthma outcomes in multi-ethnic societies.[2-4]

COMPETING INTERESTS

The authors declare no competing interests.

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